Autism Task Force

Department of Public Welfare
Commonwealth of Pennsylvania

Autism Task Force
Final Report

December 2004

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All 12 subcommittees of the Autism Task Force have researched information and synthesized subcommittee reports which follow for your review. You can view a subcommittee report by selecting a specific subcommittee report title and clicking on it with your mouse cursor. After reading any or all of the reports, please let us know what you think of them by clicking on the *Comments* button and filling in your comments, suggestions, and opinions in the e-mail box that appears on your screen. Then submit your comments by clicking on the submit button. Thank you for taking the time to review the Autism Task Force Final Report (December 2004) and sharing your thoughts with us. Please rest assured that we will process and review all of the comments we receive.*

Executive Summary
This summary provides a synthesis of the twelve subcommittee reports.

01. Family and Social Issues Subcommittee Report
Family and Social Issues

02. Education and Certification Subcommittee Report
Education and Certification

03. Information and Advocacy Subcommittee Report
Autism Taskforce report for the Information and Advocacy subcommittee.

04. Rural Issues Subcommittee Report
Autism Taskforce report for the Rural Issues Subcommittee.

05. Research Subcommittee Report
Autism Taskforce report for the Research subcommittee.

06. Funding Streams Subcommittee Report
Autism Taskforce report for the Funding Streams Subcommittee.

07. Medicaid Waiver
Developing a Medicaid Waiver

08. Early Intervention Subcommittee Report
The Pennsylvania Autism Taskforce EI-Subcommittee Report Outline Screening, Diagnosis, Referral and Intervention

09. Needs of Children Subcommittee Report
Autism taskforce subcommittee, Needs of Children, ages 6 through 12, December 2004.

10. Needs of Adolescents Subcommittee Report
Autism Taskforce report for the Needs of Adolescents, ages 13-18 subcommittee.

11. Transition to Adulthood Subcommittee Report

Autism Taskforce report for the Transition to Adulthood subcommittee. This also includes vocational training and support.

12. Needs of Adults (Ages 21 and Older)

Needs of Adults (Ages 21 and Older)

Autism Task Force - Abbreviations and Acronyms List

This table contains an alphabetical compilation of many of the abbreviations, acronyms, and corresponding meanings, which are found in the subcommittee reports.

Autism Task Force - Public Comments

Executive Summary

DECEMBER 2004

In the past 15 years, the number of individuals in Pennsylvania diagnosed with Autism Spectrum Disorder (ASD) has risen by over 2000%, from 2 per 10,000 people to over 40 per 10,000. State and local agencies responsible for providing care to this population, especially the Special Education system and the Mental Health/Mental Retardation system, have struggled to meet their needs, but have lacked appropriate resources, planning, and vision.

In response to this growing problem, Estelle B. Richman, Secretary of the Pennsylvania Department of Public Welfare, created the Autism Task Force. This Task Force, which is comprised of over 250 family members of people living with autism, service providers, educators, administrators and researchers, was charged with developing a plan for a new system for individuals living with autism and their families that would make Pennsylvania a national model of excellence in autism service delivery.

The Task Force met for the first time on July 26, 2003, in Harrisburg, Pennsylvania. The Task Force leadership includes Secretary Richman, as the Founder and Executive Chair; State Representative Dennis O'Brien, as an Honorary Chair; the Administering Co-chairs are David Mandell, ScD, Assistant Professor of Psychiatry and Pediatrics at the University of Pennsylvania School of Medicine, Nancy Minshew, MD, Professor of Psychiatry at the University of Pittsburgh, and Nina Wall-Cote, MSS, LSW, a certified behavioral therapist and mother of a child living with autism. The Task Force was divided into twelve subcommittees, each of which focused on current practices, problems and potential solutions in one of the following areas:

- Family and Social Issues
- Education and Certification
- Information and Advocacy
- Rural Issues
- Research
- Funding Streams
- Developing a Medicaid Waiver
- Early Intervention, Ages 0-5
- Needs of Children, Ages 6-12
- Needs of Adolescents, Ages 13-18
- Transition to Adulthood, Ages 18-21
- Needs of Adults, Ages 21 and Over

After the initial meeting, each subcommittee met in person and by phone, and communicated regularly to develop a report specific to their area of concern. These reports were circulated first to the Task Force membership for comment, and then were made available to the public through the Internet and postal mail for a three month comment period. Revisions based on the comments were then incorporated into the final reports by the subcommittees. All of the feedback received during the comment period is appended to a separate section of this report.

This summary provides a synthesis of the twelve subcommittee reports. While each subcommittee report provides information on challenges and solutions to problems specific to their respective areas, there was remarkable consistency across the reports in the broad themes that characterized problems in the current system and their potential solutions. This summary details the eight broad themes and related solutions that were apparent in most reports. The final section of this summary is devoted to the five major solutions that cut across all of the themes, and would dramatically improve the organization, financing and delivery of services to people with autism in Pennsylvania:

1. Create an Office of Disability within the Department of Public Welfare that has a Bureau or Division of Autism Spectrum and Related Disorders;

2. Create a consumer-led organization that provides information about autism services in multiple systems and advocates for the needs of individuals living with autism;

3. Develop an autism-specific Medicaid Waiver to allow for greater flexibility and creativity in providing services for this population;

4. Situate Regional Autism Centers across the state that provide high quality services to individuals with autism, train professionals in the area to assess and evaluate the needs of people living with autism, provide education and supports to families, and create opportunities for research to continually improve treatment and supports.

5. Develop creative mechanisms for blending and braiding funding between education and Medicaid to ensure coordinated, collaborative care across systems.

SPECIFIC PROBLEMS AND SOLUTIONS

THEME 1: The Current Mental Health/Mental Retardation System is not Structured to Meet the Needs of People Living with Autism and Other Chronic Neurodevelopmental Disorders.

Unlike most states, Pennsylvania administers the needs of people living with autism through multiple program offices, rather than through a single Office of Disabilities. Individuals with IQs over 70 receive services through the mental health system. These services are accessible to children, but are not readily available to adults without means testing. People with IQs below 70 are cared for through the mental retardation system.

The children's mental health system is structured primarily to address mental health challenges. The overwhelming majority of children in this system live with serious mental health challenges due to any number of possible causes, for which the expectation is that treatment and other supports will facilitate an individual's introduction into and/or autonomy within the mainstream. Autism is a chronic neurodevelopmental disorder that may improve with treatment, but will almost always require continuous services and ancillary supports throughout an individual's lifetime.

Because of the mental health system's reliance on a short-term treatment model, service providers are consistently pressured to discharge children from care, or at least reduce the volume of services provided. Nowhere is this more clear than in the requirement that all children be re-evaluated every four months and services reauthorized. This frequent re-evaluation, which rarely evidences change over such a short period of time, has many drawbacks: considerable costs associated with professionals' time, parental stress related to the potential that their child will lose needed services, child burden associated with disruption of routines, and valuable resources diverted in a system that already is experiencing a shortage of qualified professionals. Regardless of the appropriateness of these services, they are only available to those under 21 years of age, leaving the majority of adults living with autism without access to needed services.

While the mental retardation system is designed to care for individuals with chronic cognitive impairments, fewer than half of those living with autism also live with mental retardation. The needs of individuals living with autism can vary greatly from those of individuals with mental retardation, and often are not accommodated by the mental retardation system. For example, most children with autism can live in the community with certain supports, but many related services, such as respite care, are sometimes not easily available to those with IQ's below 70, while those with IQ's above 70 do not qualify for these services at all.

Solutions:

Certain immediate steps could be taken to alleviate problems of service delivery within the Mental Health/Mental Retardation system. For example, regulations could be changed so that for children with chronic conditions and disorders, reauthorization occurs on an annual basis. Services could be decoupled from IQ requirements so that all people with autism can be treated through the same system. Finally, services for those living with autism could be considered an entitlement throughout the lifespan.

While these solutions address some of the immediate problems facing families with autism, they do not go far enough in creating a comprehensive system that is specifically designed to meet the needs of this population by 1) regulating and licensing providers, 2) making appropriate services available, and 3) establishing appropriate protocols for receiving those services. Pennsylvania should create an Office of Disabilities that has, as part of its mandate, the implementation of these three goals.

THEME 2: Pennsylvania is Experiencing a Dearth of Qualified, Trained Professionals to Evaluate, Treat, Educate and Provide Other Services to People Living with Autism.

Pennsylvania lacks professionals who can provide timely diagnosis, are trained to educate or treat individuals with autism, can provide other services such as social skills and vocational training, respite care and crisis management, or who can train other professionals to provide these services. This lack of qualified professionals results in delayed diagnosis and inappropriate care. We have too few professionals in this area for a number of reasons: there are few places to obtain proper training, reimbursement rates are too low to retain qualified persons, some necessary services are not reimbursed, no continuing education is available to professionals, training is not reimbursed, providers are burdened by complex and changing requirements including extensive paperwork, and there is no incentive for improving one's abilities or a provider's services because poor quality services are reimbursed at the same level as high quality services.

Solutions:

Some immediate problems can be addressed by reimbursing for training, creating more stringent licensing and regulation requirements, reimbursing at higher rates for quality services, recruiting nationally for qualified providers, and specifying the services for which people with autism are eligible. These action steps should be implemented in the education and treatment systems.

Training should not be limited to secondary and tertiary specialists. All professionals who have the potential to come into contact with children living with autism should be able to recognize the core symptoms of this disorder and make appropriate referrals. Primary care doctors, teachers, and school psychologists, as well as speech language therapists, neurologists and developmental pediatricians must be able and motivated to screen for and recognize autism and refer where appropriate. Professionals who may come into contact with people with autism, including those in law enforcement and other first responders, must have resources available to them so they can learn about the state of the science for assessing, treating, and appropriately interacting with individual's living with autism.

The long-term solution is to improve the state infrastructure and incentives for developing professionals with the capability and interest in working with people with autism. The Pennsylvania Departments of Education, Health and Public Welfare should work with local colleges and universities to create and improve training and licensing programs; loan forgiveness programs can be expanded to include those specializing in the field of autism; providers can be rewarded through performance based contracting. It is critical that training efforts occur across the continuum of available services to improve care for individuals with autism at every level of functioning.

THEME 3: There are Almost No Community-Based Services for Adults with Autism.

As a rule, there are fewer services available to individuals living with autism as they age. Nowhere is this more apparent than when individuals turn 21. Adults living with autism have no entitlements to any services. Depending on their abilities and needs, adults with autism could benefit tremendously from various levels of vocational, educational, and life skills training, as well as supported housing arrangements. If proper community supports are put in place, many (if not most) adults living with autism can become productive, tax-paying citizens. Without the proper supports, these same adults often live at home, resulting in personal hardship for themselves and their families. When families are unable to assume the financial realities or caretaking responsibilities for their loved ones living with autism, these individuals are often sentenced to a life in an institution or heavily supported housing. This can cost the state upwards of $100,000 per individual, per year.

Solutions:

Services for adults with autism should be an entitlement. This will allow for continued services through the lifespan, permitting coherent, coordinated delivery of appropriate services and ultimately resulting in significant cost savings because of reductions in residential and inpatient service use. Most importantly, it will allow a greater proportion of adults with autism to become contributing members of society.

The array of available services should be broadened, recognizing that autism is a spectrum disorder, and that individuals have greatly varying abilities and needs. Depending on the level of need, vocational support options should include, but not be limited to, vocational skills training, a job coach with experience with adults with autism and long-term supported employment. Life and social skills training and support can allow many adults living with autism to live independently and be integrated into their communities. Those with autism continue to learn and often can benefit from post-secondary education, if given necessary supports. A variety of housing options is needed to reflect the varying levels of independence of this population. Preparation for adulthood should begin in adolescence; vocational assessment and training should begin in middle school. The special education system regulations require that transition planning starts at age 14. This regulation must be enforced and made meaningful and effective. Training in appropriate social and life skills should be a central part of services during this transition period, reflecting the increased complexity of these skills needed in adolescence and beyond. Beginning this skill development before adulthood will maximize the potential for independent living.

One important mechanism that should be used to implement these activities is a Medicaid Waiver. Waivers of state Medicaid plans offer states the flexibility to provide needed services that are outside the traditional scope of care. The Autism Task Force has already begun the process of crafting a waiver.

THEME 4: There is a Lack of Coordination Within and Across the Multiple Systems that Provide Care for People Living with Autism.

Services are provided to individuals with autism in multiple systems, including Medicaid, Education, Child Welfare, Vocational Services, Housing Services, and even Criminal Justice. Currently, there is no centralized entity to coordinate services and promote cooperation among the various agencies involved with a particular individual. Because of this, gaps and overlaps occur, different agencies may work at cross-purposes, agencies try to pass responsibility to each other, and opportunities for consistency of therapy across settings are missed. This lack of coordination results in scarce funds not being used in the most efficient manner.

In the current system, assessment and treatment are often not provided by the same specialists. Doctors who diagnose autism may not know where to refer patients for additional care. The education system is authorized to evaluate a child for services, but often does not refer families to the Medical Assistance system for additional services. When children are receiving services from both Medicaid and school systems, which is often the case, two parallel sets of interventions are often developed. These plans often have different goals and methods for achieving those goals, despite the fact that they often occur concurrently. It falls to the parents to coordinate their child's services across two systems with fundamentally different missions, which are often attempting to transfer accountability to each other, and are therefore antagonistic towards each other.

Within the education system, there are several transition periods: from services provided to children from birth to three years of age to those who are three to five years of age; from this Early Intervention period to primary school, and then to secondary school, and finally out of the education system at age 21. Even within a single school district, the administrations responsible for each age group may not coordinate with each other, causing inefficiencies of care, additional stress for the family and the potential for the child to lose hard won gains in functioning.

This lack of coordination continues for adults, where vocational, educational, and housing supports, if provided at all, are provided by separate, uncoordinated agencies, which have no information about the individual's previous experiences and needs.

<u>Solutions:</u>

A minimal response to the need for cross system coordination is a series of interagency team meetings that involve representation from every system serving individuals living with autism. This team meeting is

necessary but not sufficient. Funding streams and services also must be coordinated to provide efficient, effective services and to ensure that individuals have one coherent service plan. A Bureau or Division of Autism Spectrum and Related Disorders in an Office of Disabilities could do much to address this deficit. This Bureau or Division could coordinate funding across agencies. It could also create incentives to ensure that different care plans were tied together into a single, coherent plan.

Since different agencies and funding streams operate under different regulations and have differing criteria of compliance, care must be taken that the different regulations governing the different agencies involved are followed, and that accountability is clear.

THEME 5: The Current System Provides No Incentives for Delivering Quality Care.

There are many barriers to providing quality care in the current system. No criteria exists at the state or local levels regarding what constitutes an appropriate care package for people living with autism. Furthermore, there are no standardized methods for measuring related processes and outcomes. Providers struggle in conflict with funding agencies to identify appropriate treatment goals and related supports. Each new treatment plan can result in protracted negotiations regarding appropriate level, intensity and duration of care and related reimbursement. In addition to the high volume of burdensome paperwork this system creates, it atomizes localities and providers, and stagnates opportunities to improve care models. Training is not standardized and is rarely reimbursed. Providers feel threatened by the potential for services to be denied and reimbursement rates to change.

All of these factors contribute to the problem that pay scales are not competitive with alternative employment options. Many providers do not offer health insurance or other benefits. This also contributes to the high staff turnover rates. This in turn leads to higher training costs and staffing shortages.

Solutions:

Pennsylvania should initiate a two-pronged approach. The first component consists of establishing appropriate standards of care and working with providers to improve their capacity to meet those standards. Other states such as California, Indiana, New York, and Washington have implemented such programs in a limited way, and could be used as an initial model. The second component is to begin performance-based contracting with providers based on quality of care, outcomes, and client satisfaction. An Office of Disabilities could determine appropriate quality and outcome measures that should be implemented consistently across the Commonwealth with room for some local flexibility to meet location-specific needs.

An ongoing review entity, either centralized or tied to regional centers, should be created to provide guidelines and to oversee the implementation of quality standards and performance-based contracting. This organization should include significant representation of family members.

The amount of required paperwork should be reduced and streamlined, so that, for instance, basic client information does not have to be entered separately for each form. Switching to an annual evaluation/authorization schedule would do much to contribute to this goal. Paperwork requirements should be consistent across the Commonwealth.

The pay scale for those providing direct therapy – Therapeutic Staff Support (TSS) and Behavior Specialist Consultants (BSC), in particular, must be increased to a level competitive with alternative employment. (TSS professionals are required to have a bachelor's degree in a relevant field; BSC professionals must have a master's degree.) Training and attendance at evaluations should be billable expenditures, in turn reducing the overhead for providers, which may make higher salaries possible without significantly increasing the hourly reimbursement rate from the state.

Providers should have a complaint mechanism to appeal to when there is a conflict with their Managed Care Organization (MCO).

Methods to address the creation and maintenance of employee satisfaction and retention of employees must be developed. A tremendous amount of time, skill and resources is lost to high turnover.

THEME 6: There is No Cohesive Set of Policies and Plans to Provide Consistent Care and Education to People Living with Autism Across the Commonwealth.

There are 501 school districts and 29 Intermediate Units in Pennsylvania. They operate with a great deal of independence, with only cursory approval and oversight by the Pennsylvania Department of Education. In Pennsylvania there are 67 counties, which also exercise a great deal of autonomy with respect to their use and administration of Medical Assistance services. Except for a few counties with cooperative arrangements, there is virtually no coordination of services from one county to another. This creates different levels and quality of services. Families moving from one school district or county to another within Pennsylvania may face an entirely new set of circumstances. They may be motivated to relocate within the Commonwealth to receive better services from the education system or the MH/MR system elsewhere. This is very disruptive to families that are already under considerable stress.

Solutions:

Development of a core set of required services, supports and regulations with room for local flexibility is needed. The state should develop guidelines for individuals across the lifespan regarding screening, assessment, diagnosis, treatment and related support services. In this document, we have attempted to provide what the Task Force Membership thinks some of those guidelines should be.

Disparities in local school district funding hinder our ability to implement uniform services across the state, as the more affluent school districts generally offer a wider range of services. The Pennsylvania Department of Education should take a proactive role in developing and implementing a consistent educational standard of practice for children living with autism. Each, and every, school district should be held accountable to the same developed standard of practice.

Regional centers that would serve as sources of the most current information on the nature and treatment of autism could also be used as a resource for providers to coordinate consistent practices across regions. They can also serve to update treatment options as research warrants, so that Pennsylvanians living with autism receive the benefit of the latest research in a timely fashion.

THEME 7: The Existing System is not able to Address Differences in Individuals Living with Autism.

Just as autism is a spectrum disorder with a wide range of presentations, families living with autism vary widely, reflecting that persons of all ethnic and socio-economic groups are affected. It follows that families have differing beliefs, strengths and resources to bring to bear in facing this challenge. The current system places the burden on families to seek information on autism, learn what services are available, apply for those services, and, once receiving them, coordinate services from different sources. At the same time, it provides few resources to assist families in doing so. Families who do not have necessary financial resources, do not have a strong command of English, are not aware of how state and local bureaucracies function or related responsibilities, do not live in locations where services are readily available, do not have the tools to advocate for their children, or come from groups that are traditionally underrepresented or discriminated against, face even greater challenges in obtaining appropriate services for their family members with autism.

Solutions:

Services for individuals living with autism must reflect, respect and accommodate the diversity and multicultural composition of the Commonwealth, while still providing a single point of entry into the service system. This single point of entry should provide, as necessary:

- Materials in different languages
- Easy access to professional advocates who can work with families
- Methods to eliminate disparities in access to services
- Training that makes parents aware of their rights and responsibilities
- Culturally sensitive and competent providers that can work well with families from a variety of different backgrounds
- Improved access to services regardless of where families live

More research is needed regarding the effect and implications of geographical, socio-economical, educational, and cultural differences, with respect to disparities in access to services and care for individuals living with ASD. Therapists and other providers working with people living with autism must receive targeted training in researched methodology that includes sensitivity to these differences.

THEME 8: The Current Education System does not Meet the Needs of People Living with Autism.

The Office of Special Education within the Department of Education serves more people living with autism than any other agency in the Commonwealth. Since 1990, autism spectrum disorders have been a separate category of conditions that qualify individuals for special education services. Since then, the number of people with autism served through this program has grown over 1000%. The education system has struggled to develop coherent and meaningful policies and services for this population. While the issues addressed under this theme overlap with those addressed in many other themes, the role of the education system is critical enough to warrant special attention, especially given that the Federal government has never provided all the funds for special education services that were originally promised, and recent legislation regarding school accountability may further imperil the acceptance of children with special education needs in public schools.

School districts in Pennsylvania have considerable autonomy in defining autism-related services, resulting in great variation within the state. Without established protocols, there is inconsistency regarding the available menu of options and families must fight to obtain sufficient and appropriate services, as evidenced by the fact that 25% of families in Pennsylvania have engaged in a grievance proceeding against their school district, and approximately 20% of families change residence to be in a school district that provides better services. The nature of the problems these families face are far ranging. Teachers, including those in the field of special education, rarely have any autism-specific training. Regular education teachers are not given enough support from other professionals to appropriately include children living with autism in their classrooms. In addition, there are too few professionals available for evaluation and treatment support.

Few school districts have inclusion as their policy of first resort. Despite the mandate provided in the IDEA legislation, schools rarely, if ever, provide services that extend beyond the school day and year. Many children do not receive social skills and pragmatic language training, which address core deficits of autism. There are few opportunities for adolescents to receive vocational training, which is often a prerequisite to productive citizenship.

Exacerbating the problems in both the education and Medicaid systems is the fact that there are few mechanisms to coordinate care between them. The education system is responsible for creating an environment in which a "free and appropriate education" can occur in the "least restrictive environment" possible. The behavioral health system is responsible for addressing the symptoms of ASD and maximizing functioning. Obviously, these goals overlap, and the goals of one system must be addressed in order to make the goals of the other possible. However, each system requires a separate care plan and has different criteria by which the appropriateness of services and supports is determined. Because of the separate funding and regulatory silos for these two systems, school districts and behavioral health care providers must rely on two separate plans and create artificial distinctions between educational and behavioral services and supports. There is little opportunity for coordination of care. As a result, services are often provided in a fragmented, less effective and inefficient manner, which results in additional costs.

<u>Solutions:</u>

Solutions for addressing this theme can be separated into three categories. The first addresses ways to increase service capacity in the education system. The second addresses the inconsistency in educational services available across the Commonwealth. The third addresses ways in which services provided in the education and behavioral health systems can be coordinated to improve care.

The overwhelming priority in education is to increase the number of trained professionals educating children living with autism. These activities should take a three-pronged approach that include a) in-service training for current regular and special educators, b) incentives such as loan forgiveness programs for pre-service training in autism, and c) efforts to increase the capacity of local colleges and universities to train people in autism education. Equally important, along with training activities there must be

opportunities for school districts to receive technical assistance in autism education, including methods for inclusion and appropriate transitions from one level of education to the next.

Second, to ensure consistency of educational options and opportunities, regardless of the school district in which a child resides, Pennsylvania must develop cohesive, statewide rules for administering a menu of appropriate services based on best practices. Such rules would ensure that inclusion be the first option considered, that social skills and pragmatic language deficits always be addressed, that there be a consistent policy regarding services beyond the regular school day and year and that vocational training be given high priority. Developing this protocol would go a long way towards producing a system that is proactive, rather than reactive.

Finally, an infrastructure must be created to facilitate the coordination of Education and Behavioral Health services. A Bureau or Division of Autism Spectrum and Related Disorders, housed in an Office of Disabilities, could be central in this effort by acting as a liaison with the Department of Education. Both sources of support must be coordinated, and must develop a single, coherent treatment plan for each child.

GENERAL SOLUTIONS

Many of the challenges and related solutions facing individuals living with autism overlap in scope and scale. Each theme outlined above is important in its own right, but is not a discrete entity, and will not be completely addressed until the others are also addressed. Four general solutions present themselves as ways to address many of these themes concurrently. Implementing these general solutions will help ensure that efforts are coordinated in an efficient and effective manner, as services for people living with autism are improved in Pennsylvania.

1. Create an Office of Disability within the Department of Public Welfare with a Bureau or Division of Autism Spectrum and Related Disorders.

In at least 46 states, autism services are administered through an Office of Disabilities rather than the Mental Health/Mental Retardation system. An Office of Disabilities provides a number of advantages in the provision and coordination of these services. Perhaps most importantly, these offices recognize autism as a lifelong disorder that requires specific supports throughout an individual's lifetime. This means that service provision would not stop when individuals turn 21, but would continue to be an entitlement throughout adulthood. A Bureau or Division of Autism Spectrum and Related Disorders, housed in an Office of Disability, would provide a single point of entry into care for people living with autism so that caregivers do not have to negotiate multiple systems. These offices can coordinate services for people living with autism across the systems in which they receive care, in large part because they have the authority to coordinate funding and planning processes so that treatments are developed and services are provided in an efficient and effective manner. Finally, they can coordinate training and licensing of the professionals who provide assessment, treatment, education, and other supports to individuals living with autism, which safeguards the quality of autism care.

2. Create a Consumer-led Information and Advocacy Organization

The autism community in Pennsylvania requires a single advocacy organization that addresses the needs of families across the Commonwealth. States like New Jersey, whose advocacy organizations receive state dollars, have experienced great success in advocating for individuals and families living with autism, and disseminating information to families and professionals, thereby improving autism services. In Pennsylvania, this organization should advocate for individuals and families living with autism to county and state systems. This type of information and advocacy organization could also provide up-to-date information to families about available treatments and services, and act as an advisory body to relevant state and local offices.

3. Develop an Autism-specific Medicaid Waiver

The federal government allows states to request that Medicaid regulations be waived so that appropriate services can be provided to specific groups of Medicaid-eligible individuals. This waiver process can greatly increase the flexibility and creativity states have to provide care. Pennsylvania should submit a Medicaid

Waiver application for children and adults living with autism that broadens the scope of available services and develops mechanisms to improve the quality of care provided to people living with autism.

4. Situate Regional Autism Centers Across the State

Pennsylvania is a large state with considerable variation in resources and needs. Regional autism centers, such as those established in North Carolina, have two advantages in meeting these needs. They can ensure that citizens in every part of the Commonwealth have access to the same high quality assessment, treatment, services and supports. They also provide a mechanism for disseminating best practices throughout the state to professionals working with people with autism, thereby ensuring that services are consistent and of high quality.

5. Develop Creative Mechanisms for Blending and Braiding Funding Between Education and Medicaid to Ensure Coordinated, Collaborative Care Across Systems.

Currently, individuals living with autism may receive services from a number of disparate sources, including Medicaid, Education, Child Welfare, Vocational Services, Housing Services, and even Criminal Justice. Mechanisms to coordinate services and promote cooperation among the various agencies involved would address gaps and overlaps in services, avoid agencies working at cross-purposes, and ensure that opportunities for consistency of therapy across settings are not missed. This in turn would result in scarce funds being used in the most efficient manner.

Autism Task Force
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Submitted to the Honorable Estelle Richman, Secretary of the Department of Public Welfare And Task Force Co-Chairs, Nancy Minschew, M.D., David Mandell, Ph.D., and Nina Cote, LSW, MSS

01. Family and Social Issues - Subcommittee Report

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Subcommittee Report Summary

The Family and Social Issues Subcommittee focused on the current state of the Pennsylvania health and education systems in meeting the psychological, social, emotional, and educational needs of the Autism Spectrum Disorder (ASD) child, adolescent or adult and the family. These needs are examined within the context of life stages (Leblanc, Schroeder & Mayo, 1997), from birth through adulthood (age 21+). It is clear that the current systems do not adequately address the needs of the ASD individual due to the fragmented and inconsistent nature of services, particularly for adults, for which services are, for the most part, nonexistent. These disjointed services, in conjunction with a lack of perspective and knowledge concerning the ASD path, results in delayed or incorrect diagnosis and the misapplication of the medical intervention model (Greenspan, Weidner & Simmons, 1998; Schopler, 2001).

Although the mental health system is currently the primary funding stream for persons with ASD, this model does not encompass all of the needs of the ASD individual. The base model inappropriately presumes that: 1) the ASD path is a "disease" state that requires "mental health" intervention; 2) the behavioral and social/emotional issues manifested in the ASD individual are distinct from the learning and communication challenges these individuals face; 3) the goal of the intervention program is to periodically (every 4 months) evaluate the "ASD state", determine if the services (treatment) provided have resulted in improved social /emotional functioning, and reduce or phase out these services accordingly. This system results in sustained and increasing stress for the ASD individual and his/her family as the child passes through the life stages from birth to adulthood (Marcus, Kunce & Schopler, 1997; Bristol, 1984). The challenges of dealing with fragmented and confusing services within the context of a health, education and welfare system that often does not recognize or acknowledge the unique needs of the ASD individual only serves to create additional life stresses for the family.

The committee proposes that the Department of Public Welfare, through the auspices of a newly created "Department of Disabilities" work cooperatively with the Department of Education to envision and create an integrated system of services to address the needs of the ASD child and the family from first diagnosis onward through adulthood. This endeavor would include the following essential elements: early assessment and diagnosis; increasing public awareness of ASD; increased awareness and training of educators with regard to ASD; integration of psychological, emotional, sensory, social, communication and learning supports through a one-on-one aide paradigm in the educational and other social environments; providing respite and other support services for siblings and parents; "mainstreaming" ASD individuals and families into social and educational programs; and most importantly, providing consistent "seamless" support and services for the ASD individual and family throughout the life stages.

1.0 Introductory Materials

The Subcommittee Membership includes:

Name	**Location**	**Region**	**Affiliation**
Richard Barbour	Lancaster/Lebanon	South East	Educator
Dennis Brayley	Allegheny	South West	Educator
Barry Diamond	Allentown	East	Parent
Deborah Ferraro, BS Child Development	Allegheny County	South West	Professional
Michelle Ford	Reading	South East	Parent
Pat Fowler	Chester	South East	Educator

Shayen George, MA	Sharon	West	Professional
Renee Georgi	Pittsburgh	South West	Parent
Jeff Hudale	Pittsburgh	South West	Self Advocate
Keri Ann Iannotta	Reading	South East	Parent
Irene Kolker, Licensed Social Worker	Delaware County	South East	Professional/ Administration
Susie Lovejoy	Pittsburgh	South West	Parent
Lori Mattern	Berks	South East	Educator
Robert Naseef, Ph.D.	Philadelphia	South East	Parent/Professional
Jim Owens	Harrisburg	Central	Health Professional
Gina Pfeifer, Licensed Social Worker	Pittsburgh	South West	Professional
Tom Purcell	Delaware	South East	Educator
Chris Remick	Scranton	North East	Professional
Colleen Sari, MD.	Pittsburgh	South West	Professional
Rhonda Shough, CPA	Wind Ridge, Greene County	South West/rural	Parent/Professional
Janet Sloand Armstrong	Dauphin	Central	Educator
Dee Taylor	Harrisburg	Central	Parent
Debra Thompson	Erie	North West	Parent
Jane Thurston	West Grove	South East	Parent
Ken Thurston, MA Clinical Psychology	West Grove	South East	Parent/Professional

Overview and Mission Statement

The Family and Social Issues Subcommittee focused on the current state of services available to families of individuals with Autistic Spectrum Disorder (ASD), and the impact that the system has on the ASD child, his/her parents, siblings, other family members and the immediate community. The Mission Statement of the Subcommittee is as follows:

Identify and recommend solutions for family and social issues that impact the coordination of services and quality of life for individuals with autism and their families.

Meeting Times and Formats

The subcommittee met for the first time in Harrisburg, PA on July 26, 2003 with the entire Task Force. At this meeting, the group brainstormed issues and potential solutions and began their discussion. Subsequent meetings were held on August 30, 2003 from 9:30 am until 12:30 pm and September 13, 2003 from 9:30 am until 12:30 pm. For those two meetings, members of the group who live in the eastern part of the state met at the Thurston's home in West Grove. For the August 30 meeting, members who live in the western part of the state met at Colleen Sari's office in Trafford, PA and for the September 13 met at Deb Ferraro's office in Wilkinsburg, PA. In addition, through the Department of Public Welfare, facilitators arranged for speakerphone conference for members who could not attend in person. Members who were not able to attend either meeting were able to join in via teleconference. The group also met via teleconference on November 15, 2003 from 10:00 am until noon. Another meeting of the subcommittee was held on January 3, 2004, at the Thurston's home in West Grove. Members who were unable to attend this meeting were able to join via teleconference. A final teleconference was held on January 18, 2004 to review the report draft and incorporate committee member comments.

After the initial review period a number of educators and other Task Force members were added to the group. New members were given four weeks to read, review, and respond with additional comments. A teleconference was held on May 15, 2004 to review comments received to date and determine an action plan for additional work on the report. On July 22, Estelle Richman held a public input session on issues related to Underrepresented Populations at the Barber Center in Erie, PA. Comments derived from that meeting are also reflected in the final report. A final conference call was held on October 16, 2004 to discuss the public input and to make final changes to the report. Facilitators attempted to contact members via e-mail and phone to notify them of upcoming meetings and discussion of the group. Debbie Thompson, Michele Ford and Jane Thurston worked to coordinate and facilitate the group. During the group meetings, Debbie Thompson recorded the discussion of the group, and made edits to the report using her PC.

Report Formulation

The subcommittee reached consensus early in its discussion that there were overarching themes, issues and solutions that were common throughout the lifespan of the ASD individual and family members. The group also felt that there were few, if any, differences in the perspectives of the parents, professionals or administrators within this subcommittee. Because the needs of the family are somewhat different based on the age of the ASD individual and where he/she might fall on the autism spectrum, the subcommittee decided that it was more important to format the report based on life stage, and highlight the various issues and impacts on the family through the life stages. Thus, the subcommittee did not follow the recommended global format of reviewing perspectives within current practice, problems with existing practice, and then solutions to improve existing practice.

The layout of this report includes the overarching issues that permeate the lifespan, and then considers the specific issues and needs of the families through each of the life stages of the ASD individual. These issues were identified and discussed in the first three meetings of the task force. The current state of services and its impact on the ASD child/family is addressed at several life stages, from birth to age 3 through adulthood (age 21+). For each life stage, the current practice is noted with the needs/gaps in the system, how it relates to the family/social issues (impact), and possible solutions are suggested. The basic information for current practice and recommendations were discussed during the subcommittee meetings. At the September 13 meeting, it was agreed that various members of the subcommittee would work on selected "life stages" and complete the information in the appendix table. Subcommittee members submitted input to Debbie Thompson who compiled it into the report appendix table. A complete listing of the current practice, issues, needs and solutions upon which the report narrative is based are included in the attached Appendix 1.

In early November, Jane and Ken Thurston drafted the report narrative. Edits and changes were submitted to Debbie Thompson. Any special considerations for cultural and spectrum differences were highlighted, either through group discussion or by comments submitted by a subcommittee member. At the January 3 meeting, members agreed to include personal "vignettes" to the extent possible within each section to highlight personal "stories" highlighting the family and social issues outlined in this report. Vignettes were submitted by various Task Force subcommittee members and families in the larger autistic community.

One of the subcommittee members, Robert Naseef, Ph.D., has written and contributed to numerous articles and publications on the affects of autism and ASD on families. He and a group of colleagues including Ron Oberleitner, Princeton Autism Technology, Inc & e-Merge Tech Services, Princeton, NJ; James Ball, Ed.D., Youth Consultation Services: Sawtelle Learning Centers, Montclair, NJ; Dan Gillette, Ed.M., Research Associate, IDEA Lab, CalState TEACH, California State University at Monterey Bay; Robert Naseef, Ph.D., Independent Psychologist & Family Consultant, Center for Autistic Children, Philadelphia, PA; B. Hudnall Stamm, Ph.D., Institute of Rural Health and Department of Psychology, Idaho State University are in the process of finalizing an article entitled "Technologies to Lessen the Distress of Autism." This article will be published in a special issue entitled "Innovative Trends in Trauma Treatment Techniques" in the Journal of Aggression, Maltreatment, &Trauma. This report includes a number of excerpts directly from that article that support the recommendations of this subcommittee.

In Early 2004, the report was reviewed by Task Force chairs and the general public. Comments made by the reviewers were forwarded to the Task Force members, who incorporated the suggested revisions into the narrative. The report was revised in May, 2004 and posted on the website for public comment. Public Comment was received by the task force in September and incorporated into the final document.

Background and Definitions

"Autism Defined"

Autism is a devastating, pervasive developmental disability that usually appears between 15 and 20 months of age (Akshoomoff, 2000). Although all people with autism do not present exactly the same symptoms and deficits, the disease is characterized by social, communication, motor, and sensory problems that frequently create distressing behaviors. The diagnostic criteria address impairment in three areas (a) social interaction, (b) impaired communication and (c) stereotypic and repetitive behaviors (APA, 2000). The first diagnostic criterion—impaired social interaction, includes reduced eye contact; failure to develop peer relationships; absence of spontaneous joy or interest; and lack of social or emotional reciprocity. The second diagnostic criterion–impaired communication, involves delay in, or failure to develop, spoken language; impaired ability to have a conversation; stereotyped, repetitive, idiosyncratic language; and lack of symbolic play. The final criterion is stereotypic and repetitive behavior, including preoccupation, inflexibility and rigidity, motor mannerisms such as hand flapping and spinning, and preoccupations with parts of objects.

There is a broad spectrum of behavioral manifestations upon which the diagnosis of autism is made. Also, there are related and heterogeneous abnormalities responsible for the complexity in the way this disorder presents itself. Understanding the individual profile of the child is crucial to developing the most efficacious treatment plan (Greenspan & Weider, 1999).

While some children with autism will never speak, most will progress through many familiar developmental milestones. Some have the beginnings of speech in early development and then lose it. These children may regain speech, or they will likely be able to develop some form of communication through gestures, signs, or picture exchange. Because autism remains throughout one’s life, they may not be able to marry or live independently, resulting in long-term demands on caretakers. People with autism may have symptoms that include sleeplessness, obsessions, hyperactivity and even self-injuring behavior. These behaviors put the person with autism at risk and pose severe challenges, including isolation, for their caretakers.

How the condition of each individual progresses is largely dependent on the interaction between his or her innate factors and the individual’s caregivers and treatment modalities.

Growing Incidence and Awareness

In the last decade there has been an explosion in the number of new cases of autism-related disorders. The Autism Society of America estimates between 500,000 and 1.5 million people in the United States alone have a disorder on the autism spectrum (ASA, 2002). Whereas the incidence was 5 in 10,000 for many years, now some studies are referencing up to 1 in 149 births (CDC, 2000). Researchers and families are struggling to discern if this is truly an epidemic or due to better diagnosis.

A recent study reported by the Journal of the American Medical Association (Yeargin-Allsopp, M.,Rice, C., Karapurkar, T., Doernberg, N., Boyle, C., Murphy, C., 2003) reported the prevalence of autism among children aged 3 to 10 years in the 5 counties of metropolitan Atlanta, Georgia, in 1996. Cases were identified through screening and abstracting records from multiple medical and educational sources, with case status determined by expert review. A total of 987 children displayed behaviors consistent with autistic disorder, pervasive developmental disorder–not otherwise specified, or Asperger's syndrome. The prevalence for autism was 3.4 per 1000. Overall, the prevalence was comparable for black and white children, and 68 percent of children tested (n = 880) showed some type of cognitive impairment. The rate of autism found in this study was higher than the rates reported during the 1980s and early 1990s. While some of the increase can be explained by widened definitions of the disorder, **Yeargin-Allsopp and colleagues** claim that the cause for the increase is unknown.

This increase is consistent with other recent studies, such as done by the M.I.N.D. Institute at the UC Davis Health System in California. MIND reported a 273% increase in autism cases between 1987 and 1998 (Byrd, 1999), and also concluded that broadening the diagnostic criteria and other proposed factors do not account for this increase.

How Autism Puts the Family At Risk

The constant and evolving struggles of the family who must cope with chronic depletion of resources make family members vulnerable to a variety of problems. These problems may require intervention, and may diminish with finding concrete help for the child. Parents report feeling more relaxed when they have enough resources to help their child. (Seligman & Darling, 1997).

Preexisting vulnerabilities may rekindle with the stress of caring for a child with autism precipitating new clinical episodes. One of the most draining problems families deal with is hyperactivity and the lack of sleep a child with autism may experience. Sleep can be a major issue for people with autism; for example, after only two hours' sleep, a child affected by autism may be up and on the move for the next day (Durand, 1998). For weary parents, this lack of sleep can challenge the family's coping and exacerbate physical and mental risk factors.

In addition to the feelings of loss a family may feel learning that their child has autism, the child's behaviors can add to the family's distress. Many children with autism cry and tantrum incessantly, break things, injure themselves, and shriek at high pitches. These behaviors may arise because the child cannot communicate or experiences pain caused by his or her environment. In some cases, the child's behavior may incorporate a very clear life threat such as running out of the house into traffic, into pools or lakes, or even up high-tension towers. They may break windows or dart into a neighbor's house to search for items they are obsessed with, such as video players, remote controls, and televisions. Just to ensure that the autistic child will not escape, families may essentially barricade themselves into their home, placing the whole family at risk should they need to evacuate the home such as in the case of a fire. This environment of captivity, designed to gain at least a modicum of safety and control for the family, has been identified by Herman (1992) as a major contributor to long-term, complex traumatic stress. In addition, these highly-charged environments present multiple risk factors for family violence, a commonly recognized precipitant of traumatic stress.

A hallmark of traumatic stress that it is an overwhelming experience that affects mind and body and impacts people's ability to think and make sense out of current experiences (van der Kolk, et al., 1996). Stress and extreme stress threatens one's sense of coherence (SOC) (Antonovsky, 1979, 1987). SOC includes comprehensibility of how ordered and consistent one's world is. It also includes manageability, e.g., one's ability to mobilize resources to cope, and meaningfulness of one's experiences. Extremely stressful events not only challenge SOC, they may color one's interpretation of new experiences such that the stressor is the pervasive organizing schema of one's life (Jannoff-Bulman, 1992; Stamm, 1999a, 1999b).

It can be difficult not to react to autism-related experiences with fear, helplessness or horror because of the dramatic characteristics of the disorder and its chronic nature. Just as the family overcomes one crisis, another crisis takes its place, intensifying, as the child grows older, larger, and stronger.

And there are other traumas like Jimmy hitting me, especially as he gets bigger. It physically hurts more, but I'm also not able to restrain him effectively. Now when he yells he's gotten a lot louder. It brings up all of the years of being hit and yelled at by him. When Jimmy obstructs a turnstile, or lies down on the floor of a bookstore, the trauma there is more looking into the future. I fear he'll have a run-in with the police, or even be shot for resisting arrest. (From a Parent of a Child With Autism)

Hyperarousal symptoms are fed by the constant exposure to highly affectively-charged environment brought about by living with a person who is constantly on the move, potentially engaging in high-risk behaviors, and who may emit frightening or nerve-wracking sounds in their attempt to communicate. The constant vigilance to protect ones' child, one's family, and one's partner as well as one's self can leave parents irritable and on edge indefinitely. These symptoms may cause clinically significant problems in daily social and occupational functioning both from the perspective of stress on the family and other physical, oral, and mental/behavioral health perspectives.

Deepening the suffering of these families is the fact that it is difficult to construct a reasonable reality and interpret the experiences with which they are confronted (McCann & Pearlman, 1990). As a result of the person with autism's impaired social awareness, they may show no remorse, no reciprocation of appreciation, or no normally expected signs of love. This leaves families wondering if their children are indeed happy, if they care about or love their families, and, always, if "we are doing the right thing."

Yet another cause of stress to the family is the lack of general awareness about the disorder on the part of the general public. The child with autism has no physical characteristics to indicate that there is a disability. When the family attempts to go out in public, they may be shamed or embarrassed if the autistic child enacts bizarre behaviors. People may assign blame the child's parents for these unusual behaviors. As is common with stigma (Krikwood & Stamm, in press) feelings of being judged and rejected may cause parents to isolate themselves (Miller and Sammons, 1999), further reducing their coping resources.

Add to this humiliation the vestige of shame caused by the previously accepted, but misguided, medical hypothesis that cold or abusive parenting caused autism (Rimland, 1984). In the past and occasionally still, doctors remove the child from the care of the family and place the child in an institution, suggesting that the parents seek professional help for their own problems. Families who are otherwise confident that they have not abused their children wonder, "Did I let him cry too long in his crib? Should I have held him more as an infant? Did I give him enough time and love?" Because there are no clear answers to what causes autism, parents may speculate that they caused the autism.

Today, it is an ongoing challenge for the members of a family with an autistic child to adjust to the reality of their situation and find fulfillment together (Siegel, 1996). The cost of therapy and education for an autistic child is enormous. In most places, there is no day care or after-school care for the child with autism. Finding a babysitter who can deal with the disruptive and dangerous behaviors is extremely difficult. The problem of constant care for the child may prevent parents from working or spending time together. Given the stress and the financial drain on the family, the parents are at high risk for marital conflict as well as divorce (Seligman & Darling, 1997)." (Oberleitner, Ball, Gillette, Naseef, and Stamm (2004) (In Press)

As noted above, society does not always understand the behavior of the ASD child. While families endure enough stress from the greater society, they are often rejected and isolated from their own families as well. A strong support network is a valuable asset for these children and their families. Unfortunately this is not always the case, as illustrated in the following vignette:

Isolation occurs in many different ways. They range from subtle nuances to blatant exclusions. For example; Kayla's parents report that invitations are conditional. Kayla is invited to color Easter eggs with all the grandkids, but only if her mother comes to attend to care for Kayla's needs and assist her with the planned activities. Yet, the other grandchildren attend parentless and are invited to stay overnight. Kayla receives no invitation to spend the night. Most often times, Kayla's parents learn of family activities from Kayla's cousins, revealing that Kayla did not receive an invite. In 7 ½ years, Kayla has participated in one outing with extended family members for a grand total of 1 ½ hours, and she was not allowed to get out of the car. On holiday occasions, Kayla and her mom are isolated to a separate room on a different floor. Family members come and go, but no one actually stops to visit.

The following article, written by one of the subcommittee members, articulates well, the plight of families dealing with autism.

Sometimes it seems like yesterday, since my only son and my oldest child, Tariq, was a seemingly normal happy toddler. At 18 months he was just beginning to speak and had a small but useful vocabulary. Then autism struck, and life has never been the same. When I found out my son had autism and that the condition would last for his lifetime, I can remember believing that I would never smile or laugh again.

When I first glanced at the cover of TIME featuring a boy with autism, I shuddered. The boy's hands and his far away look brought me back 20 years. That was my baby's hands at 2—and now at 22. A knot formed in the pit of my stomach. My head began to spin. Momentarily, I got short of breath. I decided to go on with my day and read it another time. Later, I read the article in its entirety, and I feel grateful to TIME for bringing the complex issues around the causes of autism, the exploding number of new cases, the impact on families, the status of research, and the need for intensive treatment to the fore.

As a psychologist, I help families deal with the often treacherous emotional landscape once autism strikes. It's been called the "autism bomb." People often spontaneously describe to me how the diagnosis of their child's autism was a bomb that exploded their hopes and dreams. The calendar of their lives was ripped off the wall and replaced by an uncertain future as they began intensive intervention to help their child, while they struggle to find hope and to regain their footing in life.

- Just last week in my office, one mother sobbed as she told me that her 10 year old son with Aspergers syndrome had told her, "I wish my imaginary friends were real and that I could play with them."
- Another mother recounted how her life seems like "one long day." Her 8 year old son rarely sleeps through the night. His autism includes seizures which have been elusive to control despite excellent care at Children's Hospital of Philadelphia.
- In a group of fathers I meet with regularly, one man reiterated how not a day goes by that he doesn't wish his son didn't have autism. Like me, he would read TIME later. He had read enough about autism for right now. Another man who had two boys with autism wept as he recalled when his oldest son had stopped talking.
- A mother I have known for several years told her support group, "I wish the autism was a thing, and then I could drag it out of him and beat it to death. But it is a part of him and I love him." The group concurred virtually in unison.

No longer is it hard to find people who have been touched by autism. I couldn't help but notice that two of the first person accounts came from the TIME family—arts reporter and parent, Amy Lennard Goehner, and Karl Taro Greenfeld, sibling and editor of TIME ASIA. Everyone in the family unit is deeply affected. As Greenfeld's father, Josh, wrote so poignantly in A Child Called Noah in 1970, "There is a strain on any marriage whenever a baby is sick. And we always have a sick baby."

It gives my life and my son's life meaning to do the work I do. Still I can't help but wonder, when I see a father with a small boy, what might have been. Like Noah Greenfeld, my son is nonverbal and very limited in what he can do. Like most other parents, I have learned to enjoy and celebrate everything he learns to do. I am consoled by the reality that people with autism teach the rest of us profound and spiritual lessons in acceptance and in honoring the diversity of the human condition.

Yet there are things we must change. When my son was diagnosed, the incidence of autism was widely cited as 5 in 10,000. Nobody I knew had any knowledge or experience of it. It was a very lonely and dark time. Now we are told that the incidence is more like 1 in 250 for various and mysterious reasons. So many children have been affected, and so many families have had their lives disrupted. I hardly feel alone anymore, and I do laugh and smile, but I never wished for this much company.

The money being spent on research is a tiny fraction of what is needed. For example, we need objective research about the vaccines independent of the scientists who have financial links to the pharmaceutical industry. We need answers about why certain parts of the country, such as areas in California and New Jersey have much higher incidences than other areas. We need to understand more of the neuroscience of autism, so that effective drugs can be developed to reverse the condition regardless of the cause.

Equally urgent is the need for state of the art services for children and their families who have been struck by autism. Research has demonstrated that early and vigorous treatment can make a huge difference in the outcome for individuals affected by autism and other developmental disorders. Alarmingly, a two year old child just diagnosed with autism gets only a few hours of home based services per week, while experts recommend 30 to 40 hours of programming. Parents shouldn't have to beg and scream for services when their child enters public school. Many of these schools are poorly funded, especially in the inner cities, and have inadequately trained staff and few or no opportunities for developing social skills by including children with autism with their same aged peers.

It is heartening to have the issues in public focus. Now let's do our best as a society to find solutions--before it's too late—for someone else. Robert Naseef, Ph.D.

The stress placed on the family of a child with autism is enormous. When there are two adult parents in the home, stress is evident. As articulated throughout the current practice sections of this report, one parent is often designated as the "system navigator" who gives up a significant portion of their life and/or career in order to ensure that their child receives the appropriate services. In a single parent family, this role must be subsumed by an already overburdened single parent.

Life Challenges for the Family of Individuals with Autistic Spectrum Disorder: Issues and Solutions

It is unquestionably clear that the individuals with ASD and their families face unique and significant challenges: psychologically, emotionally and financially, on a daily basis. The ASD individual on his/her special path, struggles to find a way through life's social, emotional and intellectual complexities that we on a more traditional path take for granted. For the family members whose lives are inextricably tied to the special path of their loved one (s), the emotional and psychological stressors are an integral part of their perceptions of themselves, and how they relate to the "outside" world. The relationship of the "ASD spectrum family" to the community and how the community perceives and interacts with the family of the ASD individual presents opportunities to address the needs of the family living the ASD path. This endeavor involves creating awareness, knowledge, understanding, and most importantly, embracing the ASD family as integral members of the community. The report that follows provides some perspective concerning the existent mental health and education programs in the State of Pennsylvania, and how these programs present challenges to the ASD family. These entities comprise two of the most salient links between the family of the ASD individual and the community, and therefore provide critical opportunities for first, providing the ASD family with resources to deal with the aforementioned challenges, and second, assisting the ASD family in integrating into the "mainstream". However, in the considered opinion of the ASD individuals, family members and professionals who comprise this committee, and who deal with these entities on a daily basis, a "paradigm shift" toward integrated assessment, diagnosis and intervention is paramount to accomplish this goal. The committee realizes that these changes cannot be implemented "overnight" and that the political and economic considerations are complex.

Nonetheless, the overarching issues and recommended solutions summarized below, and detailed in the report that follows are both real (issues) and attainable (solutions). The committee unanimously concurs that the State of Pennsylvania move expeditiously to realize the recommendations outlined below.

Overarching Issues (that permeate the lifespan) include:

- Autism Spectrum Disorders are chronic, running through the families' and individuals' entire life span.
- Families experience high levels of stress due to having to navigate a horribly fragmented system. A parent or caretaker must "devote" much of their life/time to deal with the system in order to get their child what they need. Families who do not have an individual able or available to provide this support have greater difficulty accessing necessary services and supports. In a single parent home, this role must be tackled by an already overburdened parent.
- Autism Spectrum Disorders cause families to feel isolation because people (general public) don't understand what it "means" to deal with a person with autism and are often rude and non-supportive as a result.

- The system is designed for intervention for the child/individual only; little support is available for the families.
- Lack of early identification & diagnosis, causing delayed interventions and support to individual and family members.
- There are extremely limited services available to adults.

Recommended Solutions include:

- Establish an independent state-level Department of Disabilities (DOD).
- Establish an improved system whereby the departments, functions and systems that interface with ASD individuals communicate and collaborate together to meet the needs of individuals and families.
- Engage the Department of Education to work cooperatively with DOD to conceptualize solutions, identify goals and implement the programs required.
- Create services, support systems, and networks specifically designed to provide services and support for persons with autism and their families throughout the lifespan (especially including family support services and respite).
- Earlier diagnosis & intervention.
- Establish a case management and advocacy system independent of financial interest to assist families with various issues.
- Eliminate barriers between funding streams to better integrate and customize services for individuals and families.
- Provide consistent access to services across all counties.
- Provide opportunities and services to support social learning and social interaction.
- Public education must provide a leadership role for peer interaction and support. This would include taking a proactive position in understanding that children are in school with their peers for the majority of the day and that curriculum and support services provided to children in the school system must be provided in the least restrictive environment with the opportunity for appropriate and typical peer mentoring and support.
- Identify ways to reach out and connect with individuals from minority groups and other cultures and include cultural competency in all proposed solutions.
- Begin to more fully research the impact of ASD on families, the stressors and the impacts.

A proposed sample model for the Department of Disabilities can be found in Appendix 3 of this report.

2.0 Life Stage: Birth to Age 3

Current Practice and Needs/Gaps

The most salient issue at this life stage is the extended waiting lists for appropriate evaluation and diagnosis. There appears to be a dearth of professionals who are cognizant of the ASD Spectrum and recognize the special needs of the ASD child. There is no comprehensive list of available resources indicating where and how to access services. This creates tremendous stress on the family for lack of recognizing the ASD path and "not knowing" what resources are available to address the issue. Many professionals who have been in the system for "years" are not aware of the recent research or developments in the field of ASD and provide much incorrect or inappropriate information to parents. Many parents are either getting no diagnosis, or the incorrect diagnosis, which compounds stress on the family. These latent diagnoses lead to further delays in critical intervention needed during the early developmental stages of the ASD child's lifespan.

In many communities, Early intervention (EI) services for the ASD child are either non-existent or not known by the general community. Many Early Intervention providers appear to lack knowledge and perspective to share concerns and respond to the ASD family. The experiences of the parents and professionals on the task force indicate that practice varies widely from county to county, and without the resources to poll and compare the practices within each county, it is difficult to state the full extent of the problem that is apparent to task force members. Child-care centers and early education providers also exhibit the same characteristics as early intervention services and often lack the resources to support children with special needs. This may result in alienation of the ASD child within the daycare environment, if a daycare can even be found to provide services.

After Jesse's first 15 months, Roy and Cheryl started to sense differences in his development, as compared with their two older children. They spent the following year nervously and repeatedly visiting their pediatrician to seek reasons for Jesse's gradual loss of language, peculiar and challenging behaviors, crying tantrums, and periods of unresponsiveness. They also went beyond the pediatrician's guidance and had Jesse's hearing tested and an EEG done.

When his preschool handicapped class psychologist finally threw out the possibility of autism, a neurologist who fit them in after a two-month waiting period confirmed a diagnosis of autism within five minutes of looking at Jesse. They struggled through many doctor visits to rule out sore throats, earaches, and other medical ailments that Jesse was not able to communicate. They made these visits as a last resort; because she dreaded Jesse's intermittent screaming outbursts in a full waiting room (Cheryl still does not know what it is about this environment that precipitates these outbursts).

Seven years later, the family has been to four different health professionals for autism and has told its history of care (while disagreeing about what really worked, what didn't--including such treatments as auditory training and dietary intervention). The family currently doesn't know whom to go to next, and Cheryl and Roy disagree about whether Jesse should be put on medication to treat his increasingly frequent self-injuring rages. They have already spent roughly $20,000 in self-funded medical expenses (representative example drawn from postings on online communication service (TalkAutism, 2003).

Another example of an early intervention experience follows:

My son was born 6 weeks prematurely. My mother and grandmother had died both within a month of each other and one month before my son was born. Basically my last trimester was very emotional and the premature delivery was not that uncommon. We had a very difficult delivery and even rougher recovery for me (18 stitches). For other medical reasons I was unable to breast feed and have always thought that this was the reason for his constant illness as an infant.

During his first year, he had been hospitalized twice. At 2mos, for RSV, and then again at 1 year for dehydration due to a blocked bowel. My son then went on to have many ear infections when he was 9mos-18mos (some back-to-back) that by age 2 we thought he had hearing problems. This brought on our concern about his development. By that time he had not muttered a word. Only babble and jargon that was not understandable. He was inconsolable and really did not like to be held. I just thought he was "high strung". His pediatrician told us not to worry that all kids develop on their own terms and that we should not be too concerned. Well by age 2 1/2 I knew something was not right. Nothing had changed.

I consulted a different Pediatrician and of course he was the person I should have been going to all along because he was knowledgeable in PDD. But being a first time mother, I really did not know what I needed to know. Anyway, I was then directed to a Neurologist who did some tests and gave us the diagnosis. After we left the Neurologists office, I looked at my husband and said now what? It was the most confusing, emotional and upsetting time of our lives. It got worse because not a lot of doctors had experience with Autistic children and the ones that did, you couldn't get an appointment with them for several months.

I came to quickly realize that if I was going to get help for my son, it was going to have to come directly from me. That is exactly what I did. I was ravenous for information. I read anything and everything I could get my hands on. I talked with researchers, I met with therapists and as many parents I could find with similar concerns. As a result, I had come up with a cross-pollination of different therapies that I knew would work for my son based on his abilities, and personality.

I hired several college kids over the years who were going to school for special education and would work with my son for 20-30 hours per week. The main reason I did not take this task on myself was an emotional one. I needed to separate myself from this so I could be the Mother and not the instructor. Kids behave differently when they are in front of their parents than they do with others, so I took advantage of that fact. I could not begin to tell you how well this worked out for us. In life, when you don't know something, you ask someone who does.

That is why I formed a Personal Board of Directors that I could turn to answers for Michael. When my son exhibited a behavior that we knew needed to be changed, the board members were contacted (parents,

family, friends, educators, therapists, volunteers) and we all got together to discuss what needed to be done. Most of the time is was just me addressing all of my son's issues. A clear example of this was at age 2-3 my son was not sleeping. Could not get him to nap or go to bed till very late at night, sometimes until 3:00am. This was very exhausting. So, I decided that he had a lot of energy and he needed to "run it out" on a daily basis. I took my son to the park near our home after work everyday and let him "run it out". I did this for about 6 months. By doing so I was able to get him on a regular sleep schedule. This greatly improved some of his other behaviors that were caused by lack of sleep.

My point to telling you all this is that, if I had to do this all over again, I would wish that any mother in my shoes facing this very issue would have the information, foresight and ability to get their child the help they need at the time they need it most. We were lucky, but my son will still have a tough road in front of him. That is why I am so eager to be a part of this initiative and to help others. My experience has taught me a lot. My son is doing well; he still attends special ed, and is in the 4th grade, and making good progress. Our biggest concern is his future. How do we plan for this? I am committed to helping and working with other families that have the same diagnosis and would help the committee to build individualized "Board members" for each of the families who find themselves battling this issue. I look forward to working with the task force and helping others.

In addition, barriers cultural barriers exist for full utilization and effectiveness of early intervention services in many minority populations. Anecdotal comments received from providers suggest that it is difficult for Caucasian professionals to engage members of other cultures into supporting the intensive interventions required by the family members to fully benefit from the early intervention and other services. As one woman beautifully stated:

"We (the blacks) always feel discriminated against. I have work insurance, or otherwise I wouldn't get any services. We (people of color) take care of ourselves and we don't look for outside help. When we face indifference, we don't want any help at all. I tried respite, and I didn't like it. (They told me) you got to do it this way to get that. I just need a time out, but they do not have the right type of program to meet my needs. I take advantage of the programs that I can, but they don't relate to me…There needs to be a respite house of children of color. If it is predominantly white, we can't relate to them."

Solutions

Early diagnosis and intervention is paramount if the ASD child and family are to be served effectively with minimal stress. Immediate connection with an independent advocacy and support network is essential to the facilitation of early diagnosis and intervention. These resources need to be linked to the ASD family through awareness programs and existing infrastructure in the early care and education environment. Education and resources to provide an inclusive child care environment from birth through the early developmental stages is essential. Existing early intervention programs that have demonstrated success need to be funded and propagated throughout existing public and private daycare paradigms.

There is a need for more clinical people who are highly skilled and certified but certification should not be a barrier for highly skilled persons working in the field.

There should be incentives for people to go into these fields. Colleges and universities need to offer programs as well as continuing education and training programs for persons who have been practicing for years. Princeton Child Development Center, Educating Children with Autism (National Resource Council) 2000 is one example of an outstanding program.

Information and resources at this stage are paramount. An 800 number for information and referral either through the Special Kids Network or other resources would be beneficial.

More emphasis needs to be put on recruiting and training professionals from underrepresented populations to support those populations.

3.0 Life Stage: Ages 3-5

Current Practice and Needs/Gaps

Early intervention and a highly structured education program are regarded currently as the best treatments for children with autism, offering the best chance for normal schooling and a more typical life. Families look to professionals to guide them and help their child. However, because of budgetary problems, philosophical differences and lack of understanding of treatments available, parents and school districts and mental health providers can find themselves in conflict about what type or scope of special education is appropriate for the child. Care needs to be taken to examine what therapies and interventions are appropriate for the individual child and family.

Currently, treatment approaches can vary dependent upon the therapist or school. It is imperative that programs in both education and mental health are aware and supportive of treatments that have evidence based results. Currently, there is much evidence for several therapies.

First, much success has been documented in using Applied Behavioral Analysis in the treatment and education of children and adults with autism. It is a technique for teaching tasks or skills by dividing the tasks into small parts and using positive reinforcement strategies to reinforce the skill building. ABA can include, discrete trial therapy, generative instruction and other behavioral interventions.

Another form of therapy used successfully, is Sensory Integration Therapy. This therapy is highly individualized to promote motor development, cognitive development and language. A series of motivating physical activities are used to stimulate the sensory system of the child and encourage skill development. Often these therapies are provided by an Occupational therapist or by therapists trained in SI Therapy.

Another therapy that many families find effective is the model developed by Dr. Sydney Greenspan. Greenspan’s intervention method revolves around a concept he calls "floor time" -- time which the caregivers, generally the parents, spend entering the child's activities and following the child's lead. If the child wants to line up cars in a row or twirl a top, the parents will join the child in his or her preferred activity (with the intent of developing this action into an affective interaction) rather than demanding that the child join them in their preferred activity.

Starting with this mutual, shared engagement, the parents are assisted to draw the child into increasingly more complex interactions, a process known as "opening and closing circles of communication." This method is used to develop language and social interaction.

Since a major difficulty for children with Autism is the use and understanding of language, Speech and Language therapies are crucial. Auditory and Language therapies must work on pragmatics, comprehension, and processing. Speech and language therapy in isolation is not as effective as tying the therapy to the everyday therapy in the home or educational placement.

Others therapies such as medication, vitamins, music and movement therapy have shown success in specific cases and need to be assessed on individual basis for children. Families need to have support and guidance when investigating therapies appropriate for their child.

When they brought little 5-year-old Alex, a nonverbal child with autism, to his first ever "special ed" class, his parents, John and Susie, were unsettled by the fact that he was in a class that did not specialize in autism. After a series of drawn-out meetings with the over-worked child-study team that spanned months, they inquired why the school did not approach their child’s education with the recommended 40 hours per week of intensive therapy cited in Dr. Lovass’ study. "We’re doing everything we can," said the well-meaning learning consultant, whose school was already over budget in this area, due to the influx of students with autism.

With the increasing incidence of autism, school districts are trying to stay ahead of the exploding numbers of cases, increasing the pressure on school districts’ special services programs. However, many school districts fall short of both parent and teacher expectations when it comes to actual management of the classroom and adhering to the students’ Individual Educational Plans (IEPs) (Mayerson, 2003). Some

dedicated private schools provide an out-of-district option, but due to a growing trend toward community integration and the IDEA requirement that students be taught in the least restrictive environment (LRE), more school districts are attempting to establish their own.

Public school districts typically look outside their district to "consultation models" for guidance in establishing their programs. A typical consultation model begins by training staff in regard to autism and to the educational philosophy that will be utilized, and this training is followed up with weekly or monthly visits to provide feedback and ongoing training. Among the many challenges inherent in this model are the ongoing supervision needs of staff, the occurrence of unique episodes requiring immediate consultant guidance, data collection to gauge progress, the breadth of educational autism-related techniques needed by teachers, and the demands of supplemental home programs to support families. In addition, staff turnover is a chronic problem for school districts and has a particularly negative effect when teachers with specialized skills leave.

Alex's teacher struggled to provide him the regimented teaching she had learned was necessary for him to progress and to measure his success. But she was not able to make him sit still for her as the textbooks told her to, and the autism consultant was not expected until next week. She wondered, should she hold his hands when he flailed them? How was she supposed to record all the required data and still have time to prepare the specialized props Alex and her other students for the next day? (representative example drawn from postings on online communication service (TalkAutism, 2003) (Oberlietner, et. Al, 2004)"

Children must transition out of Early Intervention into the educational system at the age of 3. Instead of a family-friendly, seamless transition, parents now find themselves dealing with a completely separate and confusing program. The current system is lacking appropriate educational placements for the ASD child, especially if they are developmentally delayed. Parents are faced with making an educational placement for their ASD child with little knowledge of available programs and services further compounded by the fact that very few options are even available. The initial educational experience leaves parents facing several critical decisions which they will subsequently second guess based on the limited information and time they had available to make the initial placement. The amount of time involved with Individualized Education Plan (IEP) meetings and various services adds increasing stress and demands on the family system. The ASD child and family invest a great deal of time, emotions, and finances on the initial educational experience.

Despite a desire on the part of parents to understand and be trained in dealing with ASD, there is insufficient time or ability to do so. Parental focus on the ASD child may alienate siblings who perceive that the child is getting more attention. This can exacerbate an already stressful environment due to the isolation of siblings with resultant behavior problems.

My son's therapy at home for the past 3 years precluded most family activities because we were required to be at home during his 30 hours of therapy. This meant his typical sister Zoe was often left to her own devices, unable to invite friends over for fear of interrupting or sidetracking Cal's therapy (small house), and subject to many visits to Staples for copying of datasheets, programming info, IEPs and the various paperwork that is quarterly or ongoing. She was also left feeling very unwanted as much of the visitors to our house were there to discuss or observe Cal, and many phone calls were discussions about Cal, or coordinating his various therapies and interventions. Cal was constantly getting new things, and had more access to candy (a primary reinforcer for much of his efforts), a particularly irksome occurrence. On top of this Zoe is a gifted child, and thus has special needs of her own, that are simply not being addressed.

The extended family may also be affected due to a lack of understanding the ASD path and / or taking exception to the course of action. The result may be a "pulling back" of the extended family, who could represent a vital support during this challenging life stage. As a result the time and financial commitment for the ASD parents increases, creating additional stresses on the family.

We have yet to take a vacation, and after 3 years, are just starting to dig ourselves out of the debt of the combination of reduced billable hours and expensive therapies that are not covered by insurance, ignored by early intervention and sorely needed. We are just beginning to feel not exhausted by the constant badgering, nitpicking and fighting to get services. We feel lucky-- because we are still married, and don't have major health issues of our own.

Family members are often seen as resources for the ASD child rather than individuals with psychological needs of their own. There can be a very distinct impact on siblings who may feel overlooked or ignored, due to the inordinate amount of attention given to the ASD sibling. Parent's needs are often also overlooked. There is often little time to focus on other family relationships, or even one's own needs when focus is constantly focused on the needs of the ASD child. According to Marshak, Prezant, and Seligman (1999), in nearly every case, the family of a child with a serious disability will also be affected to the extent that they would benefit from family therapy.

"It is more likely that the family is attempting to cope with recently encountered new stresses or emotions related to the changes, tasks, and role changes that disability creates for family members. Marsh (1992) stated, Psychotherapy offers many potential benefits, including opportunities for family members to improve relationships within the family, to develop more effective coping skills, to achieve a greater sense of mastery and competence, to improve their self-esteem, and to replenish their energy for meeting the challenges that confront them." (p. 207)". Family support groups, respite care, family counseling for ASD families, should all be essential components to an ASD treatment program."

The general public lacks information on ASD and public and social encounters with ASD children may or may not be a positive experience.

We used to visit our local Hallmark store every week when Alyssa was in her Beanie baby obsession. One time they had moved a display and she couldn't see her beanies, she was greatly distressed. They made sure that they never placed a display to block the view of the beanies, and they didn't change the beanie display either. They even gave her a large cardboard heart with TY on it that was sent to be hung from the ceiling near the beanie display. We hung it up in her room at home.

My son has an obsession with "visiting" his favorite billboards. (he is a big fan of logos and advertising). One property owner thought we were stalkers because we often parked in front of his house (which happened to be on a very busy 4-lane highway) for a few seconds on the way to school to get a "good look" at the billboard that was adjacent to it. The property owner yelled and screamed at me and my children and threatened to call the state police on us because he could not understand why we stopped in front of his house. Not everyone is gracious and accomodating.....Interesting twist to the story, however, the day after the property owner yelled at me (my son was in the car), when I told him that the man would be mad if we stopped there again, it was ok with him and he could control the obsession. Go figure.

Solutions

Mandate a health care education partnership from birth through 5. This partnership would remain in effect throughout the 3- 5 years of age. Merge the behavioral plan and IEP into one document that follows the child. Each individual/family should have an intensive case manager who understands the system and can advocate for the necessary services for the individual/family, and that moves through the system with the family. There needs to be a family component and sibling support in the system, before family members are in crisis. Establishing a parent-mentor system would be a helpful support.

4.0 Life Stage: Grade School

Current Practice and Needs/Gaps

The most problematic issue during the formative grade school years is the fragmentation of ASD assessment, evaluation, and provision of services. There is tremendous disparity among school districts in providing services for the ASD child: some environments attempt to be inclusive, others exclusionary; some parents want more special environments and "protection" for the child; others prefer total inclusion, depending upon the family's experiences and histories in the various school systems. Many parents resort to legal counsel to ensure that basic rights are not violated and the child has access to services. Educational services and special needs learning paradigms are not coordinated or consistent.

The MH/MR and education systems are difficult to navigate for families with newly diagnosed children, or those new to Pennsylvania, and little information is readily available. There is no organized list of available resource locations, etc. such as physician's offices, psychologist's offices and most importantly, those specializing in ASD children. There are no clear guidelines concerning how the present system (such as it

is) works, where to obtain resources, order of priority, etc. This results in total bewilderment and confusion regarding a path to solutions.

The intervention approach for ASD children in PA is both inappropriate and inconsistent with their needs. The program comprises a mental health paradigm with release dates for services not reflecting the reality or ongoing path of the ASD child. A neurological developmental disability model that spans the lifetime of the child would more effectively address his/her special needs and problems.

I work at Montgomery County Office of Children and Youth. In my experience I have had the privilege of working with two autistic boys. One boy, let's call him "Josh", was probably diagnosable around the age of three. Sadly, he lived in a situation of abuse and neglect with his siblings. His older brother (12 at the time when Josh was six), was doing his best to take care of Josh. Josh was non-verbal and never saw a medical professional from the time day he was born until he came into foster care at age six. No intervention, no prevention. His teeth were messed up because he was still drinking from a baby bottle for his primary source of nutrition. He still wore diapers. He was also not allowed outside to see the light of day which made his skin virtually translucent and his toenails were grown over the ends of his toes. When Joshua came into placement, you would think it would make things better. While his situation clearly improved, it was a VERY uphill climb to get him services in his foster home. The educational system wanted to wait for an educational guardian to be appointed but they didn't ask for that in the beginning. A bigger nightmare was that Medical Assistance was being managed by an HMO program. They had no clue about the child welfare issues Josh faced. They expected him to be transported 1 ½ hours each way for evaluations in Philadelphia, because that is where they approved him to go to. In the meantime, Joshua, who had no memories of riding in a car, was scared to death of being transported anywhere. This led to Joshua's placement destabilizing to the point that the foster parents couldn't manage him anymore. Josh moved from one temporary home to the next. This added to the difficulty of establishing services. Additionally, his placements led him further and further away from his home area making sibling contact harder and harder. What could have made this better for Joshua? - More funding available for specialized/ therapeutic foster homes (state approved); A centralized system which, once a child/adult is established in that system, follows them with services wherever they go - More funding to enable more ICF/MR placements for adults and children who need that type of placement (while Joshua has benefited from home-like placements, he will need that and there IS a shortage) - More support for the educational system to help maintain autistic children of school age

The transition from pre-school (ages 3-5) to grade school and the complete disconnect between this time period and the grade school education system is particularly problematic. Assuming that parents have acquired support systems in the pre-school years, they are now faced with a new environment with educators who may be ignorant and/or apathetic to the children’s special needs. Many educational administrators in PA have no knowledge of ASD and its nuances. As a result, the transition into the grade school environment is a "starting over" for the ASD family, and the stress induced often exceeds that of the original diagnosis process. Under the mental health model, there is a constant threat of reduction or discontinuance of TSS services every 4 months.

The TSS workers are also often not formally trained in ASD. Moreover, TSS services and support are mental health based and chaotically provided. As a result, the school day now revolves around a 2nd or often 3rd individual to provide social and learning support, making the school day more chaotic rather than structured to the needs of the ASD child. This inconsistency is overshadowed by the constant threat of TSS withdrawal under the mental health model (i.e. reduction in services over time as the child becomes more successful; the "mental deficiency" has been "cured"). This makes it virtually impossible to plan effectively for the child’s school year.

In some districts, periodic school/community "theme" or "activity" days provide opportunities for students, parents, and siblings to participate and socially interact with one another. However, family issues are not the area of concern in these forums; rather the focus is academic.

There is no information and support for those relocating to the state from other areas. Moreover, there are no guarantees that the educators in Pennsylvania have knowledge of, understand, or are interested in addressing the special path of the ASD child. This is painfully obvious from the following story of one committee member’s personal experiences with a Pennsylvania School District:

Jonathan was a joyful child, born and raised in the state of New Hampshire, up until the age of seven. He could read at age three, do simple math, tell time, and many remarkable things, However, Jonathan also clearly exhibited PDD related symptoms and all the difficulties that diagnosis entails ... it was painfully difficult for him to simply communicate and socially interact with his peers. Luckily, NH had a remarkably seamless and effective system, which kicked in immediately to Jonathan's benefit. There was cooperation across state departments, and even school districts, so that he received wonderful services from preschool age on. He had the services of aides who were always well trained in his disability and knew how to help him communicate, socialize and participate in academics, as well as OT and speech, etc. on site. The private preschool (of our choice) was also paid for, because of his desperate need to be around typically developing peers and to learn from them. When Jonathan was going into first grade, and had to leave his preschool (had been there since age 21/2), and transition to his home school district, his aide met him at his new school, two weeks before classes started. For a few days, she spent some time with Jonathan in his new environment. Before school began, he knew his new school intimately. He had played on the playgrounds, and met the lunch ladies (who plied him with cookies), knew his teacher, and was very comfortable. When the first day of school arrived, out he hopped and joined in with the throng of children. Those few hours of the aide's time, cost the state very little, but it meant the world to Jonathan and his family, and avoided much more costly interventions down the road. Jonathan thrived in his totally inclusive first grade setting, just as he had in his inclusive preschool. He participated in plays and all other activities and was a joyful, loving little boy, with friends and school teachers and administrators who loved him and respected him.

Toward the end of first grade, Jonathan's dad accepted a position in southeastern PA and moved there, while Jonathan and Mom stayed in NH so that Jonathan could finish out a very happy and productive first grade year. Our family, having had such positive experiences in New Hampshire, had no inkling that there could be such vast differences between states for our disabled son. We eagerly looked forward to the move, despite the usual sadness in any goodbyes, and Jonathan became more and more excited as he watched his new house going up, and learned that his favorite ocean spot was now so close, as well as some beloved older "cousins" (our godchildren), He had toured his school beforehand, with Mom and Dad, and met the head of Special Ed. for the district, and so he entered his brand new school that first day, with some apprehension, but also with his customary smile and eagerness to please. How could we ever know that we were actually sending our precious son off into a long nightmare?

I could go on forever about the things Jonathan endured at the hands of his new PA elementary school. It is painful to even have to relive them here. Jonathan was referred to, by the school administrators, from day one, in grossly inappropriate terms, as if their first priority was to "protect" their staff and the other children from our son. I found out that his assigned aide knew nothing of his disability at all. No one had even bothered to discuss what Asperger's was and how to handle any situation at all. They lost my little, scared 7 year old one day. I arrived at school to find that no one even knew where he was. I raced, with heart pounding, to find him myself and finally located him outside, in a construction zone, near where I always picked him up in the afternoons. He was lying, face down, on the cold ground (it was winter) and he told me that he was "dead" in this school and that is why he was there. He looked terrified. The Principal and Asst. Principal were furious at HIM, and screaming at me, and were not the least bit apologetic about his disappearance or the many dangers he could have faced. Jonathan changed into a different little boy, right in front of the horrified eyes of our family, in very short time. He rarely laughed or sang anymore, as he had in NH, he had trouble sleeping and hated to get out of the car and go into school in the mornings. He became so thin that his ribs protruded from his body. He had always had such a joyful, playful personality and it all disappeared so dramatically, I hovered by the phone each day, jumping every time it rang, worried all day long about how Jonathan was being treated for all those hours. The only peace I had was when he was at home, and I could keep him safe from their ignorance and hostility. I began to find out slowly, from other parents in the area, that our school district always "shipped" ASD children out to places like Vanguard, and other non inclusive environments, and did nothing but document reasons why that should occur from the first day they entered the building. We just could not comprehend this, at first, even though we discovered that another little boy in our neighborhood endured that 50 mile journey each day. We continued to try to "hang in" and educate the administration to preserve our son's customary inclusive environment. Dr. Teresa Bolick, (Jonathan's NH specialist), quite renowned for her work in ASD, called the school. She talked to the administration for over an hour and gave them her telephone number to call at any time. They never made use of her number. Then, to out HORROR, we discovered that the school administrators were repeatedly locking our beautiful, trusting little boy in a small dark room, and for extended periods of time. No wonder Jonathan had told me "they

treat me like a wild animal in PA, Momma"! Jonathan was absolutely terrified of this room and began to kick at them and try to fight back, when they came to drag him off, humiliating him in front of peers and staff, which they then used as their justification that they had had to be protected from him all along. The end came one afternoon at 1:30, when I received another call from the school administrators, telling me to come and pick up my son. I literally raced to the building that day and walked in to discover my precious little boy, locked in a small dark room, terrified eyes looking out through the small, slender pane of glass in the door. He was humiliated for his Momma to see him that way, his spirit broken in pieces. He had apparently, been removed from math class (math was at 9:00 am), for" not sitting down, when asked twice". I have never gotten an answer as to how long my child was in that dark room that day, before I was called, but I suspect it was many hours. After begging to be let out for so long, he had finally thrown a plastic chair toward the door, desperately trying to get out of his prison. They had the audacity to tell me that they had then called the police when he had done that (although he was the only one in the room and so the only one who could have gotten hurt by it)!! I told them calmly that I cared not at all what they did from that day forward but that I was taking my terrified little seven year old and heading home. I rushed past them to hug my son, who was apologizing for being such a "failure" in PA and sobbing... I am proud of myself that I stayed calm for my Jonathan, who desperately needed his calm and reassuring Momma at that moment, but how I would have loved to have given each adult standing around me, a detailed opinion as to their value as human beings. My Jonathan begged me to hide him from the police all the way home, and kept apologizing over and over for being a "failure" in PA, despite my reassurances that HE was NOT the one who had failed at that horrible school. I tried to explain to him that it was all the adults who had failed and that I was proud of him for being so incredibly brave as to head into that awful school each day, trying anew. I told him that he had more courage than I could ever even imagine and that now it was my turn to protect him and find him a new school, with nice people like New Hampshire waiting, where he would be happy again. I begged his forgiveness for keeping him in that school so long and promised him that he would never have to go back there again ... ever.

Jonathan was schooled at home for many months, after his first school experience in PA. We spent hours and hours searching for totally inclusive environments, similar to New Hampshire, where Jonathan could, hopefully, begin to recover and be happy again. While many were far better than what we had left behind, we still found there was a serious underlying problem in this state, in almost all schools, with their attitudes toward our ASD children. We began to feel that we had literally destroyed our son's life, by moving him to PA, and even contemplated a move back to New Hampshire. Fortunately, the ending of Jonathan's story is a happy one, by one of those sheer miracles that happen from time to time. Just as we had all but given up, a brand new charter school opened up quite near us, with probably the best educator we have ever seen at the helm, as principal. Jonathan has been at his new charter school for over a year now and absolutely adores Dr. Kevin Brady, a virtual dynamo of a principal, who understands our ASD kids, and gives them every opportunity to shine and feel good about themselves. All of this on a very small budget, I might add. Knowledge and compassion are not expensive. In fact, it is when they are lacking, that everyone pays a very dear price. My Jonathan is absolutely thriving again, in this totally inclusive setting, and can't wait to get to school each day. Dr. Brady now has him in a very gifted math program and this language impaired child even adores his Spanish class. His wonderful spirit and joyous outlook have returned, slowly at first, but back at last! Happiness has, once more, descended on our family, however, we are constantly thinking about all those other children, and their families, still dealing with school administrators like those who abused my son so horribly. Or the countless others who are in totally isolated environments, despite needing so desperately the interaction with typically developing children to flourish and develop. Yes, the educators in PA need educating about our children, … and desperately so.

Solutions

The most important endeavor for the Department of Public Welfare is the creation of a state-level "Department of Disabilities" (DOD) addressing all life stages on the ASD path. The charter for the Department of Disabilities would be to create an integrated state system with consistent services from diagnosis onward. The goals of the program would include the following essential elements:

- The Department of Public Welfare, through the DOD and the State Department of Education should coordinate efforts to develop and integrate systems for diagnosis, treatment, program development, training, providing inclusive environments to the best abilities of the child, and one-to-one aids or related support for ASD children.

- Educational administrators and teachers should be mandated to receive training and education concerning ASD and its impact on social, emotional, and learning aspects of the educational paradigm.
- One-to-one aides (now TSS) or related staff should be properly trained and state accredited. The state should take responsibility for providing one-to-one services that are integrated into all aspects of the ASD child's educational and social development. This would include school, social activities, after school plays, community based activities, summer camps, playgrounds, preparation for transitions to new schools or classrooms, etc.
- ASD children should be included and mainstreamed within the educational system and community programs with typically developing children as much as possible to facilitate their social and emotional development (Harris & Handleman, 1997; Burack, Root & Zigler, 1997; Whetherby, Schuler & Prizant, 1997; Marcus, Garfinkle & Wolery, 2001). Obviously, parents' choice of setting and level of comfort are paramount.
- Model pilot programs such as the Avon Grove Charter School in West Grove with a totally inclusive environment for ASD children (and all others) integrated into the school culture, accompanied by a family atmosphere. While no one school is "perfect", with a knowledgeable principal at the helm here, ASD children's special needs are most often recognized by peers, teachers, and the children are treated with respect for their unique path. The Avon Grove Charter School example, or similar models, should be further studied, refined, and funded as a cost-effective paradigm to meet the need of families and their ASD children.
- Public Schools model program from Grade School through High School called "Friends need Friends." A working example is located at Trinity Area School District in Washington Pennsylvania.

Some recommended programs (not all inclusive) to facilitate the above goals include:

- television Ads and public awareness programs
- creation of common resource directories for state-wide programs
- information on ASD in all pediatric offices, clinics, mental health professional offices, hospitals, etc.
- school based programs, literature, and informational pamphlets
- establishment of advocates to assist parents in navigating the portfolio of available resources
- ASD training and education programs for educational administrators, teachers and support staff, and the community at large
- choice of resources within and across school districts tailored to individual family needs
- establishment of parental and family networks to provide education and support
- implementation of a "Best Buddy" program where typical children volunteer to be a "buddy" for a child with a disability and have contact with them once a week
- modeling and propagation of successful mainstream programs into school districts on a state-wide basis

Special Consideration for Cultural and Spectrum Differences

It has been pointed out that families of other cultural backgrounds are more reluctant regarding home visits due to intrusiveness and suspicions. Another venue where they can feel more comfortable with delivery of support services is required. For example, a local clinic with professionals trained in their own communities and/or languages.

ASD children with more severe disorders (regulatory, perceptual, sensory, emotional) may require special environments with less stimulation and more relaxed atmosphere ("low and slow"). Programs need to be customized to meet individual needs.

5.0 Life Stage: Junior High

Current Practice and Needs/Gaps

Private schools appear (in some cases) to be able to provide supportive environments and programs that benefit students with far less resources provided (and consumed) in the public sector. However, these entities cannot access resources and supports available to public school districts.

Social issues intensify during this life stage. Peer pressure clearly begins to influence behavior and alter self-perception in the ASD child. This may result in further isolation and stress for the child, siblings, and the remainder of the immediate family.

Puberty issues/hormones also begin to impact the teen. Concerns in this area underscore the need for new tools and skills that may not be easily integrated. Sometimes this results in increased aggression in the lower functioning individual.

Medication issues due to hormones/depression/emotional concerns often need to be addressed. The lack of coordination for these services causes families to be unable to make informed decisions regarding medications and behavior management of symptoms.

After school and respite care are an ongoing issue that continues to impact time and family emotional resources. The lack of such care creates an additional burden for working families who are unable to appreciate the "regular family time and social interaction."

Social prejudices begin to become more visible during this stage. As the child gets older, the community becomes less tolerant of differences. As a result, families become more isolated.

There is a need for activity programming. Families are often unable to find activities/programs that interest the teen and that are appropriate for his/her developmental and chronological age. This results in continued isolation, family relationships are threatened, there is a high risk of marital problems, etc.

There is a lack of professionals who have experience in assisting parents with looking at education and training options for individuals with ASD. Because of many challenges that ASD individuals begin to experience, coupled with the lack of public of public awareness and understanding of ASD and how to deal with persons with ASD, adolescents frequently get "into trouble" and often end up interfacing with other public systems, like Children & Youth, Juvenile Justice, etc. If the family and other systems do not appropriately support the family, interfacing with other systems could happen earlier. Regardless of the timing, ASD individuals that must deal with additional multiple systems put additional stressors on the family, with one more set of professionals to deal with, and another group to attempt to educate regarding how to handle persons with ASD.

Solutions

Private schools that can provide supportive environments for ASD individuals should receive funding allocations: allow the resources ($$) to follow the students.

Peer support groups can assist the ASD teen in dealing with social issues and peer pressures. Sibling training and support groups can support siblings and reduce stress for these individuals. Skill training for families can assist the family with puberty issues.

More accessible respite and development of after school programming will permit more quality family time.

Medication and behavioral concerns may be addressed through intensive family case management.

More community education and awareness about Autism, including parent-to-parent support; and the fostering of social groups across diverse populations can mitigate social prejudices. Education should be provided to teachers, community service workers and others (particularly police) in how to deal with persons with ASD.

After school programs and activities tailored to the needs of ASD teens will provide much needed support and respite for families.

Increased and funded programming like the model being developed in Chester County would go a long way toward increasing awareness of and support for ASD individuals.

Special Consideration for Cultural and Spectrum Differences

Depending on where the teen is on the ASD spectrum, socialization issues and peer support may require a different approach. Single parents or working parents are in particular need of respite and after school programming (Powers, 2000).

6.0 Life Stage: High School

Current Practice and Needs/Gaps

There are currently no high school programs to help ASD teens adapt socially to the subtle demands of the high school environment. High schools are neither aware nor equipped to reach out to the community for assistance, or facilitate the transition to vocational training or college environments. This only serves to foster continued social and emotional alienation from the "mainstream". The lack of awareness and even a policy that would begin to address the transition from the Junior High stage make this a critical needs area.

Some school districts have programs that pair typical kids with ASD kids that are beneficial to those who participate in them. Transitional Employment Consultants (TEC) are provided in some areas to assist in helping to find gainful employment for individuals who will not be college bound.

Specific stressors on the individual/family during this life stage:

- concern over what will happen to students if they are not there, what will these students do without parental support
- worry about sexuality issues
- looking ahead to losing BHRS and supports

Solutions

A top priority is increasing the awareness of ASD and the social / emotional challenges of the ASD individual. Assessing the resources and support that would provide maximal benefit to the ASD student would be appropriate. A needs assessment to identify current gaps in the system and the most appropriate allocation of funding and programs might be warranted.

Student support groups and advocacy for ASD individuals are a must. There are programs which provide skill building for the ASD individual (e.g. Washington County's Transitional Employment Consultants) but the need far exceeds the capacity and training offered through such programs. There need to be a variety of programs available to help ASD individuals at this life stage obtain much needed skills to help foster inclusion and peer relations.

Students that can perform academically may need social and other supports.

7.0 Life Stage: College (18-21)

Current Practice and Needs/Gaps

Educational, behavioral and social challenges of the college environment will most likely be overwhelming to the ASD individual first entering the higher education system. There are currently limited resources available at this life stage, since ASD is either not recognized as a major issue in the higher education system, or there is a lack of awareness of ASD and its challenges for the individual involved.

This life stage is further complicated by the decision by the ASD individual and family as to where the college-bound individual will reside. Parents are either faced with the stress and worry associated with letting their ASD child leave the home or the continued housing and responsibility of the individual at home. Either option is likely to cause additional stress and there is little information or resources available to help the individual and parents make an informed decision.

Solutions

The first and essential mandate is to build awareness of ASD and the sensory / regulatory and social challenges that the path entails. An open question within this life stage is the extent to which there is an immediate need for major resource allocation in the college environment. What is the extent of ASD students in the college population? Given that ASD awareness and support programs continue to evolve in the earlier life stages, the number of ASD students in college environments may expand rapidly when the successes from these programs transition into college.

In the interim, there are specific programs that may be undertaken. For example, provide one to one interventions and other support services to maximize the likelihood of success for students in school. The support individual must be multi-disciplinary to appreciate and assist with both academic & social issues. College/University professors need to have training on how to support/ deal with individuals with ASD; information regarding how to design class schedules so that individuals with ASD aren't overwhelmed and can be successful.

A "buddy" program with typical individuals would also be helpful. Social and support groups that include both typical and ASD individuals could be a major resource. Consider developing internship programs for special education and psychology majors who are studying to be professionals in these areas to provide support services for ASD individuals at the college level.

8.0 Life Stage: Transition to Adult (18-21)

Current Practice and Needs/Gaps

There is currently a less than optimal match of skills to job that increases the likelihood of failure, resulting in family stress and an individual sense of failure.

For those individuals who choose the business environment, there is a paucity of support services and vocational skills training. ASD individuals require assistance to maintain success on the job. The challenges of the ASD path create stress in the work environment. There may be concerns on the part of peers and employers on how best to help ASD individuals succeed. There is often a frantic search for supports with no integrated source to obtain them or awareness of programs that do exist.

Counseling, relief, and respite are generally not available or not affordable.

Transportation may be difficult to arrange; social skills opportunities to meet typical and ASD peers; family and ASD individual may feel isolated, may experience anxiety, depression; or sense of missing important life goals. Problems may jeopardize parents' employment or marriage.

I do have a daughter who has HFA, is 17 years old, and has not received one iota of transition services from our school district or IU. They totally ignored her when she was 14. Despite having IEPs that list a variety of transition services that she needs, nothing has been delivered and she is not even invited to IEP meetings.

It is my understanding that a group here in Southeast PA is preparing to file a class action suit against the state regarding transition services since children in this area are not receiving any services.

Solutions

The concept of a job coach who can provide one-on-one assistance to maximize the ASD individual's success on the job may be appropriate. Earlier educational focus on marketable skills; e.g. computer science and math, would help prepare ASD individuals to successfully enter the workforce.

Training and funding for people who provide respite, relief or specialized counseling could provide needed guidance and support to individuals and families.

Relief care could provide several hour breaks during the day or evening for parents to attend functions, keep appointments, and focus on another child. Relief care could be provided by a team member who would go to a house or a drop off site.

For those individuals who are more independent, assisted living arrangements may be required.

Special Consideration for Cultural and Spectrum Differences

Some ASD individuals will benefit from counseling. Some may need sheltered workshops or day programs such as those the MR system can offer.

9.0 Life Stage: Adult (21+)

Current Practice and Needs/Gaps

There is little information available regarding the actual incidence of ASD in the adult population. Professionals cite that years ago individuals were diagnosed with schizophrenia or other mental health diagnoses, rather than with ASD. As those who are now in grade school/high school transition into adulthood, the question of who is going to be the caretakers when the aging parents are either deceased or can no longer take care of them is a difficult issue for families. ASD Adults can often perform well in the job environment once trained. However, they may have difficulties surrounding changes in environment and social situations; this again results in stressors; parents and siblings are concerned that there "is nothing out there" for ASD individuals.

ASD individuals often experience great difficulty with police or emergency room staff, whether a medical, psychiatric or behavioral crisis is involved. Hospitals lack knowledge and resources to help. Police sometimes overreact; causes extreme stress; risk of injury.

Housing is a huge issue for adults. There are some emerging models for housing for persons with ASD, but there are not options in every area.

The voice of one of our subcommittee members speaks eloquently to the special path that the ASD individual faces throughout life and are further complicated as he/she reaches adulthood:

The most hard part was being part of the school for school work but not being part of the school for the social part. I never got invited to any parties or things. It made me think. " Why am I not invited? What's wrong with me?" Even people I thought were my friends didn't invite me. When I got upset, they would tell me to just calm down. I went to events like basketball games by myself and sometimes I would sit with a group but mostly I went solo. I went to the prom but with my cousin, I tried not to let anyone know.

I have never had a first date. There were girls I was interested in but never went out. Some people made fun of me for this too and said some things about me I can't even tell you. Even now with my working at night, I do not have the chance to meet a girl.

Since I am really good in math, some kids made me feel bad by making me do math problems in front of everyone. I felt really funny about that. If it was to get into GATE or something that's different.

I wish that I would have been given more chance to go to special ed in the regular school. I didn't go until I was in 12th grade. When I went to school I felt like a regular senior. I wish there had been a "Be a Buddy system" for me to have someone to be with and help.

Although I am functional, my case of autism has caused me to be somewhat of a shy person. People have mocked my raspy voice and asked me to do complicated calculations for no legitimate reason. Also, I never dated any women. Some people teased me about this as well. At times, I have a hard time determining whether people are joking with me or insulting me. On the positive side, I have an uncanny knack for quick mental calculations. I earned a BS in Civil and Environmental Engineering from the University of Pittsburgh. I got financial aid from the office of vocational rehabilitation. Also, I have a recollection of facts and figures from other walks of life. To summarize everything, autism has been an intellectual boost but a social disaster. I hope and pray that a cure will be found soon. Jeff Hudale

It should be noted that although Jeff has an engineering degree, he is currently employed as a stock clerk in a grocery store. He did have a job in his field, with a company whose owner had a child with autism. He was laid off due to economic conditions and has not been able to find another job in his field.

Feedback from families and professionals also suggests that many adults with ASD may never be able to fully in the work setting without supports. While it could be true for some that they could obtain employment and be successful once making the initial transition, others have exceptional difficulty interviewing well and negotiating the hidden curriculum or office politics on the job making it almost impossible to maintain employment without sustained supportive services.

Solutions

Evaluation of vocational and residential programs for adults with ASD indicate that with appropriate support, they can be contributing members of the community and experience good quality of life (Van Bourgondien & Reichle, 1997 and 2001; Van Bourgondien & Woods, 1992; Person, 2000). Additional research and evaluation is required to extend, evaluate and apply the encouraging results attained with these programs to the adolescent and adult ASD community (Mesibov & Handlan, 1997; Gerhardt & Holmes, 1997).

Job coach, skill training, etc. (see transition to adult in section 10.0) There needs to be people who are specifically trained to deal with adults with ASD and how they should be supported. Services and supports for adults and seniors with ASD are important to have available.

Advocacy and information concerning available resources for the ASD adult.

Training for police and emergency personnel. Medical website with information and emergency advocate information would be a valuable resource.

Add a registry of individuals to police database per parental consent, so that police are informed that individuals have a disability and are not a threat.

There needs to be a range of appropriate options for housing and supports for ASD individuals.

The concept of one-on-one aides proposed for the earlier years could also be propagated to the adult ASD individual.

Provide a job coach and supportive services to adults who need them to maintain employment.

Special Consideration for Cultural and Spectrum Differences

Some ASD individuals will not have marketable skills and will fare better in a sheltered workshop or day program such as are provided by the MR system; intensity of services and support and degree of need are different across the spectrum.

The intensity of services, support and degree of need are different across the spectrum. The severity of symptoms reduces the likelihood that an individual will respond to conventional resources.

10.0 Other Needs

The Medicaid System

The Medicaid system is a physical health plan that can provide respite and home health aid. In addition, it is also a source of funding for Behavioral Health Rehabilitative services for Medicaid Eligible children. However, the current system often cannot meet the needs of persons with Autism.

Since Medicaid is a medical necessity model, training and support cannot be obtained. There is a Mental Retardation component that cannot be accessed by ASD children, unless there is an MR diagnosis in concert with the ASD diagnosis.

Since the ASD path comprises a neurological and/or communication disorder, it does not fit in the mental health paradigm

Families cannot afford the out of pocket expenses to pay for support services.

Solutions

Mobile outpatient therapy services are available for the family. Programs can be created to address sibling needs in dealing with the ASD path.

Since Medicaid is a health-based paradigm, systems need to be linked so that services may be accessed through alternate funding streams.

Case managers within the system can provide the family with alternate paths to support services through alternate systems.

Siblings of ASD Families

There is a lack of sibling and support services for families affected by autism. The impact of the ASD individual's path on siblings is a recurring issue throughout the life stages, including: 1) siblings' feelings of alienation due to the inordinate family time commitment to the ASD child during the early years; 2) increasing peer and social pressures on siblings from the community during the adolescent / junior high stage; 3) sibling concerns regarding the future of the ASD individual during the transition to adulthood. Although there is a historical awareness regarding the impact of the ASD path on siblings (McHale, Simeonsson & Sloan, 1984; Fromberg, 1984; Konidaris, 1997), intervention programs are lacking.

Current research indicates that the family environment modulates both sibling acceptance of the ASD child, and the social/emotional relationships between the child and other siblings. As expected, some families of ASD children are adversely affected, while others are better adjusted.

Compromised sibling relationships in the ASD family are associated with increased stress on the marital relationship, the family system and lower levels of coping compared to typically developing families (Rivers and Stoneman 2003; Sivberg 2002). In a study of 22 siblings of children with autism, siblings were found to have more behavior problems and fewer prosocial behaviors than a normative sample (Hastings 2003a). Similar results were reported in a comparison of sibling relationships among autistic children, Down syndrome and normally developing children (Kaminsky and Dewey 2001). Sibling relationships among children with autism were characterized by less intimacy, prosocial behavior, and nurturance, than those of the two comparison groups. However, both siblings of children with autism and siblings of children with Down syndrome reported greater sibling admiration and less quarreling and competition in their relationships compared to normally developing children. Parents of ASD children may compensate for the ASD child's difficulty in relating to siblings, as reflected in increased initiation of play behaviors toward the ASD child (el-Ghoroury and Romanczyk 1999).

Other research has indicated more positive adjustment in the ASD family. In one study, behavioral adjustment of 78 siblings of children with autism on Applied Behavioral Analysis (ABA) programs indicated that there were no increases in behavior adjustment problems for siblings of ASD children compared to a normative sample (Hastings 2003b). Moreover, siblings of less severely autistic children had fewer adjustment problems when more formal social support was also available to the family. The siblings of children with High Functioning Autism (HFA), although experiencing more behavioral problems than the siblings of normal children, did not have increased adaptation problems (Verte, Roeyers and Buysse 2003). Large family size has also been found to facilitate healthy adjustment in siblings of children with autism (Kaminsky and Dewey 2002).

Thus it appears that sibling relationships in the ASD family may be affected by several factors including the severity of the disability, family size, outside social and psychological support, and the relationships among family members.

Clearly, there are challenges for the family and siblings of the ASD child. Probably the most significant challenge is the disproportionate amount of time and attention that the parents devote to the ASD child

relative to the typically developing children (Wing 2001). Other issues include: 1) ability of the typically developing sibling to socially interact with the ASD child; 2) acceptance of the ASD sibling by the typically developing siblings' peers; 3) siblings' concerns regarding the behavior of their ASD sibling in social situations; 4) adolescent siblings' concerns regarding their future children's risk of the ASD path.

Appendix 4 contains excerpts of sibling stories, please review to hear first hand what it is like to be the sibling of an ASD child.

Solutions

- Parental awareness that typically developing siblings may feel neglected or resentful of the inordinate time and attention given to the ASD sibling. Parents should be cognizant of this, and provide for social interaction and time with the siblings accordingly.
- Education and sensitivity training of typically developing siblings about the ASD path, its challenges, and opportunities for emotional growth and understanding the uniqueness of the ASD sibling.
- Typically developing siblings should have opportunities to socialize with peers outside the immediate context of the family environment.
- Awareness and education of sibling peers, with facilitation of social interaction among peers, the typically developing siblings, and the ASD sibling to encourage respect for individual differences.
- Encouraging open and candid discussion regarding sibling perceptions and emotions regarding their ASD brother / sister. Where appropriate, counseling services for siblings should be made available.
- Ongoing, direct assessment with family members along the life path of the ASD child and the possible need for sibling intervention. This issue may become more apparent during transitions in the life path (e.g. grade school, early adolescence).

Intervention for siblings and families should occur before they are in a crisis situation. This area requires further assessment and program recommendations. There are programs available in the State of Pennsylvania, such as SeaShore House within the Children's Hospital of Philadelphia system.

Community & Other Systems

Advocacy – it is difficult to get consistency among programs and services in a geographically large state.

There is a lack of funding for other family support (e.g. babysitting, after school care, family support groups, other respite care).

Families cannot navigate through the process due to differences between and among people on the autism spectrum; it has been challenging given the diversity to rally around a common cause. Many families of more profound autistic individuals feel "left out of the process" and under represented at many forums.

There is a significant need for programs to support families of the more severely affected individuals on the ASD spectrum as related below:

My name is Susan F. Rzucidlo. I am mother to 4 wonderful children. My second born son, Ben, is 12 years old and has Autism. His original diagnosis was "SEVERELY IMPAIRED WITH INFANTILE AUTISM." How¹s that for a kick in the stomach! Nothing like hitting rock bottom from the beginning. Ben now speaks on about a 2 - 3 year old level. He was non verbal until he was 6 years old. He had language at 12 months and lost it all by 15 months. He reads and does math on a First grade level. He is a non-aggressive child who only during the past summer has been partially potty trained (urine only). When Ben was diagnosed I never, in a million years, thought that I would be changing a diaper on a child with pubic hair. Imagine that! When you go into a drug store and buy deodorant and diapers for the same individual you know your life is surreal.

Ben is a confirmed runner. He has been picked up by police in 4 states. While he has been taught to give his name and phone number to anyone who asks he has NEVER given it to a police officer when he really needed to. My house is locked up tight 99% of the time. What can I say, I can¹t be 100%. I could go into a long letter about the numerous therapies both medical and behavioral that we have tried for and with Ben. It is a long and sometimes interesting story. I could tug at your heartstrings and make you cry for

my family. I could make you laugh out loud at some of the antics and situations we¹ve been in. I could make your blood boil at the injustices that have been perpetrated on Ben and my family, but what I really want to tell this panel is what needs to be done for families in Pennsylvania.

In Pennsylvania we need:

- services that are NEED driven and not driven by the DSMIV alone.
- true communication and coordination of services across the many agencies we must work with.
- access to trained individuals to work with our children.
- after school programs for the 9 and up age range that gives respite to families and gives a more typical activity schedule for these kids.
- programming for the 14 and up that teaches good work skills at whatever level these kids can work at.
- A fully funded ALAW project for the state
- More educational settings and opportunities
- Staff that can take these kids out and teach them in the community
- education for medical personnel about Autism. What it is and What it is NOT.
- education for medical personnel so that they can diagnose early on and not have the wait and see approach
- shorter wait times for access to medical personnel.

In Autism we need:

- a less subjective diagnostic tool with more defined categories
- more acceptance of the wide range of interventions.
- fewer professionals who make a financial killing off of our kids. Everyone has a right to make a living but it is wrong to gouge our families.
- Fewer people self-diagnosed at 40 with autism who make the rounds at conferences giving a false sense of the significance of the diagnosis to families.

I hope that my input is taken into consideration. It is my sincere hope that families with lower functioning children are listened to. Many are not as politically active that is because of the significance of what they live with. Many are dealing with aggressions that keep them virtual prisoners of their children, unable to leave the home, unable to advocate for themselves. They are unable to find staff to work with their children because of the severity of the behaviors. The same behaviors that "experts" say they are there to correct. Even the experts leave these kids alone. They are exhausted, financially, emotionally, and physically. I am fortunate, I have the passion to speak and I do speak out. Know that we are here and we do have needs that are not being met by the current system. Our children who can't speak for themselves need a voice in government.

Insufficient networking among parents to provide support and information to each other has led to the need for increased awareness within the autism community and general population at large. There is often considerable conflict and misunderstandings among various parental groups.

There are insufficient community services and assistance focused on the families.

There is a tremendous need to increase awareness and educate the police and medical personnel:

Police interacting with nonverbal ASD individuals and the high risks associated with that, combined with the extreme impulsivity of kids and others on the spectrum, can often be disastrous, if not fatal. Many more profoundly affected kids often leave homes in the middle of the night, etc., despite parent's best efforts to keep them safe and at home. Many families have also had a terrible experiences when facing a medical emergency with their autistic family member. Entering a hospital emergency room or needing an ambulance or other medical intervention, often takes on a scope that far exceeded the original medical problem, when medical personnel make matters worse by dealing grossly inappropriately with the ASD individual and their family members.

I met with a remarkable person this morning who is attempting to do much along these lines for autistic individuals in Chester County and, ideally, later statewide. Since 2002, the police training statewide does

require a brief course in various disorders, including autism. However, it is still extremely limited (I looked through their two brief training manuals) and is given by a fellow police officer most often.

Susan, who herself has a son who often "escapes" on a whim in the middle of the night, has worked diligently to come up with solutions and has done some remarkable things that could be considered on a statewide basis, with minimum funding. First, she has distributed forms, for any parent who feels it appropriate for their child, whereby the local and state police are informed that there is an autistic child or adult at that location, should they be summoned to that home for any reason. There is also a space for a photo so that the local police would recognize the child or adult on sight, should they be found wandering at 3:00 AM, or an a neighbor's property, or in a public place that has the potential of being entirely misconstrued and seen as a "threatening" situation by the police. One can also apply yearly to have an automatic 911 recognition as well. Any 911 call made from that location would go out automatically with the information that an autistic child or adult was at that location and to please take note of this additional need when responding. Susan has also come up with "boards" (laminated picture cards), that fit perfectly into the books that police carry at all times, with picture and word symbols (Sp. and Eng.) so that they could more appropriately communicate when coming across a nonverbal autistic individual or any other communication impaired person for that matter. Chester County police now have them and other districts would like them but, as yet there is no funding. There are also larger laminated cards for hospitals to better communicate with language impaired individuals and it would also be wonderful for school administrators to have access to similar aides. Even our more verbal children, when frustrated and excited, often lose much of their ability to communicate their exact needs.

A sample of the picture boards, and the voluntary police forms mentioned above are included in Appendix 2 of this report.

A police training video to alert police to the circumstances and special needs of ASD individuals is also available. The video is entitled "Autism & Law Enforcement Roll Call Briefing Video" by Debbaudt/Legacy Productions. Information on purchasing copies of the video may be found at the following website: http://www.risingbird.net/asr/email.html

Further information concerning the video may be obtained by contacting the following individual:

Dennis Debbaudt
2338 SE Holland Street
Port St. Lucia, FL 34952
Ph: (772) 398 9756
E-mail: ddpi@flash.net

Develop parental and professional advocates (resources) that know and understand the systems (separated from the funding streams) that are funded independently. For example, the Federation of Families has been involved in developing these types of services.

Issues of socialization with autistic children need to be further researched and funding needs to be made available for socialization groups.

The concept of the drop-in center may be a viable service for some individuals on the autistic spectrum.

More education about ASD for hospital and police personnel and the general public is necessary. Voluntary police registration forms should be made available for parents who find that helpful.

"Picture communication cards" should be distributed to police and hospital personnel statewide to help them communicate with non-verbal individuals.

Services should be tailored to cultural differences; providers need to reach out to parents in their own languages and their own neighborhoods.

The state should be responsible for finding additional Federal funding so that these programs can be implemented consistently across the entire state of Pennsylvania.

Families with members who have ASD are often isolated from their spiritual communities, a place that could provide a "natural" support system. However; it is difficult to take a child to church when they can't 'sit still' and when the volunteers in the youth ministries don't know how to handle the kids. There are several ways this might be addressed through the ministries of the churches, if funding supports were available to assist. For example, in the Catholic Church, there is a ministry called the "Elizabethan Ministry". Many churches have this ministry and many more are developing it. Part of the mission of this ministry is to help families of children with special needs. There are many "50-something, empty nester couples" who would love to volunteer as part of this ministry to help a family with special needs. They would, however, be reluctant to undertake such a role without training and support. If resources could be made available to have professional staff train and support these volunteers until they are comfortable caring for an ASD child, networks of "rent a grandparent" support resources could be developed through the state that could provide support and potentially respite for desperate families seeking support.

Having employers understand the need of parents and families of ASD individuals is critical. The following remarks were received from one family in response to the initial task force report:

My husband is currently in limbo with his employer of nine years because they are unwilling to understand his need for a consistent work schedule do to our child with ASD. This alone is frustrating to us because even though he has discussed this issue with his employer numerous times they fail to acknowledge his need as a responsible parent in wanting and needing the consistency to prevent our child with ASD from having numerous seizures due to the fluctuation in his father's work schedule. He is looked down upon and has even been reported to be a problem employee due to the fact that he will and always put his family's needs first. For us it is the need of a consistent schedule for our child. We like the ideas for running commercials and for informative information to be passed for public awareness. Living in rural PA, the awareness for the general public is limited.

11.0 Concluding Remarks

As presented in this report, the challenges faced by ASD families as a result of their loved one's disability are considerable, and permeate all aspects of their social, emotional and intellectual lives on a daily basis. These challenges follow the family throughout the life span of the ASD child and severely affect "intra-family" relationships. The family's interactions with the community at large also present further challenges that are modulated in large part within the context of the educational system. The mental health and educational systems in the state of Pennsylvania offer unique opportunities to leverage and streamline the crucial support that is desperately needed by the ASD family. However, before this can be achieved, awareness and "education" about the ASD path is paramount. As recommended by the subcommittee, the creation of the "Department of Disabilities" working cooperatively with the Department of Education is the first and most important step toward realizing this goal. The family and social issues sub committee unanimously endorses this view, and respectfully requests that the Department of Public Welfare make this a top priority as the program moves forward. We would like to thank Secretary Estelle Richman, and the Autism Task Force co-chairs for the privilege to work with them and the opportunity to have our voices heard on these most important issues.

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Appendix 1

Life Stage	State of Current Practice	Needs/Gaps in the system as they relate to family/social issues and their impacts	Solutions	Special consideration for cultural and spectrum differences
Birth - 3				
Community & Other Systems	Waiting lists for evaluation and diagnosis	**Gaps:** *Problems with the waiting list *Appointments that may not be local *Lack of knowledge of professionals **Impact:** *The "not knowing" stressors *May get wrong diagnosis or no diagnosis *Wasted time *Need for second opinion	Immediate Connection with advocacy & support groups	
		Gaps: *Early Intervention services are not known by all in the community *Lack of knowledge about different programs available across the country **Impacts:** *Maneuvering of the different systems *EI providers are unable to share concerns with the parent (time lost) *Daycare problems		
		Gaps: *Child care centers and early education providers often do not have knowledge or resources to deal with children with special needs **Impacts:** *Not all child care centers provide services to children with special needs	More education & resources to provide inclusionary childcare	
Ages 3-5				
Education System	Must transition out of EI into school system at age 3	**Gaps:** *Lack of services *More knowledge of treatments **Impacts:** *The entire school experience *IEP meetings *Loss of services *Lots of different decisions/choices that the family must make *Always second guessing what is right for the child (time	Eliminate the age 3 transition	

		consuming and frustrating) *May lead to additional financial burden (lawyers, advocates). *Parents may want to be trained in different methods		
Community & Other Systems		**Gaps:** *Lack of services *Limited support *Lack of general awareness *Finding services that are recommended *Going through the system **Impacts:** *Lack of time spent with the family as a whole *Siblings feel the disabled child is getting more attention which can lead to other children having problems *Other children are isolated *Denial, acceptance, grievance stages *Family denial *The extended family may not approve of the course of action *Pulling family apart *Lack of extended family support *Depression amongst family members/siblings *Financial burden/stress (one parent may need to leave work to take care of the child) *Day care problems		

Life Stage	**State of Current Practice**	**Needs/Gaps in the system as they relate to family/social issues and their impacts**	**Solutions**	**Special consideration for cultural and spectrum differences**
Grade School				
	Services are fragmented Ways of evaluating and assessing children is fragmented	**Gaps:** *Disparity and inconsistency in providing services for autistic children among school districts *Some school districts have an inclusive environment; while others segregate the children **Impacts**: *Some parents want segregation; others want inclusion	*Every parent needs a knowledgeable advocate because parents are not aware of all the possible services provided for autism *Offer choices and resources for parents to access choices within and across school districts; parental and family networks should be created and expanded	

		*Lots of parents are forced into a situation to hire an attorney to ensure that the child's basic rights are not being violated and that they can get access to services	for families to provide support and information on autism to each other	
	Educational services are not coordinated		*There needs to be state wide standards *Autism services need to be more effectively integrated *We need credentialing to make sure that Behavioral Health Workers and Educators (especially special education teachers) in the schools are adequately trained. *There are interventions such as Carol Gray's Social Learning Model "Teaching Social Understanding"	
Cont.	Lack of Information and confusing system	**Gaps:** *No information for present system or source for those entering the state for the first time or for a new diagnosis on the spectrum. *No organized list of available resources *No clear guidelines for how the present system works: where to go; addresses; order of priorities, etc. **Impacts:** *This causes total bewilderment and confusion regarding path to solutions. *Feeling of helplessness as the family attempts to navigate through a complex, fragmented multi-layered system with competing services	*Information in all pediatric offices, clinics, mental health professional offices, hospitals, etc. *Advocates (parents & professionals) for information and guidance for families on how to deal with current PA state education system and Department of Public Welfare. *School based programs, literature and informational pamphlets, etc. *Television Ads and public awareness programs.	It has been pointed out that families of other cultural backgrounds are more reluctant regarding home visits due to intrusiveness and suspicions. Another venue where they can feel more comfortable with delivery of support services is required. Local clinic with professionals trained in their own communities and/or languages may help them feel more comfortable.
Cont.	Children treated under an inappropriate paradigm for their needs	**Gaps:** *Totally inappropriate & inconsistent system, rather than a neurological developmental disability	*New Hampshire model: consistent services with integrated state system from diagnosis	ASD children with more severe disorders (regulatory, perceptual, sensory, emotional) may

		model which would address their special needs and problems more effectively. *Release dates for services not reflecting reality **Impacts:** *Families have to go through so many systems, starting with federal forms and hoops to navigate, followed by all the convoluted system of state services which are often scattered and hard to locate and matter of luck *Hours and hours of family time and experimentation to find good services *Once decent services are finally secured by families, constant re-certification, threat of discontinuation, reductions every 4 months, for ASD children who need extreme consistency and predictability, it is tragic.	onward. *ASD children should be included and mainstreamed within education system and community programs as much as possible to facilitate their social and motional development with typically developing children. *Obviously, parent's choice of setting and level of comfort are paramount.	require special environments with less stimulation and more relaxed atmosphere ("low and slow"). Program needs to be customized to meet individual needs.
Cont.	Complete Disconnect between established services and education system	**Gaps:** *For this age group in particular, the complete disconnect between the educational system and the pre-school age services become glaring and alarming. *Many educational administrators in PA have absolutely no knowledge of ASD and its nuances *There is a constant threat of discontinuance of TSS services every 4 months *TSS services and support are behaviorally based and provided chaotically. School day organizational or practical issues now revolve around a 2nd or often a 3rd individual providing the services, making the school day more chaotic	*Common sense approach (New Hampshire model). *TSS or related workers should be properly trained and state accredited. *The state should take responsibility for providing TSS services that are integrated into all aspects of the ASD child's educational and social development. This would include school, social activities, after school plays, community based activities, summer camps, playgrounds, preparation for transitions to new schools or classrooms, etc. *The Department of	

		for the children, not less. *TSS personnel are not trained consistently regarding ASD, and often view their jobs as temporary, entry level, high turnover jobs **Impacts:** *Parents have often worked long and hard to acquire support systems, etc. Suddenly, their children are now in a school environment for the vast majority of their days, with many educators totally ignorant and/or apathetic to the children's special needs. *Many cases of abuse reported due to lack of knowledge on ASD. For example, locking children in dark rooms, terrifying and punishing situations, calling police on small children, because schools have no appropriate training. *Really a "starting all over" point for many families and adds extreme stress to the family environment, and often exceeds the stress of the original diagnosis process. *.No consistency, predictability for children or their families. *Cannot plan a consistent, predictable school year ahead for the ASD child, with everything up in the air every 4 months *At this vital school age, the multi-layered and very compartmentalized system of services now becomes particularly problematic for families. *When parents are fortunate enough to get the services of a great TSS, there is the constant stress of losing or decreasing hrs. of their	Public Welfare and the State Department of Education should coordinate efforts to develop an integrated system for diagnosis, treatment, program development, training, totally inclusive environment, and TTS or related support for ASD children. *Model pilot programs such as the Avon Grove Charter School in West Grove with a totally inclusive environment for ASD children (and all others) integrated into the school culture, accompanied by a family atmosphere. ASD children's special needs are most often recognized by peers, teachers, staff and other parents and the children are treated with respect for their unique path. The Avon Grove Charter School example, or similar models, should be further, studied, refined and funded as a cost- effective paradigm to meet the need of families and their ASD children. *Common Sense Approach: Simple example: other children know not to jostle in-line a child with sensory issues or it may be misinterpreted. Typically developing children are aware of and sensitive to needs of ASD peers. *Implement the "Best Buddy" program where typical children volunteer to be a "buddy" for a child with a disability and	

		hard found provider. Children need predictability, especially outside the home, and are now exposed to a more unpredictable and stressful environment.	have contact with them once a week.	
Cont.		**Impacts:** *There is too much paperwork and bureaucratic processes involved in providing services; there is too much time delay in receiving services	*Decrease time lags and paperwork burden *Streamline the system	
	Monthly community activities days where students can participate in the community & learn about them exits (elementary level) in some places Services are not universally offered; Commonwealth of PA allows for autonomy across counties & school districts; subcommittee does not have comprehensive services list	**Gaps:** *Family is not an area to talk about; school districts do not want to talk about social; they want to talk about academics *People can't find resources available	*Create lunch bunch or other opportunities for social interactions *Encourage participation in activities that already exist; create resource directories in communities so people know what is there	
Medicaid System		**Gaps:** *The system of providing services is often adversarial in nature **Impacts:** *This causes stress for families	*There needs to be cooperation between the health & education systems *There needs to be a mechanism in place to follow when the professionals don't agree.	
Community & Other Systems		**Gaps:** *Wraparound model with 120 day reauthorizations is not appropriate for children with autism *Not allowing TSS workers in schools to work on education curriculum is ridiculous	*Allow TSS workers in the classroom to provide educational support *Less frequent auth review for children requiring long term service	

Life Stage	State of Current Practice	Needs/Gaps in the system as they relate to family/social issues and their impacts	Solutions	Special consideration for cultural and spectrum differences
Junior High				
		Private schools appear (in some cases) to be able to provide supportive environments and programs that benefit students with far less resources provided (and consumed) in the public sector; cannot access resources and supports available to school districts	Allow the resources ($$) to follow the students	
		Need: *Social issues intensify with this age *Peer pressure issues **Impact:** *Further isolation/stress	Peer support groups	Different issues dependent on severity
		Need: *Increased sibling stress **Impact:** *Stress on entire family	Sibling training/support groups	
		Need: *Puberty issues/hormones **Impacts:** *New concerns bring need for new info and skills. *Sometimes increased aggression in lower functioning child	Skill training for families	
		Need: *After School and Respite Care **Impact:** *Lack of such care causes problems for working families *Families unable to get breaks	More accessible respite and development of after school programming	Single parent or working parents are in dire need of these.
Cont.		**Need:** *Medication issues due to hormones/depression/emotional concerns. **Impact:** *Non-coordination of services causes families to be unable to make informed decisions re. medications and behavior management of symptoms.	Intensive Family Case Management	
		Need: *Social prejudices **Impact:** *As child gets older, the community becomes less tolerant of differences. *Families become more isolated	*More community education and exposure for Autism *Parent-to-Parent support * Social groups across diverse populations	
		Need: *Activity programming.	Develop centers /activities	

		Impact: *Families unable to find activities/programs that interest child and that are appropriate for developmental and chronological age. *Continued isolation; family relationships threatened; high risk of marital problems, etc.	especially for children with autism.	

Life Stage	State of Current Practice	Needs/Gaps in the system as they relate to family/social issues and their impacts	Solutions	Special consideration for cultural and spectrum differences
High School				
	(See also Junior High)	(See also Junior High)	(See also Junior High)	(See also Junior High)
Education System	No HS programs to help children with autism stay socially with kids they have class with	**Gaps:** *Schools not prepared to go into the community to support them/facilitate transitional support for vocational training, etc. **Impacts:** *Social? *MA? *Educational?	School support encouraging joining in clubs, etc. (e.g., Washington County's Transitional Educational Consultants, group which teaches such skills)	
College (18-21) if appropriate				
Education System	There are no resources available to support students in college		*Provide one to one interventions and other support services for students to be able to be successful in school. *The individual support must be multi-disciplinary to help with both academic & social issues. *College/University professors need to have training on how to support/ deal with individuals with ASD; information regarding how to design class schedules so that individuals with ASD aren't overwhelmed and can be successful	
Medicaid System	Medicaid is only available to age 18 unless individual has SSI	Individuals cannot access medical services that they need.	Services have to support the individual throughout life and look for ways to fund outside	
Community & Other	There are no community &		*A "buddy" program with typical individuals would be helpful.	

Systems	social support systems available.		*Social and support groups that include both typical and ASD individuals. *Look at developing internship programs for special education and psychology majors who are studying to be professionals in these areas to provide support services for ASD individuals at the college level.	

Life Stage	State of Current Practice	Needs/Gaps in the system as they relate to family/social issues and their impacts	Solutions	Special consideration for cultural and spectrum differences
Transition to adult (18-21)				
Education System	Little vocational skills training	**Needs:** *ASD individuals need help to maintain success on the job *Vocational counseling and skill building: there is a poor match of job/skills **Impacts:** *Causes stress *Worry about how to help ASD individual success. *Often, frantic search for supports *Increased likelihood of family stress and individual sense of failure	*Job coach who can provide some one on one assistance to insure success *Earlier educational focus on marketable skills i.e., computer & math *OVR model of helping ASD individual find and apply for job	*Some ASD individuals will benefit from counseling. *Some may need sheltered workshops or day programs such as the MR system can offer sheltered workshops or day programs such as the MR system can offer
Medicaid System	Counseling, relief and respite are generally not available or not affordable		*Training and funding for people who provide respites, relief or specialized counseling. *Central register of same; website	Respite services needed more frequently for severely involved individuals and their families.
			*Relief care could provide several hour breaks during day or evening for parents to attend; functions, keep appointments and focus on another child *Relief care could be a team member who would go to a house or a drop off site	

Community & Other Systems		Need Assisted living arrangements	Perhaps BSU and Core Team model would be useful	
		Needs: *Transportation may be difficult to arrange **Impacts:** *Family and ASD individual may feel isolated, may experience anxiety, depression; sense of missing important life goals. *Problems may jeopardize parents' employment or marriage	Social skills opportunities to meet typical and ASD peers	
Adult(21+)				
Community & Other Systems		**Needs:** *Some degree of assisted living is a frequent need; aging parents worry about future of ASD individual **Impacts:** *Adults can often do an excellent job once trained. But may have difficulties surrounding changes in environment and social situations; causes stress, parents and siblings worry that there is "nothing out there" for ASD individuals	*Job coach, etc., see transition to adult *Advocacy, information about appropriate resources *Trained individuals to provide social training and opportunities for social interaction	Some ASD individuals will not have marketable skills and will fare better in a sheltered workshop or day program such as are provided by the MR system; intensity of services and support and degree of need are different across the spectrum system; intensity of services and support and degree of need are different across the spectrum
		Gaps: *Adults with psychiatric of behavioral crisis often experience great difficulty with police or emergency room staff. *Hospitals lack knowledge and resources to help. *Police sometimes overreact; causes extreme stress; risk of injury	*Training for police and emergency personnel. *Medical website with information and emergency advocate information. *Perhaps members of a BSU core team. *Add registry of individuals to police database based on parent consent (so that police are informed that individuals have a disability and are not a threat)	Severity of symptoms reduces likelihood individual will respond to conventional resources.
Medicaid System	Physical health plans can provide respite, home health aid	*Can't get mental health services for the family *Have to "play around" with funding to get services *Can't get family therapy in the home	*Mobile outpatient therapy for family *Create programs for siblings so kids learn how to handle having different	

	BHRS Family-based therapy	*Siblings of children feel neglected. *Medicaid is a – health insurance program - medical necessity model and you cannot do training and support through it There is a physical health component to Medicaid that meets the needs of special needs kids but they don't want a lot of people to know about it; *Sibling support was something that could have been paid for 10 years ago *MR waiver money could be spent in a different way if you can get it; MH money is different; MR funding includes right of retribution where they can get their money back if the child inherits money; the child can lose their services when they become adults *You cannot get into the MR system unless you meet certain criteria; kids on the spectrum cannot meet the criteria; Children who have a diagnosis of MR along with the Autism can be registered with the Office of Mental Retardation. They cannot be registered just for Autism. A child with Autism and an IQ below 70 can meet the criteria for the MR system and a child ages 0-3 can meet criteria for Early Intervention through the MR system without an MR diagnosis based on meeting criteria for developmental delays *Autism is a communication disorder and/or a neurological disorder; MH is not a really appropriate place for it *Families cannot afford the out of pocket expenses to pay for support services *Counties are interpreting the criteria for services differently ; providers are incentivized to use/refer to certain services because	kinds of kids at home *Systems need to "talk" to one another and be able to access services through the other funding stream *Mental health model does not work for these kids; department of disabilities *Case managers & people in the system that can give them information and can help them; things must be better organized from above *The four-month evaluation process for wrap-around should be goal oriented and not to determine whether services should continue *Allow access to services for siblings/ families BEFORE crisis happens	

		they pay more than other services *There is a lack of sibling services and support services for families affected by autism		
Community & Other Systems		*Can't get money for the other family support: *Babysitting *After school care *Family support groups *Other respite – day & night respite *Families cannot navigate through this process because there are so many differences between & among people on the autism spectrum; it has been difficult for the groups together to rally around a cause *There are a lot of families who aren't able to access the information; the case managers are not trained in how to deal with autism related systems *ADVOCACY *Its hard in a geographically diverse state to get consistency among programs & services	*Those are valuable services that are not treatment the needs to be paid for SOMEWHERE. *Funding for socialization groups *Need to get some research that socialization works for kids with autism – with other people that share their interests *There are drop in centers for people with mental health; need to have services like that for persons with autism *Need to have parent- advocates (resources) that know & understand the systems (separated from the funding streams) that are paid for. *The Federation of Families has been very involved in developing these types of services. *The state should be responsible for finding the federal funding so that these programs can be implemented consistently through the counties	
		*Not enough networking happens among parents so they can provide support and information to each other and increase awareness. *There is too much conflict and politics among parental		

		groups		
		*Not enough services are geared to families and there is not enough assistance provided to families;	*Services need to be tailored to people's cultural differences *Providers need to communicate on the parents' level	

Appendix 2

Picture Cards for Community Services Personnel & Voluntary Information Forms for Police

The first two communication boards are given to hospital personnel.

1 0f 2 Hospital Communication Boards

chest pain
dolor de pecho
headache
dolor de cabeza
stomach ache
dolor de estomago
dizzy
mareado
hurt
lastimar
nauseated
tener nauséas
sharp pain
dolor fuerte
Did someone hurt you?
¿Lo lastimó alguien
hot
caliente
cold
frío
tired
cansado
dull pain
dolor sordo
eat
comer
drink
tomar
pillow
almohada
blanket
cobija
wash
lavar
brush teeth
cepillar
shave
afeitar(se)
Time to leave
El tiempo de salir
Picture Communication Symbols copyright 1981-2003
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For additional copies contact:
Susan F. Reucidlo @ srz@dol.net

Police Communication Boards

Child-Specific handout for municipal police in the Kennett Consolidated School District area for the 2003-4 school year.
Folleto Especifico de un nino para el municipio de policia en el Districto de Kennett Square para el ano 2003-2004

Name and birth date of child:
Nombre y focha de nacimiento del nino:
_____

attach recent photo here
foto reciente

Current physical description of child:
Una descripcion fisica actual del nino:
Height_____ Weight_____
Altura Peso
Eye color_____ Hair color_____
color de pelo color de ojo

Scars or other identifying marks:
Cicatrices u otras marcas que identifican al nino:_____

_____

Any Medical conditions and/or prescription medications needed:
Cualesquiera condiciones y/o medicación médicas de la prescripción: _____

_____

Name of parents or care providers:_____
Nombre de padres o cuidado del nino:

Address/Dirección _____

Township/Condado _____ e-mail_____

Phone numbers/Número de teléfono:
Home/ Casa _____ Work/ Trabajo_____

Cell phone/ Teléfono cellular _____ Pager/Beeper _____

Name of alternative emergency contact person:
Alternativa de la persona del contacto Nombre: _____
Phone numbers/Número de teléfono:

Home/ Casa_____ Work/ Trabajo_____

Cell phone/ Teléfono de la célula _____Pager/ Beeper_____

Sensory or dietary issues, if any:
Problemas dieteticos y sonsoriales, si alguno:_____

_____

Is he/she likely to wander off?
¿El o ella le gusta vagar en diferentes sitios? _____

Favorite attractions or locations where they may be found:
Localizaciones preferidas en donde pueden ser encontrados:_____

_____

Atypical behaviors or characteristics that may attract attention:
Comportamientos o caracteristicas anormales que pueden atraer la atención:_____

_____

_____

Favorite toys, objects or discussion topics likes, dislikes:
Juguetes preferidos, objetos o asuntos de discusión que le gustan o no le gustan:_____

_____

_____

Approach, calming or de-escalation techniques most likely to work:
Técnicas del acercamiento para calmarlo: _____

_____

_____

Method of communication, if nonverbal, sign language, picture board, written words:
Método de comunicación, si no es verbal, lenguaje por signo, palabras escritas, letreros:_____

_____

_____

ID information. Do they carry or wear jewelry, tags, ID card:
Información de identificación. Usan joy as, etiquetas, tarjeta de identificación: _____

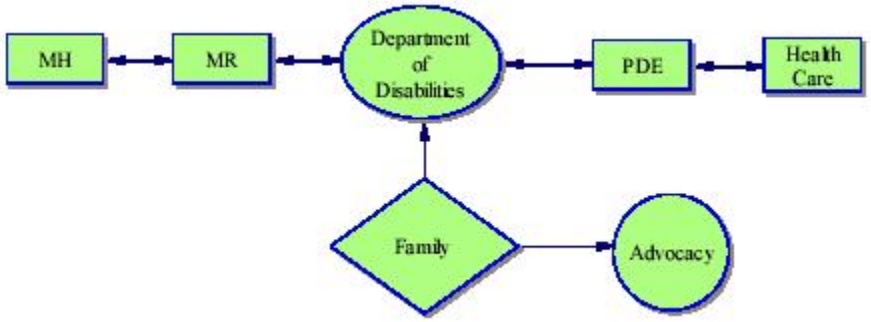
_____

_____

Appendix 3

Sample Model of the Proposed Department of Disabilities

Pennsylvania Department of Disabilities Recommended Model



Appendix 4

SIBLING STORIES
(Excerpts from Parents Speak, Plenum Publishing Corporation, ©1979.)

Siblings of Autistic Children

Ruth Christ Sullivan
Editor, Parents Speak Column
Autism Services Center
101 Richmond Street
Huntington, West Virginia 25702

INTRODUCTION

In the usual question-and-answer period after a talk, I am very often asked, "How do your other children react to your autistic child?" There is a natural curiosity, it seems, about the way sisters and brothers of autistic children relate to the strange and pervasive handicap of autism, especially during their growing-up years.

What must it be like when you first realize that other families you know don't have bloodstains or feces on the living room curtains or smeared on the front hall wallpaper (put there by an autistic sibling who likes that medium to finger-paint)? How do you come to terms with the inordinate amount of parental attention, of necessity given to your handicapped sibling, that you wish could go more often to you? What must it tell you about how your community views your family when you see your sibling denied a chance to go to school where all other children go? How must it feel to tell a special friend about your sibling and wonder about his/her reaction? How does it affect the view of your own eligibility for parenthood? Does it leave a lifetime mark?

Although it has not yet, to my knowledge, been studied formally, authorities in the field of language disorders are beginning to wonder out loud if the way language-impaired individuals are perceived might not be considerably different from the way individuals with more obvious handicaps are perceived. There seems to be something particularly stressful about living with a person whose communication skills - which almost always affect social skills - are awry.

I've invited five siblings to write down some of their own experiences for this Parents Speak section. Jesse A. Torisky, from Pittsburgh, is a freshman at Penn State and has a 22-year-old brother. Cynthia Bodenheimer, with a new doctorate in psychology, and with professional experience in working with autistic children, is from West Islip, New York. Her autistic brother is 17. Sharon Lettick's brother is Ben, now 24, for whom Benhaven - a school for autistic persons in New Haven, Connecticut - was named. She is 29, an autism professional with an M.A., also in special education. Sandra N. Ochs, 21, of Monroeville, Pennsylvania, is an only sibling of a 15-year-old brother. The fifth author, who requested anonymity, is 14 and has a 19-year-old autistic brother.

Marian K. DeMyer, M.D., a psychiatrist at Indiana University School of Medicine with many years of experience with autistic children and their families, has read what these siblings have to say. Recognizing their intense struggle for a normal family life, she formulates two questions that are basic to each family member and makes some suggestions for professionals and parents.

Professionals who work in programs for autistic persons may see these brothers and sisters occasionally, but it is still mostly from individual families that the information must come-information about long-term crisis living during formative years.

This collection of sibling stories is a modest sample, of course, but it helps to give us some "tone" of what it is like to be the brother or sister of an autistic child and how this handicap manifests itself throughout the family's environment.

It is hoped that this column will help generate some discussion about siblings' role in the "autistic family."

MY BROTHER, EDDIE

Jesse A. Torisky
Monroeville, Pennsylvania

There are two main incidents in my life that give me cause for much thought, specifically in relation to my older brother, Edward, who is autistic. I recall these particular happenings because of their significance in altering my life.

The first event occurred about 2 years ago when I was 16. Eddie had come home from Western State for an overnight on Friday. We were going to take him back Saturday after lunch, stopping first at our grandmother's house for a short visit. Friday evening was fairly uneventful, none of the usual tension in the air that is so characteristic of the times when Eddie comes home. Part of this tension is due to our own anxiety caused by the memory of previous overnights with him that have ended in disaster, when we had literally to drag him back to Western State, screaming and crying.

Saturday morning started off badly. I came down from my bedroom early and was sitting in our living room trying to wake up when the house's tranquility was shattered by some choice words that I do not care to mention. I immediately surmised that the garbage men had come for the pickup. However, after more thought on the matter, I realized that (a) the garbage pickup wasn't until Tuesday and (b) those words, which would make General Patton blush, were issuing from my brother's and my room. Oh, great, I thought. He's starting early. If he was acting this way now, in no time be would blow up and create an unpleasant situation for the family. About that time my dad was aroused from his slumber. He went upstairs and somehow managed to calm Edward. Then, while Eddie was getting dressed, my dad came down and gave me one of those "Oh.-boy-here-comes-another-fun-day" looks.

Throughout the rest of the morning, Eddie seemed very keyed up and I was starting to get worried that he would suddenly lose his control and run out of the house to Lord-knows-where and we would spend another Saturday trying to find him. My parents sensed this too, so as soon as we could, we got him to the car and on his way to Grandma's.

That's when the fun started. As soon as we got to her house, Eddie insisted that he be allowed to walk around outside. We didn't think that would be too good an idea, so we said no. Eddie didn't think that was a good idea so he ran out anyway. My father and I spent the next 35 minutes chasing him over all the scenic routes of Brentwood.

We finally caught him with the help of the local police and had him in the back seat of our station wagon. I sat with him so that he would not hit my dad while he was driving. During the whole ride back, he went through a series of emotional states-first violently upset, then sobbing, then screaming and swinging at dad, then crying again.

By the time we got to Western, Eddie seemed to be settled down. We had called the unit police before we left home and they were there waiting for us.

My dad got out of the car and as I got out, still holding him because I was afraid he would run off, he asked me to let him go. I said I was afraid he would run away. He promised me sincerely that if I let go he wouldn't run. When Eddie makes a promise, he usually keeps it, so I said all right and let go-whereupon he took off with a speed that shall remain unparalleled by any other creature. We took off after him and caught him, and this is where part of my embarrassment started. I was so hurt that he had lied to me, his brother, that on the whole way back to the doors of the unit, into the elevator and onto his floor, I screamed his ear off. This is where I later felt embarrassed. The security guards saw the way I acted and must have thought that that was the way I always was with my brother.

Then, when we went upstairs, my brother started swinging at the guards and my dad. I went over and tried to subdue him; I felt safe from Eddie because he never ever hit me. But in a surprise swift swing, he

punched me in the face. I was filled with mixed emotions, both upset and angry. I let loose again with the yelling, slamming my brother up against the wall with my arms.

Finally, the police got him to his unit and we left. On the way down in the elevator, I kept saying half out loud that I couldn't believe he hit me, because he never did before. Then I broke down and started crying. The security police saw how I was taking it and said, "Don't worry, son, you'll get used to it." I felt like telling him, in so many choice words, that I knew as much, if not more, about how to handle my brother as anyone else, but I realized he was only trying to help.

Despite the fact that I was familiar with these situations, I couldn't help feeling terrible about Eddie hitting me for the first time. I also couldn't help being upset that the security police thought that I probably acted like that all the time. It's just that sometimes it gets to you.

The second thing that really influenced my life was more of a realization than an actual occurrence. It happened while I was at Penn State in my Speech Communications class. This class was unique in that we all did exercises in perception and self-awareness. One exercise in particular dealt with birth order as it relates to personality. Our professor divided us into groups: the people who were the youngest in their families in one group, the oldest in another group, and the ones who were in-between in the last group. I went in the youngest group but felt misplaced because, of all the people in the class, those in my group were the ones that I would never hang around with after class-they just weren't my type. I felt that I belonged in the middle or oldest group.

I wasn't prepared for what happened next. Our professor asked the class if we felt there was anything wrong with the way we divided, and several people immediately said that I looked out of place in my group. I was astonished that other people had noticed what I had felt. The professor asked me if I had any idea why this might be. I thought for a second, then it suddenly hit me. The reason I seemed to belong in the middle or older group was that, although Eddie is older than I am, I tend to act like his older brother. This realization made me appreciate my situation with Eddie in a way that I hadn't thought of before. Being in a family with someone "special" to take care of not only makes you mature faster but gives you more experience and a better understanding of how to handle people as well.

FOR THE SAKE OF OTHERS

Cynthia Bodenheimer
West Islip, New York

"For the sake of the other children, send him away." Thirteen years ago this advice was given to a set of parents recently faced with the reality that their child was severely handicapped - "autistic." It was posed as an admittedly difficult choice to make: sacrifice the flock to save the lamb or tend to the needs of the group at the expense of the individual. Fortunately for all those involved, those parents chose not to heed the advice, and instead accepted the forbidding task of raising a severely handicapped child along with his three normal siblings. Hardly an easy assignment. I can say that with confidence, having been one of those siblings.

In this piece, I would like to share my perceptions of, and reactions to, growing up with a severely handicapped autistic brother. It is interesting to me to realize that my child-sized perceptions from those earlier years soon after Chris entered our family may differ tremendously from those of my parents.

It was hard in those early days when none of us knew much about this strange little fellow who had so many interesting behaviors. I remember wondering if we had somehow miscalculated his age, because at 18 months he was so much less responsive than the other babies I saw when I took him to the park.

And I remember the turmoil surrounding the pursuit of his elusive diagnosis. The whole family shared in the knowledge that "something" was wrong-he doesn't talk; he doesn't seem to hear, yet he loves music and keeps rhythm, he will only eat bananas, he's fascinated with water, never wants to cuddle, won't sleep through the night, seems to be "in a shell" that we can't break. Knowing all these things made it even more difficult when those professionals sought out gave confusing and conflicting reports: "He's just

slow-take him home and bring him back in 6 months." (Oh, so nothing's really wrong. Then why do mom and dad look so worried and why isn't he learning?) "He's severely retarded." ("Retarded"-it means he'll be a baby longer than other babies; oh, isn't that great! I've always wanted a baby to play with, and of course, he'll get better by the time he goes to school-all kids can talk when they go to school.) "He's deaf." (But I know he's not; he can hear his bath water running all the way upstairs, and he loves to listen to the man tune the piano.) And finally, "He's autistic." For that, there was no explanation.

As time passed, our beautiful, growing "autistic" baby became more difficult. And it was hard to be a good sister to him. It's not much fun to play with a baby who can't play, feed a baby who won't eat, or tuck in a baby who won't sleep. And what's so great about watching a record go around all day, anyway? Looking back, it seems to me that what got the fami1y through difficult times was a special talent of responding to the small but wonderful things. When accomplishments come slowly, it's easy to get excited over small steps toward progress.

My parents were very helpful in assisting us to readjust our "normal" expectations. It was a good meal if Chris ate half of his strained banana without screaming and spitting. I remember the day Chris finally held his bottle by himself. The pride I took in his accomplishment could not be dampened by the fact that at his age other children had long been weaned from bottles and were drinking from cups. Living with Chris made us aware of the little things one hardly ever notices. "Chris pushed his chair to the sink today to climb and play in the water!" "Mom, he's watching me change the record!" "Today when I put his coat on, he helped put one arm in!" "He raised his arms so I could pick him up today!" We quickly learned the meaning and value of individual differences.

An especially difficult part of living with an autistic sibling is the ever-present question of etiology. Why??? As a child, it's hard to live with someone who has difficulty learning, gets upset, and acts strangely when no one seems to know why. Children expect adults to have the answers, but so often in the case of the autistic child, the siblings are left on their own to grapple with this question. What could have gone wrong? Did the hospital stay harm him? Was it the fever? Is his diet OK? What about his frequent earaches? Can he hear? Is it our fault? Anyone's fau1t? Could it happen to me? Does he know we love him? Yes, a lot of questioning, and anger-anger that a helpless beautiful child could be so inexplicably damaged. But in time I was helped to understand that the best we could do was to meet his needs as we saw them, enjoy his engaging personality, and accept what seemed impossible to change. The model of caring consistently displayed by our parents made it easier for my brother and me to assume this kind of acceptance.

Giving Chris the care he needed was difficult and draining. Progress was slow. At times we were frustrated and disheartened. But each family member pitched in and we felt valued for our effort. In light of my own childish needs, I could not have made such an effort had I not received from my parents the emotional support and security I needed. I believe that within all of us, given that our basic needs are met, is a willingness to give and to help someone who is hurt, be it brother, sister, friend, or acquaintance.

From my past professional experience in working at both residential and day treatment facilities serving handicapped children and their families, I see my own experience repeated in family after family. The same sets of issues and questions arise for sibling after sibling, family after family. Many siblings I have met were constructively struggling with a multitude of questions, problems, and issues regarding their dealings with their autistic brother or sister. They needed not only a forum from which to speak but also information and, where possible, answers. Sibling support groups may be one way to deal with concerns such as: What is the future like for my brother/sister? How can we explain him/her to our friends? Is there always this much tension? What can I do when he throws tantrums? What's his school like? Will he/she ever talk?

(In spite of the difficulties, it can be fun to have a special brother because sometimes I'm the only one in the world who can teach him something and I feel so proud!)

It is urgent that professionals and parents think creatively about the kinds of support-for the entire family-needed to raise a special child at home.

BEN

Sharon Lettick
Chapel Hill, North Carolina

We were walking home from school, she and I, and the discussion was focused on my unusual little brother. Unusual, that is, to everyone else. To me, he was just my little brother. Since I only had one, he was unique, regardless of his other qualities. Anyhow, my friend asked me why my brother did not talk yet, as he was almost 5 year old. I thought for a moment and said, very seriously, "Well, he only speaks French and none of us can speak or understand French, so it presents a terrible problem." She nodded with a vague comprehension of the "problem." I chuckled all the way home. We were in the fourth grade.

Almost 20 years later, I look back on that little chat, especially the innocent truth behind my explanation. My brother is nonverbal and autistic. The language that most of the world uses for communication is simply not available to him. Yet, he did have a desire to communicate. He did not know our method, nor we his. That is not so far removed from speaking only French in a place where everyone else is speaking English!

I feel that my position in my family was fortunate. I am the second oldest of four children. I have one older brother and a younger sister who is just 2 years older than our autistic brother. By the time our autistic sibling was born, I was already old enough to be somewhat independent. (I am 5 years older than he.) I had already had the attention so necessary in those first few years of life. I was old enough to play "mommy" without the emotional stress and pain that comes with being her. My sister was most affected, unfortunately, by the shift in balance within the family. There was no right or wrong, it just was that way. Her younger brother was very demanding. She and my mother have taken years to deal with the consequences, with promising results. My older brother was already in his own social world, and it was not until years later that he became more involved with the family.

I once did a study while a student at UCLA, in which I spent time with various siblings of autistic people. The resulting pattern that I found is interesting: one sibling usually goes into some type of helping profession, if not specifically autism; one usually is more social and "distantly romantic" in nature; and if there are others, they usually are somewhat aloof from the family sphere in general. One always thinks his own family situation is unique. Oh well"

Along with a maternal feeling, I found I also was purely fascinated with my brother - Why didn't he speak? How did he think if he did not know words? As a sibling, I could be intrigued without the pangs of reality and natural motherly awareness of a son's abnormalities. I could take him out shopping in supermarkets, which he loved, and not be bothered or embarrassed if he accidentally knocked down a huge display. My sister would have become nervous and distraught, while my mother would be close to tears. Taking a walk around the beach with him was an education in people. I learned from their fearful expressions, their sympathy, their ignorance. Yet, some did not notice anything unusual, as he was so physically beautiful, except when he would flap his hands or do his little foot shuffle. Then they often noticed. It wasn't one's usual mode of strolling. Some people grimaced, others were shocked or afraid. The young children just showed honest, naive curiosity: "Why is he doing that?"

I am still involved with autistic people. I have made it my profession. (Am I sibling Type I?) Actually, all I have done is to continue what I did most of my life: spend time with unique, unusual autistic folks. I consider myself to have had a very special upbringing. I learned so much from my brother, indirectly. I enjoy being around people like him, although, of course, there is no one as special as my brother Ben.

SIBLING OF A HANDICAPPED CHILD

Sandra N. Ochs
Monroeville, Pennsylvania

Growing up in a family with a handicapped child can affect a person in many ways. It can make him strong, self-sufficient, and helpful, or weak, emotional, and dependent.

In my case, stress has been an everyday occurrence during the past 12 years- Wanting to help with my younger brother and yet not being able to withstand the pressure of his impatience or anger has given me tremendous feelings of guilt-guilt that need not have been. Not everyone is cut out to go into the field of special education and I, for one, am not that kind of person. For three summers, I had volunteered at a camp for mentally handicapped children, and after the 3rd year I definitely knew it was not for me.

I have often wished that my brother were normal. Since we are the only two children my parents have, I really can't imagine what it would be like to have a true brother-one that you could talk to about special things or share secrets with, as most siblings do. I guess that is why all during my school years and even now, I tend to be closer to guys, platonically of course, than to girls. They provide me with a brother or a reasonable facsimile.

I know that my parents would like me to take more interest in my brother, and 1 have tried. It's not that I don't love him. That is simply not true. There is a great deal of love in my heart for him, but it is difficu1t to show it because he is not the kind of child who exhibits or requires a lot of affection. In fact, he is very much the introvert and retreats to his bedroom as much as possible while at home. It is odd, though; when he goes to school, he is completely different. He does things for his teachers that he would not think of doing for our parents or me. This is why he needs special people to work with him and not someone who is related to him and feels that it is his obligation or duty.

Recently I got married, and even though I regret leaving my parents, I'm glad to be on my own. There is not nearly as much stress in my life as there had been while I was growing up. Sometimes I avoid helping my parents with my brother and I don't always like myself for copping out. I know that I have my own life and responsibilities. If, God forbid, someday I were to have a retarded or handicapped child, I hope I would find the strength that my parents have found. And I hope I would handle it the best way possible without affecting someone else's life.

MY ROOMMATE

Anonymous
Age 14

Having an autistic brother has made me different, I'm sure, but I don't know how, because he is my only brother close to my age and I don't have anyone else to compare him to. I probably get in more arguments with him than anyone else, because we have shared a room all of my life.

We get on each other's nerves just like any other brothers, but it is over other different things, like when he wrote "poo poo plastic diaper" all over the front of my brand-new notebook.

I used to think about how nice it would be if I had a normal brother, and our family was "normal" like all my friends' families. But after a while I realized that everyone thought that their families were weird, and became-well, not exactly proud of my brother-but I never get embarrassed because of him anymore. In the long run, I am and will be a better person because of him.

COMMENTS ON "SIBLINGS OF AUTISTIC CHILDREN"

Marian K. DeMyer
Indiana University School of Medicine

Jesse Torisky learned in adolescence about his response to extreme and continued pressure, which is the usual condition resulting from living with an autistic sibling. Much of the time Jesse responded by being helpful. On the other hand, Jesse found a limit to his own emotional control when Eddie reneged on the promise and then hit him. Over a lifetime, Jesse has learned to control his own anger and to postpone his own wishes in order to help his parents control Eddie, which caused him to mature early and thus be psychologically the "older" child of the family. What humiliation he suffered when the security guards saw him yelling and out of control. I think the mixed feelings Jesse had about Eddie are probably found in every sibling of an autistic child. It is the expression of these feelings that varies. For some siblings there

is nearly complete identification with the parents' attitudes of sacrificing almost everything for the sake of the autistic family member. These siblings, like Cynthia Bodenheimer and Sharon Lettick, may become members of the helping professions, often involved in working directly with autistic people. I think this type of normal sibling tends to deny or gloss over strong feelings of anger, sorrow, or jealousy about giving so large a share of themselves to an autistic sibling.

For other siblings such complete identification with the parents is not possible. They find, like Sandra Ochs, that their most rewarding life-style is not one of service to autistic people but of self-expression in other endeavors and in other relationships. These are the people Sharon Lettick describes as either "distantly romantic" or "aloof" from the family.

As Sandra Ochs points out, most "aloof" siblings pay a heavy price of guilt and even some family resentment for going their own way. Some have told me about their continuing anguish. One such case concerns Debra,2 a 22-year-old woman who had left home 2 years previously to work in a distant city. The parents, while sympathetic with her needs to develop into an independent adult, felt Debra had deserted the family and were hurt and angry. They had demanded that she return home to help with Timmie during her vacation.

Debra expressed her dilemma to me while sobbing uncontrollably: "My parents think I don't care about them or my brother or my sisters-but I do. They don't know how tom up I am inside when 1 go home. It breaks my heart to see Timmie hit and pinch my mother. It seems to me he gets worse when I go home. But the worse thing-my mother and one of my sisters are just so sad all of the time. I think we need help fast just to save the family."

This family finally solved a part of the problem by finding residential care for Timmie and having long discussions where rules were set that all family members could speak their minds without fear of rejection or of having their remarks taken as affronts.

The central questions for every family member with a severely autistic child are: (1) How much time and effort can I give to the autistic person without giving myself away? (2) Am I handling my grief and anger in such a way that I can do my best not only for the autistic but for other family members? There are no easy answers to these questions. For parents the only possible solutions may be "least worst' ones; but whatever solutions are decided upon, the normal siblings' development must be taken into consideration. These siblings who choose to be "second parents" to the autistic should be commended for their strengths, but the siblings who choose a life apart from direct involvement need just as much moral support and love. If given time to develop on their own and regroup their defenses, the "aloof" ones generally find a way to give their own kind of help later to their parents and autistic brother or sister.

Many siblings need a forum to ask questions, vent their feelings, and find solutions that are right for them. While professionals can and should provide this service for some families, it seems to me that members of the National Society for Autistic Children could initiate sibling groups where their other children could get help during their formative years for the stress that their autistic siblings bring to the family.

02. Education and Certification (Broad) Subcommittee Report

I. INTRODUCTION

A. MISSION STATEMENT

Initially, this committee considered its mandate to be an investigation of the efficacy of the training that prepares professionals to provide services for individuals with autism spectrum disorder (ASD). However, it became clear that there are also tremendous barriers in accessing the professionals and resources that currently exist within the Commonwealth of Pennsylvania. Without addressing these fundamental access issues, further education of professionals will fail to improve the outcome of those children currently being served by the system. Hence, we present a report with two primary foci: An examination of our state's system for educating professional providers, and an examination of our state's system for allowing potential clients with ASD access to educated providers and to appropriately designed educational programs.

1. How can we improve training in effective and evidence-based practices for the professionals and assistants who serve individuals with ASD? e.g., What additional educational opportunities and certifications are required to improve PA's current provider system? How is the efficacy of training currently monitored, and how can this monitoring system be improved? What additional training is needed for non-provider staff, administrators, and supervisors so that the systems may offer greater support to individuals with ASD and their families?

2. How can we remove the barriers that hinder individuals with ASD from accessing appropriate educational programs, supports and services? e.g., How is accountability for services monitored? What is the pattern of success and failure for educational programs? How is the educational outcome data for approved private schools, school districts and IU programs tracked with respect to children with ASD? What are the mechanisms for monitoring compliance with state and federal regulations and how can this system be improved?

B. COMMITTEE MEMBERS

Initially, the Education/Certification (Ed/Cert) Committee included 17 members from various regions of PA. In mid-November, 2003, three of the original committee members resigned and one new member was added, resulting in 15 participants. However, strong differences emerged among these participants regarding the scope of the committee's mission. Eventually, the 15 participants agreed to split the committee into two divisions. One division (**Ed/Cert-Focus**) consisted of 6 members that agreed to focus exclusively on the education and certification of professional providers. The other division (**Ed/Cert-Broad**) consisted of 9 members who agreed to focus on issues of access as well as education and certification. The present report was prepared by the 9 members of the Ed/Cert-Broad division. (See Appendix A for a list of names).

All members of the Ed/Cert-Broad Committee have had extensive experience with services provided to children with autism spectrum disorders (ASD). Members include parents of children with ASD, service providers, professors/researchers at universities. Some members serve more than one rule.

The service providers on this committee include educational administrators, educators (special and general), behavior analysts, speech-language pathologists, occupational therapists, psychologists, and advocates.

The parents on this committee have had experience with service providers from the public schools, Approved Private Schools, and wraparound agencies. The specific services that have been provided to their children include categorical classrooms, home-based behavioral interventions, learning support classrooms, resources rooms, mainstream inclusion (with and without supports), speech therapy, occupational therapy, physical therapy, and social skills instruction. In addition, the parents on this

committee have frequently found it necessary to privately pay for services, including psychological counseling, home-based behavioral intervention, speech-language therapy, music therapy, occupational therapy, and social skills training. Further, a number of the parents have experienced the need to consult legal professionals in order to obtain appropriate services and educational placements for their children. Some have hired private advocates, reported complaints to the PA Department of Education Bureau of Compliance, and engaged the dispute resolution system (mediation, pre-hearing conferences) Several have gone to due process at the state or federal levels.

C. COMMITTEE PROCESS

Committee members have communicated with each other in various ways over the past four months. All original members of the Ed/Cert committee met for the first time in Harrisburg on 7-26-03. Subsequently, a Yahoo Listserve was created to support ongoing daily communications. Phone calls were also exchanged between individuals. These systems supported the development of the first draft of a report.

After the first draft was completed, communication continued through the Yahoo Listserve and through phone conversations between committee members. For ease of communication, the subcommittee was broken into five regional groups. Each group met or had telephone conferences to review the first draft. In addition those members who later joined the broadly focused group met to compose a second draft on 10-26-03. A summary of the findings from this second draft was presented at the Task Force Facilitators meeting on 11-22-03.

When the Ed/Cert Committee split into two divisions during mid-November, 2003, another Yahoo Listserve was established to support daily communication among the 9 participants on the Ed/Cert-Broad Committee. Additionally, these committee members communicated by phone and during two follow-up face-to-face meetings.

D. FORMULATION OF THE REPORT

The Ed/Cert Committee's initial discussion regarding barriers to services and recommendations for improvement were typed into an MS word document on 7-26-03 (the day of the initial Autism Task Force meeting). This document served as the "Talking Points" for a discussion among committee members on the Ed/Cert Yahoo Listserve. Messages containing recommendations for additions, deletions, or modifications to the original Talking Points were used to shape the content of the first draft. A second draft was created based on feedback contributed by committee members during regional meetings. A more refined draft was reviewed and approved by members of the Ed/cert-Broad committee during a meeting on 11/30/03. Further refinements were made in the subsequent two weeks. All committee members approved the final draft.

II. CURRENT PRACTICES

Ideally, the adequacy of educational preparation of service providers might be assessed by considering the standards of best practices in service delivery for learners with ASD and data reflecting the actual status of service delivery in PA. However, a public document does not exist which describes the standards of best practices for individuals with ASD in the PA. The New York State Department of Health, Early Intervention Program (circa 2000) published The Guideline Technical Report: Autism/Pervasive Developmental Disorders – Assessment and Intervention for Young Children (Age 0-3 years). This report offers a summary of best practices based on an extensive review of outcome data published in peer-reviewed journals across disciplines. However, this publication is limited by its restricted focus on the 0-3 population. Educating Children with Autism (NRC, 2001) also provides a cross-discipline review of the treatment efficacy literature, but it offers less detailed recommendations for application.

With regard to empirical data, we are unaware of any formal publication documenting the efficacy of educational and therapeutic interventions currently provided by the school system or by the behavioral health system to individuals with ASD in PA. Therefore, we have no objective data to guide an evaluation of the efficacy of current practices (be they best practices or otherwise).

In the absence of formal guidelines for best practices, and in the absence of efficacy data reflecting current service delivery, this committee drew from personal experiences, informal reports and interviews with members of the ASD community at large (e.g., parents, advocates, administrators, service providers obtained from personal interviews by subcommittee members). We also reviewed information on barriers and potential recommendations contained in the DPW report of July and August 2002 regarding early intensive behavioral intervention for children with ASD as discussed in statewide public meetings. Finally, we reviewed other task force reports: New York State's Autism Program Quality Indicators, 2001. Report of the Caring of Oregon's Children with Autism Spectrum Disorder Task Force, 2000; Report of the Maine Administrators of Services for Children with Disabilities Autism task Force, 2000, The Nevada Provider Rates Task Force Strategic Plan for Services for Individuals with Autism, 2002, Ireland's Educational Provision and Support fo persons with Autism Spectrum Disorders: the report of the Task Force on Autism, We acknowledge that these informal resources are limited; and we emphasize the need for an unbiased, systematic effort to assess these issues empirically.

In the following section of our report, we present 11 barriers and recommendations pertaining to the education of service providers and to the access of appropriate educational services for individuals with ASD in Pennsylvania.

A. STATE-LEVEL ADMINISTRATIVE BARRIERS AND RECOMMENDATIONS

In this section, we address barriers and recommendations that are connected with organizations and processes that function (or could function) at the state level to influence the appropriate preparation of service providers and the access to adequately educated service providers by families for their children with ASD.

Barrier A-1: **Absence of a Central Agency for ASD**	**Recommendations**
Unlike other disabilities (e.g., mental health, mental retardation) there is no state-level agency to supervise, coordinate, or advocate for appropriate services to individuals with ASD.	Establish a state-level agency (or a division of an existing agency) with regulatory control over the delivery of services to children with ASD and their families. For the purposes of this report, we refer to this as the ASD-Agency. Purpose: The purpose of the ASD-Agency would be to monitor and coordinate all services (educational, behavioral health, medical) to individuals with ASD and their families across the life span. It would also develop measures of accountability associated with all of the recommendations that follow in this report. Representation: The ASD-Agency must have a means to obtain equal representation by service providers and families. • Service provider participants must represent the full range of educational service providers, behavioral health service providers, related area specialists, and medical specialists. • Family participants must represent children with autism at all ages and levels of ability, and cultural contexts. • There must be representation among service provider and family participants that includes all types of municipalities and economically diverse groups within the Commonwealth of

PA.

Barrier A-2:
Absence of Best Practices Guidelines for Individuals with ASD

There is an absence of best practice standards for interventions provided to individuals with ASD in PA. Consequently, the autism community is limited in its ability to evaluate the current practices of any agency (e.g., schools, behavioral health, private practitioners); and it is subject to the influences of alternative sources of information (e.g., word-of-mouth; internet listserves, etc.) which advocate an ever increasing number of strategies, many of which lack empirical validation. This makes parents particularly vulnerable to fads and pseudoscience.

Recommendations

1. Develop a board (within the ASD-Agency discussed under Recommendation 1A, above) that establishes and updates the standards of best practices for autism interventions based on an unbiased, cross-disciplinary review of the current efficacy research. Such standards should include (but not necessarily be limited to)

a. the identification of 3 levels of intervention:

1. Interventions with empirical validation.
2. Promising interventions that lack empirical validation.
3. Interventions that have been found to be ineffective through systematic empirical research

A model similar to that used by the state of New York should be considered. e.g., See New York State Department of Health Early Intervention Programs (1999) Clinical practice Guideline: Report of the Recommendations – Autism and Intervention for Young Children (Age 0-3 Years) at http://www.health.state.ny.us/nysdoh/eip/menu.htm

b. the identification of best practice standards for how the services should be delivered.

Barrier A-3:
Absence of state-wide research on the efficacy of autism interventions.

Many of the concerns raised in this report are based on impressions of committee members and on the impressions of members of the autism community with whom committee members have consulted. We would prefer to base our conclusions on evidence based scientific research. At the present time, this research is not available.

Recommendations

The Commonwealth of PA should support controlled scientific research into the efficacy of interventions provided to individuals with ASD with varying degrees of severity across the life span in all settings (e.g., home-based, schools, community-based, job-based). This research should include (but not be limited to)

- The range of services needed by individuals with ASD
- Family evaluations regarding the strengths and weaknesses of services provided to individuals with ASD
- An efficacy based analysis of current services delivered to individuals with ASD and recommendations on how to improve and augment these services
- Educational outcomes of various intervention

options

Barrier A-4:
Lack of State-Level Certification in Autism

ASD is the third most common developmental disability in the USA. Individuals with autism present a complex and unique profile requiring the specialized application of strategies for assessment and intervention. Despite these challenges, and in contrast to communicative disorders, learning disabilities, and other disability categories, a specialty certification does not exist for teachers who manage classrooms for individuals with ASD. Without this certification, there is no guarantee that teachers of students with ASD have the required background needed to meet this challenge.

We are aware that PSU and PaTTAN have collaborated to develop an Autism Certificate program. However, we note several limitations of this program:

- Completion of this program is not a requirement for teachers of students with ASD.
- Enrollment is only available through PSU.
- Although the program includes a week-long "practical" segment during PA's Summer Autism Institute, the largest segment of the curriculum is taught via videotaped lectures. We question whether this is the best means of delivering this information.

Recommendations

1. The state should offer and require a specialty certification for educators who teach classes for students with autism.
2. The curriculum should include and expand upon the Core Elements of Best Practices listed in section "B", below.
3. Details of the certification process should be designed through systematic input from
    - Parents and professionals representing individuals with ASD at all ages, severity levels, educational levels, cultural backgrounds, municipalities, and socio-economic ranges.
    - Researchers and practitioners representing (but not necessarily limited to) the following areas:
        - Psychology
        - Education
        - Communicative Disorders (SLP)
        - Applied Behavior Analysis
        - Occupational Therapy
        - Physical Therapy
        - Adapted Physical Education
        - Music Therapy
4. Required university courses should be taught by professors from education and from as many related disciplines as possible within a given university context (e.g., psychology, special education, communicative disorders, applied behavior analysis, etc.)

Barrier A-5:
Limitations in State-Level Efforts to Support the Continuing Education of All Service Providers and Families.

• Each summer, PaTTAN and PSU sponsor an autism conference. Parents and professionals have the opportunity to participate in short courses and seminars, many of which emphasize evidence-based practices. However, attendance is voluntary and there is no requirement that information gained at this conference be integrated into the service delivery system. This is extremely frustrating to families.

Recommendations

1. Provide incentives for professionals (e.g., teachers, therapists, BHR professionals) and for paraprofessionals (therapy support staff, educational assistants) to attend this and other conferences that emphasize evidence-based practices. These incentives could include tuition reimbursement, continuing education credits, public recognition, etc.
2. Provide incentives for professionals and paraprofessionals to demonstrate appropriate applications of information gained at conferences on evidence-based practices.
3. Provide parents, on request, information about specific training courses that providers

have completed.

B. LIMITATIONS OF UNIVERSITY TRAINING PROGRAM

In this section, we address barriers and recommendations at the university level, including issues related to the education of all professional service providers, in ASD for special education teachers, limitations in the education of all professionals who deliver services, and limitations in the university faculty who teach courses on topics related to ASD. As an introduction to these issues, we present the following **Core Elements of Best Practices in ASD** that should be included in the training of all teachers and service providers

- In-depth description of the characteristics of autism spectrum disorders throughout the life span.
- In-depth presentation of the uneven profile of strengths and weaknesses characteristic of individuals with ASD
- In-depth discussion of the unique communication characteristics of individuals with ASD
- In-depth discussion about the unique sensory-integrative challenges of individuals with ASD
- In-depth description of the special characteristics and unique challenges of individuals with ASD at all levels of intelligence (e.g., low, mid-range, high)
- Emphasis on the learning potential of individuals with ASD
- In-depth presentation of the principles of evidence-based practice
- In-depth exposure to a broad-range of evidence-based interventions
- Emphasis on the use of objective, individualized, quantitative, measures for tracking progress.
- Emphasis on the importance of cross-disciplinary collaborative service delivery, including an introduction to the unique and overlapping expertise of specialists who provide services to individuals with ASD.
- A discussion (presented by a panel of parents) of the importance of including parents as partners on an intervention team
- In-depth description of inclusive practices, including exposure to books such as You're Gonna Love This Kid by Paula Kluth (2003)
- In-depth description of the ways in which cultural differences may impact the assessment of individuals with ASD and the design/implementation of individually-appropriate intervention programs
- Experience working with individuals who have ASD and with their families (as partners on the intervention team) under the guidance of a well trained, ASD-knowledgeable supervisor.

Barrier B-1:
Inadequate basic training in ASD issues

There is a lack of standardization in training of future service providers and educators on ASD issues. Based on the performance of service providers, we find university training programs to be deficient in the following ways:

- Insufficient emphasis on the developmental profiles of individuals with ASD e.g., Programming decisions are sometimes made based on the lowest or highest skill in a student's repertoire rather by considering a student's different ability levels across developmental domains. This error can result in programs that are both too challenging and not challenging enough.
- Insufficient emphasis on the concept of evidence-based practices. e.g.,

Recommendation

1. The university training of all professional service providers (special educators, SLPs, ABA professionals, psychologists, etc.) must include (but not be limited to) the Core Elements of Best Practices in ASD described above.

Programming decisions are sometimes made based on the specialty training of service providers or on the availability of materials rather than on an analysis of a student's performance data.

- Insufficient emphasis on principles of program decision-making. e.g., It is sometimes assumed that students with ASD can't learn to read when they haven't had the opportunity to participate in reading instruction.
- Insufficient exposure to a broad range of evidence-based interventions: e.g., When service providers are not aware of the range of evidence-based practices available to individuals with ASD, they may fail to recommend the most appropriate treatments.
- Insufficient emphasis on the importance of cross-disciplinary collaboration in the service delivery process: There is a tendency of professionals representing different specialty areas to operate independently even though a more collaborative style is in the best interest of the individuals they serve.
- Insufficient emphasis on strategies for including the input of parents into the design of intervention programs. Parent committee members have had repeated personal experiences during which their input as a member of the intervention team was either completely ignored or dismissed. Parents know their children's unique patterns of behavior, communication signals, and educational needs, and they have a right to participate as equal members of their child's intervention team.
- Insufficient emphasis on strategies for adjusting intervention programs in consideration of cultural variations and family structure: Consistent with the population at large, individuals with ASD live in diverse cultural contexts. Educators and other service providers are not sufficiently prepared to understand or to be sensitive to the potential impact of cultural diversity on the content and/or design of service delivery.
- Insufficient emphasis on inclusive practices. Some service providers understand inclusion as the simple addition of students with ASD into settings with typical children (e.g., classes, social groups). Failure to make the necessary and appropriate accommodations can compromise the learning experience for all individuals in the setting.
- Insufficient supervised clinical practicum with individuals who have ASD and their

families: Some university programs do not systematically include within their programs supervised practicum experience involving individuals with ASD and their families. Consequently, new service providers are often forced to learn from children with ASD rather than to teach children with ASD how to learn.

Barrier B-2:
Limitations in the university training of related service providers

The university experience of many professionals (e.g. ,psychologists, ABA professionals, SLPs, OTs, PTs, social workers, music therapists, professionals who teach adapted physical education, etc.) is limited with respect autism-specific training.

The following are examples:

Limitations in the education of SLPs:

The American Speech-Language and Hearing Association (ASHA) does not require SLP students to take a course in ASD; and such courses are taken infrequently by SLPs, even as electives (Koenig & Gerenser, 2000). While information about ASD is included as a unit in required language disorders classes, and while some SLP students take an elective course in ASD, it is technically possible for SLPs to receive a graduate degree and a certificate in clinical competence (CCC-SLP) from ASHA without ever having taken a single course in ASD and/or without ever having worked with a single individual on the autism spectrum.

There is a tendency for some SLPs to focus on deficits in speech production and linguistic form when deficits in pragmatics present the greatest problems for individuals with ASD.

Many SLPs receive relatively little training in ABA and behavioral approaches to language instruction despite the evidence that these approaches are effective for individuals with autism.

Limitations in the education of OTs and PTs:

The pre-professional training of OTs and PTs has been based, traditionally, on the medical model. This model approaches assessment and intervention with the assumption that an identification of the cause of a disorder will lead to the selection of an intervention. It ignores the fact

Recommendations

1. PDE and DPW should require all students in related areas to take a course on the **Core Elements of Best practices in ASD** (see above) as a prerequisite to working in school and BHR settings.
2. PDE and DPW should provide incentives for faculty from special education and related areas to team-teach the **Core elements and Best practices in ASD** course.

that the causes of developmental disabilities are often not identifiable and can not be treated directly.

The training of OTs and PTs often appears not to include information about the identification and measurement of behavioral manifestations of a disorder. Without knowing how to identify or measure target behaviors, OTs and PTs are limited in their ability to measure the efficacy of intervention. Without efficacy data, it is impossible to analyze the features of therapy that need to be altered in order to support student progress. This increases the risk that the blame for a child's failure to achieve intervention goals will be shifted from the therapeutic procedures to the developmental disability itself or to the child's lack of motivation to address the goal.

Limitations in the Education of ABA Professionals:

Professionals with a degree and certification in ABA often have excellent training in the behavioral approach to language instruction. However, their training often does not include exposure to developmental research. When ABA professionals and SLP professionals are working with the same student on similar goals, this can create misunderstandings.

Barriers to Cross-Disciplinary Collaboration of Related Service Providers

Confusion created by misunderstanding the expertise of colleagues in related professions: There is confusion within each of the related services about the content of the other professions. For example, many professionals (and many consumers) misunderstand "ABA" to mean "discrete trial instruction". Similarly, many professionals assume that if a child is receiving SLP, the intervention is not related to ABA. Neither of these assumptions is accurate. These misinterpretations lead to confusion among service providers in the process of program design, among administrators in the assignment of specialists to case loads, and among families in their understanding of the services delivered by various specialists.

Confusion Created by Overlapping Roles: Professionals in different related areas often provide services that overlap. For example, ABA professionals and SLPs both provide language instruction. OTs and SLPs both provide social skills training. Overlap in the professional roles of different specialists may be confusing for parents and may result in conflicting recommendations

unless each professional is clear about his/her boundaries.

Confusion Created by Over-use of Technical Jargon: The literature and language of all professions includes technical terms that are unique to each profession. These technical terms enhance the communicative efficiency between professionals within each field. However, these same terms can reduce the communicative efficiency between professionals from different fields as well as the communicative efficiency between professional and parents.

Barrier B-3:
General Educators Lack Preparation about Inclusive Practices for Individuals with ASD

We have countless examples of instances in which general education teachers were greatly challenged by the inclusion of a child with ASD in their classrooms. Below is a listing of some of the situations that have come to our attention:

- The teacher had never before met a person with autism.
- The teacher was unaware of the scattered profiles and of the learning styles exhibited by children with ASD.
- The teacher defined "inclusion" simply as the physical placement of a student with ASD in a typical classroom.
- The teacher had low expectations of students with ASD.
- When individuals with ASD also displayed skills in the gifted range, there were no attempts to provide an enriched curriculum for the area in which the individual excelled.
- The teacher was unaware of countless possible accommodations that can help students with ASD to function more appropriately in classrooms.
- The teacher failed to incorporate the recommendations of parents who brought them resources for identifying and implementing accommodations.
- The teacher assumed that a child's paraprofessional should be responsible for all accommodations.
- The teacher was unaware of strategies to support interactions between students with ASD and their typical peers.
- The teacher was overwhelmed with the combined demands required to accommodate the typical students in his/her classroom as well as the students with ASD.

Recommendations

The university training program of future educators, including future teachers of special subject areas (e.g., music, library, computers, PE, etc.) must include (but not be limited to) the following:

1. Information about the developmental profiles and learning styles of individuals with ASD, including the profile of gifted students with ASD who must be supported through enriched learning opportunities.
2. Information about the philosophy and goals of inclusion.
3. Information about accommodations that can be made to support the performance of students with ASD to achieve academic goals, including (but not limited to) the principles of reinforcement and strategies for using a student's special interests to motivate work on skills targeted by the IEP.
4. Information about methods of supporting interactions between students with ASD and their typical peers.
5. Information about strategies for including the suggestions of parents in the design of programs for students with ASD, including parental perspective information presented directly by parents of children with ASD.
6. Strategies for helping students to structure unstructured time.
7. Effective strategies for the prevention of bullying.
8. Organization of time and preparation for changes (however small) to the classroom routine.
9. Ways to coordinate with health care professionals when an included child requires health care support

Similar limitations have been observed in the performance of some individuals who teach special subject areas (e.g., art, music, library, computers, PE, etc.)

Barrier B-4:
Limitations in the practical experiences of university faculty who train future professionals.

Based on the feedback we have received from therapists and teachers regarding their university curricula, and based on information we have received from individuals who teach at the university level, we question whether most university instructors have the practical (service-delivery) experience needed to enhance the education of future professionals, and whether updated practical information about service delivery is incorporated in the education of future professionals (e.g., Special Education, Psychology, Speech-Language Therapy, Applied Behavior Analysis, Occupational Therapy, Social Work, etc.)

Recommendations

Provide incentives for university instructors to gain an understanding of ongoing changes in the service delivery system. For example:

- Offer sabbaticals for the purpose of participating in service delivery
- Encourage research into the efficacy of intervention and service delivery issues.
- Support collaboration between service providers and university instructors
- Offer grants devoted to linking university professors and service providers in joint applied research projects.

C. LIMITATIONS OF ALL SERVICE PROVIDER AGENCIES

In this section, we address barriers and recommendations regarding education and hiring practices that span across both education and behavioral health service agencies.

Barrier C-1:
Limitations in the quality of in-service training and continuing education for professional service providers

- School districts provide staff with in-service training for professionals who work with special challenges. However, these in-service presentations often appear not to include practical information on serving individuals with ASD. Moreover, in some instances, there is no requirement for educational staff to attend these trainings.
- BHR service providers do not necessarily provide a format for natural mentoring to occur.

Recommendations

1. Develop case-based in-service trainings that are specific to the issues presented by the students included in the case load of the service providers who are receiving the in-service.
2. Provide time for weekly discussion meetings where staff may exchange ideas about problematic cases.

Barrier C-2:
Limitations in the training of support professionals

- Limitations in the Education of school-based paraprofessionals. Committee members have personally experienced situations in which paraprofessionals were hired without

Recommendations

1. Raise the standards for hiring school-based paraprofessionals:
    - Whenever possible, hire individuals who have had experience in working

any previous background in the educational system or in working with individuals with ASD. Based on the tenets of No Child Left Behind, it will be a requirement that all aides have an associate's degree. However, this requirement has not yet been implemented. At the present time, there is no requirement for paraprofessionals to have any background in ASD or special education.

- Limitations in the Supervision of Paraprofessionals: Frequently, a paraprofessional is the primary implementer of a child's behavior plan. Despite the fact that this role involves the use of behavioral interventions, paraprofessionals are frequently not trained in basic behavioral techniques. Further, they are often not supervised by a certified behavior analyst or by a certified psychologist.
- Limitations in the Training of Therapeutic Support Staff (TSS): TSSs provide a crucial role in supporting the behavioral programs of individuals with autism. Training of TSS often occurs as an ongoing process, and we know of no requirement within the behavioral health service systems to insure that the training is being provided by certified or credentialed professionals.

with individuals who have ASD.
    - If no individuals with experience are available, require a trial period of service delivery under the direct supervision of an experienced mentor; and make subsequent hiring contingent on adequate performance during the trial period.
2. Improve the supervision protocol for paraprofessionals:
    - Require paraprofessionals who have the primary responsibility of enforcing behavior plans to be supervised by a certified behavior analyst or a licensed psychologist.
    - Include an on-site observation component in the supervision process.
    - Provide incentives for paraprofessional to improve their skills.
3. Improve the training of TSS. A TSS new to PA who is working with individuals with ASD should:
    - have at least 10 hours of training in ASD issues and complete 15 hours of Kirk T Training prior to beginning to work with individuals who have ASD
    - Work for a minimum of 1 month under the supervision of a qualified behavior specialist (as defined above). The supervision should begin as full time for the first week with hours gradually decreasing in subsequent weeks.
    - Provide incentives to hire TSS with previous ASD experience. We are defining an "ASD-experienced TSS" as one who can produce at least two letters of recommendation from a qualified behavior specialist and three letters of recommendation from parents of children with ASD.
    - Support TSS by providing more frequent supervision and more varied supervision formats and compensation for supervision time.
    - Develop a means of insuring more frequent on-site observation component in the supervision process
    - Provide incentives for the paraprofessional to improve his/her skills. For example, provide increases in salary commensurate with experience and letters of support from families.

Barrier C-3:
Limitations in the Training of non-educational Staff

A number of non-education staff employees (e.g., bus drivers, cafeteria workers, maintenance workers, nurses, security officers, etc.) routinely interact with individuals who have ASD. These employees are often completely unaware of the characteristics of ASD, and we are not aware of any systematic training provided to these employees. Yet employees are sometimes the only adults present in more unstructured settings. The failure of these employees to receive this training places individuals with ASD at safety risk.

Recommendations

PDE and BHRS must insure that these employees receive training in the following areas:

- Strategies to protect individuals with ASD from being bullied and/or assaulted by others.
- Strategies for helping individuals with ASD to de-escalate during emotional or violent incidents
- Strategies for protecting and guiding individuals with ASD in socially challenging situations.

Barrier C-4:
The practice of hiring BSCs lacking certification in ABA.

Many behavior specialists lack certification in applied behavior analysis. Without certification in ABA (CABA, BCBA), it is difficult to assess the qualifications of a behavior specialist. There is no guarantee that such an individual possess the academic and practical experiences necessary to provide competent behavioral services. In the worst case, it places individuals with ASD at risk for receiving services that may actually exacerbate their symptoms. At the same time, national certification in ABA is a relatively recent development (2000) and there may be some qualified ABA professionals who have not yet taken the steps to acquire their certification. For the protection of individuals with ASD, this situation needs to be addressed.

Recommendations

1. By 2013, the proposed Autism Agency (see State-level barriers, above) must require all BSCs to have earned advanced certification in ABA as specified by the Behavior Analyst Certification Board (BACB). See http://www.bacb.com/.
    - This will insure that BSCs demonstrate a set of clinical and ethical standards that are endorsed by the Association for Behavior Analysis (ABA), an international professional association.
    - Violations of standards can be reported to the Behavior Analysis Certification Board (BACB); and families can verify whether a BSC is in good standing with the BACB.
2. Additional requirements of BSCs must include:
    - Evidence of having completed coursework that includes the **Core Elements of Best Practices in ASD** (see above)
    - Evidence of supervised experience in treating children with ASD at all levels of the spectrum. Evidence can include at least 3 letters of recommendation from families and 2 letters of recommendation from employers.
    - Demonstrated ability to interact with parents of children with autism in a variety of family configurations and culturally diverse contexts.
    - Breadth of knowledge about other

specialty areas to support collaboration with an interdisciplinary team consisting of other specialists with expertise in autism (e.g., Teachers, SLPs, OTs, psychologists, etc.)
    - Completion of CASSP training in service delivery and an overview of BHRS within the first two years of service.
3. Incentives should be provided to professionals who are hired as BSCs and who are working towards earning their certification (BCBA). For example they could be offered tuition assistance and greater compensation upon attainment of the certification in exchange for a commitment to work in PA under DPW or PDE for at least 2 years.
4. As an interim measure before 2013, non-certified BSCs must receive at least 8 hours annually of inservice trainings in applied behavior analysis presented by a certified behavior analyst (BCBA).

Barrier C-5:
A lack of service providers with Cognitive Behavior Therapy (CBT) training.

Depression is a commonly co-occurring condition among individuals with ASD, owing both to biological factors and environmental stressors (e.g., social isolation). Moreover, research indicates that children with high functioning autism (HFA) and Asperger's Syndrome (AS) are at increased risk for suicide without appropriate intervention (Ghaziuddin, Weidmer-Mikhail, Ghaziuddin, 1998; Kim, Szatmari, Bryson, Streiner, Wilson, 2000). Fortunately, cognitive behavioral therapy (CBT) has been shown to be the most effective non-pharmaceutical intervention for treating depression and anxiety in adults and children (e.g. Evans, Hollan, DeRubeis, & Piasecki, 1992; Gillham, Reivich, Jaycox, & Seligman, 1995). Despite these facts (and despite the fact that that PA is the world center for training and research in CBT), BHR services lack a sufficient number of mobile therapists trained in this therapy. As a result, many individuals with ASD are denied this necessary service.

Recommendations

1. Require Mobile Therapists to have a minimal level of training in cognitive behavioral therapy (CBT).
2. BHRS should allow clients to access professionals who are proficient in CBT, including those certified by the Academy of Cognitive Therapy.
3. BHRS should provide continuing education certification opportunities in CBT. For example, offer scholarships to the Beck Institute Training Programs in exchange for a guaranteed term of services as a BHRS mobile therapist.

Barrier C-6:
Assigning unreasonably high case loads to specialists

Committee members have experienced numerous situations which appeared to reflect unreasonably

Recommendations

1. The Commonwealth of PA should support the hiring of more SLPs, BSCs, OTs, PTs, and

high case loads for those who provide services to individuals with ASD. For example:

A. Agencies assign high case loads and claim that specialists must use a set number of hours per week. This prevents service providers from being available when there is an immediate need to increase the intensity of service for a particular individual.
B. Providers are often forced to serve a very large geographic area, rendering them unavailable to step in when emergencies arise.

psychologists with demonstrated expertise in ASD. The number of these professionals should be determined based on empirical evidence of the number of individuals with ASD who reside in various regions.
2. Agencies must be required to build flexibility into the schedule of service providers so that intensity of services can be delivered in home when issues arise unexpectedly and so that staff can attend interdisciplinary meetings as these arise.
3. Agencies should be required to have on staff a professional who serves as a "floater" between those clients who may have an immediate temporary need for increased attention.
4. Agencies should be required to restructure services such that a given provider can primarily serve a limited geographic area.

Barrier C-7:
Failure to provide incentives for individuals to make autism service delivery a career goal

The turn-over of individuals who work as paraprofessionals, therapeutic support staff, and behavior specialists appears to be high. While many of these individuals begin their work out of a true interest in helping individuals with ASD, they tend to leave this work for the following reasons:

- poor working conditions
- low salaries
- unreasonable case loads
- little support or reinforcement for continuing education
- no means of moving up within the system

High turn-over among service providers directly contradicts the need for stability of programming that is so essential for individuals with ASD.

Recommendations

Incentives should be provided for agencies to reduce the high turn-over by providing incentives to hire and retain competent workers. For example:

A. Provide appropriate working conditions, including limiting the need to travel extensively to fill caseloads, and career development opportunities.
B. Offer competitive salaries to attract and retain competent service providers.
C. Provide financially affordable, geographically accessible, and pragmatically workable means of accessing post-graduate courses in autism-specific interventions with credits toward certification (once that is established)
D. Offer internal advancement to those who earn continuing education credits and/or participate in other approved learning experiences.

D. LIMITATIONS OF THE BEHAVIORAL HEALTH AND REHABILITATION SYSTEM

The following points reflect the general perception that BHR services do not (and were not designed to) meet the needs of individuals with ASD or their families.

Barrier D-1:
Inappropriate use of resources

BHR services were designed for individuals with

Recommendations

1. Publish all DPW Interpretive Guidelines

mental health including drug, alcohol, and mental retardation problems. This model is inappropriate for individuals with ASD, whose needs for behavioral support are fundamentally different and continually evolving (DPW EIBI public meetings, 2002).

For example, at the present time, individuals with ASD must be re-evaluated every four months to determine if they continue to present with the diagnosis and to require behavioral health support. Given that ASD is typically a life-long disability, the money spent on psychological services to confirm a life-long diagnosis three times a year could better be spent. More directly to the point of this committee's concerns, these systems limitations divert the attention of service providers from issues that are more relevant to the behavioral needs of individuals with ASD by requiring service providers to conduct tasks that are irrelevant to the population.

related to BHRS since 1992.

2. Expand the purpose of behavioral health services to include the unique needs of individuals with autism and their families.
    A. This should be done by a team of individuals including professionals who have had extensive home-based service delivery experience with individuals at all levels of the autism spectrum and with all types of family configurations. It should also include parents who have had experience with the system and whose children represent the full range of ASD. It should also include parents and professionals who represent diverse cultural groups.
    B. The committee's work should be informed by a systematic needs assessment and by information about successful models in other states and/or countries.
3. Revise the schedule of periodic psychological evaluations so that assessments are conducted less frequently unless a specific request is made.
4. Discontinue the policy (motivated by Managed Care organizations) of stating that the purpose of behavioral health services is to educate family members. Emphasize, instead, that BHR services are designed to support family members in the management of their children's behavior.

Barrier D-2:
Inappropriate Assumptions about the Needs of Families

Agencies often claim that the primary purpose of BHR Services is to provide parents of individuals with emotional and/or drug and alcohol abuse problems training in methods of behavior management. The actual stated purpose of EPSDT services (OBRA '89) is to prevent or ameliorate disabling conditions identified in individuals under the age of 21.

Recommendations

1. In the upcoming restructuring of BHRS, take into account the needs of people with ASD. Any new structure should include:
    - Less frequent assessment schedules for individuals with ASD whose conditions are typically lifelong.
    - Provisions for long-term treatment
2. Parents should be fully and accurately informed of the purpose of EPSDT and of the guidelines underlying the scheduling of services for their children.

Barrier D-3:
BHR health care plan representatives lack appropriate training

- There is a wide spread public perception that "Those with the power to approve or deny

Recommendations

1. Health care plan representative must be educated about autism. (See

services, such as health care plan representatives, do not understand what is needed to successfully support those with Autism Related Disorders. However, since they can supersede recommendations of qualified professionals, inappropriate goals are often set" (DPW EIBI Public Meetings, 2002).

- Many agencies do not comply with published regulations regarding BHRS, including the necessity to measure intervention outcomes.

recommendations for the education of service providers above).

2. Parents must be informed about BHRS regulations, including the requirement to measure intervention outcomes (in order to document amelioration). Parents should have input into reports on intervention efficacy, and they should receive a copy of the encounter forms that document intervention progress.
3. Parents have the right to receive a copy of the monthly service delay report that they are obligated to sign under the Kirk T requirements; and the codes used on this form should be explained to parents so that they can authenticate that data that were recorded accurately. When parents are not provided with this information upon request, or are not informed about their right to acquire this information, the agency should be reported and appropriate disciplinary action should be taken.
4. Outcomes must be measured, defined and monitored. This is essential for monitoring the effectiveness of a program and for deciding if changes are needed. Further, data that document the effectiveness of interventions provide the evidence that is needed to justify the continuation of services.

Barrier D-4:
Inconsistent support of cross-discipline communication across BHR service agencies

Some agencies inform parents that there is no means for their service teams to consult with each other when in fact consultations may be necessary to administer a particular child's intervention program adequately and are therefore permissible and billable.

Recommendations

DPW should require agencies to document that they are providing mandatory training to all service providers and that …

- This training is accessible to parents.
- It includes regulations on intra-agency coordination, including what types of services are and are not permissible.
- It includes a thorough overview of CASSP Principles which must be honored in order to provide services to individuals ethically.
- It includes a parent panel to represent the experiences of families.

Barrier D-5:
Behavioral health services are not set up to participate in inter-service coordination initiated by external agencies.

In some counties, parents and behavior specialists

Recommendation

See recommendations for DPW training of BHRS

are informed that behavior specialists will not be paid to attend IEP meetings at schools. As a result, there is marked variance within and across agencies with respect to inter-service coordination. This variance appears to be based on each individual agency's interpretation of regulations. Again, in the absence of appropriate coordination, service providers are prevented from engaging in dialogues that would enable them to enhance the quality of services they can provide to individuals with ASD.

providers and administrators.

Barrier D-6:
Limited options for families with multiple stressors

Some families are not able to meet their obligations within the typical structure of the wraparound system. For example, both parents may have to work, and they will need to hire a baby sitter to be responsible for their child with autism while they (the parents) are working. When this has occurred, some parents have been told that they had to remain present in the room during the entirety of the service delivery period in order for services to be rendered.

Recommendations

See recommendations for DPW training of BHRS providers and administrators.

E. LIMITATIONS SPECIFIC TO THE SPECIAL EDUCATION SYSTEM

This section examines barriers and recommendations that would require changes to PDE's policies, regulations, or training procedures.

Barrier E-1:
Culture of Special Education system appears to systematically exclude families from being partners in the process.

Parents are supposed to be full partners in the entire IEP process, when, in reality many service and placement decisions are prearranged before the actual IEP meeting occurs.

Some draft IEPs are being created without parental input – parents feel that they can only criticize and object rather than participate from the ground up.

Parents are often given limited placement options and limited options about services. At times, parents recommend (and their child needs) a more appropriate environment, but the only option they are given is the one that pre-exists in the school district. The pre-existing option serves the district's needs but it ignores the student's needs. At other times, children are denied a least restricted environment without full consideration of potential supporting services (i.e., giving the choice between

Recommendations

Provide training, changes in regulations, and public access to information that will begin to alter this culture:

1. Educators, education staff, and parents need to be trained in IDEA, Chapter 14 regulations, 504 regulations, ADA, ad state guidelines (BECs)
2. If a school district chooses to prepare a draft IEP prior to the IEP meeting, parents must be presented with a copy of this draft IEP a full 10 days prior to the scheduled meeting. This draft must clearly say on the top that this document is only a draft, and it must be dated.
3. Give the parents the opportunity to sign IEPs and ERs to show that they are in agreement with the documents. Currently, parents only sign IEPs to indicate attendance at the

full time mainstreaming with no supports versus a self-contained classroom) because that's what the school has to offer.

Some school districts invite attorneys to IEP meetings if the parents appear to be advocating strongly for their children.

meeting.

4. Inform parents of the full range of services, including BHR and IU services. Periodic parent surveys should track the delivery of this information to parents at every IEP meeting.
5. If parents advocate an inclusive environment, schools should attempt to support this placement with full range of available services and interventions before determining that this placement cannot function. Periodic parent surveys distributed by the PDE should document that these attempts were made by the school district. For example, parents could receive a copy of PDE's parental inclusion survey (see Appendix B) at each IEP meeting, to be filled out and returned directly to PDE.
6. Include parent panels and parental perspective on IEP process in continuing education programs for administrators and teachers.
7. Regulate that schools may not invite attorneys to IEP meetings unless parents announce that they will do so as well.

F. LIMITATIONS IN EFFORTS TO ACHIEVE COMPLIANCE

Improvements in compliance with IDEA and Pennsylvania special education regulations will lead to more inclusive placements and will improve future outcomes for students with ASD.

Barrier F-1
In many cases, a family's only recourse in the case of a dispute over FAPE is litigation.

Parents are sometimes subjected to retaliation if they strongly advocate, file a complaint, or file for due process.

There is a perception that some due process officers are not fully aware of federal and state regulations. Some are not fully trained on core knowledge regarding ASD.

School districts sometimes file for due process against parents rather than considering more inclusive placements. Many parents cannot afford a retainer to hire an attorney to defend their case.

Some due process officers come from the ranks of school officials, and are personal friends with school staff and/or legal representatives, introducing a possibility of bias.

Compliance officers tend not to fully investigate

Recommendations

1. Expose the public to patterns of litigation and dispute settlements in school districts. Publish on the PDE web site the following information:
    - Number of IDEA compliance complaints filed with PDE, topic of complaint, and if the school district was found to be in violation.
    - Number and outcome of Due Process hearings, broken down by the school district and special education category. List whether the parents or the school district filed for due process.
    - Number and outcome of mediations in which the district participated. Also list the number of mediations that the school district declined.
2. Change regulations such that compliance investigations will include interviews with the

compliance complaints. They rely almost exclusively on paper documentation, rather than interviewing staff and parents. At times, a letter from the special education director is taken as the final description of what occurred.

Compliance officers personally know educational staff but not parents, introducing an issue of bias.

Compliance officers only investigate procedural complaints. For violations that are more systemic, such as not considering the Least Restrictive Environment, the parents' only recourse is due process litigation.

staff involved in the complaint. Allow the parents to review all records provided by the school district, and to offer rebuttals to these documents, before providing a final decision. Have a feedback system where parents are asked to rate how well their complaint was investigated, and if the complaint was resolved to their satisfaction.

3. Parents should be able to file a complaint to ODR if they are subjected to retaliation for advocacy, for filing for due process, or for filing compliance complaints. Any and all retaliation complaints should be investigated immediately by a state compliance officer. Pilot facilitated IEPs with efficacy data on outcome.
4. Allow a panel of professionals and parents, comprised of at least half parents, to annually review the qualifications and record of due process officers and compliance officers. Create a way to complain about potential bias or conflict of interest issues concerning compliance officers and hearing officers.
5. Publish redacted versions of compliance complaints and resolutions.

G. LIMITATIONS IN ACCESS TO SUPPORTING SERVICES

Often, supporting services are crucial to the educational programming of students with ASD. In many cases the presence or absence of supporting services determine whether the child will function in a more mainstream environment.

Barrier G-1:
Appropriate behavioral and ASD support services are currently not available to many students.

Schools have the option to bring in autism or behavioral consultants from the IU or PaTTAN. However parents are not given this option — if the school district declines such consultation the child does have access to these experts. Since few schools have an autism or behavioral expert on staff, the child may not receive proper evaluations unless the parent agrees to a more restricted placement (e.g. IU classroom or APS school).

Schools often create FBAs without the benefit of a certified behavioral analyst to conduct this assessment.

Special education certification does not require an expertise in behavior analysis—yet it is often the special education teacher who creates the Behavior

Recommendations

Institute a policy where parents can directly call in IU or PaTTAN specialists when there is a clear need for these services.

Regulate that all FBAs in schools be conducted by certified behavioral analysts or licensed psychologists with a documented record of experience conducting FBAs.

Students with ASD should additionally be entitled to have someone with clearly documented experience in ASD to conduct their FBA.

Manifestation determination meetings for children with an autism spectrum disorder should include a certified behavioral analyst and an expert in the characteristics in ASD. Any suspension of a child

Intervention Plan for an individual with ASD.

There is no requirement for a manifestation determination meeting to include a certified behavior analyst or psychologist to interpret the child's behaviors. If the 2004 version of IDEA reauthorization becomes law, special education students will lose the right to pendency if the student's behavior is not found to be a manifestation of their disability. Given the complex nature of ASD, it is crucial for students with ASD that the manifestation determination team includes an expert on autism and on autistic behaviors to discuss possible manifestations of ASD.

with an ASD should be considered a change in placement under 22 Section §14.35(c), entitling the child to all protection that apply to changes of placement for disciplinary reasons.

H. LIMITATIONS IN THE IDENTIFICATION OF INDIVIDUALS WITH ASD AND IN THE IDENTIFICATION OF EDUCATIONAL OUTCOMES

In the 2001-2002 school year, PA lists 3,951 students (.22% of public school enrollment) with the autism designation in the special education system. This is probably an under-representation. If the Autism designation were assigned to all students with ASD, this would result in improved services and programs as well as a better instrument for tracking the outcome of these students.

Barrier H-1:
Unclear protocols for determining disability designation. Lack of protocols to accurately track student outcomes.

Many schools are reluctant to identify high functioning students with ASD under the autism category listed in IDEA. At times, these students are placed under the Emotionally Disturbed category. While designation is not supposed to determine placement or services, it does in fact hold influence over these decisions. Furthermore, it is difficult to track outcomes among students with ASD if these students are not correctly identified.

Exit data are currently tracked for all children in the special education system. However, no parental confirmation of this data exists. More accurate accounting will make it possible to do research on long-term outcomes of individuals with ASD and on the efficacy of ASD-oriented educational programs.

Recommendations

Standardize protocols for choosing special education disability category and increase oversight of outcome tracking measures.

1. Amend chapter 14 identification definitions such that children showing characteristics consistent with Aspergers syndrome or PDD NOS would clearly meet the eligibility criteria for autism, given that other threshold requirements for special education eligibility are met.
2. Establish a means of confirming the validity of special education exit data. Parents should receive a letter from the state documenting their child's exit status and designation (e.g., graduation, moving and known to be continuing, moving and not known to be continuing). Insist on parental signatures to confirm special education exit designations. The letter should contain a number to call if information is inaccurate. This will allow for more accurate tracking of students with an autism designation.
3. Research is needed to follow the adult outcome of students with ASD, as broken down by placement and services offered to the student during the school years.
4. Collect parent satisfaction ratings on school

programs. Publish this data in a format that breaks down all information by school district and by disability type.

5. On each School District Report Card on the PDE website, publish data on the schools' placement decisions and graduation rates as broken down by disability type.

I. CHANGES IN IDEA THAT ARE BEING CONSIDERED UNDER THE 2004 REAUTHORIZATION HAVE THE POTENTIAL TO REMOVE CHECKS AND BALANCES THAT ASSURE A FREE AND APPROPRIATE EDUCATION FOR CHILDREN WITH ASD.

Barrier I-1: **Changes in IDEA will affect progress monitoring as well as the ability of parents to obtain a special education attorney for due process.**	**Recommendations**
Reauthorized IDEA law will eliminate measures of progress: The proposed new version of IDEA would eliminate short term objectives and benchmarks from IEP measures of progress. This is problematic for individuals with ASD, since standardized tests are not sensitive to these individuals' progress towards the attainment of social or communication-based IEP goals. Short term empirically-validated objectives and benchmarks are the only way to monitor progress objectively for many individuals with ASD.	Regulate that for in the Autism category IEP's are required to have short-term objectives and/or benchmarks as part of annual goals.
Attorney fees and LRE:-. The new IDEA may allow state governors to cap recoverable attorney fees by parents who go to due process over special education disputes; there would be no such cap on school district attorney fees. This imbalance places families at a disadvantage. Currently, placement and enforcement of the Least Restrictive Environment for students with autism is often a point of contention for parents and schools. A recoverable attorney fee cap may limit parent's ability to enforce the Least Restrictive Environment clause of IDEA when disputes over this issue arise.	PA should decline to set lower attorney fee caps, even if federal law allows this privilege. At times, parents can only obtain a free and appropriate education for their child via Due Process. Reducing recoupable attorney fees will severely limit the ability of lower or middle income parents to dispute an inappropriate program. Students with autism who are not properly educated are at increased risk for depending on state financial support as adults.

J. INTEGRATION OF BEHAVIORAL HEALTH AND SCHOOL AGE PROGRAMS

Behavioral health and rehabilitation (BHR) services are designed to support an individual with ASD across all environments, including the school and community. For this resource to operate as intended, providers and administrators need to be aware of resources available within other agencies or schools, as well as the regulations and laws that govern those agencies or schools. (Center for Mental Health in Schools,2002).

Barrier J-1 **General lack of integration:**	**Recommendation**

For children with ASD, many services that fall under special education or BHR either conflict or are redundant. For example, separate evaluations are required for each agency, and separate behavior support plans are created. (PDW EIBI Public Meetings, 2002)

The administrative set-up of BHR does not lend itself to filling in the gaps in special education services.

Some school districts are reluctant to use BHR services as a resource. At times, it appears that they do not want outsiders running or determining programs within schools.

For individuals with ASD who require behavioral services in schools, there should be clear guidelines that delineate the responsibilities of schools and BHRS.

Develop pilot programs the model truly integrated services. Specifically, a child would have one full evaluation, one behavior plan, and one cross-agency team that addresses needs across home, school and community. The pilot could be attempted in city, urban, and suburban environments. Efficacy data should be collected and used to fine-tune the program.

Consideration should be given to restructure BHR to better serve children in schools. For example

- Have BSC's dedicated to serving students in a particular geographic area within a 10 mile radius.
- Build flexibility into BSC's schedules such that they could come into a school more often if a client enters a needy or crisis period.
- Design a system that makes it easier for schools to call in BHRS to conduct FBAs and design Behavioral Intervention Plans for eligible students with ASD.
- Provide facilitators that can coordinate BHRS and school provided services.

K. BHR SERVICE-TO-SCHOOL

In order to develop an effective community-based treatment plan, case managers, BSCs and BHR service administrators need to be aware of special education laws and procedures. Likewise, school district administrators and providers should be aware of the opportunities (and limitations) of services that may be provided by BHRS.

Barrier K-1: Lack of Training for Administrators

Members of our subcommittee as well as people in the wider ASD community have found that some BHR service professionals and administrators are unaware of the regulations regarding how to coordinate between agencies, and unaware of how IDEA and chapter 14 PDE laws interact with the provision of services in school environment. This can create situations where parents and schools are in conflict over BHR services. The result is that:

- BHR services are not fully utilized in schools
- Some students with ASD are denied more inclusive placements owing to a lack of support staff, when such staff could be

Recommendations

BHR Service providers should receive initial and ongoing annual training in:

- ADA, federal IDEA legislation and chapter 14 and chapter 711 regulations governing special education in PA Public School codes.
- Regulations regarding their role in schools
- Current regulations regarding how TSS services should be handled and referred to in an IEP.
- Sources for parents to acquire an advocate if the need should arise.

obtained via BHR.

Parents, schools, and BHR service providers may require instruction on how to set up IEPs to incorporate BHR services. This service is not always provided by the BHR agency.

School-to-BHR Services: School administrators and special education directors are often not fully informed about the availability of potential services under BHR services.

Schools are formally under no particular obligation to educate parents about these potential services and resources. Parents at times find that their child is denied a 1-to-1 assistant, in-school mental health services or behavioral evaluations and services, without any notice that these services could be available to the child under the behavioral health system.

Educate school administrators in

- BHR Service delivery system
- annual updates on the opportunities and limitations of BHR Services, since protocols are in constant flux.
- the limits of TSS responsibilities within schools. For example, BHR Service administrators should prohibit the use of physical restraints by TSS providers in school settings because the use of restraints by TSS providers has been ruled inappropriate and impermissible by the Department of Public Welfare for more than one year.
- how to implement a service delivery system that makes appropriate use of BHR services in areas where the school system has gaps.

APPENDIX A

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APPENDIX B

How Inclusive Are Educational Practices In Your School?

An Inclusion Survey

Directions: Read each item comparing the school practices described in Column A with the practices described in Column B for each of the listed items. Circle a number on the rating scale that represents your perception of the nature of your school's practices on this continuum.

COLUMN A Description of school practices indicative of low usage of inclusive strategies	RATING SCALE Please circle the number that represents your perception of your current school's practices	COLUMN B Description of school practices indicative of high usage of inclusive practices
1. Our school assigns most students with disabilities to special classrooms and groups most of the school day.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school assigns most students with disabilities to regular classrooms with appropriate supplementary aids, services and special education and related services, as appropriate, for most of the school day.
2. Our school provides similar or the same sort of services for most children who share similar special education categories, e.g., learning support, life skills support, etc.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school's instructional program is individualized across the curriculum for all students whether or not they are disabled.
3. Our school provides special services for certain groups of students based on eligibility determinations.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school provides the resources each child needs to explore individual interests in the school program and environment
4. Special education and regular education staff are isolated in separate rooms or departments with separate administrative and supervisory arrangements.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Regular and special educators are integrated administratively so their efforts and their resources work together as integral parts of a unified team.
5. Our teachers do not seek peer collaboration in working with some students, as they may be perceived of not having the skills and competencies necessary to their job.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our administration creates a work climate in which staffs are supported as they provide assistance each other in meeting the needs of all students.
6. Students with disabilities participate only in the academic portion of the school day.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Students with disabilities participate actively in the life of our school including co-curricular and extracurricular activities
7. Our school provides some limited services to some students with the expectation that learning is the student's responsibility solely.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school creates and alters support systems for students as their needs change through the school year so all may achieve success and feel they belong genuinely.
8. We provide separate course and curriculum offerings for most students with disabilities and/or	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	We provide most students with disabilities access to the full school regular school curriculum

special education services for some students in lieu of regular education course offerings.		and courses and provide modifications and supports as necessary.
9. Our school assumes that students with disabilities may earn the right to participate in regular classes through their demonstration of appropriate behavior and learning skills.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school assumes that students with disabilities have the right to participate in regular classes and are removed to more restrictive settings only when their individual needs require services that cannot be provided in the context of a regular classroom.
10. Our school provides transportation for most students with disabilities on a different standard than transportation is provided students without disabilities.	0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10	Our school provides transportation services to most students with disabilities as a related service determined by their unique needs.

(Adapted from Inclusion Checklist, PA Department of Education BEC July 200_)

02. Education and Certification (Focus) Subcommittee Report

I. INTRODUCTORY MATERIALS

A. List of Members

- Robert Gulick – facilitator (professional - Erie County)
- Denise McArthur-Turner (parent - Allegheny County)
- Maureen Barber-Carey (parent/administrator - Erie County)
- Landa Harrison (professional/administrator - Allegheny County)
- Lisa Tesler (parent - Dauphin County)
- Kate Fox (parent/professional - Erie County)

B. Mission of Subcommittee

1. To determine the current status of the system that educates/certifies/monitors the professionals who treat individuals with Autism Spectrum Disorder (ASD) in the state of Pennsylvania.
2. To determine the barriers that exist in educating/certifying/monitoring of professionals who treat individuals with Autism Spectrum Disorder (ASD) in the state of Pennsylvania.
3. To determine what changes can be made in the existing system to remove these barriers or, if necessary, to create a completely new system of education/certification/monitoring of professionals who treat individuals with Autism Spectrum Disorder (ASD) in the state of Pennsylvania.

C. How Often Did You Meet?

The subcommittee met for the first time at the initial taskforce meeting in Harrisburg. Subsequently, a Yahoo Listserve was created specifically for subcommittee email communication. In addition, telephone calls were exchanged between individuals. After the first report was drafted, the subcommittee chose to meet in smaller regional groups to facilitate work on refining the draft.

From the outset, the subcommittee was divided into two factions:

- One that preferred to take a more broad approach to the issue of education (including within the scope of the subcommittee the education of individuals with ASD and the related service delivery system).
- One that preferred to focus their attention more narrowly on the education/certification/monitoring of professionals.

Following several months of debate, it was felt best to split the subcommittee along these factional lines. The present document is the report from the latter group – The Certification Focus Group. This group communicated nearly daily via email and telephone as this report was developed.

Face-to-face meetings occurred on several occasions between regional members and a final work session involving all members (to complete the document) was held in December 2003.

D. How was this Report Formulated?

As this group is an offshoot of the Education/Certification (Broad Focus Group), a portion of the perspectives and input was derived from those initial meetings and correspondences. Following the division into two subcommittees, all email and telephone discussions regarding current practices, barriers, and solutions pertaining to the more specific issue of education/certification/monitoring of professionals were utilized to formulate the present document. As our group consisted of a mix of parents, professionals, and administrators, we were able to obtain the varying points of view necessary to create a balanced report.

The report was then typed by the facilitator - keeping to the Report Preparation Guidelines provided by David Mandell.

II. What Is The State Of Current Practice In This Area?

A. Family Perspective

The parents in our group have had firsthand experience with services provided by Early Intervention, Wrap Around (Type 50 Services), Approved Private Schools, and Public Education. The following is a consensus of that experience as it applies to the specific funding stream/service provider:

1. Early Intervention- Generally home-based provision of Speech Language Therapy, Occupational Therapy, and Play/Educational Therapy. Therapy sessions are typically 1:1 and can range from 1 to 15 hours per week. Speech and OT's are certified clinicians. Education/Play therapists may or may not be certified Special Education teachers.

2. Wrap Around- Both home and school/community-based provision of Applied Behavior Analytic (ABA) approach to treating individuals with ASD. Therapy sessions are usually 1:1 and can range from 10 to 40 hours per week. Behavior Specialist Consultants (BSC) who monitor these services are Masters-level professionals who may or may not have certification in ABA. Therapeutic Support Staff (TSS) who provide the direct therapy are undergraduate-level professionals with highly varied backgrounds and training experiences.

3. Approved Private Schools- Segregated provision of Academic (including "specials" – physical education, art, and music),Speech Language, Occupational Therapy, Physical Therapy services in classroom setting (SP/L and OT may be itinerant in some locations). Classrooms may have between 6 and 8 students with one certified Special Education teacher and 2-3 instructional aides. Bachelor level Behavior Specialists are typically on staff. Mental Health Therapists are included in each classroom when MH Partial Programs are present. Students attend full school days (typically 8:30am to 2:30pm). Instructional aides are usually non-degreed professionals with highly varied backgrounds and training experiences.

MH Partial Programs will also have a Psychiatrist on staff.

4. Public Schools- Generally segregated provision of Academic, Speech Language, and Occupational Therapy services in several classroom options - Learning Support, Emotional Support, or Autistic Support. The degree of inclusion with typical students varies from minimal (homeroom, lunch, recess, and specials) to full (following total curriculum with typical peers). Segregated classrooms have between 8 to 12 students with 1 teacher and typically one aide. Teachers are certified in Special Education while instructional aides may or may not have an undergraduate degree or other formal training.

B. Provider Perspective

The professionals in our group have had experience (either in direct service delivery or in collaboration) with Early Intervention, Wrap Around, Approved Private Schools, and Public Education. The following is a consensus of that experience as it applies to the specific funding stream/service provider:

1. Early Intervention- Professional members of our group have provided Speech Language services to children in home through both a private provider and through the county. Collaboration occurs occasionally with Wrap Around providers but not with any regularity or continuity. Collaboration with either APS or Public Schools has been limited to a single transitional meeting that occurs when a child turns age three.

2. Wrap Around- Professional members of our group have provided Applied Behavior Analytic services (as BSC) to children in the home and school/community settings. These services are managed through a private provider with medical necessity written by a third-party licensed psychologist. Collaboration and communication with Early Intervention has been limited in all geographic areas represented with the exception of Allegheny County. In that area, providers collaborate regularly with the Alliance for Infants

and Toddlers to assure continuity of care once a child is of transition age. Managed care companies have mandated such collaboration occur at least every 90 days. It appears that this is not the standard across the state where, in many areas the two providers conduct their own program with little attempt to insure that they are consistent with the other. Collaboration with APS has been improving over the past few years. Public School coordination varies from school to school and district to district.

3. Approved Private School- No professional members of our group are currently providing services to individuals with ASD in an Approved Private School. Collaboration and coordination has occurred as described above. Again, our representative from Allegheny County reported collaboration and communication with outside agencies occurring on a 20-day cycle (minimum).

4. Public School- No professional members of our group are currently providing services to individuals with ASD in a Public School. Collaboration and coordination has occurred as described above.

C. Administrative Perspective

The administrative member of our group has had experience (either directly or in collaboration) with Early Intervention, Wrap Around, Approved Private Schools, and Public Education. The following is a consensus of that experience as it applies to the specific funding stream/service provider:

1. Early Intervention- Services are organized by age

Birth to Age 3: Paid through DPW/OMR and MA, also Infant, Toddlers and Families Medicaid Waiver.

- The Department of Public Welfare is responsible for these services. Speech pathologists, OT, PT, Psychologist, Audiologist, and social workers are licensed clinicians. Educators may or may not be special education certified. MH/MR Title 55 Chapter 4226: Early Intervention Services define an Early Interventionist as one who delivers Specialized Instruction. An Early Interventionist must have either a Bachelor's degree in Early Intervention, Early Childhood Special Education, Early Childhood Education, Child Development, Special Education or Family Studies, and one year of full-time work or equivalent working directly with preschool children with disabilities; OR A Bachelor's degree which includes 15 credit hours in the above fields and one year experience with preschool children. There is no requirement for a Teacher Certification.

Ages 3 to 5: Funded through PDE and local school districts/IU.

- In some areas, the school district has assumed this responsibility, in other areas, the IU has. Both School district and IU have contracts with private providers. Educators and speech therapists are certified through PDE; OT, PT are licensed; Paraprofessionals typically have HS diploma. Required to meet the same training/education requirements as public school educators.

2. Approved Private School- Services are provided to children with disabilities age 2 ½ to 21 years if the local school district is unable to provide an appropriate education. The program is funded 60% by PDE and 40% by local school district. Personnel are required to meet the same education/training requirements as public school clinicians. Any additional ASD training is limited by the lack of available funding.

3. Public School- Services children age 3 to 21 years. Subsidies are received through numerous funding streams including PDE, Federal funding, local school taxes. Clinicians meet certification requirements of the Department of Education.

4. Wrap Around- Generally services children 3 to 18 years of age. The program is funded by MA dollars. Private insurance companies do not pay for wraparound services at this time. As a result of the Kirk T legislation, there are required training hours that must be met for agency personnel however, the type of training is varied and unspecific to ASD.

III. & IV. Problems with Existing Practices and Potential Solutions for Improving Them?

The extent of the problems with the existing service delivery systems identified by our subcommittee (summer meeting in Harrisburg) was so vast and pervasive that it became evident quite early on that repairs to the existing system would not be sufficient to remedy the situation. As far as the education and training of professionals serving individuals with ASD, it was clear that a new certification program would be required.

With that notion in mind, the Certification Focus Group took it as their charge to begin mapping out the framework for such a program.

Rather than focusing our efforts on providing cursory adjustments to the university curricula of Speech Language Therapists, Occupational Therapists, Special Education Teachers, and Regular Education Teachers (all systems with which we presently have little leverage), we directed our efforts toward developing a Pennsylvania-sanctioned certification program that would provide existing clinicians (whether they be SP/L's, OT's, teachers, or Behavior Specialists) with the practical skills necessary to effectively treat individuals with ASD.

For purposes of clarity, we chose to refer to this new variety of clinician as ASD Specialist.

The following section of our report addresses what we feel were the most pertinent identified problems with the existing system. It was hoped that our proposed solutions to these specific problems, would provide the details necessary to fully describe the ASD Specialist Certification that we envision.

A. Family/Provider* Perspective

(* considerable similarities of input from these two perspectives led us to combine them under one heading)

Problem 1

A substantial number of service providers are not motivated to respect families or to listen to the input of family members in the context of discussions about educational, behavioral, and healthcare issues.

Potential Solution

It is paramount and it behooves the provider to first listen to the family's perspective. That information is a critical component in the development of an individualized and strength-based treatment plan.

Since some of what the ASD Specialist will be suggesting as treatment for ASD children may run contrary to popular opinion about child-rearing, it will be incumbent upon the ASD Specialist to properly orient and train families as to the rationale behind proposed treatment.

Certification of ASD Specialists should also include course work in family dynamics, family training, and the team process. Monitoring of this dimension of service delivery could be accomplished via the systematic utilization of customer satisfaction surveys tied to a central monitoring body that could result in a rating system (available to families seeking an ASD Specialist).

Problem 2

Service providers are not sufficiently prepared to understand or to be sensitive to the potential impact of cultural diversity on the content and/or design of service delivery.

Potential Solution

Again, this is an issue of including coursework that will assist the ASD Specialist in taking this important variable into account when designing programs and training the family in their implementation. This

training should include specific cultural sensitivity training that will assist the candidate in understanding how each ethnicity may view the "provider practices" or possibly impede the child's progress indirectly.

Ongoing in-service training in the form of workshops and/or conferences addressing cultural diversity should be mandatory.

Case distribution during the supervised clinical practicum (see below for details) should include as much cultural diversity as possible so that Specialist candidates can experience such variability before working unsupervised.

It was also suggested by one group member that perhaps DPW should monitor the hiring practices of providers to insure the recruitment of culturally competent staff.

Problem 3

Service providers often set the bar inappropriately low for children with ASD. If the child fails at a task, the provider finds it easier to blame the disability rather than analyze the effectiveness of their instructional design.

Potential Solution

ASD Specialists need to understand that children with autism, as well as other developmental disabilities, can be taught. This understanding can be aided by both course work (in understanding the neurological impairments that come with autism) and by practical experience (in observing a wide variety of children diagnosed with ASD). A solid background (theory and practice) in applied behavior analysis will provide the ASD Specialist with the skills necessary to analyze instructional design and to prescribe alternate methodologies so that these failures can be overcome.

Problem 4

In-service training for professionals often does not include practical information on serving children with ASD.

Potential Solution

It is our group's conviction that any training or certification program designed to prepare professionals to teach children with ASD must be competency driven and performance based. We suggest that the certification process for the ASD Specialist include a clinical practicum year similar to that required by ASHA for its Speech Language Pathologists.

Our goal is to provide a basic, standardized training that focuses directly on the primary needs of the child with ASD. Depending on the background of the candidate (education, SP/L, OT, Behavior Specialist), once this training is completed, the ASD Specialist would then receive additional training to augment and complement his or her discipline.

Problem 5

Individuals that are called "behavior specialists" lack education/certification in ABA and/or ASD-specific information. Moreover, quite a few of those possessing certification (such as Board Certified Behavior Analysts) do not have any practical experience working with children with ASD or in designing complex programs designed to teach language or social skills. The lack of a standard measure across the state for assessment of ASD children further compounds this problem - resulting in the same child receiving very different diagnoses (e.g., PDD vs. Asperger's Syndrome) when evaluated by more than one "expert."

An academic degree (based on course work alone) does not prepare professionals for the therapeutic/educational responsibilities involved in treating children with ASD. University and certification

programs fall short of preparing most future professionals adequately for the realities of work in the autism community. The Commonwealth of Pennsylvania does not offer a certification in ASD. The existing ASD Certification program (under the auspices of Pennsylvania State University and PaTTAN) has several shortcomings:

- enrollment is voluntary and expensive
- a large portion of the instruction is provided via videotaped lectures
- the practical portion of instruction is limited and of questionable effectiveness

Potential Solution

The training of "Behavior Specialists" as they are called in APS or "Behavior Specialist Consultants" as they are called in Wraparound should include the following:

A. course work in applied behavior analysis or learning theory equivalent to 12 graduate credits (this should be from an approved ABA program such as that provided by Penn State and include the theoretical and empirical bases for the experimental analysis of behavior and their application to autism and other developmental delays). The candidate should be made familiar with evidence-based, research-oriented practices and treatment options. Additionally, course work should be provided in how to assess a child for ASD - which should be based on DSM-IV TR criteria and include standardized methods for data tracking and ascertaining the behavioral, social, language, and emotional needs of the individual child.
B. certification by a national professional organization (e.g., ASHA, BACB)
C. supervised clinical observation and clinical practicum (similar to what Speech Therapists must complete to obtain their Certificate of Clinical Competence). This should include:
    1. a specific number of clock hours working with ASD individuals
    2. being supervised only by those who currently are recognized as ASD Specialists
    3. Clinical Observation- time spent prior to the actual clinical practicum observing a certified ASD Specialist performing assessments and treatment of individuals with ASD. (SP/L's CCC's require 25 hours)
    4. Supervised Clinical Practicum- direct time spent in actual evaluation or treatment of individuals with ASD. Ancillary activities such as writing programs or assessments, preparing materials, attending meetings or staffings would not be counted among the required clock hours (SP/L CCC's require 350 hours).
    5. Between the Practicum and Fellowship Year, the candidate would submit a videotape demonstrating their ability to work 1:1 with an ASD individual. The ASD individual should be someone with whom the candidate has worked at least 10 hours. The tape should include the candidate conducting at least three instructional programs
        - Approximately five minutes each. Movement on to the Clinical Fellowship Year would be contingent on the candidate passing this video review.
    6. Clinical Fellowship Year- paid time spent working under the supervision of a certified ASD Specialist (SP/L CCC's require 9 months).
    7. As a final review prior to certification, the candidate would be required to submit another videotape of their working 1:1 with an individual with ASD. This individual should be someone with whom the candidate has never worked. The candidate would be required to teach novel items to the individual in the areas of 1) verbal imitation 2) receptive language and 3) expressive language
    8. Oversight of the entire training process by a Clinical Mentor (preferably a PhD level clinician).
        - The administration and monitoring of this certification process would require the development of a Certification Board. This governing body should be composed of parents, providers, and administrators with at least 50% of its membership having certification as ASD Specialists.

Problem 6

TSSs are often poorly trained in applying the basic principles of behavior to the day-to-day core issues of children with ASD (safety, language deficits, and behavioral excesses). They often rely on the parents to guide them in the treatment of the child, when it is the TSS who is supposed to be training the parents.

It is also the family members' perception that both TSS and instructional aides are the least prepared members of the service delivery system – despite their crucial and direct role. Training for TSS and instructional aides often occurs "on-the-job" and is provided by equally untrained individuals.

TSS and instructional aides are often poorly paid, making recruitment difficult and rapid turnover problematic.

Potential Solution

Creation of a ASD Therapist position that would be afforded orientation and extensive training in the teaching of individuals with ASD. That training and orientation would come exclusively from a certified ASD Specialist. Training would include:

A. lecture or course work on the basic principles of behavior and learning theory (as they pertain to the analysis of behavior and teaching skills to ASD individuals) and lecture or course work on Autism Spectrum Disorder (all to occur within 40-hour orientation week).
B. Shadowing of existing ASD Therapists for two weeks (80 hours). If possible, 75% of these hours should be with the child to whom the candidate will eventually be assigned.
C. Weekly workshops/clinical training sessions with the ASD Specialist (1-2 hours each over a 90-day probationary period)
    1. each workshop will have "homework" – e.g., assignments/video submissions from their case(s) which will be followed up on during the first portion of the next week's workshop.
    2. ASD children will be present for the latter portion of each workshop to provide in-vivo demonstrations and practice opportunities for the candidate.
    3. Evaluations will be conducted during each workshop. Criterion for "passing" the workshop will be based on the candidate's performance of the target skill being taught and on completion of all assignments.
    4. Candidates can be combined together in groups of 3 or 4 to facilitate the ASD Specialist's management of this mentoring process.
D. Ongoing ASD Specialist monitoring of ASD Therapists would occur on a weekly basis with critical skills checklists being completed intermittently during direct observation of the Therapists working with ASD children.
E. On going training for the ASD Specialist and ASD Therapist – (requirements should look like the CEU's for continuing teaching certification).

Problem 7

Wraparound has experienced a massive increase in children diagnosed with ASD. Burgeoning caseloads of ASD children (for whom these services were never intended) is causing considerable stress on the Wraparound system and a decline in service quality.

There are not enough properly educated and certified specialists to meet the needs of the autism community. Caseload numbers are too high (and growing daily) to accommodate the intensity of programming needed for many children with ASD. As a result, many children receive too few hours of direct service.

Potential Solution

Properly trained Specialists will be better able to adequately train ASD Therapists. With a core of effective and experienced Therapists working under them, the ASD Specialists would then be able to manage more cases (as less of their time would be taken up with issues or problems that could be solved on site by the well-trained Therapist).

Increasing the pay for these professionals will also decrease turnover and insure that therapists will grow clinically and professionally.

Our goal will be to insure that any ASD individual within this proposed system is being served by a certified ASD Specialist and a team of trained ASD Therapists – providing the therapy hours deemed medically necessary.

B. Administrative perspective

Problem 8

Training of both TSS and BSC's are not billable services. In order to properly train a BSC or TSS "on-the-job", an agency must be able to fund these overhead costs up front. Paired with the low pay/high turnover situation with TSS, these costs place an agency at great financial risk (when the TSS decides to look elsewhere for a better paying position after only a few months of employment).

Potential Solution

Managed care would allow for the training of staff at a reduced rate to insure that staff are properly trained (standardized training as described above).

Providers would receive incentives from the State for training personnel - tuition rate cuts, loan forgiveness, reimbursement rates increased based on a specific number of qualified trainers/personnel in an agency, etc.

03. Information and Advocacy Subcommittee Report

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I. INTRODUCTION

A. Mission of the Subcommittee

The mission of the Information and Advocacy Subcommittee is to develop and implement a system in the state of Pennsylvania that provides easy access to informational resources for individuals with Autism Spectrum Disorder (ASD), their families, and those responsible for providing diagnoses, services, therapies and education.

This system advocates ensuring that individuals with Autism Spectrum Disorders are treated with understanding, respect, acceptance and inclusion in the community.

B. Committee Process

The Information and Advocacy Subcommittee met initially at the planning meeting held on July 26, 2003. Upon the conclusion of this meeting, C. Waeltermann established an Internet listserv for the purpose of facilitating ongoing communication regarding our mission.

Conference calls were held on the following dates:
September 4, 2003
October 3, 2003
November 13, 2003
November 20, 2003

Additional meetings were held on the following dates:
November 9, 2003
December 6, 2003 (cancelled due to inclement weather)
January 25, 2004
February 29, 2004

Meeting minutes were maintained and can be provided upon request.

C. Report Formulations

The subcommittee report was formulated from the following methods:

Subcommittee meetings, which included in person meetings as noted above and conference call meetings.

Ongoing contact and dialogue was maintained through individual phone contact, e-mail, and conference calling.

Additionally, all members were encouraged to provide either written or verbal feedback to the facilitator(s) for inclusion in this report.

INFORMATION REPORT

II. CURRENT PRACTICES

A. Family Perspective (Barriers)

Our subcommittee identified several variables that affect what information is currently being disseminated across the state of Pennsylvania on Autism Spectrum Disorders.

The information that a parent receives varies widely based on the following:

- Geographic location.
- School district.
- Resources in particular location, region.
- Level of knowledge of the professional who is the initial point of contact.
- Proximity to an Autism Center of Excellence.
- Strength of local support groups.
- Access and proximity to non-profit organizations for autism.
- General community awareness.

In general, information was more readily available to parents in the western area of the state. Parents from the more rural settings reported greater difficulty in accessing information from local resources and other points of contact. In addition, parents located in areas with very strong support groups reported better abilities to obtain information.

During our discussions, the majority of parents in the subcommittee stated that little or no information was given to them at the time of diagnosis. Many parents reported that primary care physicians are not knowledgeable about early detection and assessment of individuals with Autism Spectrum Disorder (ASD). Since parents did not have an accurate or suspected diagnosis for their child, the parent was unable to access any type of information to begin the Early Intervention process or obtain other appropriate services. Some parents noted that some Early Intervention professionals and many educators, school psychologists, and learning support teachers dismissed parents' concern that ASD could be the problem, again hindering the access to appropriate ASD related information.

In order to obtain information, the overwhelming majority of parents stated that they needed to be "active learners" and seek out their own information sources. Typically, physicians, County Case Workers, DPW/ Medical Assistance personnel, school personnel, Early Intervention providers, nurses, social workers, and behavioral health providers do not distribute any written information on parent education programs, advocates, support groups, community services, or state, national resources for ASD. In fact, most parents expressed frustration that they are often the "experts" on their child's care; hence, parents are most likely providing information to educate the providers about ASD.

Many parents and providers used the Internet as a primary resource to obtain information about ASD, support, and treatment modalities. By using the Internet, individuals can find a wealth of information on various topics; however, most parents had difficulty locating information specific to Pennsylvania. Many parents have searched sites from other geographical regions such as autismlink.com in Pittsburgh, Pittsburgh and Philadelphia ASA, as well as neighboring states including COSAC and ASPEN in New Jersey and CARD in NY. Several other states have excellent autism websites including West Virginia, Minnesota, and Indiana.

A variety of autism related sources exist, but the burden is put on the parent to find the information. In Pennsylvania there is no centralized source to assist individuals in obtaining pertinent informational resources on autism. As caretakers, parents are unable to take time out to research information on autism, therapeutic options, research programs, resources, and support. Many noted that "getting through the day" and "surviving" are initially the top priorities. All parents are in agreement that some type of written booklet should be made available as a resource. Currently, the state of Nebraska provides parents with an excellent booklet for this purpose.

The second most widely reported method of gaining information was through parent networking. Again, this process involves the parent being an active participant in their child's care to seek out basic information to assist them in their daily lives with an ASD individual. Parents noted that this is extremely difficult due to time constraints and demands of caring for a child/individual with ASD. Likewise, many areas do not have strong support groups to assist with this process. Many parents noted that doctors, social workers, county caseworkers, MH/MR providers, county medical assistance workers and others do not provide information about autism, support groups, or basic treatment options. In western PA, a parent did have access to ABOARD and received an informational packet, but this has not been the standard of care across the state. Two parents on this subcommittee stated that the Special Kids Network number and

Parent-to-Parent contacts were provided but reported limited success in obtaining autism-specific information through these organizations.

One parent was given the Special Kids Network number by the county caseworker; however the caseworker denied early intervention and wrap around services, stating that Special Kids Network was sufficient intervention.

One parent reported that written materials on ASD were provided, but the materials came from a private therapist.

As noted in our ongoing dialogue, the only consistent written information provided on a regular basis is the Procedural Safeguards. One problem noted with the Procedural Safeguards is that the document is written in "legalese" and is not understandable to parents. Also, parents are provided with their procedural rights; however there is no information provided about local advocates and/or special education attorneys. In addition, there is a general knowledge deficit among many civic leaders including attorneys, probation officers, social workers, district justices, police and judges about ASD.

In summary, information dissemination is lacking and varies across the state. Dissemination of materials is dependent upon many factors. There is no Autism Information Center or Autism Clearinghouse. No parent educational booklet on autism is readily available. All parents need to have equal access to information.

B. Provider Perspective

There is no specific ASD center in Pennsylvania. Several disability organizations including Special Kids Network and Parent to Parent provide information and support for autism, but they are not autism specific. Both parents and providers report that the nonspecific disability programs have not been able to address the multitude of therapeutic complications and interventions specific to the ASD population. Moreover, information is not being disseminated from a single point leading to a disorganized and fragmented system. There is no uniformity across the state. Obtaining information requires searching multiple sources to find materials from many organizations. Gaps in service have been identified across the state as reported by our subcommittee members.

Local support groups typically provide best information, but not all areas have access to strong support groups. Level of information dissemination depends on the strength of the group, finances, active members, web capabilities, and mission of the group.

C. Administrative Perspective

Since there are multiple providers within a county, each provider" does their own thing" regarding information. This results in multiple providers either "reinventing the wheel" or providers that may not think it is their responsibility to fill the need. The current system is unorganized with no one point of entry or one body designated to provide information.

There is currently no funding from either the DPW or education system allocated for patient/parent education. Monies are used to provide basic services with little or no money left for education either parent or professional. To enhance information services, administrators rely heavily on parent information. Much information is disseminated orally or via personal email contact to save on cost. There is no all inclusive information source for autism related issues.

There are some non-profit corporations started by parents and providers that provide both information and advocacy. These organizations may have good sources of information, but struggle to survive based on funding.

III. PROBLEMS WITH EXISTING PRACTICES

A. Family Perspective

The following barriers identified in obtaining information are as follows:

- Red tape, bureaucracy, and "passing the buck." Parents don't know what services are available and which group provides these services i.e. school district vs. behavioral health for example a classroom aide or a TSS. There is no information source that provides information on how to navigate the "system" or to help a parent or individual find the help they need.
- PA does not have Autism Resource Center to disseminate autism information in the state of PA.
- Many providers do not have or provide written materials related to ASD.
- Providers are often lacking knowledge to provide information on ASD to parents and no parent booklet is being used in PA.
- The DPW and Education systems are not mandated to provide any information on Autistic Spectrum Disorders.
- Information may not be provided because providers are unable to offer services related to that information.
- There is no updated listing of service providers in PA for parent to access.
- Knowledge deficits among providers create a litigious system to obtain basic care.
- There is no funding or monies allocated for information services for autism.

B. Provider Perspective

The following barriers have been identified:

- Providers are not consistently able to access appropriate training and development programs from knowledgeable professionals.
- There is a lack of funding to send individuals for training programs, lack of access to knowledgeable individuals, and lack of current research based on "best practices" standards for care. Many providers indicated that they have used their own monies to attend programs and use the Internet and network with parent groups and other providers to forward their knowledge base.
- Limited written materials are being distributed to providers.
- In addition, providers have reported relying heavily on parents, support groups, and Internet Listserves for current information on ASD, noting that parents are often "experts" in current treatments and therapies.
- Several providers expressed frustration at having to "re-invent the wheel" in preparing educational materials for parents, only to discover that another organization has already accomplished this. Finding information is a major contributor to job stress. Also, many companies have information sources available but charge fees that employers are unwilling to pay.
- No standardized autism information brochure is available. Materials are dependent on factors such as resources in the region, access to strong support groups, proximity to Center or Excellence or knowledge level of professionals in the geographical region. Presently there is no one-source Autism "clearinghouse" or Internet access to autism information in the state.

C. Administrative Perspective

The administrators voiced problems with current funding for payment of services. Many reported having limited funds to provide educational services for employees. Since there are no set standards for training development, employees do not consistently get training for autism related disorders. Orientation for employees varies by organization. Several administrators identified that they are uncomfortable in providing information because they do not have adequate knowledge themselves. Access to qualified "experts" in the field for training and development was identified as a obstacle as well as cost for programs provided by experts. Administrators fear giving information because they may not have staff, budget, or resources to provide services based on autism information.

Administrators voiced concerns that no standard of care exists, thereby contributing to each region and locale "doing their own thing." Local task forces are being established, but there is no consistency or guidelines for initiatives in providing services for individuals with ASD. This in turn creates individuals "re-inventing the wheel" to develop a program in their area only to later find out a program exists in another region.

Moreover, administrators report that due to the increasing numbers of individuals with ASD, the financial strains created by these increases has burdened budgets. Administrators do not have adequate resources and finances to support funding informational programs.

IV. POTENTIAL SOLUTIONS AND RECOMMENDATIONS

From our ongoing discussions and deliberations, **the Information and Advocacy Subcommittee recommends the following solutions to improve existing practice**:

- Community awareness programs to help foster understanding and mutual respect toward individuals with ASD and consequently, aid in dispelling the myths and misconceptions associated with autism.
- A standardized Autism Parent Information Booklet provided to parents and individuals with ASD statewide. The committee recommends and has obtained permission to adopt the Nebraska Autism Parent Booklet for use in the Commonwealth of Pennsylvania.

T**o establish consistency across the state, a PA Autism Resource Center should be established and include the following**:

- Toll free autism information number in PA so that parents, providers, and administrators have one direct information source pertaining to ASD.
- A website for PA autism which would include the following: access to information, listing of state resources, listing of advocates, listing of support groups and various other links for therapeutic interventions.
- Providing appropriate educational training to providers will reduce and eliminate frustration of parents who currently appear to be the "experts" in care management of their child.

The following changes would improve the ability to provide information to improve the quality of care:

- Quality training for all providers done by individuals with knowledge about ASD.
- Ongoing training and development for providers to adequately support individuals with ASD.
- An Autism Handbook written in parent friendly language to benefit families who receive the diagnosis of ASD for their child.
- A Provider training manual on ASD that may support understanding and enhance skills development for those providing support and services to individuals with ASD.
- An Autism Center to include a data bank, resources, informational clearinghouse with web access for both provider/professional and parent education. Provider continuing education could be done via distance learning or web courses.
- Consideration of clinical care guidelines "best practices" model to eliminate confusion and debate on "standard" of care for individuals with ASD. Embrace the "psycho-educational" model as a model to integrate both medical and educational perspectives.
- An "autism clearinghouse" would be helpful to aide with the flow of information including current "best practices."
- Acceptance of a standardized information booklet for parents on ASD that is disseminated to all parents across the state.
- Establish a statewide information service on autism to include the following:
    1. Establish a state wide toll free number (1-888-4autism) for access to informational resources in PA.
    2. Establish a state run website specific for autism information that includes links to PaTTAN, Special Kids Network and non-autism specific sites such as those addressing special education, legal, advocacy and developmental issues.

3. Establish an autism clearinghouse for ASD related information.
4. Adopt the Nebraska Autism Parent booklet with adaptations to include PA state resource information.
5. Provide community awareness programs on ASD that promote a basic understanding of autism and foster mutual understanding and respect for such individuals.
6. Adopt and implement First Signs program across the state to be distributed to all pediatricians, family practitioners, behavioral health care providers as a tool to provide information on assessment and early detection of ASD.
7. Physician trainings on autism by experts in the field. Provide CME credits. Build capacity for autism experts to "train the trainers" so that there is consistency in training.
8. Defer educational training issues to the Education Subcommittee report findings but support the following:
    - Educating physicians through the First Signs program.
    - Educating teachers on "what they need to know" and offering Act 48 credits.
    - Offer college level courses specific to autism (as specialty degree) such as courses offered by the West Virginia Autism Training Center.
    - Offer continuing education programs on autism specific issues. Offerings should be presented as a "nuts and bolts" approach to working with individuals with autism. Offerings should be readily accessible possibly through online web courses tied in to state web site under the PA Autism Resource Center.
9. Establish an advisory board to develop and implement the above recommendations. Members of the advisory board should include professionals in the medical and behavioral community such as developmental pediatricians, neurologists, psychiatrists, psychologists, behavior specialists, and parents.

- Establish a marketing committee to promote the use of the toll free number and website throughout PA.

ADVOCACY REPORT

II. CURRENT PRACTICES

A. Family Perspective (Barriers)

- Parents are lacking information to be able to contact and obtain access to advocates/attorneys. The DPW and Education systems do not provide information on how to access an advocate or attorney if there is a dispute.
- DPW does not routinely provide information on the grievance procedure for individuals denied services.
- Parents have difficulty understanding the grievance process. There is a lack of clarity in how to pursue a grievance. The procedure is costly.
- There is no centralized list of advocates or attorneys specializing in special education law or list of organizations that provide this information. The state of Massachusetts provides a comprehensive listing that is available online at www.masspac.org
- Parents are not allowed to have advocates represent them in due process hearings. PA is one of only two states in the U.S. where this is the case.
- Parents are unable to access trainings that would provide them with the skills necessary to navigate through the bureaucracy of the grievance process or to obtain services for their child.
- Parent trainings should include terms of the laws, special education process as well as training in written/verbal communication, negotiation, team dynamics, conflict resolution, and learning how to advocate.
- Parents do not understand due process procedure despite being provided the procedural safeguards. Information is written in "legalese" and not tailored to parents' level of understanding.
- The only consistent information parents receive is the Procedural Safeguards.
- Parents have noted that the most helpful information has been provided by the Education Law Center. While the attorneys at the Ed Law Center do not usually provide in-person advocacy services they do maintain a website with fact sheets on special education law and process; provide trainings in special education; offer telephone consultation regarding questions/issues; pursue legal

remedies for education violations of a systemic nature or for some individual cases that are likely to have systemic impact.

- The Ed Law Center also maintains a database of "Special Education Buddies" who are mostly parent volunteers and who are geographically distributed throughout the state; however the variances between school districts, counties makes it difficult to pair buddies in similar situations.
- There are special education attorneys in the state; a partial list is maintained by COPAA. This list should be more complete.
- Many special education attorneys are concentrated around urban/suburban settings. There is a lack of knowledgeable attorneys in rural settings.
- Individual school districts interpret the law differently lead to variances across the state. This leads to conflicts and increases the need for advocacy.
- The Disabilities Law Project and the Pennsylvania Health Law Project are resources for information concerning fair hearings/denial/reduction of services; however, they cannot provide individual representation, focusing their efforts on empowering family members with the information to self-advocate, providing training, and litigating class action cases and those likely to have systemic impact.
- Autism specific advocacy seems to rely most heavily on the existence of local support groups such as SAFE, ASA, ASAP, parent networking, and "word of mouth."
- Many civic leaders including attorneys, probation officers, social workers, district justices, police, judges lack training in procedures and basic understanding of ASD.

B. Provider Perspective

- PP&A maintains a Children's Project whose staff of three is organized around priority issues: children with disabilities living in institutions, children with disabilities in the juvenile justice system, and children with disabilities access to mental health services in the least restrictive environment. Toward the goal of improving the lives of children around these issues, staff provide training, participate in state and county level stakeholders' groups, conduct research, and refer class action situations to PP&A's legal contractors, DLP and ELC.
- PP&A's Children's Project staff provides informational assistance to family members and professionals through phone contacts, email, and the PP&A newsletter, "On The Move." When resources permit, staff may provide individual advocacy.
- Mental Health Advocacy: Parents Involved Network and the Mental Health Associations do distribute information outlining consumer rights and grievance procedures, but those in the autism community are not receiving this information on a consistent basis.
- Mental Retardation Advocacy: The Office of Mental Retardation (OMR) has instituted Consumer Satisfaction Teams and FSS Advisory Boards on the county level. Regional OMR offices have often been of assistance in resolving issues, when the county seemed unresponsive.

C. Administrative Perspective

- PP&A provides advocacy services on a priority basis, that is, in furtherance of the goals and objectives determined by the Board and Advisory Councils, with input from the staff. Like our legal contractors, DLP and ELC, our efforts are focused on addressing and resolving issues of a systemic nature.
- PP&A is charged through three federal mandates with the protection and advocacy of individuals with development disabilities (PADD), individuals with mental illness (PAIMI), and individuals with other disabilities (PAIR). The overriding responsibility of the organization is to investigate incidents of abuse and neglect of individuals with disabilities. While the advocates may not personally conduct the investigation, they will oversee investigations as the responsible parties complete them.

III. PROBLEMS WITH EXISTING PRACTICES

A. Family Perspective

- Education law is a barrier: Parents are bound to public education but have limited choices. Class size poses multiple issues for ASD children. There are not enough appropriate choices for educating

the ASD child whether it is a school district based classroom or an approved private school. Many people have to resort to home schooling because there is not an appropriate school environment to support their child.

- Advocates do not have appropriate environment to advocate and parents often "settle" for an inappropriate choice. School districts often provide a mediocre "in-house" solution rather than have to pay to send a child to an expensive approved private school.
- There is no system to give information about advocacy to parents immediately.
- Money for parents is a barrier. If there is a disagreement with Department of Public Welfare, Education, or other systems, the financial burden is put on the parent. Many parents do not have financial resources to advocate for their child/individual. Attorney fees prohibit many parents/individuals from pursuing a grievance.
- Current system outlined in procedural safeguards wastes time. It takes months or longer to resolve problem while the child is enduring difficulty.

B. Provider Perspective

- There are a number of excellent advocacy organizations that do not have the resources to address parent/family/consumer needs with the individualization and immediacy that families in crisis require.
- Resource shortfalls include staffing, time, and location.
- Additional funding is needed for the above organizations to effectively get the job done.

C. Administrative Perspective

- State and federal laws dictate procedures.

IV. POTENTIAL SOLUTIONS/RECOMMENDATIONS TO IMPROVE EXISTING PRACTICES

A. Family Perspective

- Increase accessibility to individualized advocacy services.
- Develop a listing of organization that provide a resource list of advocates representatives/supports and attorneys within the Commonwealth of PA, with expertise in dealing with autism related issues. This listing should be made available on the website and toll free number of the Autism Resources Center. Such areas of expertise include the following:
    - Education.
    - Health care related: insurance, services, managed care.
    - Respite.
    - Behavioral Health Services: access to services and competency of services provided.
    - Transition from one service, school, or provider to another.
    - Employment and work services.
    - Assistive Technology.
    - Civil rights.
    - Litigation.
    - Guardianship and assessing competency.
    - Estate planning.
- Compile a comprehensive list of currently available resources for parent training seminars, books, and materials on advocacy.
- Enforce meaningful compliance with IDEA's procedural safeguards notice, most particularly access to free or low-cost legal services.
- Support efforts to allow advocates to represent parents at due process hearings. Minimally, make available to family members a list of attorneys in Pennsylvania who work with disability issues, and who accept cases on a contingency basis.
- Establish credentialing procedure as a standard for advocates.
- Establish an advocacy initiative in PA modeled on SPAN in NJ.
- Promote the use of disability advocates in juvenile proceedings. Often advocates working together with parents can readily identify system failures that have exacerbated the child's symptoms and resulted in inappropriate referrals to law enforcement and judicial authorities.

- Support the remediation of inappropriate educational programs and access to quality community-based behavioral/mental health supports, instead of punishment of the child.

DECREASE THE NEED FOR ADVOCACY

- Through increased information/education/training efforts, enhance the quality of care and services, increase compliance with applicable regulations and standards, and reduce the number of problems, thereby reducing the need for problem-solvers.
- Provide information to the public about those providers who specialize in ASD individuals and hold these providers accountable for the services they provide.
- Provide a centralized location for ASD families to receive standardized information to ensure that families acquire needed information.
- Provide more training for parents regarding the issue of advocacy.
- Increase education regarding ASD amongst all providers that offer a specialized service for ASD clients.

B. Provider Perspective

- Through a needs assessment, identify those areas of the state that are most lacking advocacy services and prioritize those areas of need.
- Increase accountability of restrictive, high-cost placements. Insist on data based measurement of progress and outcomes in settings such as Residential Treatment Facilities and other segregated placements.
- Scrutinize the use of involuntary hospitalizations through referrals by schools to county mental health delegates for children with autism whose behaviors are a manifestation of the disability.
- Develop a protocol to be used in these situations. Release a child whose "harmful" behavior can be resolved through return to natural environment and/or managed at home by family members.
- Compile a listing of advocates and attorneys and include this on the website and toll free number.

C. Administrative Perspective

- Parents are not on equal level with providers. Attorneys for DPW, PDE are paid from public funds. Parents must pay for services to remedy grievance disputes. Parents are not able to challenge these administrative powers.
- There are a number of excellent advocacy organizations that do not have the resources to address parent/family/consumer needs with the individualization and immediacy that families in crisis require.
- Resource shortfalls include staffing, funding, time, and location.
- Providers need to enhance behavioral health trainings to increase the level of care currently provided with the hope of decreasing the need for advocacy.
- Individuals who provide a service not directly related to ASD families need to have some familiarity about the needs and difficulties of these individuals.
- Increase funding to providers to decrease staff turnover and increase the availability of high quality personnel.
- Individuals who provide a service not directly related to ASD families need to have some familiarity about the needs and difficulties of these individuals.
- Separate the services provided for ASD children and other developmentally challenged children; thereby enabling ASD children to receive support services for a longer period of time because of the pervasive nature of their disorder.
- Look to NY as a model to establish and Advocacy Services Bureau. Areas of focus are listed in the previous section.
- Provide an avenue of equal access to attorneys and funding. Consider tapping into law schools as a resource for low cost advocates/attorneys as in the NY model.
- Increase the accountability, the compliance, and the consequences for providers and school districts, which are not in accordance with existing laws, regulations, policies and procedures. Currently there is no organization to "police" or hold systems accountable for compliance.
- Providers need to enhance behavioral health trainings to increase the level of care currently provided with the hope of decreasing the need for advocacy.

- Individuals who provide a service not directly related to ASD families need to have some familiarity about the needs and difficulties of these individuals.
- Implement a universal outcome procedure for providers to assess and evaluate the level of care provided and establish a system to ensure that quality of service is appropriate.
- Encourage and support peer review, external and independent consultation.
- Develop Quality Assurance and Quality Improvement programs with parent stakeholders as part of the process.

RESOURCES

Autism Information Centers

COSAC
www.njcosac.org
1450 Parkside Ave.
Suite 22
Ewing, NJ 08638
609-883-8100
800-4autism (in NJ)

WV Autism Training Center
www.marshall.edu/coe/atc/
400 Hal Greer Blvd.
Suite 316
Huntington, WV 25755
304-696-2332
800-344-5115

Center for Autism Related Disorders Florida
www.card.ufl.edu/state.html

Center for Autism Related Disorders NY
www.albany.edu/psy/autism/autism.html

Indiana Resource Center for Autism (IRCA)
Indiana Institute on Disability and Community
www.iidc.indiana.edu/irca/
2853 E. Tenth St.
Bloomington, IN 47408-2696
812-855-6508

Advocacy

Educating Children with Autism. 2001. ISBN 0-309-07269-7

Massachusetts Association of Special Education Parent Advisory Councils
www.masspac.org

Council of Parent Attorneys and Advocates
www.copaa.net
1321 Pennsylvania Ave., SE
Washington, DC 20003-3027
202-544-2210

NY Clinical Practice Guidelines

www.health.state.ny.us/nysdoh/eip/menu.htm

www.albany.edu/psy/autism/fact/html

Autism Program Quality Indicators

www.vesid.nysed.gov/specialed/autism/apqi.htm
www.albany.edu/psy/autism/fact/html

NY Advocacy Programs

NY Commission on Quality Care
www.cqc.state.ny.us/pamaj.html

Quality Services for Autism
www.qsac.com

VESID
www.vesid.nysed.gov

Pennsylvania Advocacy Organizations

Education Law Center
www.elc-pa.org
1315 Walnut St.
Suite 400
Philadelphia, PA 19107

PA Health Law Project
www.phlp.org
924 Cherry St.
Suite 300
Philadelphia, PA 19107
515-625-3663
800-274-3258

Disabilities Law Project
www.dlp-pa.org
1315 Walnut St.
Suite 400
Philadelphia, PA 19107

Pennsylvania Protection and Advocacy, Inc.
www.ppainc.org
1414 N. Cameron St.
Suite C
Harrisburg, PA 17103
717-236-8110
800-692-7443

Additional

Special Kids Network
www.paskn.org
800-986-4550

Parent to Parent
www.parenttoparent.com

Advisory Board on Autism Related Disorders (ABOARD)
www.aboard.org
35 Wilson St.
Suite 100
Pittsburgh, PA 15223
800-827-9385

First Signs
www.firstsigns.org

APPENDIX A

Subcommittee Members

Information:
Debi Achey (parent) - Co-facilitator
Stacey Groder (parent) - Co-facilitator

Advocacy:
Jackie Martin (provider) - Co-facilitator
Janine Cope (provider) - Co-facilitator

Subcommittee Membership:
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Lynn Karasik (parent/provider)
Sallie Lynagh (parent/provider)
Debra Shafer (parent/provider)
Rosa McAllister (provider/administrator)
Lindsay Miller (provider/administrator)
Angela Murphy (parent/provider)
Kyle Smith (parent)
Sue Tuckerman (parent)
Jennifer Valenzola (provider)
Barb Zimmerman (parent/provider)
Cindy Waelterman (parent)
Bonita McCabe (parent)
Dawn Elliot (parent)
Priscilla Conley (provider)
Davy Wildman (parent)
Terry Serafin (parent)
Jamie Grossman (parent)
John Listrud (parent/provider)
Jennifer Mingori (provider)
Lisa Gaylor (provider)
Nancy Carey (parent)
Dossie Cavallucci (parent)
Connell O'Brien (provider)
Sharon Birnbaum (provider)
Joseph Cautilli (provider)
Paul Clifford (provider)
Patricia Thornton (provider)

APPENDIX B

PA Autism Resource Center

The Information and Advocacy Subcommittee recommends establishing an autism resource center. The following actions should be considered:

- Establish an Advisory Board to include leaders in the autism field, members of the Information and Advocacy Subcommittee, and parent representatives.
- Establish a Toll Free Number to include the following:
    - Basic Autism Information.
    - Autism Parent booklet (adopt Nebraska parent booklet).
    - State resources by region.
    - Service providers by region.
    - Support group listing.
    - Speaker's bureau.
    - Information on Centers of Excellence.
    - First Signs information.
    - Conferences, Autism Training programs.
    - Research.
    - Listing of advocates/special education attorneys.
    - Education resources/links – i.e. PATTAN.
    - Parent Education programs.
- Establish an autism specific website to include the information for the toll free number and the addition of online courses for parents and providers.
- Establish an Autism Clearinghouse of information to include the following:
    - Archived information.
    - Research findings.
    - Best practices model.
    - Sources for books, journals.
- Establish a marketing committee to promote and encourage the use of the Autism Resource Center.

APPENDIX C

Nebraska Autism Parent Booklet

Chapter/Topic Outline

1. What is Autism?

- What is Autism?
- Myths About Autism
- Autism Fact Sheet
- CHAT
- Indicators of Sensory Processing Problems

2. Diagnosing Autism

- Diagnosing Autism
- Educational Vs. Medical Diagnosis
- Educational Label for Autism from Rule 51
- DSMV-IV, Pervasive Developmental Disorders

3. Educational Therapies

- How to Determine if a Treatment Really Helped
- Research on Autism Therapies
- Applied Behavior Analysis/ABA
- Verbal Behavior/AVB
- Floortime/DIR/Greenspan
- TEACCH
- Option Institute/Son-Rise Program
- Pivotal Response Training
- Relationship Development Intervention/RDI
- Social Stories
- Power Cards

4. Medical Therapies

- Nutritional Therapies
- Anti-yeast Therapy
- Secretin
- Chelation
- Neuro-Immune Dysfunction Syndromes/NIDS
- Defeat Autism Now (DAN) Protocol
- Medications
- IVIG Therapy
- Transfer Factor
- Sulfate Deficiency/Epsom Salt Baths
- Vaccinations
- EEG Biofeedback
- Hyperbaric Oxygen Therapy

5. Additional Therapies

- Dietary Interventions
- Occupational Therapy
- Sensory Integration
- Speech Therapy

- Physical Therapy
- Listening Therapies
- Fast ForWord
- Earobics
- Vision Therapies
- Animal Therapies

6. IEPs/IFSPs/State & Federal Law

- Special Education Law
- Special Education and the IEP in Nebraska
- Ten Ways to Take Charge of Your Child's IEP Meeting or Family Support Plan
- The IEP: What do we do if it isn't working?

7. Medicaid/SSI/Respite

- SSI - Supplemental Security Income
- Medicaid
- Kids Connection
- Disabled Children's Program (DCP)
- Disabled Persons and Family Support (DPFS) Program
- Early Intervention Medicaid Home and Community-Based Waiver
- Medically Handicapped Children's Program (MHCP)
- Transportation for Children with Disabilities
- Nebraska Respite Network
- Respite Subsidy Program Across the Lifespan
- Other Respite programs

8. Nebraska State Resources

- State Agencies and Organizations
- Disability-Specific Organizations
- Organizations Especially for Parents
- Other Disability Organizations
- Additional Nebraska Resources (broken down by regions)

9. National Organizations

- Federal or Federally Funded Agencies
- National Organizations

10. Websites

11. Books Reviews

12. How To Keep Sane

13. Special Education Abbreviations & Definitions

APPENDIX D

Letter of Permission (Content) for Nebraska Autism Parent Handbook

Dear Ms. Grossman,

I am sorry it's taken me so long to respond to your original request, the message on the answering machine was lost due to a power outage and I have been unable to locate your contact information.

Regarding the booklet, it was put together by a number of autism groups in Nebraska through a grant from the DD Council file by Unlocking Autism. We've given permission to several agencies in other states to use the booklet information and I'd be happy to do so for you as well. (I'm the head project manager and am both a board member of ASN and a UA representative). Our only request is that you keep relevant resources listed with the materials that you use.

As for the section regarding Wisconsin you posted below, that section of the booklet (regarding IEPs) was obtained from the Nebraska PTI (Parent Training and Information Center). They adapted their information from the Wisconsin agency.

When we put together this booklet, we drew upon many, many resources and everyone was happy to offer help. Our local PTI helped provide information on Chapter 6 (IEPs/IFSPs/State and Federal Law). Each chapter has listed resources we drew from in order to put the booklet together and if there wasn't a local representative available to grant us permission to use the materials (i.e. the Autism Society of Nebraska President gave us permission to use the ASA material we used as long as ASA was referenced as the source), then permission was obtained through email contact.

Part of our desire to put together this booklet was to give parents one place to go to get the majority of the information they would need to learn about autism and resources to continue their research and information on resources. We purposely did not want to censor ideas as so many of us have encountered that along the way. We wanted to give parents the tools to make their own decisions.

With the grant we received, we've been able to provide the booklet free of cost to parents (as you know we have enough to pay for and this kind of information shouldn't come at a cost concerns,I feel). Our next project is to get the booklet onto a website.

Please consider this e-mail permission to use the booklet for your state. If you have any other questions, feel free to contact me.

There is one correction in the book I would like to let you know about. Under the What Is Autism section in the first chapter, under Rett's Disorder, it is incorrect when it says it occurs only in girls. This was one mistake we did not catch before printing. It is more common in girls but also does occur in boys. In the DSMV section, there is no mention of Rett's Disorder only affecting girls.

Sincerely,

Connie Shockley
ASN Board Member
NE UA State Representative

APPENDIX E

Clinical Practice Guideline

Report of the Guideline Recommendations
Autism/Pervasive Developmental Disorders
Assessment and Intervention for Young Children (Age 0-3 Years)

Sponsored by New York State Department of Health Early Intervention Program

This guideline was developed by an independent panel of professionals and parents sponsored by the New York State Department of Health, Early Intervention Program.

Clinical Practice Guideline, Report of the Recommendations

- **Ordering Information**
- **Acknowledgment**
- **Table of Contents** - Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years)
- **Clinical Practice Guideline Development Panel**, Autism/Pervasive Developmental Disorders
- **Project Staff**, Autism/Pervasive Developmental Disorders
- **Foreword**
- **Preface**: Why the Early Intervention Program is Developing Clinical Practice Guidelines

Ordering Information
Single copies of the guideline publications are available free of charge to residents of New York State. Multiple copies are available free of charge to New York State Early Intervention providers and municipal officials for use with parents and staff. To order, contact:
Publications
New York State Department of Health
P.O. Box 2000
Albany, New York 12220

A small fee will be charged to cover printing and administrative costs for orders placed by non-residents of New York State and for multiple copies requested by other than those above. To order, contact:
Health Education Services
P.O. Box 7126
Albany, New York 12224

Mastercard and Visa accepted via telephone:
518-439-7286

1. **Clinical Practice Guideline: Report of the Recommendations**. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 5½" x 8½", 322 pages. 1999 Publication No. 4215
2. **Clinical Practice Guideline: Quick Reference Guide**. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 5½" x 8½", 108 pages. 1999 Publication No. 4216
3. **Clinical Practice Guideline: The Guideline Technical Report**. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years). 8½" x 11", 434 pages. 1999 Publication No. 4217

For permission to reprint or use any of the contents of this guideline, or for more information about the NYS Early Intervention Program, contact:
NYS Department of Health, Early Intervention Program
www.health.state.ny.us/nysdoh/eip/index.htm
Corning Tower Building, Room 208

Empire State Plaza, Albany, New York 12237-0618
518-473-7016

The New York State Department of Health gratefully acknowledges the contributions of individuals who have participated as consensus panel members and peer reviewers for the development of this clinical practice guideline. Their insights and expertise have been essential to the development and credibility of the guideline recommendations.

The New York State Department of Health Early Intervention Program especially appreciates the advice and assistance of the New York State Early Intervention Coordinating Council and Clinical Practice Guidelines Project Steering Committee on all aspects of this important effort to improve the quality of early intervention services for young children with autism/pervasive developmental disorders and their families.

The contents of the guideline were developed under a grant from the U.S. Department of Education. However, the contents do not necessarily represent the policy of the Department of Education, and endorsement by the federal government should not be assumed.

The New York State Early Intervention Program does not discriminate on the basis of handicap in admission, or access to, or treatment or employment in, its program and activities.

If you feel you have been discriminated against in admission, or access to, or treatment or employment in the New York State Early Intervention Program, you may, in addition to all other rights and remedies, contact Donna M. Noyes, PhD, Director, Early Intervention Program, New York State Department of Health, Room 208, Corning Tower Building, Empire State Plaza, Albany, NY 12237-0618.

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Subject Index

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Foreword

Providing an optimal program of early intervention for young children with developmental disabilities and their families requires knowledge of the most current information on research and practice. However, analyzing research studies and determining their relevance to practice can be a perplexing task even for the professional. Differing methodologies and conceptual frameworks often make it difficult to judge the quality of the research and to discern outcome patterns that can and should influence practice.

Despite the fact that this is a difficult task, practice guidelines based on a sophisticated and rigorous analysis of the extant research literature can convey essential information for the design and implementation of optimal early intervention programs. The Clinical Practice Guideline for Autism/Pervasive Developmental Disorders has been the result of just such a sophisticated and methodologically sound approach to accurately gather and summarize information based on the available evidence.

This document provides an extraordinarily thoughtful and balanced presentation of the critical issues in assessment and intervention for this group of children. There is no doubt in my mind that readers will find the Guideline to be a valuable resource, as it will allow numerous individuals with different levels of expertise to gain a firm understanding and make highly informed decisions with respect to assessment and intervention for young children with autism and pervasive developmental disorders.

MICHAEL J. GURALNICK, PhD
University of Washington

04. Rural Issues Subcommittee Report

Participants of the Rural Subcommittee

Name	Background
Janiece Seldomridge	Family Member
Carol Varadi	Family Member
Susan Calhoun	Professional
Sherry Kidd	Family Member
Kim Beard	Professional
Theresa Zlotnicki	Family Member
Melissa Morgan	Family Member
Barb Burba	Family Member
Suzanne Miller	Family Member
Michele Ruano-Weber	Professional
Patrice Zanis	Professional
Bonnie Schaefer	Family Member
Dennis Maclay	Individual Living with Autism
Marcy J. Hardinger	Family Member
Mary Ferry	Professional
Michael Maslayak	Professional
Shelly Mieczlowski	Professional
Barb Mowery	Professional

INTRODUCTION & MISSION STATEMENT OF RUAL COMMITTEE

The importance of the work of the Autism Task Force cannot be emphasized enough. We need to remember that we must review four major areas: what the present system provides, what the needs of the autistic individual and his/her family are, how we can provide for these needs with modifications to the current system considering the major budget constraints that we are facing, and prioritize the changes that need to be made.

Parents, whether their child carries a diagnosis of Autism Spectrum Disorder or not, whether they are astute or not as to the services their child needs, remain the best educators and advocates for their children. If nothing else comes out of this, this should be the very first thing that is apparent and the basis for the "mission statement". Parents will continually need to advise and educate their providers throughout the lifespan of their child. They are the experts on their child and unfortunately will likely be the experts on autism until there on substantial improvements in the experience of the professionals with regard to autism.

As we all worked on our specific subcommittees, issues in need of change abound (i.e., benefits that need to be updated and/or included, policies that need to be changed, and legislation that needs to be drafted). As we tried to determine the specific needs of the rural population, we found that many of the needs were the same as those state-wide However, there are obvious differences. Many resources are not present but there are also strengths in a rural setting that are not available in urban settings, We thought we would start by examining these differences.

ADVANTAGES TO LIVING IN A RURAL COMMUNITY

With that in mind, we are starting our report in a positive tone with some advantages of living in a rural community with an autistic person. One of our committee members, not only has an 11 year old son who has Asperger Syndrome, but her brother, who is also a member of our subcommittee, was diagnosed three years ago with High Functioning Autism (HFA) at the age of 47. We are presenting her narrative that includes advantages, disadvantages and observations that also includes the opinions of other committee members:

Advantages to Living in a Rural Community for the High Functioning Autistic Person (HFA)
There are some key advantages to the ASD person who lives in a rural area. We must not lose sight of these, because for many adults, the benefits may outweigh the disadvantages, or at least the disadvantages can be somewhat "fixed". I feel strongly that my brother would not be able to thrive and lead the quality of life he does, with minimal need of county and state resources, were he not living here in this rural community.

1. **A small community may be more understanding since individuals are more willing to learn about HFA:** For example, in the neighborhood, more may extend themselves for that person or are more willing to accept and adapt to having someone with ASD as a customer, neighbor, etc.
2. **A small community is easier to learn and navigate:** Getting hooked up with day to day services (grocery, car mechanic, doctors, hairdresser, pharmacist, and service people) is more straightforward so that independent living is not so scary and overwhelming as it might be in a more populous area.
3. **It is easier to express needs:** Because of the "trust contract" in a small town, it is easier for Dennis to be able to express his needs and ask for help from service people, clerks, strangers, etc. here. He has greater confidence than he used to, now believing that people will be willing to help, and that helps him to be more independent.
4. **We have a simpler, less hectic lifestyle here:** People living with ASD can more easily fit in because of their own simple lifestyles. The pace is generally slower; people have time to chat; there's an interest in other townspeople because so many have known others for years. My brother says that the stress level for him is so much lower, which helps tremendously.
5. **Employment opportunities:** I was able to connect my brother with the owner of a restaurant in town to help out at times. I happened to know the owner (and one of the staff who knew of his needs) through community work. The owner and staff have been very willing to learn about ASD and to flex with his needs. They love him at the restaurant (he helps in the kitchen and with the dishes) because he works hard, is fastidious, and is very reliable. I don't see how a situation like this would have come about where Dennis formerly lived. Contrast Dennis's work experience here with those in suburban Pittsburgh: There, he was always the first one laid off, and he would sometimes have trouble getting the hours he wanted because he didn't have the skills to advocate for himself. There, he would be bullied in some jobs, and the day-to-day experience was hard and unpleasant because people neither understood him, nor wanted to. His last employer, in fact, cheated him of his last paycheck and we tried to pursue this but got nowhere. These experiences have been very demeaning.
6. **Benefits from the numerous civic and church organizations, again, because of the people-oriented nature of the small town:** This allows Dennis to contribute to the community at no cost to the taxpayer. For example, our church (membership 900) has a ministry where they bake cookies to raise money for missions work. One of the leaders, who became aware of Dennis through another church person, came to me to ask if Dennis might be able to serve there. I am giving her some "training" so that Dennis and the group can get the most out of this relationship.
7. **Knowledge of individual by his/her involvement in a large church in a small town:** People run into Dennis through their work and they already know him from church. My son had a wonderful experience at the Y's Day Camp, in part because several of the staff were already familiar with his needs through previous experiences, say, at school and at church. Another family had a similar situation-found that some doctors/therapists suggest theater/music. At first they were discouraged, (Pittsburgh has a year long youth theatre with summer day camps), but found two youth theaters in neighboring towns that had a policy of accepting everyone who auditioned. They knew that no large or even medium sized city could possibly offer that. With a smaller group of children, chances were better their daughter could get a speaking part, which she did. She is also in dance and choir. All the directors of these groups allow the mother or her wraparound to attend practices to learn the

movements/dance steps so that they can practice them at home. This atmosphere also provides peace of mind for the parents when they learn who they can trust with their children.

8. **Simplified transportation needs:** Although my brother can drive a car, it has really helped that we can walk or ride our bikes to many places in town. This would no doubt benefit someone who can't drive. For example, we walk to church, library, grocery store, McDonald's, pizza place, "downtown" to the stores, etc. It keeps miles off of his car, which helps Dennis financially in addition to being a calming experience for him. This also provides a lower cost of living compared to living in a metropolitan area.
9. **New model test site:** The small rural community may be an ideal place to test new models of best practices in autism intervention and support. It might be easier here to measure outcomes not only at an individual level but to the community as a whole.

DISADVANTAGES TO LIVING IN A RURAL COMMUNITY

1. **The lack of peer groups to provide him with friends:** My brother's biggest complaint is the lack of friends, which is a huge disadvantage and he constantly talks about it. Examples are other ASD adults, singles, and people with a hobby in common. Particularly he gets discouraged that "there are no single people here" (and there are probably more ASD children/adults out there, but who are afraid or unable to come to the support groups). Through ABOARD, I got him hooked up with a group of ASD adults, which has been wonderful for him (first time in his life to have this). Having those friends is so important and helpful to him that he is willing to make the hour-plus drive to attend the gatherings of this support group. Unfortunately, because of the distance, he is often not able to go because he can't get there in time after his commitment at the restaurant.
2. **Lack of services:** We expect to have to make the big trip to Pittsburgh to get the diagnosis, but because successful treatment depends so much on frequency and intensity, support resources need to be at the community or at least area level. On my street alone there are four people with HFA, counting my son and brother. In the local school district (about 1500 students in grades K through 8), we know of about twelve students (there are probably more; this is about 1 in 150) who have wraparounds for ASD. But we still have to make a 45 – 60 minute trip for regular meetings with occupational therapists (O.T.) who have S.I.D. (sensory integration dysfunction) training, qualified psychotherapists, and psychiatrists. There are no autism support classes as such in our school district and acceptable private schools (with smaller classes) are long distances away.
3. **Education, training, dissemination of new research, and knowledge about autism in general are much slower to reach a rural community:** Children are losing valuable time in being diagnosed and treated, and the parents are frustrated because it is so difficult to learn about ASD and get connected with the right supports as they start their own journey with ASD.
4. **Takes long time frame to fight through the bureaucracy with the amount of time travel involved:** Barriers to service that the other subcommittees report are also an issue in the rural area, but they may be more accentuated. For example, it was very difficult, and took a long time, for me to navigate the labyrinth of bureaucracy to secure essential services for my brother. This was made worse by having to drive distances to Hermitage, a larger community about 35 miles away, to investigate county, state, and area services. At minimum this represents a huge cost in travel expenses and time. In particular, this cuts into Noel's school time. (One family had to drive 200 miles every week for 2 years to see an O.T certified in S.I.D. The first year was okay, the second year they had to be back by noon for their daughter to go to afternoon kindergarten, then had to quit when daughter started first grade.)
5. **Support groups for advocates/parents are not readily available:** These groups could also provide training for other people in the community: babysitters, police, firefighters, emergency rooms, teachers, etc. I have even trained the hair stylist.
6. **Adjustment in rural area may be more difficult:** It may be more difficult or easier to get connected with the autism community if you live in a rural, small town; it all depends on whom you know. Especially discouraging is the time when parents at the beginning of their journey aren't yet tapped into parents who are more knowledgeable. Everything seems so complicated. There is no way my brother could have set himself up on his own without an advocate in me. On the other hand, the process may not be as difficult in the future especially if services are streamlined, since more people are speaking out about autism and word travels fast within a small community.
7. **Providers do not accept M.A.:** A big frustration has been that certain providers do not accept M.A., which in my brother's case is the only way he can pay for medical help. Examples of these are

dentists, family practitioners, and eye doctors. We were able to get psychotherapy services and a psychiatrist for the med management through the county. (Often the providers are limited to the number of M.A. patients they are allowed to accept-loosing money because of the low reimbursements.) The providers tell me that people on M.A. are usually irresponsible, don't keep appointments, etc. and that the reimbursement for services is lower than the insurances give. The person with autism, though, is in my experience very reliable, punctual, and compliant.

OTHER OBSERVATIONS

1. **Some areas have wraparound programs:** We are fortunate in our area that there is an excellent wraparound program available for youngsters, and the TSSs will come to Grove City. The Connections program through Sharon Regional Health System focuses exclusively on children with autism spectrum disorders and I credit much of my son's progress to this. The training in behavior management I have received as a byproduct has helped me be more effective with my son, and I often have opportunity to pass along my learning to moms of ASD and typical children alike.
2. **Living independently depends upon the individual and the individual's support group:** My brother, Dennis, is doing very well – better than any of us had ever hoped – in terms of living independently, enjoying quality of life, contributing to the community, and not needing services besides SSI/SSDI. However, this would not have been possible without having me to be his initial and ongoing advocate. I believe ASD adults, particularly high functioning people, can do very well in our small rural towns as long as they have a person to serve as an advocate. It helps if that person has training, if only from peer advocates (I taught myself). This again emphasizes the importance of having an ASD advocate for each county that could train family members, friends and others who want to help.
3. **Socialization improved with virtual charter schools or home schooling:** Becoming part of a larger community as they grow to adulthood, in many cases, is not a major problem when the children are schooled in a home setting (virtual charter school or home school). By being educated in a home setting, these kids are becoming better prepared to not only survive, but to contribute to their community. The reason is, we are taking them out of an extremely negative socialization experience (according to the statistics, some 95% of autistic children are bullied at school) and teaching them social skills in a positive environment. The child can learn these and other life skills with adults first, and then practice them with a peer group. It is important for the parents of these children to actively seek positive socialization opportunities, both in groups and with individuals -- just as they would for a typical child schooled at home. But we do this consciously, like it's another subject at school, rather than let it happen haphazardly. My son has been able to overcome the huge barriers to his being educated successfully by opting out of the local school district altogether. Noel is a student in the Pennsylvania Virtual Charter School ("PAVCS", Norristown, PA), which is based on a model of "public school in a home environment". I have both special education teachers and regular teachers who help me educate Noel. Distance is not an issue because the model, by definition, does not rely on the children being together daily in a classroom. For example, Noel, at age 8, when in the local school district, could hardly speak to anyone. He was anxious and afraid, and often unable to control his outbursts. He was so afraid of getting in trouble, which happened often and most of the time he didn't understand the reason why. Today at age 11, after three years in the Pennsylvania Virtual Charter School (PAVCS), where I am his immediate teacher, Noel can participate in groups, and he will spontaneously speak to others and initiate conversation. He knows his difficulties, but he has had intensive training to deal with them. His closest friends will never be typical children, nor will he have many, but he can certainly participate and contribute at a similar level as others his age. PAVCS has "classroom days" where Noel's assigned teacher has all of her students together for a day of learning. Except for some needed "alone time" breaks, Noel takes part in these, and looks forward to them, which could have never happened if he had stayed in the prior learning situation. Other parents of special needs children are, like I am, reporting significant success with PAVCS in educating their children. Another example is one twelve year-old girl started speaking for the first time! It is a joy to get together with the moms (this is facilitated by the school), to share our learning about how to effectively teach our children. At my ABOARD support group, the difference is striking: we PAVCS moms are engaged in positive, excited, creative conversation, while the rest of the group laments their difficulties in the schools and spends the time figuring out how to overcome these problems. In fact, the proportion of special needs kids enrolled in PAVCS is higher than in a typical population.

4. **Other support groups:** I and a few others started a group for our church and community called, "Parents as Advocates," to raise the awareness and educate the public about special needs adults and children. This has given me numerous opportunities to speak to groups, who have been very receptive. (My present goal is to speak at in-service days at the local schools.) I think we've had significant impact. Also, (and here again the nature of the small town facilitated this), I have had the privilege numerous times of teaching the education students at our local college about autism. Surely this is a good thing and should be encouraged. The people in our group act as resource people around the needs of people with autism and their parents.

PROMINENT CONCERNS OF TASK FORCE AND COMMITEE

Reading through the reports from the other subcommittees, it is obvious that several issues are of prominent concern to all of us. These are our issues:

1. **Lack of education of medical professionals:** All parents of children with autism, regardless of urban or rural setting, are concerned with the lack of education that the physicians (i.e., pediatricians, family docs) receive regarding diagnosis and treatment options available for families. Considering that early identification/diagnosis of autism is critical to a child's outcome, limited knowledge of this disorder can be devastating. This is especially pertinent in the rural areas of Pennsylvania where those individuals working with children with autism have limited access to current information, research and training opportunities.
2. **Lack of standard health benefits across the state:** County agencies, health providers, and insurance companies are not providing standard health benefits across the state. The terminology utilized to access benefits varies from county to county, thus creating confusion, wasted time, money and variability in the distribution of services. This again is extremely important in the rural areas of Pennsylvania where currently some families have to travel up to two hours away from home and community in order to receive the necessary treatment for their child because the managed care organization that operates in their county does not fund providers that may be closer to the family's home.
3. **Accessing services from MH/MR:** A major complaint is the need to access services from both the Mental Health and the Mental Retardation Systems. There are often duplications and gaps in the services. For example: Through the MH system one family has support to help deal with their 14 year old daughter's behavior issues. The staff is trained in autism, is paid fairly well, and receives supervision on a weekly basis, yet is not allowed to be alone with their daughter. Through the MR system, the daughter receives habilitation support and the parents receive respite care through the waiver. The MR staff receives virtually no training, not paid very well, nor do they receive any supervision. However, they are permitted to be alone with their daughter. Because both parents are employed, there are many hours when double staff is in their home or community (MH staff and MR staff) both billing their hours.
4. **Use of IQ scores:** Using the IQ scores as a determining factor for eligibility for services has screened some young patients out of the MH/MR system. More focus should be placed on a functional assessment across the entire autism spectrum.
5. **Requirement of re-assessments:** The frequency of re-assessments to verify the need for services is time consuming, costly and unnecessary. Unlike some other childhood psychiatric disorders, services for children with autism do not fluctuate drastically from month to month. Decreasing the frequency of re-assessments is especially pertinent for families living in rural areas that may have to travel hours to get to an appropriate facility.
6. **Lack of research:** Clinical practice lags behind research by at least 20 years. This situation is exacerbated in rural areas. Behavioral Health Rehabilitation Services (BHRS) are predicated on medical necessity criteria; therefore BHRS is not the right venue for treatment of children with autism. BHRS services were designed to be specifically tailored to the child/family. The reality is that the least skilled are working with the most difficult clients.
7. **Lack of training in educational staff:** Teachers, administrators, and all personnel that have any contact with children in the school systems need to be educated on the different aspects of autism. All teachers and administrators, no matter what grade level or specialty, need training on learning profiles (i.e. strengths and weaknesses unique to autism), behavioral interventions and preventions for children with autism and other special needs. Perhaps, this could be accomplished through coursework and competency exams leading up to obtaining a teacher certificate, or salary increase for those not

working on a specific teaching certificate but willing to make an extra effort for their job or include the training in a new updated job description.

8. **Children required to take PSSA tests for a grade level that does not match their intellectual ability:** Schools are mainstreaming the children, possibly ignoring the IEP's, which frustrates the child, sometimes for several weeks, and does not present an accurate state level.
9. **Lack of provider training:** Direct service providers are inadequately trained: Behavioral Specialist and Therapeutic Support Staff, TSS.
10. **Lack of funding:** For research, training, respite care, benefits.
11. **Families are isolated:** There is no central location for families to obtain information regarding training, services, research, parent support, etc.
12. **Lack of coordination of transitional care across the life span of individuals with autism:** Keeping in mind that the children do grow up to be adults. This again emphasizes the importance of having an ASD advocate, under the Department of Disabilities, for each county that could train family members, friends and others who want to help.

RECOMMENDATIONS:

1. Establish a Department of Developmental Disabilities/State Autism Office, which actually deals with all disabilities, provides a website, 800#, information booklet, central registry, speaker's bureau, parent/professional/consumer support groups, and free/low cost legal services.
2. Teleconferences; partnerships/alliances with colleges, medical society, emergency personnel.
3. Cross system collaboration: because private insurers only cover rehabilitation services, families are forced to turn to the Commonwealth. Pennsylvania must consider ending its relationship with Behavioral Health Organization (BHO) subcontractors because of their close-ended approach (three month evaluation). Providers need increases in reimbursement rates and the ability to provide a continuum of care across an individual's lifespan.
4. Educational staff and school personnel (as well as the next 4 bullets) need appropriate education on a uniform state-wide basis, which means that all receive the same information in the same manner for the appropriate environment.
5. New models in education and other services that don't rely on physical proximity should be tried and encouraged. The Virtual Charter School (VCS) is an excellent example. Note that today a home setting for schooling is considered "most restrictive", not "least restrictive environment", even though for the child it serves as the least restrictive environment. Also regarding the VCS, many parents took on the responsibility of educating their child at significant economic cost (i.e., some had to quit their jobs). The reward of seeing our children reach their learning and functioning potential is more than enough to make this worthwhile. For the local school, the parents have taken a difficult child out of school's classrooms, so they benefit, too. But parents are still fighting to be able to have access to IDEA/FAPE mandated services such as access to the district's SLP, psychologist, and the like. Another aspect that is difficult to deal with is the lack of availability of some assistive technologies and occupational therapy equipment that would be enormously beneficial to the student, which they would get in the local school district, but that the parent simply can't afford (having quit their job and spending so much money on the many drives to other places in order to help their child). The PA Department of Education needs to work out their policies in this area in a way that addresses the case of the virtual charter school.
6. Each county in the state should have a contact professional and regional center of care. These regional centers would serve several counties, providing general resources and someone to contact in their area to discuss current treatment options, availability of services, etc. Parents need clear and concise information at the time of diagnosis about what to expect in terms of how the diagnosis was made, medical coverage, educational placement, medication possibilities, role of advocacy and access to support groups and literature. This again emphasizes the importance of having an ASD advocate for each county that could train family member, friends and others who want to help.
7. Training for pediatricians and general practioners about autism including early identifiers, treatment options, need for referrals to specialist and links to community-at the Medical School level and practical/clinical level, needs to be implemented. Standardized assessment protocols could be developed for use by pediatricians, Head Start and preschool teachers that would be completed at various intervals during the child's first few years of life. Documentation of changes in typical development would send a 'red flag' to those involved with the child and potential need for further evaluation. This is extremely important for the doctors, because very few doctors spend enough time

with a child at the time of an office visit for a true evaluation. The training is extremely important, but so is the observation of a child when there are questions of possible problems.

8. There is a need for a centralized training program for service providers (BSC, TSS, therapists, etc.). Training should focus on methodologies and/or treatments being used with children/adults with ADS. These could include: Applied Behavioral Analysis (ABA), DIR/Floortime, sensory integration, auditory integration/listening therapies, TEACCH, Picture Exchange Communication System, gluten and casein free diet, numerous supplements, medication, and others. Some of these have been said to have a 'near miracle' effect on a few, while having little to no effect for others. Consequently, the need for research continues.
9. Develop a competency-based ABA program, which is the most widely used therapy, to address the need for qualified staff in that specific methodology and require staff to participate in supervised practicums and pass competency exams. In addition, provide an incentive program to prevent high turnover among staff (i.e., earn merits for Continuing Ed).
10. Increase in funding for research founded on empirically based outcome studies (i.e., what works best for these kids and why) that are longitudinal and prospective.
11. Changes in the insurance coverage that would provide discretionary funds based on what child/family needs-it has been suggested that the medical assistance insurance be the secondary provider, pay for what the regular insurance will not do-this may be done by some insurances.
12. Look at states, counties, areas, agencies where things are going well.
13. Hold a series pf public forums throughout the state after the policy/regulation changes are in place to evaluate the changes that have been made and assess any additional needs and gaps in service.
14. RESPITE for these parents needs to be increased 1000% for them to live outside their child's needs as well. Recreational supports need to be available to them with no strings or limited hours attached. Recreation and leisure opportunities need to be addressed for this autistic population as socialization is generally affected. Whether the family lives in a rural or metropolitan area, parents need to research the availability of clubs/organizations, such as Boy/Girl Scouts, Big Brother/Big Sister, and musical or theatre groups to help promote the socialization skills of the autistic individual. Project Together, a service provided to increase recreation and leisure opportunities for individuals with disabilities can play a vital role in the acquisition of recreation and leisure as well as relationship building for individuals and their families. Project Together can be referred to families as a resource for such findings.
15. Vocational, not just educational supports need to be available and cater to the individual needs of the child/adult. On that vein, we have created a business within now two of our county contracted sites that we refer to as "The Lighthouse". Where was this established and how is it working? The Lighthouse was created to give consumers the training and knowledge to feel valued. We make candles, crafts, wreaths, soaps and lotions, wooden trinkets, etc. and then we sell them. Every item is made by the consumer. Every item has a label that states who the person is that made the item. No matter how well you do in this business, nothing is dependent on your skill level. There are jobs available to everyone no matter what their ability is, no matter what their physical/mental capabilities are. For those with autism, it presents a warm environment with reduced stimuli, where every job is determined based on individual likes and dislikes, and hopes and dreams. The product that is produced is a beautiful product or a great smelling candle. The Community is not buying our wares because they are developed by people with disabilities. They are buying them because it is a great product. People who could not sit to work, people who were so behaviorally involved work was never discussed as a viable service are now earning a paycheck, learning a marketable skill and increasing their independence in day living skills. We were recently approached by a family with a son who carries an autism diagnosis. They were particularly interested in the service because his individuality and interest with numbers has not yielded a productive life style for him. Inventory tabulation at the Lighthouse meets his needs and goals. Another person with autism just started in the program and with minimal assistance creates the most beautiful wreaths that sell to the public for 20-25 dollars. Since every item is hand tagged, some of our consumers have created their own "customer base" that they fill orders for.
16. A system of advocacy for these clients should be encouraged. For example, it may not be that difficult to find people in towns who would be willing to act as advocates for one or more autistic adults. Ideally, the advocates would have some training (even some sort of certification for completing training and hours of service, and they could teach others), opportunity to meet together, breaks on conference fees. This could be a very low cost way to support autistic, especially HFA, adults. It would enable more ASD adults to live independently. This again is where an ASD advocate for each county would help, one who can train family members, friends and others who want to help.

17. For these children to remain safely in their homes, a waiver needs to include funding for adaptations to the home, custom designed for each child.
18. Parents currently do and will have to continually network with the medical, educational, and provider staff advising and educating them in an attempt to deal with the lack of knowledge and support issues throughout the lifespan of their child.
19. Research that is shared by the industry needs to be reaching the parents in SIMPLE non-medical terminology.
20. Small rural communities should be considered the sites for the testing of new models of autism interventions and treatments.

PROFESSIONAL COMMITTEE MEMBERS' CONTRIBUTIONS

One of our professionals has listed some things that she and other associates are doing in Dauphin/Cumberland/Perry counties: locally she is on the Autism Committee of the Capital Area Interagency Coordinating Council, which has been in existence for several years. Their focus is children birth-5. They developed a packet (included audiotape of local developmental pediatrician discussing autism, a checklist for them to use, resources, etc) that was sent or taken to approx. 200 area physicians about 2 yrs ago. They also developed a resource manual that is given to local agencies and therapists who provide early intervention services. They have had training sessions for service providers and families. They are currently in the process of planning one based on a survey that was sent out to the service providers and families who have a child with ASD.

A second professional has worked for over 24 years in the Mental Health/Mental Retardation system. She is well aware of all the lack of supports, lack of funding, etc. She knows that the reality of living in a rural area is that the parents can expect to travel for almost everything that they need. With the current state of the budget not very promising, her suggestion is to duplicate some of what has been done. For years and years, the children in her particular area have had very little medical intervention for issues with cerebral palsy and bone disorders. So for many years, providers contracted with orthopedic surgeons, heart specialists, neurologists, etc. to provide services in the county 1-2 days a month. Most, if not all, of the physicians were from Philadelphia and DuPont. We have "clinics" etc. to assist parents and the services mobilize instead of the parents and their children. On that same breath, so should all the other providers "mobilize" themselves for additional clinics. If some of the rural counties could work together, costs could be minimized to individual counties, and instead be a shared resource.

Another professional on this subcommittee is a researcher, who has five articles published in the area of autism in peer-reviewed journals. Her associate at the Hershey Medical Center travels the state, lecturing on research findings and implications for children with autism.

On our Rural Committee: there are parents identified as resources plus others out there willing to offer their assistance. We need to make sure families know about resources, e.g. Parent to Parent, ABOARD, Special Kids Network.

TESTIMONY OF ONE FAMILY'S RURAL PROBLEMS

The following describes the problems of the rural areas by one of our parents in her words. (Many families, both in rural and metropolitan areas will be able to associate with this testimony.) This is the story of Hannah, now 6 1/2:

From birth, Hannah has encountered one challenge after another. Right away it was known of her hip dysphasia. She was taken into surgery only hours after birth. We then realized her eyes were shaking and crossed, and that she was entering into more surgery, this time with her eyes. We then needed to bare the news of her having nystagmus and esotropia along with being seriously visually impaired. She faced more surgery, several on her ears. This was to open up the canals so she would be able to hear for the first time, at the age of 2. Then before she was even 6 months of age, realizing she was completely fisted. I spent hours working each day with her hands to get them open just a little, trying to block out her painful cries, to work toward her close to normal use of them today. She is also asthmatic and needed and still needs numerous breathing treatments. There were times, we wondered if these were her last breaths, as she gasped for air. She also was challenged with many feeding struggles, dysphagia, GERD and submucus cleft palate. She would throw up hour after hour, becoming dehydrated, and faced the possibility of under nourishment. At age 2 our baby wasn't walking, wasn't talking and didn't even seem to know any of us existed. Doctors discouraged us. Tests proved them right. As she grew, her problems changed. Some of her physical problems improved, but more severe developmental ones surfaced. We

have known from the start, that something was different with Hannah. Something was "just not right" but no one, including physicians, could figure it out.

On October 2001 we were faced with the devastation of being told she is autistic. She will always need our care. She has no fear of danger or her safety. This is the most difficult part of her life. We must be on total "Hannah alert" to protect her. She has climbed into a hot oven, busted through a window, head butted metal, glass, concrete and us, chewed on electric cords, popped light bulbs in her mouth, pulled out two of her teeth by their roots, constantly takes off all her clothing, has many times spread her feces all over our home, has put sharp knives down in her outfit, climbed into our fridge, and has wandered away in freezing cold weather. We are constantly "Hannah proofing" our home. We watch every move she makes and she still manages to accomplish these things. She doesn't understand, she doesn't feel the pain of her consequences. She is fast, strong, and hyper. Along with being hyper she requires little sleep, so Hannah is a full time job. Hannah doesn't fear the dangers she should, but fears the indescribable. Her fears are real, and though we are unable to understand them, we respect them. She fears the sound of a vacuum cleaner, any motor, public environments, the touch of another person, smells, and the smallest change. She lives a life of fear and anxiety.

I am very thankful to have valuable family and friends to help us. I know we could never manage without them. For an example, my father in law, Wilbur, couldn't wait for Hannah to be born. He wanted to run, play ball and take her fishing like he does with her siblings. Hannah can't do these things with her grandfather. Instead he swings her, spins her on a chair, squeezes her with deep pressure, rides her on the four wheeler for hours, and plays with beads, all to bring some happiness into her life. He loves her for who she is, and he has stated that she has shown him so much, especially Godly love. In life many people don't do for others unless they can receive something in return. In the world's eyes, Hannah doesn't have much to offer. In our eyes, she has an amazing amount to offer. She has taught us all true love, patience and compassion. We have the peace of knowing God chose us to care for His very special child. We love her unconditionally and are constantly working with her.

We continue to travel through life beside her, helping her every step of the way. She has touched so many people along this path. She has given hope to those who have none. She is truly the joy of our lives and though our lives are extremely difficult, we are so glad to be the privileged ones to protect, love and care for her. She has blessed us unconditionally. Hannah is our angel.

It is hard to explain in words, the pain I bare each day. Tears pour down my face as I type this, trying to give others just a glimpse. It is impossible to survive without help. Services are not a privilege, they are a necessity. Services have not been available to Hannah due to our living in a rural area. Below I list a few of the challenges we face.

1. After diagnosis and services are prescribed, they are not available.
We returned home from Pittsburgh, with a diagnosis for Hannah, and a list of prescribed services from the Child Development Unit on Oct. 2001. With excitement we contacted our Bedford MH/MR, to only find disappointment. Due to us living in a very rural area, most of the services listed were never heard of here. We were able to have a TSS through Wrap Around, but since that date there has only been a TSS in our home for 2 weeks because they are very limited in our area.

Once a diagnosis is given, each county should be required to follow through; making sure the family receives the services & resources needed. If the TSS, Health Aids, & Behavior specialist would receive health benefits, there would be more willing to be trained. I also believe that each county should be required to have a certain number of Music Therapists, Color Therapists, sensory Integration staff and others. These therapists are so important to children with ASD, and it is sad when local MH/MR staff don't know they even exist.

2. Lack of education in professionals.
We have taken Hannah to visit many physicians, therapists, psychologists, and pediatricians, to name a few. With each, the story is always the same. I am the one to educate them on autism. I am the one to teach them how to handle a child with autism. For years I have been driving regularly, 2 ½ - 3 hours to Children's Hospital of Pittsburgh, visiting physicians. We now have some amazing Doctors, but I have had the difficult task of finding them. After seeing several great Geneticists, they were even clueless about what was wrong with our daughter. It wasn't until she was 4 that CDU did diagnose her.

Professionals must be required to receive training related to the assessment and needs of children with ASD. They should each have a form that each parent would fill out, that would alert them of the possibility of ASD. They should then be required to refer the suspected child to the proper physician, so they may

receive the care, and resources needed. Clinics should be places in rural areas, so that parents do not need to drive long distances to get the care our children need.

3. Evaluations every 3 months, to continue services, not even available.
Every 3 months we are required to take our daughter to an evaluation 30 miles away to assure us that she will not loose her services, and to make sure she still qualifies. First off, we aren't receiving the services as I stated. Second, every 3 months is ridiculous. She doesn't change much from visit to visit. She will always be autistic. Even small changes in her take years to take place. And most importantly, the trip and visit is stressful to her.

Evaluations should be at least 6 months apart and preferably once a year. We shouldn't have to continue proving she still has her diagnosis. All these children deserve services, even when they do improve!

4. Resources aren't available.
In this area I am very fortunate but it hasn't been easy. The only reason I have the amount that I do, is because of being a head of the Autism Walk in our area, therefore NAAR is constantly sending me material to distribute. When I began the walk in our area, it was not only to raise money, but awareness. Parents are searching for anything to read on autism. They appreciate everything I pass on to them. It is sad, to see them so desperate for material.

There must be resources for parents. There needs to be a packet given to parents of children diagnosed with ASD. Materials are expensive, funding must be provided for them.

5. Special Equipment needed.
Having an autistic child changes your life. There are serious every day issues that we as parents face. Our daughter has no understanding of danger. She loves to be outside. She is constantly trying to find ways to get there. We have installed extra locks, and when she figured them out, we installed higher ones, now she pushes a chair up to them. My husband and I, along with our two other children, are on constant "Hannah alert". Even though we have Hannah proofed every possible thing in our home, she is constantly endangering herself. We try to watch her every move, but I couldn't begin to number the times she has wandered away. No family should have to live in constant fear. She has wandered off in the middle of winter, with no shoes, and when we find her, she is playing, and doesn't even realize it's below freezing. We have also found her, down by our large creek, at the water falls, throwing her ball in, and she can't swim. She is used to going there with us in the summer, because it is on our land, and this is where we swim. This is only one of our fears with her. There are many. I have asked for a security system to be put in our home, which her case worker said was a must, but it came back to only be denied. She was also denied a fence to be placed around a small portion of our yard. This is just one area she needs assistance in. We have asked for many things in this nature, not for our own convenience, but for Hannah's safety and our survival.

For these children to remain safely in their homes, this waiver needs to include funding for adaptations to the home, custom designed for each child.

It is important to remember: each child/individual and their family have differing needs and that we should not set up 'cookie-cutter services'.

05. Research Subcommittee Report

I. INTRODUCTORY MATERIALS

A. List of Members

NOTE: (P) signifies parent; (PR) signifies professional and parent)

1. Dori Anderson
2. Saul Axelrod, Ph.D.
3. Pat Bailey (P)
4. Jamie Broda
5. Lawrence Barone (P)
6. Katherine Beals (P)
7. Judith D'Angelo, Ed.D.
8. Michael DeWulf (P)
9. Joyce Douglas (P) (Facilitor)
10. Antonio Hardan (P)
11. Laura Hewitson, Ph.D. (Pr)
12. Jennifer Lachenman (P)
13. Susan E. Levy, M.D (Facilitator)
14. Richard Malone, M.D
15. Nancy Minshew, M.D., (Faciliator)
16. Zanetta Moore-Driggers (P)
17. Ken Nash (P)
18. Suzanne O'Mullan (P)
19. Cathy Roberts, M.D
20. Jeff Rudski, Ph.D. (Pr)
21. Julia Sharer
22. Lisa Sportelli-Wright (P)
23. Vincent Winterling, Ed.D.

* Initially a member, has subsequently moved out of the state.

B. Mission of Research Subcommittee

To improve quality of care provided to individuals with autism spectrum disorders and their families in the state of Pennsylvania by acceleration of scientific rsearch and translating scientific research into practice.

C. How and how often did you meet?

Ongoing communication has been primarily by email with some teleconferences.

D. Report formulated

An outline was developed from the discussion at the Autism Task Force meeting in Harrisburg on July 26, 2003 and the follow-up conference call. The initial report was the result of elaboration on this outline by individual members followed by review and editing of other committee members.

The first revision of the report was the result of editing by members of the committee. The final revision is the result of editing by the facilitators.

II. WHAT IS THE STATE OF CURRENT FEDERAL, STATE, AND UNIVERSITY RESEARCH FUNDING IN THIS AREA?

A federal agenda for autism became apparent with the recent NIMH orchestrated Autism Summit Conference, which was attended by a number of Congressmen and Senator Hilary Clinton. This Summit

conference was thematically organized around the contents of the newly proposed NIMH research plan. The research plan was in response to Congress' 2003 challenge to NIH to produce a 10 year plan for definitively addressing the problem of autism. A near final version of this plan was revealed at the IACC conference November 21, 2003 and includes reducing the incidence of autism by 25%, detection of autism in infancy, and increasing the percentage who speak to 90%. The plan was finalized April 2004.

However, , the funds to support this new research agenda have not been appropriated by Congress. The 2004-2005 appropriation for NIH has not yet been passed. It may or may not end up containing language directing NIH to set aside "sufficient" funding for the research matrix. The bourgeoning numbers of cases and assertive parent advocacy has been responsible for this recent assertive agenda and for the funding of autism research, which only began in earnest in 1997 and will only continue as long as parents remain vigilant and assertive.

Other sources of funding besides NIH are also important. Cure Autism Now (CAN) and the National Alliance for Autism Research (NAAR) are two parent organizations that developed out of the need to provide seed money for submitting grants to federal funding sources. They also support research initiatives in their own right. Prior to this there were essentially no organizations interested in providing seed funding for pilot studies in autism, which are essential for submitting grants to NIH. Other federal sources of funding include: the Federal Drug Administration (FDA), the Health Resources and Services Administration (Federal HHS), National Science Foundation, and Department of Defense (DOD).

State funding of autism research is substantial in New Jersey and California. New Jersey was the site of the Brick Township "outbreak" where the first documented prevalence of 1/170 was reported in the United States. The state of California has invested heavily in autism research through appropriations and the tobacco settlement money, recognizing that each diagnosed child was incurring $50,000 per year or more in costs to the state and the need was great to discover the cause, provide remediation, and a long-term cure.

Universities have also supported autism research. Developmental disorders can be an area of programmatic priority for funding support. The Yale Child Study Center for example has 50 faculty members who work in the area of autism. They began 15-20 years ago with 3-4 faculty members. Endowed chairs for junior and intermediate level faculty have aided their growth. Consequently, they now have one of every type of autism center described below and many RO-1s. This large group has the capacity to apply for many types of centers. Neither of the major universities in Pennsylvania has given priority to developmental disorders as an area of research.

Local foundations may provide funding for research but are generally not major sources.

The following is a brief history of autism research funding nationally followed by a summary of current autism research funding in Pennsylvania. Research funding changes yearly as new awards are made and existing awards expire. The purpose of this section is to demonstrate what resources the state has to build on. The importance of research is that it can be used to establish a high standard of diagnosis, assessment and treatment in a region, and provide not otherwise available treatment at no charge to a limited number of individuals.

A. National Funding:

1. NIH establishes the NIH/IACC:

The National Institutes of Health established a National Institutes of Health Interagency Autism Coordinating Committee **(1)** (NIH/IACC) to implement aspects of the Children's Health Act of 2000 that relate to support of autism research by the NIH.

The NIH/IACC is composed of the NIH institutes currently funding autism research: the National Institute of Mental Health (NIMH), the National Institute of Child Health and Human Development (NICHD), the National Institute of Neurologic Disorders and Stroke (NINDS), the National Institute of Deafness and Communication Disorders (NIDCD), and the National Institute of Environmental Health Sciences (NIEHS).

Federal funding for research provides stringent peer review of studies that ensures rigorous scientific standards, methods, a scientifically credible rationale, meritorious and testable hypotheses with built in protection of participants.

2. Collaborative Programs of Excellence in Autism (CPEAs)

The first significant NIH investment in autism research started in 1997 with the establishment of 10 autism research centers called Collaborative Programs of Excellence in Autism (CPEAs) to investigate the genetics and neurobiology of autism. This network **(2)** was initiated by Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development (NICHD) at a time when no other institute was willing to invest in autism. This network jump-started neurobiological and genetic research in autism, moving it from a stand still to a rapid acceleration of evolving discoveries. This network is in its second five-year funding cycle. This funding will expire in 2007 unless renewed. Unlike the STAART centers mandated by the Children's Health Act of 2000, there is no federal legislation mandating the continuation of the CPEAs. They can be defunded on the basis of institutional funding priorities.

3. Interagency Autism Coordinating Committee (IACC)

The Children's Health Act of 2000 (P.L. 106-310), Title I, Section 104, mandated the establishment of an Interagency Autism Coordinating Committee (IACC) to coordinate autism research and other efforts within the Department of Health and Human Services (DHHS). In April 2001, Secretary Tommy Thompson delegated the authority to establish the IACC to the National Institutes of Health (NIH). The National Institute of Mental Health (NIMH) at the NIH has been designated the lead for this activity. Among other requirements the Children's Health Act of 2000 required that NIMH fund at least five new research centers that included a treatment focus. These centers are called Studies to Advance Autism Research and Treatment or STAART Centers. Two were funded in July 2002 and another 6 were funded in 2003. Many of the STAART Centers are at the same sites as the CPEAs and have the same directors. However, the projects, science and scientists are different.

4. CPEA and STAART

a. Collaboration and coordination

Both networks are collaborative across sites within the individual network and across the two networks. A Data Coordinating Center has been funded and is responsible for both CPEA and STAART networks. The purpose of this is to ensure that common measures are used across networks so that data can be combined as often as possible. Each network organizes a number of cross-site studies. In addition, scientists from both networks have combined annual meetings to share pre-published data to facilitate the advance of science. The newly initiated International Meeting for Autism Research (IMFAR) and the International Society for Autism Research (INSAR) will also greatly facilitate the rapid sharing of autism research findings. This is the first autism dedicated research meeting. Because researchers are from many different disciplines, they have rarely assembled at a common meeting. Hence this is a major advance for research.

b. CPEA Centers funded by NICHD and NIDCD.

It was established in 1997 and consists of nine CPEA sites:

- Baylor University
- Boston University
- University of California, Davis
- University of California, Los Angeles
- University of Pittsburgh-Carnegie Mellon University-University of Illinois
- University of Rochester
- University of Utah
- University of Washington
- Yale Child Study Center

These are the main sites. Each main site typically has a number of collaborating sites that may be local or in other states. (The principle of the CPEAs was that because there were so few senior scientists in autism they would be used to found centers and draw senior scientists in from other fields.) This was highly successful and the initial CPEA network brought 50-60 scientists into autism. This became the model for the STAART centers.

c. The STAART Centers are funded by the NIH Autism Interagency Coordinating Committee (NIH/IACC), which coordinates autism research conducted by its five member Institutes:

- National Institute of Mental Health (NIMH),
- National Institute of Child Health and Human Development (NICHD),
- National Institute of Neurological Disorders and Stroke (NINDS),
- National Institute on Deafness and Other Communication Disorders (NIDCD), and
- National Institute of Environmental Health Sciences (NIEHS)

The STAART sites include:

- Boston University
- Kennedy Krieger Institute
- Mt. Sinai Medical School
- University of California, Los Angeles
- University of North Carolina
- University of Rochester
- University of Washington

5. CDC (Center for Disease Control and Prevention) research programs

The Children's Health Act of 2000 directed the CDC to establish regional centers of excellence for autism spectrum disorders (ASDs) and other developmental disabilities to investigate the prevalence and possible causes.

a. ADDM

CDC funds ten ADDM (Autism and Developmental Disability Monitoring) Network **(3)** projects. These projects are developing or improving programs to track the number of children with ASDs in their states. The goal of the ADDM Network is to provide comparable, population-based estimates of the prevalence rates of autism and related disorders in different sites over time. The ADDM Network Programs include Alabama, Arizona, Arkansas, Florida, Missouri/Illinois, New Jersey, South Carolina, Utah, West Virginia, and Wisconsin.

b. CADDRE

CDC funds six Centers for Autism and Developmental Disabilities Research and Epidemiology (CADDRE) **(4)** in California, Colorado, Maryland/Delaware, North Carolina, **Pennsylvania** and Georgia. The Children's Health Act of 2000 directed CDC to establish regional centers of excellence for ASD and other developmental disabilities. The centers will work with the ADDM Network to monitor the number of children with ASDs and other developmental disabilities. Other goals of the centers include improving community and service provider awareness of ASDs and other developmental disabilities, improving access of children with ASDs and other developmental disabilities to comprehensive, community-based, family-centered care. The mission of the CADDRE centers is to conduct epidemiologic research related to ASDs and other developmental disabilities. These studies will address topics such as what factors (genetic, environment, and others) make it more likely that a child will have an ASD, what other disabilities children with ASDs have, biomarkers, and the economic costs of ASDs.

The University of Pennsylvania/The Children's Hospital of Philadelphia Center for Autism and Developmental Disabilities Epidemiology is the CADDRE program studying ASDs in Pennsylvania. The

Pennsylvania counties in the project are Chester, Montgomery, and Philadelphia. The Pennsylvania center is involved in surveillance and a case-cohort study of etiology and other environmental factors.

6. NIEHS (National Institute of Environmental Health Sciences) funded autism centers to investigate environmental influences on the development of autism:

a. University of California, Davis

Center for Children's Environmental Health and Disease Prevention is a multi-disciplinary collaborative research organization to examine how toxic chemicals may influence the development of autism in children. The center supports and coordinates the efforts of projects in epidemiology, social behavior, and molecular biology **(5)** including:

1. CHARGE Study (Childhood Autism Risks from Genetics and the Environment) – is a case-control study of 2000 children with differing patterns of development (autism, developmental delay or mental retardation and typically developing children)
2. Animal models are being developed and utilized to determine how early postnatal or perinatal exposure to known immunotoxicants and neurotoxicants influences the development of autism.

b. University of Medicine and Dentistry of New Jersey

The Center for Childhood Neurotoxicology and Exposure Assessment **(6)** . This center is jointly sponsored by Rutger's University and UMDNJ-Robert Wood Johnson Medical School. The goal of the Center is to determine the influences of environmental exposure to neurotoxicants on child neurological health and development of special emphasis on autism and related disabilities. Essential partners are COSAC, Eden Institute of Princeton, NJ, and the Douglass Developmental Disabilities Center of Rutgers University.

7. RUPP (Research Units on Pediatric Psychopharmacology)

The RUPP Autism Network is a series of centers funded through the NIMH and NCRR (National Center for Research Resources) at the NIH. The network includes University of California at Los Angeles, Ohio State University, Indiana University, Yale University, Kennedy Krieger Institute at Johns Hopkins University, NIH, and Columbia University. They have collaborated on a series of studies, which included a landmark study published in August 2002 in NEJM about Risperidone treatment of children with autism and severe behavior difficulties. There are little data on the treatment of children with ASD with medications. Most drugs are off label treatment in that drugs are approved for use in adults and used in children but no data have been generated by the drug company documenting their efficacy or demonstrating side effect profiles in children. Congress has recently passed a law requiring drug companies to provide such data (ref).

8. RO-1s are individual projects.

These are individual projects in contrast to program projects and center grants which consist of multiple projects around a common theme. This category also includes small business technology transfer grants.

9. K-awards are training grants for junior scientists.

These grants are awarded to individuals who have proposed meritorious research projects and a plan of research training under one or more mentors who supervise their training and development of research skills.

10. Training grants: pre-doctoral and post-doctoral grants.

These grants provide fellowships for individuals at various stages in their graduate studies to do advanced training.

11. R-21, R-28 grants are pilot studies to investigate the potential merit of an idea, typically of drugs.

B. Funding of autism research within the state of Pennsylvania includes (NOTE: currently no centralized listing of all sites exists):

1. University of Pittsburgh

a. University of Pittsburgh-Carnegie Mellon University-University of Illinois CPEA
Director: Dr. Nancy Minshew

This center investigates the cognitive and neural basis of information processing in autism as well as its genetics. It is composed of four individual projects. The first focuses on formation of abstract concepts and face identification. The second investigates perception of details relative to the whole and how this impacts on face identification. The third project studies language and abstract reasoning to determine how the brain is functioning in autism to perform these tasks and to assess connectivity between brain regions. The fourth project investigates how the brain processes and transfers information during simple and complex eye movement tasks. Studies of theory of mind social tasks and genetic studies are also being conducted.

Participants are: high functioning verbal individuals between 8 and 55 years of age, relatives between 10 and 50 of autistic individuals of any ability level, families with two children with ASD over the age of 2.5 years, fraternal or identical twins, and infant siblings of children with autism. Typically developing individuals are also needed for comparison.

The website for the CPEA is http://www.pittautismresearch.org/

The CPEA has also obtained funding from other sources, including an award from the Health Resources and Services Administration.

Nancy J. Minshew, M.D. "Pennsylvania Mobilization for Autism Equipment Request", HRSA Grant #1C76HF01121-01-00

ABSTRACT

The applicant for this project is the Center for Excellence in Autism Research at the University of Pittsburgh School of Medicine, Nancy J. Minshew, M.D., Director and Principal Investigator. Autism is a behaviorally defined neurodevelopmental disorder that impairs social and adaptive functioning. It is a significant social problem that places demands on the health, education, and public welfare systems. The Center for Excellence in Autism Research is engaged in a number of large research projects to delineate the neurological and genetic bases of autism. Five of these projects are participants in this request. The request is an "equipment only" request to fund a number of costly pieces of technical equipment that are needed to support the advanced neuroimaging techniques being used in these projects and to enhance data collection, analysis, and dissemination. The purchase of this equipment is scheduled to begin as soon as funding is received, requested for August 15, 2003, and will continue until all the equipment is obtained. The equipment will be immediately incorporated into the ongoing research efforts. The research projects of the Center for Excellence in Autism Research are designed to provide some of the critical information needed to advance the understanding of autism. The obtained knowledge will ultimately be translated into preventative, diagnostic, and treatment procedures for individuals with autism.

b. K-awards

Beatriz Luna, Ph.D., Department of Psychiatry, Laboratory of Neurocognitive Development, Pittsburgh Pa 15260

http://www.wpic.pitt.edu/research/Lncd/

NIMH grant # MH001727, "Brain and Cognitive Maturation-- 8-17 Years of Age"

ABSTRACT

The aim of this career development plan is for the applicant to acquire the skills necessary to characterize changes in brain function subserving the acquisition of higher-order executive cognitive functions during late childhood and adolescence. This period is the time when higher-order cognitive abilities such as abstract thought, goal directed planning, and voluntary inhibitory control begin to achieve adult levels concurrently with significant reorganization of neural connectivity in neocortex. These higher level cognitive skills fail to develop normally in several major psychiatric disorders of presumed neurodevelopmental origin. These crucial cognitive and brain maturational processes during late childhood and adolescence are very poorly understood, and the field needs broadly trained developmental investigators to begin comprehensive and programmatic studies of this important epoch. In order to establish a research career dedicated to elucidating the neural substrates of normal and abnormal cognitive development, the applicant will obtain additional training in: 1) cognitive and other developmental processes pertinent to the time period of interest, 2) skills in designing and implementing a broader ranger of cognitive and imaging methodologies sensitive to developmental changes during this period, and 3) clinical aspects of neuropsychiatric disorders with a neurodevelopmental changes during this period, and 4) clinical aspects of neuropsychiatric disorders with a neurodevelopmental basis. She will also initiate a series of studies to examine patterns of development in cognition and brain organization using tasks that probe spatial working memory, voluntary response suppression and attention shifting abilities both behaviorally and using fMRI. Studies at the end of the research program will begin to investigate abnormal development in autism and individuals at familial risk for schizophrenia. To the extent that the proposed research program can elucidate the developmental trajectories of pivotal executive functions, the proposed line of work can potentially provide crucial information needed for designing more effective programs for the early recognition, treatment, and prevention of psychopathology.

Antonio Hardan, M.D., Department of Psychiatry, University of Pittsburgh, Pittsburgh, Pa 15260.

NIMH Grant # 5K23MH064027 "Neuroimaging/Developmental Neurobiology of Autism"

ABSTRACT

The career development and research plans outlined in this Mentored Patient-Oriented Research Career Development Award application are designed to enable the candidate to independently design and conduct neuroimaging studies investigating the neurobiology of autism by examining increased brain size and the involvement of the cerebelo-thalamo-frontal circuit in the pathophysiology of this neurodevelopment disorder. Autism is a severe disorder characterized by marked social and communication deficits, restricted and stereotyped patterns of behaviors and interests. A wide range of abnormalities has been reported and studies of brain structure have implicated several aspects of brain development involved in neuronal organization including the elaboration of dendritic and axonal ramifications, the establishments of synaptic connection, and cell death. Recent neuropathologic and neuroimaging studies have reported increased brain size in autism, and evidence supporting the underdevelopment of the circuitry of neural networks that involve cerebral cortex, limbic system and cerebellum. The proposed longitudinal study will use the combination of volumetric measurements obtained from magnetic resonance imaging scans and chemical shift imaging proton spectroscopy obtained at 30 months intervals from a group of children with autism (8-12 years of age) and individually-matched controls to characterize the developmental changes of brain enlargement, and the involvement of the cerebello-thalamo-frontal circuit in autism. It will also provide the candidate with the experience necessary to apply advanced neuroimaging techniques and a solid foundation from which to conduct longitudinal studies investigating the developmental neurobiology of autism and possibly identifying clinical, prognostic and therapeutic correlates. The candidate is certified in psychiatry, and child and adolescent psychiatry with four years of post-graduate clinical experience. Drs. Nancy Minshew and Matcheri Keshavan will serve as preceptors. Course work and directed reading in

biostatistcs, data management, research ethics, neuroanatorny, neuroimaging and developmental neuroscience will complement the research training.

Diane L. Williams, Ph.D., Department of Psychiatry, University of Pittsburgh, Pittsburgh, PA 15260

K23 DC 6691-01, "Neurocognitive Basis of Language Processing in Autism"

ABSTRACT

This Mentored Patient-Oriented Research Career Award (K23) will provide specialized training in the skills necessary to conduct research on the neurobiologic bases of language processing in autism. The candidate's long term objectives are: 1) To engage in research that will elucidate the neurobiologic and neurodevelopmental mechanisms underlying language processing problems in developmental disabilities particularly autism; 2) To develop an innovative model of language processing in autism based on neurophysiological and behavioral data; and, 3) To develop and evaluate therapeutic intervention for individuals with autism based on the model of language processing. The specific aims are: 1) To investigate the comprehension of complex linguistic concepts by high-functioning individuals with autism; 2) To characterize the functional and anatomical brain systems underlying processing of complex linguistic concepts in high-functioning individuals with autism; and, 3) To characterize the functional and anatomical brain systems underlying processing of mentalizing in this population. The candidate's first proposed studies will examine the comprehension of ironic and metaphoric language and theory of mind in 30 older adolescents and adults with high-functioning autism as compared to 30 matched typical controls. The data from the behavioral studies will be integrated with data from planned fMRI studies conducted under the direction of the mentor. The hope is that clearer understanding of the underlying neural mechanisms will guide the development of more efficient and effective therapeutic intervention, affecting positive change in the linguistic processing and adaptive functioning of individuals with autism. The candidate holds a doctorate in speech-language pathology and has extensive clinical experience with individuals with autism and two years of post-doctoral research training. Dr. Marcel Just, Carnegie Mellon University, a pioneer in the use of functional magnetic resonance imaging for the investigation of cognitive processing, and Dr. Nancy Minshew, University of Pittsburgh, Director of an NICHD Collaborative Program of Excellence in Autism and a nationally and internationally recognized expert in autism, will serve as mentors. Training will include coursework and directed readings in language in autism, right hemispheric language functions, neuroimaging, and modeling of cognitive processes with rotations at neuroimaging laboratories at Carnegie Mellon University, the University of Pittsburgh, University of California, Los Angeles, and Boston University.

c. R-21 awards

Benjamin Handen, PhD, Department of Psychiatry, University of Pittsburgh, Pittsburgh PA 15260

NIMH Grant # 5R21MH064941,"Donepezil HCL: Treating Cognitive Deficit in Autism"

ABSTRACT

Children with autism spectrum disorders (ASD) are characterized by deficits in social interaction, impaired communication, and repetitive and stereotyped patterns of behavior, interests, and activities (APA, 1994). Interest in the amelioration of some of the core and secondary features of ASD has led the use of a wide range of pharmacological interventions, with inattention and overactivity, ritualistic behavior, self-injury and agitation/aggression among the most frequently targeted symptoms. Recent survey data indicates that up to 34 percent of individuals with ASD are prescribed medication and/or vitamins for control of a wide range of behaviors (Aman et al., 1995). While most pharmacological research to date has attempted to treat many of the behavioral deficits commonly associated with ASD, few pharmacological studies have attempted to ameliorate the core features of this disorder (an area of particular interest for this RFA). Donepezil HC1, a cholinesterase inhibitor which increases brain levels of acetylcholine, is purported to

enhance cognitive functioning in a range of disorders, including multiple sclerosis, Alzheimer's disorder, and ADHD. A recent open-label study of the safety and efficacy of donepezil HC1 in 25 boys with ASD found significantly increased speech production and a statistical trend toward improvement in core symptoms of ASD (Chez et al., 2000). The present application will provide an opportunity to conduct further pilot testing of the tolerability, safety and effect of donepezil HCl on the cognitive deficits presumed to underlie the core features of ASD. Forty children and adolescents with ASD will be recruited to participate in a 10-week, double blind, placebo-controlled parallel groups study of donepezil HC1. This feasibility study is designed to provide documentation of medication-enhanced cognitive functioning in ASD using a 5mg and 10 mg/day donepezil HC1 dose. This study will also examine the side effects profile of donepezil HC1 in children with ASD, explore possible correlates of treatment response, and provide an opportunity to obtain initial pilot data to determine the sample size needed to conduct a full-scale intervention trial.

d. NAAR Funding:

Dr. Jana Iverson, Director of the Infant Communication Lab at the University of Pittsburgh, Department of Psychology, Pittsburgh, PA 15260.

NAAR Grant: "Early Identification of Autism: A Prospective Study"

ABSTRACT

This pilot study will provide preliminary data on infant behaviors that may signal an eventual diagnosis of Autism Spectrum Disorder (ASD). Our focus is on infant movement, vocalization, gesture, and early speech patterns in 20 later-born infant siblings of children already diagnosed with Autism. This group has been chosen because they are known to be at heightened risk for ASD. The study gathers data on variations in the frequency of occurrence, delays in development, and atypical forms of vocal, motor, and communicative behaviors in the hope that they may distinguish infants eventually diagnosed with ASD from those with no such diagnosis. Children will be followed longitudinally from age 5 to 14 months, with a follow-up visit at 18 months. Vocalizations, rhythmic movements such as banging and shaking, vocal-motor coordinations, and postural adjustments will be observed in 45-minute monthly videotaped home observations in naturalistic and semistructured play contexts. Parent report data will be obtained on the development of early vocal and motor milestones (e.g., babbling, standing), vocalizations, specific gross and fine motor, oral-motor, communicative, and language behaviors. From 8 months on, the abridged Early Social Communication Scales (Mundy, Hogan, & Doehring, 1996), which focuses on individual differences in nonverbal communication skills such as joint attention, requesting, and social interaction, will be administered at each session; and at the 18-month follow-up visit, parents will complete a widely used screening measure, the Pervasive Developmental Disorder Screening Tool-II (Siegel, 2001).

NAAR Mentor-Based Fellowship: Drs. Beatriz Luna and K. Suzanne Scherf, University of Pittsburgh, Department of Psychology, Pittsburgh, PA 15260

NAAR Grant: The Emergence of Object-Processing Deficits in Autism: A Brain Based Investigation

ABSTRACT

Although poor face recognition is a common feature of autism, very little is known about the development of face recognition skills in autistic children as they progress through childhood and adolescence. Healthy children seem to make an important transition in their ability to integrate information about face features (e.g. eyes, mouth, nose) and analyze differences in feature arrangements during adolescence (e.g. distance between eyes, nose, mouth). This allows them to make more difficult discriminations between very similar-looking individuals. No research has addressed whether autistic adolescents make this same transition. Furthermore, the existing research has tried to understand face recognition deficits by evaluating impaired responses to faces, which carry an enormous amount of social and emotional information that is difficult for autistic individuals to process. This study will evaluate the extent to which

visual perception deficits contribute to the development of poor face recognition skills in autistic children, adolescents, and young adults.

We will study developmental limitations in autistic individuals' abilities to 1) detect features in Greebles, novel space-creature looking objects that are devoid of emotional or social information, and 2) learn to integrate the features to analyze differences in their arrangement. This strategy will simulate the process of learning faces for the first time and will allow us to isolate the visual perceptual contributions to face recognition deficits in autism. We will evaluate how limitations in the use of these perceptual processes relate to existing face-recognition skills. Because we know that abnormal connectivity among distant brain regions contributes to deficits in higher-order cognition in autism, we will investigate the brain basis of the development of these perceptual processes as well. We hypothesize that autistic adolescents will fail to make the transition that healthy adolescents make in learning to integrate the novel object features and analyze differences in their arrangement. We hypothesize that autistic adolescents will fail to reach mature levels of object recognition because of a failure to develop efficient connections between important object-processing parts of the brain during adolescence.

This work is important because it will isolate the contribution of visual perception deficits to impaired face recognition in autism. As a result, it can inform behavioral and medical intervention therapies by understanding which processes need to be rehabilitated in order to help autistic individuals improve their face recognition skills.

Cibu P. Thomas and Marlene Behrmann, Ph. D., Carnegie Mellon University, Department of Psychology, Pittsburgh, PA 15213

NAAR Grant: "Integration of information and functional brain connectivity in autism"

ABSTRACT

One of the classical characteristics of autistic individuals is the marked inflexibility in their behavior and interests along with the tendency to focus on the details (local processing) present in the input rather than on the whole (global processing). The goal of the proposed research project is to establish a deeper understanding of the fundamental nature of central coherence in individuals with autism in the visual perceptual domain. To this end, we will employ two experimental paradigms, each thought to require a slightly different form of perceptual organization and integration, with one requiring more local connectivity and the other dependent on top-down or longer range connectivity. Both paradigms will be explored using a combination of behavioral and functional imaging methods and comparisons will be made to the psychological and neural signatures of normal individuals. The behavioral experiments will focus on examining the evolution of the underlying processes involved in integration of local visual information in order to achieve global coherence. The functional imaging studies, on the other hand, will focus on identifying the neural correlates for global and local visual processing. To complete the analysis, we will use a relatively new technology called diffusion tensor imaging (DTI) to perform a fine-grained analysis of the irregularities in white matter volume that individuals with autism are known to have. DTI will help us verify if there is a link between impairments in the global processing abilities of autistic individual and abnormalities in their white matter structures. The multi-pronged approach will help forge a firm understanding of the nature of visual information processing in individuals with autism and its underlying neural substrate.

Drs. Kate Humphreys and Marlene Behrmann, Carnegie Mellon University, Department of Psychology, Pittsburgh, PA 15213

NAAR Grant: Face processing in Autism: An Investigation at Multiple Levels

ABSTRACT

The goal of this study is to explore the cognitive and neural basis of face processing difficulties in people with Autism Spectrum Disorder (ASD), and the visual perceptual deficits which may underlie them. Two

major methods will be employed: behavioral studies with people with autism and normal non-neurological control participants, and functional neuroimaging methods with these same participants. The behavioral method involves detailed documentation of performance on a range of demanding face discrimination and recognition tasks. This will be compared with performance with non-face control stimuli (familiar and novel objects). Both reaction time and accuracy measures will be taken. Perceptual deficits will also be examined in a series of tasks investigating local and global processing, contour interpolation and spatial frequency analysis. Correlations will be performed between the data from the face processing and mid-level vision tasks to investigate links between the two. The functional neuroimaging experiments will employ BOLD contrast fMRI to examine neural mechanisms underlying face and perceptual processing in normal and autistic participants. Participants will perform experiments in the MRI scanner and we will obtain behavioral data as well as measures of cortical activation in tasks that require face perception, or tasks such as forming global gestalts from local elements. These studies will provide insight into how faces are represented in the brains of people with autism, and how this relates to lower level visual processes. Correlational analyses will be performed between the data from behavioral and neural studies, and from experiments concerning face and object processing and visual perceptual deficits for each individual participant, to forge links between the different levels of investigation. By adopting this close integration of data across multiple levels of analyses, we hope to shed light on the nature and cause of the difficulties in face processing in this disorder, thus paving the way for the design of maximally effective interventions.

Holly Gastgeb and Mark Strauss, Ph.D, University of Pittsburgh, Department of Psychology, Pittsburgh, PA 15260

NAAR Grant: "Concept Abstraction and Face Recognition in Individuals with Autism"

ABSTRACT

One of the most basic cognitive processes demonstrated by both children and adults is the ability to form categories. Generally, categorization is the ability to recognize that discriminably different exemplars have common features that allow them to be grouped together. By grouping items into common categories we can significantly reduce memory demand, identify novel objects, and, indeed, improve memory for specific items. More generally, categorization allows us to organize or make sense of our experiences and world around us. It is such a critical and basic ability that it begins to develop in the first year of life, and allows infants to discriminate male from female faces, recognize people, and identify basic objects prior to knowing verbal labels.

As will be discussed in the background section, there is research from both our lab and others to suggest that individuals who have autism have limited categorization abilities and process this information in an atypical manner. Indeed, Temple Grandin (2000) in describing her knowledge of categories has discussed that she does not have a generalized notion of even simple categories such as dogs and cats. Rather, she must think of specific examples. Unlike typically developing infants and children, she never learned to abstract prototypic representations of categories. Rather, she had to focus on particular details such as the shape of dog noses and the fact that cats have retractable claws.

Our research proposes that while higher functioning autistic individuals have developed compensatory mechanisms that allow them to categorize based on simple distinctive features, they are unable to abstract higher level conceptual information such as a prototypes, and that they do not have normal typicality structures. These deficits will affect their abilities in several domains including their ability to form object categories and their knowledge of facial information.

e. CAN Funding

Young Investigator Award: Dr. Rajesh Kana Kumar, Carnegie Mellon University, Department of Psychology, Pittsburgh, PA 15213

Neural Bases of Visuospatial Processing in High Functioning Autism

ABSTRACT

A comprehensive theory of autism must account for the areas of unimpaired functioning as well as the impairments. Individuals with high functioning autism sometimes have intact visuospatial ability, which often contrasts with their impaired language ability, especially pragmatic skills. The aim of the proposed research is to investigate the neural bases of visuospatial information processing in high-functioning individuals with autism using functional magnetic resonance imaging. At the neurological level, the processing of complex information is accomplished by coordination and communication among brain regions. Therefore, a second aim is to determine the functional connectivity among brain regions during the performance of complex tasks involving visuospatial information processing. This research is based on the assumption that simultaneously investigating domains in which individuals with autism are intact and impaired can be more revealing with respect to neurological functioning than solely focusing on areas in which individuals with autism perform more poorly than individuals with typical development.

2. Magee-Womens Research Institute

Dr. Laura Hewitson, Director for the Division of Pediatric Development, Pittsburgh Development Center (PDC) of Magee Women's Research Institute http://www.pdc.magee.edu

NAAR Grant: "Autism Models in Transgenic Primates: Molecular Mechanisms Investigated by Functional Brain Imaging and Behavior."

ABSTRACT

Autism is a complex developmental disability that affects an individual in the areas of social interaction and communication. There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. A number of genes that may interfere with brain development are being examined as possible autism-susceptibility genes but no one gene is favored as a potential candidate. This proposal examines the use of non-human primates, with genetically modified target genes, through innovative RNA siliencing knockdown, transgenic overexpression, alterations in genomic imprints and conventional knock-out technologies. In so doing, our internationally unique research team will determine structural and biochemical changes in the brain with characteristic behavior associated with autism. Three aims are proposed: 1) To develop a non-human primate knockout for autism; 2) To assess developmental and behavioral characteristics in knockout and control rhesus animals, and 3) To image structural and biochemical differences in the brains of knockout and control animals by MRI and microPET. Rhesus macaques exhibit very complex social behavior that has been well characterized over the last three decades in thousands of animals. Developmental milestones can be easily scored using a battery of tests to measure: (i) anthropometric data, (ii) diurnal cyclicity, (iii) neuromotor milestones, iv) object permanence concept, (v) visual acuity, (vi) recognition memory, (vii) learning-concept formation, (viii) temperament, (ix) home cage behavior, (x) behavior, (xi) immune system development and (xii) computer learning. Subtle deviances in non-human primate assessment tests manifest themselves in animals exhibiting certain characteristics of autism spectrum disorders (ASD). These animals will undergo rigorous and responsible neuroimaging to assess structural and biochemical changes in the developing brain. One of the advantages of this powerful approach is that we can non-invasively image the infant brain at an early age when changes in behavior may not yet be apparent. This provides an unusual opportunity to monitor the time-course of structural or biochemical impairments in non-human primate infants. MRI and PET imaging will be performed on animals up to two years of age at which point, behaviors consistent with ASD should have been identified. Non-invasive, functional neuroimaging also allows serial and longitudinal studies to be performed in the same animal enabling us to follow single animals over time and to monitor the effects of interventions on the animal's progression and outcome.

3. University of Pennsylvania

a. PA-CADDRE(7) (Center for Autism and Developmental Disabilities Research and Epidemiology)

This is a center which is a collaborative effort of investigators from the following academic and clinical services: the University of Pennsylvania's Schools of Nursing and Medicine, UPENN Center for Mental Health Policy and Services Research, The Children's Hospital of Philadelphia (CHOP) Regional Autism Center, the CHOP Divisions of Developmental and Behavioral Pediatrics and Biostatistics and Epidemiology, and the CHOP Children's Clinical Research Institute. The specific aims of PA-CADDRE are to:

1. Monitoring Activities

It is not currently known how many children living in Pennsylvania have an ASD. During the period 1992 through 2001, the number of children served in Pennsylvania under the Individuals with Disabilities Education Act (IDEA) increased 855%. IDEA is the federal law that supports special education and related services for children and youth with disabilities. In the three counties in this project during the 2000–2001 school year, over 2,350 children ages 3–5 years received special education services, and 613 of these children had autism classifications. Of the 10,449 children aged 6–9 years who received special education services, 430 were classified as having autism. There are, however, additional children with ASDs who are in other types of special education classes, who are in regular education classes, who attend private school, or who are home schooled.

The Pennsylvania center will use multiple sources to obtain a more complete estimate of the number of children in the project area with an ASD. The center will study whether ASDs are more common in some groups of children than in others. The center will also study whether the number of children with ASDs is changing over time. The monitoring will focus on children 8 years of age in Philadelphia County.

2. National CDDRE Study (NCS)

The Pennsylvania center will work with the other CADDRE programs to find causes of ASDs or factors that make it more likely that a child will have an ASD. Families who take part in the study will answer survey questions; children with ASDs will be tested, and staff will look at children's birth records. Children aged 3-5 years will be included in the combined centers study. Children with ASDs will be compared with children who do not have an ASD. Data will be pooled and managed by the Data Coordinating Center, which is located at Michigan State University.

3. Special Studies

The Pennsylvania center is also interested in screening children at an early age for signs of an ASD. The early projects are focusing on educating medical caregivers in strategies for universal implementation of screening toddlers aged 18-24 months for early signs of ASDs. After a child is diagnosed as having an ASD, the Pennsylvania center will study ways to help parents manage the issues that arise as they seek medical and other treatments as well as educational and other services for their child.

4. Sharing Information and Community Outreach

The Pennsylvania center plans to train nurses, physicians, educators, and other providers of health and educational services to screen children for signs of a DD and ASDs. Information will be shared through mailings to parents and support groups, and the media, and through scientific publications, and presentations to teachers, clinicians, and other professionals.

b. RO-1:

Maja Bucan, Ph.D Department of Genetics and Center for Neurobiology and Behavior of the Department of Psychiatry, University of Pennsylvania, Philadelphia, PA 19104

http://www.med.upenn.edu/ins/faculty/bucan.htm

RO1AR45325/MH57855 "Genetics of rest: activity behavior in mice" RO1-HD-28410-10 "Functional maps of a segment of Mouse Chromosome 5".

ABSTRACT

Genes involved in neuropsychiatric disorders are difficult to identify and a novel approach to elucidation of pathways underling these disorders involves analysis of intermediate phenotypes or endophenotypes. These physiological, biochemical anatomical or behavioral traits represent risk factors that are more common than fully expressed clinical syndrome and therefore may be closer to the molecular origin of the disease. Our laboratory is using ENU mutagenesis to identify mouse mutations in corresponding traits. Genes that underlie these traits can serve as candidate genes for complex neuropsychiatric disorders (bipolar disorder, schizophrenia and autism). A dominant and region-specific ENU screen identified several rest:activity mutations which are currently in different stages of positional cloning and phenotypic characterization. One of these mutations, called earlybird, represents a dominant-negative allele of Rab 3A, a small GTP-ase involved in neurotransmitter release. We showed a significant difference in molecular and behavioral phenotypes between this dominant negative and a previously described loss-of-function mutant. Our finding that a gene involved in synaptic transmission and with wide spread expression throughout the brain causes a set of rest:activity and other behavioral anomalies including anomalies in social interactions lead us to prioritize genetic/genomic characterization of a large set of genes involved synaptic function and synaptogenesis and examine their relevance to human disease.

Peter Crino, MD PhD Department of Neurology, University of Pennsylvania School of Medicine, Philadelphia, PA 19104

NIMH Grant #5K08MH001658-05, "Developmental Pathogenesis of Human Cortical Dysplasia"

ABSTRACT

Human focal cortical dysplasia (FCD) is a developmental brain malformation characterized histologically by disorganized cerebral cortical cytoarchitecture and lamination. FCD is associated with several mental disorders including mental retardation (MR) and **autism**. FCD likely results from abnormal neuronal migration during corticoneogenesis although the molecular events that culminate in aberrant cortical lamination are unknown. Previous work has suggested that FCD neurons may have failed to terminally differentiate prior to migration since these cells express proteins, such as the intermediate filament nestin, that are typically identified in immature neuronal precursor cells. These, dysplastic neurons may not express other developmentally appropriate genes necessary to complete migration and lamination. This proposal will describe three approaches to study the developmental and molecular pathogenesis of FCD. First, expression of transcription factors, neurotrophic factors/receptors and cell adhesion molecules mRNAs will be assayed in single nestin- or MAP1B-immunolabeled cells in human FCD specimens and compared with normal cortical neurons, and neuronal precursors in the ventricular zone. Because expression of these candidate genes varies during early development and because they have been implicated in corticogenesis, coordinate change in their relative abundance will provide insights into molecular pathways altered in FCD. Second, developmentally inappropriate genes such as s nestin or MAP1B will be overexpressed in cortical slice cultures and effects on migration will be assayed. Finally, dynamic changes in gene expression will be assayed in actively migrating neurons in animal models of FCD including administration of exogenous neurotrophins or antisense oligonucleotides. It is anticipated that these studies will provide for the first time a view of altered gene expression in FCD, which will shed light on the pathogenesis of these lesions. Furthermore, in identifying alterations in specific genes, the relationship between FCD and mental disorders can be rendered. These analyses may point toward new avenues for therapy.

Peter Crino, MD PhD Department of Neurology, University of Pennsylvania School of Medicine, Philadelphia, PA 19104

NINDS Grant #5R21NSo39938-03 , "Gene Expression and Clonality in Dysplastic Cortical NEU"

ABSTRACT

Focal regions of disorganized cortical lamination and abnormal neuronal cytoarchitecture (focal cortical dysplasia, FCD) are in utero developmental brain malformations that have been identified in many neuropsychiatric disorders including mental retardation syndromes (MR), autism, and epilepsy. FCD likely results from abnormal neural migration during corticogenesis although the molecular events leading to aberrant cortical lamination in these divergent conditions are unknown. The major difficulty in addressing the molecular pathogenesis of FCD is that many epilepsy and mental retardation syndromes are of unclear inheritance pattern rendering a genetic or pedigree analysis complicated. Thus, novel strategies must be implemented to address two compelling questions regarding the pathogenesis of FCD: 1) what is the phenotype of dysplastic cells and 2) what mechanisms are responsible for disorganized cortical lamination during corticogenesis. Answers to these questions will shed light on the practical question of how altered laminar and cellular cytoarchitecture in FCD contributes to the neurological manifestations such as seizures, MR, and behavioral abnormalities in such a wide variety of neurological disorders. Three sets of experiments will investigate the phenotype of dysplastic cells in human FCD specimens and assess the expression of developmentally regulated genes necessary for cortical lamination in an experimental model of FCD. Because of the heterogeneous cell types within FCD, a central feature of the proposed experiments is the use of single cell mRNA amplification technology. This novel approach permits quantification of mRNA abundance in individual immunolabeled or live neurons that are of similar or distinct phenotype. Analysis of human FCD specimens will provide a direct avenue to investigate the developmental phenotype of FCD neurons. The model FCD system will permit assessment of gene regulation during the dynamic phases of cortical migration. The overall objective of the proposal is to determine the molecular pathways that lead to disorganized cortical cytoarchitecture in FCD. Furthermore, by identifying altered expression of select genes, the relationship between FCD and various mental disorders can be discerned. These analyses may point toward new avenues for therapy.

4. Drexel University College of Medicine (Philadelphia)

Drexel University has developed a center involving child psychiatry and neurology to study treatments in autism. Few treatments are well studied in autism, especially considering the fairly common practice of treating these children with drugs. Funding for this center includes grants from the federal government.

FDAOPD Study (FD-R-002190-01), "A Controlled Study of Olanzapine in Children with Autism."

ABSTRACT

The purpose of the proposed study is to investigate the efficacy and safety of a treatment, olanzapine, in a rare condition, autism. Olanzapine is an atypical antipsychotic that is on the market and approved for the treatment of schizophrenia and bipolar mania in adults. It is not approved for the treatment of autism or for use in children. There is no drug approved for the treatment of autistic disorder and no established drug treatment for autistic disorder. Other antipsychotics, including haloperidol and to a lesser degree risperidone, have some efficacy but cause tardive dyskinesia and hyperprolactinemia - two significant safety risks. Olanzapine has advantages over these agents in that it does not seem to cause extrapyramidal symptoms, including tardive dyskinesia, and does not cause sustained hyperprolactinemia. Olanzapine also has little effect on the QTc, an electrocardiogram indice that is affected by a newer antipsychotic, ziprasidone. Our preliminary studies indicate that olanzapine shows promise as a treatment for decreasing behavioral symptoms in autistic disorder. A well-designed placebo-controlled study of olanzapine is now required to establish an optimal dosing range, and to critically assess the common short-term side effects and efficacy of olanzapine for the treatment of children with autism.

The subjects for this study will be 40 children, aged 4 to 12, diagnosed with autistic disorder. Multiple measures and raters will be employed. Following a baseline assessment, subjects will be randomized under double-blind conditions to 6 weeks of treatment with olanzapine or placebo. Primary analyses will focus on the efficacy and safety of olanzapine relative to placebo in autistic disorder.

There are also a number of other studies funded by investigator-initiated industry funding.

5. Pennsylvania State University

Richard M. Kubina, Jr., Assistant Professor of Special Education, Penn State University and Robert Stromer, Associate Professor, University of Massachusetts Medical School

"Organization for Autism Research (OAR) grant, "Fluency Research for Children with Autism."(8)

ABSTRACT

Fluency, or behavioral fluency, refers to the ability to competently perform a behavior with high degrees of accuracy and speed. Critical learning outcomes associated with fluency are long term "retention" of the behavior after terminating practice, including "Endurance," or the ability to perform a behavior at a steady pace and in the face of environmental distraction and "application" or the integration of one "element" or "component" behavior to a "compound" or "composite" behavior. Experimentally investigating fluency and its related outcomes for children with autism provides answers to longstanding problems with learning. One common learning difficulty children with autism exhibit is lack of "maintenance" or the ability to perform an acquired behavior over a long period of time. Fluency research demonstrates that individuals can maintain long term retention of acquired information. Fluency research for children with autism sets out the potential for new procedures for intervention planning and treatment.

6. Jefferson Medical College, Geisinger Health System:

Project Director: Walter F. Stewart, PhD. Co-investigators: Scott M. Myers, MD, Thomas D. Challman, MD.

Health Resources & Service Administration, Maternal and Child Health Bureau
Grant Number 1H61MC01675-01-00. "Early detection and intervention for children with autism spectrum disorders."

ABSTRACT

Organization Setting. Geisinger Health System is a comprehensive health care provider for patients who reside in predominantly rural areas in central and northeastern Pennsylvania. Geisinger is a national leader in the use of information technology (IT). Geisinger has implemented the Electronic Medical Record so that patient information is available at all outpatient locations in real-time. Patients have secure web-based access to their medical records and secure e-mail to their doctor. External physicians receive similar access to their patients' record. In addition, our electronic infrastructure allows outcomes monitoring at all of its disparate healthcare delivery sites and provides for continuous improvement in best practices.

Purpose. The purpose of this proposal is to develop a model system of care and related set of tools that can be used to improve detection of ASD, access to diagnostic and evaluation services, and continuity and appropriateness of care for individuals with ASD and for their parents.

Challenges. A challenge to improving outcomes for autism is addressing persistent gaps in early detection, timely access to evaluation and diagnosis, and appropriate continued care management. These challenges are more severe in rural areas where there are chronic gaps in expert care for ASD. Expert care is limited and geographically concentrated. Services for patients/parents is dispersed often leading to a fragmentation of and lack of continuity in care.

A. **Goals and related objectives -** The specific goals are to:
    1. Increase early detection of ASD with the following objectives:
        - To develop a screening tool construct suitable for detecting ASD across a broad age range and a tool that is easy to understand, to complete, and score.
        - To identify reliable and appropriate questions for the ASD screening tool.
        - To validate the diagnostic sensitivity and specificity of the ASD screening tool.
    2. Increase access to ASD diagnostic and evaluation services with the following objectives:

- To devise a process-flow model that substantially increases the number of patients per day who can be evaluated by an ASD clinical expert.
- To develop on-line tools to improve the efficiency of ASD diagnostic/evaluation services.
- To pilot test and optimize the new process flow model.

3. To improve continuity and appropriateness of care with the following objectives:
   - To describe current gaps in continuity and appropriateness of care for ASD patients/parents.
   - To develop cost effective strategies for improving continuity and appropriateness of care.
   - To develop appropriate tools that can be used as part of a pilot test for a new model of care designed to improve continuity and adequacy of care.

B. **Methodology. -** The proposed work will be completed through three integrated projects directly linked to each of the above three goals.

1. The following specific steps will be involved in developing and testing the screening tool for early detection of ASD in primary care settings:
   - Complete literature review and develop conceptual model for screening.
   - Develop draft instrument and conduct one-on-one testing with parents of known ASD patients and with parents on non-ASD children.
   - Evaluate test-retest reliability of question items and psychometric properties of the questionnaire in cases and controls and preliminary evaluation of discriminative validity.
   - Use diagnostic tool (Autism Diagnostic Interview) as reference gold standard diagnosis for validity study
   - Prospective validity assessment of the screening tool in potential cases and controls.
2. The following steps will be taken to improve access to ASD diagnostic and evaluation services:
   - Establish objectives, document current process flow, and evaluate business management.
   - Evaluate parental satisfaction with current model of care as a point of reference.
   - Develop clinical neurobehavioral assessment tool to formalize data capture.
   - Develop new process flow model and identify need for related tools.
   - Develop on-line tools for intake, infant/child history, neurobehavioral assessment, and parental needs assessment. In part, these instruments will be designed to formalize data capture from parents to yield higher quality data (ie, use of structured questionnaire modules), reduce demand for time on clinical services, and provide a foundation for and management of care, and tailored education. Pilot test new model of care to improve access to diagnostic and evaluation services and evaluate parental satisfaction with care.
3. The following steps will be taken to improve continuity and appropriateness of care:
   - Establish goals and objectives for managing care.
   - Document current process of care, parental satisfaction and characterize gaps.
   - Develop follow-up visit assessment tool, interim visit assessment tool to be completed by parents, and a module to create a tailored report for parents. We will develop a process to integrate information from different sources and to automate the creation of the report. This report will be used to educate parents about their infant/child's disorder, to provide a roadmap for next steps, and to answer anticipated questions.
   - Initiate pilot testing of care management process

7. Serenix Pharmaceuticals, Inc., Neal Simon, Ph.D

Serenix Pharmaceuticals Inc. 111 Research Drive, Bethlehem, PA 18015.

NICHD Grant #5R42HD037290-03 "Treating Self-Abuse in Autism and Mental Retardation",

ABSTRACT

Serenix Pharmaceuticals LLC (SPL) will develop drugs to treat impulsivity, violence and self-injurious behavior in patients with autism, Tourette's syndrome, and mental retardation. These drugs, termed serenics, stop violent behavior without disrupting normal behaviors. No other products are available for these indications. SPL required a series of vasopressin receptor antagonists from Eli Lilly Company that block the vasopressin receptor subtype involved in aggression. With Phase I STTR support, SPL chemically modified the original lead series, producing several candidate molecules that exhibit high binding affinity and block biological effects at the target human receptor. The overall objective of Phase II research is to file Investigational New Drug (IND) applications are two promising candidates. To reach this objective, SPL will test two candidates for i) oral absorption and bioavailability, ii) acute and chronic toxicity, and iii) prepare these molecules for GMP grade bulk synthesis and formulation. The completion of the proposed research will provide the data required to meet the chemical and biological criteria established by the FDA for IND applications. PROPOSED COMMERCIAL APPLICATIONS: SPL is focusing on the development of drugs to help in the control of impulsivity, violence, and self-injurious behavior for the management of autism, Tourette's syndrome, and mental retardation. It is estimated that more than 500,000 patients in the United States alone would have a need for these drugs, with a worldwide market of 1.5 million. These drugs also may be used in the control of violence associated with mania, conduct disorder in a subset of children with ADHD, and Alzheimer's disease. There are no other products on the market for these indications.

C. For those interested in updating their information on Federally Funded Research, log on to http://projectreporter.nih.gov/reporter.cfm

1. Computer Retrieval of Information on Scientific Projects (CRISP)

CRISP (Computer Retrieval of Information on Scientific Projects) is a searchable database of federally funded biomedical research projects conducted at universities, hospitals, and other research institutions. The database, maintained by the Office of Extramural Research at the National Institutes of Health, includes projects funded by the National Institutes of Health (NIH), Substance Abuse and Mental Health Services (SAMHSA), Health Resources and Services Administration (HRSA), Food and Drug Administration (FDA), Centers for Disease Control and Prevention (CDCP), Agency for Health Care Research and Quality (AHRQ), and Office of Assistant Secretary of Health (OASH). Users, can use the CRISP interface to search for scientific concepts, emerging trends and techniques, or identify specific projects and/or investigators.

2. Food and Drug Administration (FDA)

Information on funding by the Food and Drug Administration can also be accessed directly at http://www.fda.gov/search.html

3. National Science Foundation (NSF)

Information on funding by the National Science Foundation can be accessed at http://www.nsf.gov/statistics/grants.cfm

4. Private research foundations

Private autism research foundations, have provided funding for many pilot autism studies:

NAAR (National Alliance for Autism Research) has funded almost $15 million in the last few years.

CAN (Cure Autism Now) has awarded over $20 million in the last 8 years. Additional information available on their website, http://www.cureautismnow.org

III. What are the Problems with existing research and funding?

A. NIH and individual grant funding:

Federal funding for autism research is limited though Pennsylvania does have 2 NIH centers- a CPEA and a CADDRE that could provide a basis for growth in funding and for the developmental of regional centers of excellence. There are also a few basic neuroscience and developmental biology research grants of potential relevance to autism.

Smaller individual grants awarded in Pennsylvania are also present (as listed above) but limited.

B. State funding:

In Pennsylvania there is essentially no state funding for research. A number of states do have model programs, which also serve to educate the community-at-large about autism.

Autism and developmental disabilities are also not a programmatic priority at any of the universities.

There is, thus, a clear and urgent need to identify sources of potential funding for research in Pennsylvania. New Jersey recently passed legislation to add one dollar for each traffic ticket written in the state as a source of funds for autism research. This is an example of the creative thinking that must be considered to ensure funding for research. Given the importance of this issue, it may well necessitate convening a state-level work group composed of parents, research groups, and legislators to consider how to increase funding.

C. Link between research and clinical services:

There is no defined link between currently federally funded research programs in Pennsylvania and its clinical services. Other states, such as New Jersey and California, have a defined link.

IV. What are the problems with existing practice?

A. Issues of Treatment and Practices

1. Current practices do not reflect research and are not always evidence-based and/or only have limited scientific research studies.
2. There is a gap between research findings and dissemination to practitioners and families to help shape practice - could be as long as 10-30 years.
3. Some practices would be very difficult to study in rigorous fashion (e.g., withholding educational or therapeutic treatments and comparing to another group).
4. Other practices in common usage (e.g., Complementary and Alternative Treatments) have not been studied to reflect the efficacy or potential for harm.
5. Other treatments have only been studied in a limited number of children and warrant further research to assess the efficacy. This includes dietary modifications (which may include the use of mineral or vitamin supplements).
6. Overuse of medications versus other more appropriate treatments commonly exist for various reasons including lack of knowledge of autism by clinicians.
7. Lack of research contributes to poorly implemented, costly treatments with little to no monitoring.
8. Children are prescribed widely variable treatments regardless of degree of disability.
9. Treatments may vary in implementation practices (sometimes due to the experience and level of training of the direct care giver).

B. Issues of Diagnosis

1. Standardized assessment(s) not used throughout the state;
2. There is a delay in diagnosis due to long wait for appointment and inadequate training of pediatricians in early signs;
3. Lack of qualified practitioners for assessment;
4. Lack of agreement regarding which standardized assessments are necessary for the diagnosis;
5. Lack of general awareness of importance of research in improving diagnosis in the short and long terms;

6. Difficulties in diagnosing high functioning individuals; diagnoses may be unnecessarily delayed until after the age of 5 years and into teen and adult years; adolescent and adult psychiatrists untrained in diagnosis and treatment;
7. Verbal individuals with autism at risk for late or wrong diagnosis, inappropriate and/or poorly implemented treatment, and inappropriate adult services;
8. Early concerns reported by parents may not be taken into account by pediatrician.

C. Prevalence

It is unclear what the current prevalence of autistic spectrum disorders is in state of Pennsylvania. This is due to a lack of recognition of ASD as a reportable entity. Pennsylvania does not have a comprehensive approach to track persons with ASD. Comprehensive approaches to track persons with ASD are available in other states. For example, California has a comprehensive system that identifies children with ASD, communicates with the early intervention or educational providers (as part of regional centers) and tracks them over time. These data are readily available to answer vital questions.

D. Validity of Proposed Treatments

Clinicians and families may find it difficult to make judgments regarding validity of proposed treatments. It is important to understand the scientific validity of evidence provided in studies or by practitioners. Important issues to consider:

1. How to understand, assess, and/or evaluate quality scientific study reports;
2. Consideration of the validity of evidence provided by the research study to make a judgment about proposed treatments;
3. Need for professionals to encourage family participation in well-designed and approved studies;
4. Lack of research about transition to adolescence and adulthood;
5. Vocational training and development of appropriate independent living or jobs;
6. Supports in middle and high school.

V. What are potential solutions to improve existing practices?

A. Regional Centers

Regional centers are a cost-effective approach to overcome many of the above-listed problems to fill gaps in diagnostic and treatment services and quality assurance.

One of the biggest challenges for autism is to provide services and treatment that reflect current state of science, while working to ensure better treatments for the future. Regional Centers will address needs that may not be addressed by individual providers, will assure that services delivered by providers are quality-based and accountable, will provide training and certification in key services, and will help to develop jobs and living arrangements. Another key element is that these centers will be academically based and linked to research centers so that there is ongoing improvement in the state of diagnosis and treatment. It is also anticipated that regional centers could positively impact the dissemination lag that delays the translation of potentially positive research results into intervention practices.

Regional centers will be established in collaboration with a consortium of academic centers, including universities, tertiary-care or university based hospitals, and state agencies already involved in the care and research of children and families with ASD. Effort will be made to assure equitable representation for all parts of the state. A board of advisors would be established to oversee the structure and functioning of the regional centers, and determine the locations throughout the state (e.g., regional centers located in western, mid-central and eastern portions of the state) to assure accessibility by families and clinicians. The board and subcommittees would establish the criteria and standards for the diagnosis and treatment of children with ASD. Sources of funding might include State funding, federal grant funding and private foundation support. No one agency or institution would "own" the regional centers to assure independent functioning. The directors of each regional center would report to the board of advisors, which would in

turn report to the newly established Department of Developmental Disabilities of the Commonwealth of Pennsylvania, and ultimately to the Secretary of Public Welfare.

Some key issues to be addressed by the proposed regional centers include:

1. Early recognition:

Reduce the wait from 6-9 months to 3 weeks or less. The lag until diagnosis delays treatment, a critical step in improving outcome and reducing later treatment costs.

Determine the first concerns that parents express to pediatricians and the pediatricians' response to parents so pediatric practices can be improved. The ultimate goal is to help general pediatricians become diagnosticians or first alert-responders.

These toddlers provide subjects for studies of early signs of autism and in turn the cause of autism. Infant siblings can enroll in studies of early signs to support the development of new diagnostic instruments for even earlier diagnosis of autism.

2. Diagnosis of individuals with autism spectrum disorder (ASD) across the lifespan:

Practitioners and educators are generally not able to diagnose verbal individuals with ASD and need training that can be gained at research centers through the use of standardized instruments.

The quality of the initial diagnosis of autism will improve with standardization of instruments and the use of research instruments at regional centers.

3. Treatment programs:

Training and certification programs for treatment methods according to best practice standards can best be achieved at centers that are independent of service delivery.

Monitoring fidelity of treatment methods to ensure that the treatment being provided by agencies is of high quality.

Collect data of results and effectiveness of treatments, including those treatments that have not yet been subjected to empirical validation.

4. Vocational training:

Job development: many of these individuals are capable of working if appropriate jobs are developed and the appropriate environment and coaches are provided. These resources are inshort supply if not non-existent for most individuals with autism. The Office of Vocational Rehabilitation is not familiar with the ability-disability profile of this population and does not know how to place them. This is generally true of jobs programs. Jobs appropriate to their profile have not been developed. Tax incentives for employers have not been developed by the state nor have employers been educated as to the value of these individuals as employees. In addition, programs need to be developed so that these individuals are hired by an agency and subcontracted to the business so the business does not incur an irreversible risk of a bad match and then the inability to terminate the employee because of disability. This results in refusal of businesses to take risks.

New jobs need to be developed that reflect the ASD profile of abilities and limitations and the vocational resources to develop and support employment opportunities need to be provided. This will reduce dependence on welfare payments and will reduce depression from lack of productive activities

5. Psychopharmacology:

Extension of training to non-psychiatrists, as resources (e.g., personnel, reimbursement, others) may be limited in this realm.

Many individuals with high-functioning autism are treated by adult psychiatrists. These physicians generally do not have training about autism or its treatment, pharmacologic, behavioral or environmental factors. Medications are often used instead of appropriate environmental supports, resulting in over-medication and its attendant complications. Mis-diagnosis and missed-diagnosis of autism is also rampant.

6. Psychosocial support:

Therapists need to be trained for individuals with high functioning autism and Asperger's Syndrome. There are very few psychologists with the appropriate skills to deal with intellectually talented individuals who are often operating socially and emotionally at a very young age, which is further compromised by deficits in language comprehension, theory of mind, and abstract reasoning-problem solving. These impairments are often disguised by the high factual knowledge and academic achievement of such individuals. Family members may also be partially affected and desire counseling for themselves by individuals with insight into the broader spectrum of impairments. Again such therapists are lacking.

Research documentation is necessary regarding most effective means of providing emotional and psychosocial support for families.

7. Personnel Preparation:

It is increasingly recognized that an obstacle to the implementation of best practices has been dissemination of research-based practices to students being prepared to teach persons with autism and related disabilities throughout the span of the education entitlement (i.e., ages 3-21). To the extent that personnel preparation institutions throughout Pennsylvania were affiliated and maintained close ties with the proposed regional centers, it is anticipated that teacher training curricula would be revised and updated in a timelier manner than it is currently. Closely related to the instruction of teachers is the instruction of instructional assistants, related service personnel, and other support personnel (e.g., wraparound staff) who will be working in classrooms and other educational settings where children with autism receive education services. Some states (e.g., West Virginia) have developed autism endorsement programs that certify staff members who have received additional training (i.e., supplemental coursework, supervised practicum experiences). Such a program could be developed in Pennsylvania and their activities coordinated with the proposed regional centers to ensure that the curriculum is updated as needed.

B. Surveillance

Establish system of surveillance to support studies to identify the number of individuals with ASD and provide input for planning for resources and treatment. This will aid in identifying potential environmental causes. It will also help to determine if incidence is increasing, decreasing or stable in response to changes in environmental factors. It can also aide in determining the outcome to various interventions.

C. Dissemination of Information

Provide basic information "describing what we know about autism, and what can be done immediately to help someone with autism."

Accessibility to all populations is an issue (e.g., those who do not have access or use internet).

1. Statewide system

Develop statewide process or system of public relations for dissemination of information regarding ongoing research, valid treatments and others. NICHD has funded a group of scientists to develop a web site of this type. The estimated completion date is approximately two years. This will not meet all the needs described below but will meet some of them.

2. Website

Develop informative website for parents and professionals. At a minimum, website should link to various research engines available (e.g., PubMed, CAN or others).

Develop interactive website easily accessible to individuals with various levels of understanding (This is the ideal but not perhaps financially feasible at the state level).

Need quality control (peer review) of what is contained in the website; need to establish criteria to make these determinations. This will be controversial because of different perspectives of the definition of effective practices or treatments.

3. Informed consumers

Provide education to professionals and parents on how to assess the validity of a reported study using scientific principles. This would provide information about how to become an informed consumer, and make decisions based on safety and efficacy.

Serve as a source of entry for referral to existing research projects or for development of new research proposals.

Provide source of communication and education regarding existing resources.

Other media (video or other materials) to explain best practices and information about ongoing research.

Lecture series or educational workshops - should be done in collaboration with other Pennsylvania agencies or departments. (e.g., Department of Education)

4. Judging Science: Nancy Minshew, M.D.

Initially the goal of this section was to prepare parents to judge scientific research and findings. However, it has since become apparent to me that this goal is not possible and fraught with danger. I do not consider myself sufficiently expert to be a reviewer of most autism manuscripts (papers under review prior to publication) and I thus realized that no matter how bright parents are, they lack the expertise required to judge scientific issues safely. Even reading reports or papers is risky because they do not come with warnings such as "this is not peer reviewed but personal opinion". Even peer review does not guarantee that the paper or its interpretations will stand the test of time.

The autism community has been bombarded in recent years with research findings and various interpretations and commentaries on those findings. Unfortunately, the media has tended to be very narrow in their focus on the research, and has frequently added drama and exaggerated the dilemma for families trying to discern what it all means for them. The point of all of this is that each issue requires a high degree of expertise to make judgments and parents do not possess that, nor does the media. Media is often far more interested in drama than accurate science or public health. We need to rely on our best scientists to make those judgments for us. We need to be skeptical about dramatic accusations and remember that every article published in a journal is not peer reviewed, which is our first level of safe-guard.

The second issue is that investigation is like an archaeological dig. Many scientists uncover a little piece of the dinosaur but until the whole dinosaur is unearthed through a great deal of research over years, no one really knows which dinosaur it is or what it looks like. Hence, research is a work in progress. In some sense, there is no answer, only stages of knowing. There are no simple answers. Autism is not a simple problem.

Hence, it is incredibly important to let those with the highest degree of expertise make judgments about the meaning of findings. Second, it is important to recognize that we only have a finite amount of resources-time in a child’s life, parents’ time, scientists’ time, and research dollars- and we must spend

those resources as wisely as possible. If resources are poorly spent, it is the children and their families who lose the most. Over and over again, I and all those my age have seen families and a few scientists convicted that they had the cure or more recently the cause only to be found with the passage of time to be very wrong. It is the story of looking under the lamp post for the lost article because the light is best or so they thought. The question everyone must always consider is what if the lamp post is the wrong place to look? What will you have and are you the best person to make that decision? Are you willing to rest your child's life and future on what you know about the brain? I often think about the plane crash many years ago outside Pittsburgh International airport and I think "Would we send reporters out to interview six people on the street for their opinion about what caused the crash and rely on their opinions or would we do what we do which is assemble a team of experts and put them to work on finding the answer?" Would you ever feel safe on a plane again if we used the first approach? Which approach do you want to trust your life to and that of your child and grandchild?

As to the science of judging science, there are classes of evidence that are used to determine how much credence should be given to the findings of a study e.g. how likely the findings are to be correct and repeatable. These follow the same principles across studies but the details require a great deal of expertise to know if good methods are being followed. For example, studies should adhere to research standards in making a diagnosis, employ an appropriate control group, be double blind and involve a placebo if drug treatment is involved, involve a large enough sample to be reliable (if another investigator does the same study with the same methods they will get the same results), use the proper procedures to measure what they are measuring, do so reliably, use appropriate statistical methods to analyze the data, and provide an appropriate discussion of the findings which considers limitations of the study and avoids going beyond what the data can support. This is a minimal description of an adequate study. To determine if a study meets these standards obviously requires someone or usually several someones who are true experts in the areas involved to make these judgements. I hope that this conveys why lay people are not competent to judge research results and why every autism expert is not competent to judge every autism research study. Research is highly specialized and requires highly specialized expertise to make a competent assessment of the quality of a study and its implications. The meaning of an area of research also takes place over time from the accumulation of research studies.

D. Pennsylvania Interagency Autism Coordinating Committee

Establish a comparable Interagency Autism Coordinating Committee for the Commonwealth of Pennsylvania, which would serve as an advisory board to the Regional Centers and work with administration for oversight and coordination of research and education of children, families and caregivers of Autistic Spectrum Disorders.

This committee would include representatives from academic centers (universities, colleges, medical schools, and university-based hospitals), schools and other agencies throughout Pennsylvania involved in the care and research of children and families with ASD. Members would be nominated and chosen based on past experience and activities related to these activities. They would serve for a period of 5 years, and meet biannually, providing a yearly report with recommendations to the Regional Centers and administration of Section of Developmental Disabilities of the Department of Public Welfare. Funding would be obtained through governmental sources, private foundations and/or federal grants. This committee would be modeled after and benefit from the experience of the Federal IACC.

Its functions would include:

1. Maintain list of active research studies with human subject approval and scientific peer review approval. with eligibility requirements and contact information.
2. Promote awareness of research and participation in studies by families. Report results of studies on website.
3. Identify existing funding sources and develop new mechanisms for funding studies as has been done in other states.
4. Develop a priority list of projects for funding which matches clinical needs and feasibility given the resources provided.
5. Develop priority list of a limited number of scientific questions from the public for answers by scientific experts.

6. Develop link to NIH website on autism that is under development.
7. Ensure that a representative from the state attends the NIHIACC meeting each quarter and posts a report on the state website.
8. Ensure that a member listens to state and congressional appropriations committee meetings and reports back on autism relevant comments.
9. Ensure there is one representative to HRSA or other agencies that might provide funding to initiatives as prioritized by the committee.
10. Members of a state IACC for autism: include a combination of a representative sample of parents/families, researchers, clinicians involved in care, other professionals (e.g., educators, therapists, social workers, speech/language pathologists, occupational therapists, and others) and governmental administration. After an application and review process members would be appointed for a set term on a rotating basis to provide stability to the board.
11. This Board would provide a yearly update on the progress towards goals regarding the transfer of science to practice and the support for increasing research in the state and family participation.

VI. Directions of future research

A number of areas of research should be addressed in a coordinated fashion throughout the state, to maximize available resources (existing research programs, experts in the field, staff, and financial supports) and promote collaboration. The Pennsylvania Interagency Coordinating Committee would provide oversight and communication with the Regional Centers and the Academic Institutions participating in the research. In many instances centers throughout Pennsylvania are participating in this research already. The PIACC would provide centralization and in cooperation with the Regional Centers expand the ability of each research program to fulfill the goals of their study.

The recommendations of the Research Committee should include (but not be limited to) the following areas:

1. Causes or etiology of ASD, including surveillance, changes in prevalence, the development of appropriate animal models
2. Best practices for clinical care, means for implementing and studying the effectiveness and accuracy. A number of practice parameters and clinical guidelines have been developed, and it is important to determine the best means of communicating them and implementing them by practitioners.
    A. Diagnosis including first signs, second signs, and recognition in minorities
    B. Treatment
3. Effectiveness of Behavioral treatments
4. Effectiveness of Educational treatments
5. Effectiveness of Psychopharmacological treatments
6. Effectiveness of Biomedical treatments
7. Characterization of subtypes (reflecting the diversity of ASD, and its impact on response to treatment and outcome)
8. Social supports and quality of life
9. Access to services
10. Transition to adolescence and adulthood
11. Surveillance/ tracking
12. Outcome
13. Methods of family and clinician education and/or dissemination of information
14. Training models for the dissemination of information to personnel working directly with persons with autism at all levels of the service system

High Risk	**1.** Peripheral biomarkers (e.g. gene expression assays) developed to provide the biological characterization (i.e. phenotype) of autism **~**	**1.** Individual characteristics that predict response to behavioral and drug treatments are identified *****	**1.** 25% of cases of autism prevented through early identification and early treatment
	2. Efficacy established for drug treatments that target symptoms associated with autism *****	**2.** Susceptibility genes and animal models of autism are identified for further study of phenotypic characteristics of autism **~**	**2.** Methods developed and implemented to allow 90% individuals with autism to develop speech
		3. Environmental factors (e.g. viruses, medications, lifestyle factors, environmental chemicals) that contribute to the development of autism and their associated developmental windows identified	**3.** Genetic and non-genetic causes of autism and their interactions identified
			4. Efficacious drug treatments that target core symptoms of autism developed *****
Medium Risk	**1.** Resources established for genotype/phenotype studies (i.e. bioinformatics, genetic repository)	**1.** Biological and/or behavioral markers identified to develop indices of risk for the development of autism *****	**1.** Feasible, sensitive autism screening method for young infants developed *****
	2. Existing data studied to begin to characterize the autism phenome, as part of the larger Phenome Project	**2.** Multi-site randomized clinical trial implemented to identify moderator variables and effective ingredients (e.g. dose, intensity, mode of delivery, age of onset) of early intervention treatments **@**	**2.** Basic, common neuropathological and neurochemical features of autism defined **#**
	3. Infrastructure, such as enhanced brain acquisition, established for neuropathological investigations, to characterize the morphological aspects of the pathophysiology of autism	**3.** Intervention methods for infants and toddlers developed, to lower the age for which there are efficacious interventions **@**	**3.** Treatment algorithm for autism developed, to provide guidance for practitioners and educators *****
	4. Technology and infrastructure developed for multi-site in vivo imaging studies, to identify the neuropathology of autism **#**	**4.** Neuropathology of autism characterized, to identify brain structures and functions associated with autism **#**	
	5. Randomized clinical trial developed for the evaluation of the effectiveness of early behavioral intervention and moderator variables predicting response to intervention **@**	**5.** Developmental time course characterized for alterations in brain structures and connections in autism **#**	
Low Risk	**1.** Autism Phenome Project defined and planned **~**	**1.** Multi-site longitudinal study of subsequent pregnancies and infant siblings of children with autism implemented, to identify risk factors, broader phenotype and early	**1.** Longitudinal follow-up of early intervention randomized clinical trial implemented **@**

	characterization of autism ~	
2. Outcome measures improved, to enhance their effectiveness in evaluating treatment studies *	**2.** Neural circuitry and neurochemistry defined for several functions impaired in autism #	**2.** Appropriate efficacious interventions implemented for school and community settings, throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education @
3. Twin resource developed, to study heritibality and environment factors influencing autism	**3.** Innovative intervention strategies evaluated to improve outcome in the school and community settings throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education @	**3.** Second-generation, intensive, community-based prevalence studies with clinical evaluations planned and implemented. **$**
4. Innovative intervention strategies developed to improve outcome in the school and community settings throughout the lifespan, including transitions (e.g. academic functioning, social and adaptive behavior, family functioning, employment) in collaboration with the Department of Education @	**4.** First-generation, intensive, community-based prevalence studies with clinical evaluations implemented, to have initial data for detecting changes in prevalence of autism **$**	
5. Research Communication Network (both local and national) developed to disseminate findings among researchers and the public to increase ongoing communication		
1-3 years	**4-6 years**	**7-10 years**

~ Characterization of autism (i.e. phenotype); ***** screening; **#** neuroscience; **@** school and community interventions; **$** epidemiological studies; Blank = remaining items

F. Conclusion

In conclusion, the above stated solutions will directly and indirectly break-down above-listed barriers by focusing on best practices in the areas of diagnosis, education (including appropriate and timely dissemination of information), treatment methods, social supports, and outcome while maintain essential data for tracking and continuous quality improvement. The above stated solutions also provide the necessary links from research to direct care providers and directly improve the gaps to needed services.

G. Summary

There is, at present, limited research funding in the state of Pennsylvania. There are two major centers, the CPEA and the CADDRE, which provide the potential for enhanced development of research in the future. However, there is no state or university support for such a program. Research brings funding for autism into the state and provides a foundation for the enhancement of the quality and comprehensiveness of services and treatment. At a national level, an ambitious agenda has been set to reduce the incidence of autism by 25% through early identification and treatment and to increase the proportion who are verbal to 90%. In the longer term the goal is to achieve biological treatments. Research is aimed at achieving these goals. CPEA and CADDRE are currently participating in research that parallels these goals. Regional centers that are consistent with this plan can be established to enhance research in Pennsylvania and substantially expand services in the near future.

(1) Website address for IACC: http://www.nimh.nih.gov/autismiacc/index.cfm
(2) Website location of CDC ADDM Networks: http://www.cdc.gov/ncbddd/dd/aic/states/default.htm#addm
(4) Website location of CDC Centers for Autism and Developmental Disability Research and Epidemiology: http://www.cdc.gov/ncbddd/dd/aic/states/default.htm#caddre
(5) Website location: http://BeInCharge.ucdavis.edu/
(6) Website location: http://www.eohsi.rutgers.edu/childhood/index.shtml
(7) Website Address for PA CADDRE: http://www.cdc.gov/ncbddd/dd/aic/states/pa.htm
(8) Website location: http://www.ed.psu.edu/news/autismgrant.asp

06. Funding Streams Subcommittee Report

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Attachment No. 1
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Summary

The Funding Streams Subcommittee ("Subcommittee" or "We") of the Commonwealth of Pennsylvania ("State") Department of Public Welfare ("DPW") Autism Task Force ("Task Force") determined that there are three primary obstacles inhibiting the flow of revenue from its sources to consumers of Federal and State funded services: (1) Fragmentation of State and local agencies responsible for funding, or providing services to, children with Autism Spectrum Disorders ("Autism" or "ASD"), (2) inadequate utilization of existing governmental and private sector revenue streams, and (3) inefficient or ineffectual use of funding by administrative agencies, local entities, and providers.

Consistent with the Subcommittee's understanding of its current remit, we have confined these preliminary recommendations to a review and evaluation of programs whose funding is presently controlled by DPW. This review and any resultant changes – like the efforts of our fellow Medicaid Waiver Subcommittee to develop a Medicaid autism waiver – are important interim steps as we seek to create a new system of services for individuals with ASD and their families.

However, if we are to develop "dramatically different ways of addressing the needs of all people" and the kind of overall systemic change envisioned by Secretary Richman and the Task Force Co-Chairs, the Subcommittee believes it will be necessary to move beyond these interim goals to full cross-departmental collaboration and shared funding between DPW and the state Department of Education, extending down to the local level. We must seriously and creatively explore models that blend both DPW and Education funding and service delivery, requiring the cross-training and performance collaboration of behavioral health and education professionals so that the delivery of therapeutic and education services to individuals with ASD and their families is unified and seamless.

Furthermore, we believe that efforts to achieve cross-departmental collaboration and shared funding streams would be greatly facilitated by changes to the Federal Regulations permitting Federal funds for individuals with Autism to flow from, and be regulated by, one Federal administrative agency and governed by a single set of Federal Regulations. Services covered by such Federal funding should be indiscriminate as to whether or not the service provider is public or private, community or facility based, or whether the service is educational or related to behavioral health.

Such new Federal Regulations would do much to eliminate the administratively determined line presently dividing educational services from behavioral health services and vastly enhance the States' abilities to design individualized services to those with Autism. Accordingly, we recommend that DPW, together with the Pennsylvania State Legislature, Governor Edward Rendell, and other interested State government bodies and officials, petition the Federal government to form a Federal Task Force to begin this process.

The following represents the efforts of Subcommittee members to identify obstacles within the categories noted above, to begin identifying other potential sources of revenue, and to begin exploring how current governmental programs can be amended or expanded to begin removing the abovementioned obstacles.

[U] – Unanimous Support
[M] – Majority Support
[D] – Discussion

I. Sources of Revenue

A. Expansion of Current Commonwealth of Pennsylvania Programs:

1. Commonwealth of Pennsylvania State Corporate Tax Credit Program - **[U]**

We recommend that the Department explore the enactment of a tax credit program similar to the Education Improvement Tax Credit ("EITC") program (Act 4 of 2001), to help defray the cost to provider agencies to provide training to professionals providing direct services, or supervising those providing

direct services, to children and adults with disabilities **(1)**. Under the EITC Program, when a corporation makes a contribution to a state-approved organization, the state will match it up to nine times. This means that for every dollar of net cost to a participating business, and additional nine dollars from redirected corporate taxes can be used to work toward raising the achievement level of Pennsylvania's school children. For example, if a corporation chooses to give $111,000 (the 2002-2003 maximum) per year for two years, $100,000 will be fully deductible from the business's state tax bill each year.

Just as educational outcomes depend heavily on highly trained education professionals, strong treatment outcomes for children with disabilities depend heavily on highly trained professionals providing such treatment. The EITC Program has been highly successful in Pennsylvania and Commonwealth Department of Community and Economic Development staff administering the program report that Governor Rendell is supportive of it. This is evidenced by the Rendell Administration's recent expansion of the EITC Program to encompass a larger class of qualifying contributors.

2. Student Loan Forgiveness for Behavioral Health Professionals - **[U]**

An abundance of research exists demonstrating the indivisible link between program quality and the availability of well trained and supported professional staff. The "revolving door" of therapeutic support staff, behavior specialists, and other professionals providing direct services to people with disabilities is both a deterrent to providers challenged with implementing high quality services and a significant source of frustration to parents and people with disabilities who are forced to adjust to frequent staff changes and interruptions of service. Furthermore, this "revolving door" significantly increases the administrative costs of providers faced with the frequent training of new staff.

In order to further empower provider agencies to retain staff, we recommend that the Department enlist the support of the State Legislature to pass new legislation or expand the applicability of The Early Childhood Education Professional Loan Forgiveness Act (24 P.S. § 7103) and the Urban and Rural Teacher Loan Forgiveness Act (24 P.S. § 5194) to encompass professionals providing direct service to children and adults with disabilities**(2)**.

On June 4, 2003, Representative Thomas C. Petrone introduced a bill in the Pennsylvania House cited as the Mental Health and Mental Retardation Staff Member Student Loan Forgiveness Program Act. On October 15, 2003, the bill was reported out of the Education Committee and laid on the table, at which time we discovered it. Funding Streams Subcommittee members assisted Representative Petrone's office in developing amendment language that would expand the HB 1530 to capture employers of Private Providers under contract with the Office of Medical Assistance Programs ("OMAP") and HealthChoices Managed Care Organizations and secured the support of Representative P. Michael Sturla, who introduced the amendment language. This amendment language would enable BHRS providers to benefit from the new Student Loan Forgiveness Program. While HB 1530 enjoyed unanimous support in the House and was progressing through the Senate, last minute concerns regarding the means of funding caused the bill to stall and ultimately die at the close of the 2003/2004 Session of the Pennsylvania General Assembly.

The Mental Health and Mental Retardation Staff Member Student Loan Forgiveness Program Act will be reintroduced in the 2005/2006 Session. We strongly recommend that the Department of Public Welfare and Governor Edward G. Rendell voice their renewed and tacit support for the bill to the legislature in order to facilitate its swift passage and, furthermore, to commit to adequately funding the resulting Act so that its full benefits can be realized.

B. Private Insurance:

1. Market-Based Cost Control - Private Insurance - **[U]**

We recommend that the Department enlist the support of the State Legislature to prohibit private health insurance companies from excluding coverage on the basis of an autism/PDD diagnosis.

Although private sector health insurance plans may appear less generous than Medicaid plans, one key advantage is that they usually enable participants to access a greater range of providers and health care facilities. This may be beneficial to some children and adults affected by autism.

Beneficiaries who do not have access to employer plans should be able to participate in state-operated insurance exchanges to directly enroll in individually owned health insurance plans. The state would organize the exchange, solicit information from various health plans, and make information available to Medicaid beneficiaries.

Deductibles and/or co-payments could be paid or subsidized by Medicaid funded health care savings accounts.

C. Partnership with Private Foundations for Model Program Pilots - **[U]**

DPW should encourage the development of model programs in autism intervention that incorporate best practice principles and reflect current research in the field. Model programs may not fit neatly into existing funding streams. Yet, it may be premature to revamp statewide procedures to accommodate a new program before the model is fully developed and tested.

Support for model program will help to ensure individualization of services and avoidance of "one-size-fits-all" systems. Encouraging the development of model programs provides a means of fostering incorporation of the most current research in autism.

In order to survive and flourish, model programs must have an identifiable means of support. Therefore, we recommend that the Department work with private foundations to establish a funding source for the development and implementation of model programs for children with autism and their families. A model program should provide a new or more efficient means of providing services that promulgate a best practice approach to autism intervention.

II. Uses of Revenue

A. Efficiency Issues:

1. Redundancy in Paperwork for Managed Care - **[U]**

Redundant paperwork is time consuming for providers who cannot bill for much of this work. Even when providers have all vital client information, each form requires the client's Medical Assistance ("MA") number, date-of-birth, and social security number. We recommend that the Department develop a means of streamlining paperwork (e.g., using standard electronic forms that utilize fields that duplicate required information on forms, refer to a central file which includes the vital statistics of the person receiving services).

2. Inefficiency of 4-month Evaluation Periods - **[U]**

For individuals with autism, we recommend that the State eliminate the 4-month evaluation period in determining eligibility for behavioral health rehabilitative services ("BHRS"). The time allotted to evaluators to prepare these evaluations makes the cost of doing a comprehensive evaluation prohibitive. Following a comprehensive, initial evaluation, annual evaluations would include testing, observation in various settings (clinical, educational, home, and community), and a review of provider reports supported by measurable outcome data. Treatment Plans, developed annually, would be supplemented by quarterly progress reports. When practicable, the Treatment Plan should be developed concurrently with the development of a child's annual Individualized Education Plan ("IEP").

3. Inefficiency of Overstaffing - **[U]**

We recommend that the State add "Group TSS" as a fee service to provide behavioral health services to more than one child in school and community settings when necessary and appropriate.

4. Inefficiency of Multiple, Arbitrary Transitions - **[U]**

Multiple transitions for young children with autism is not only inefficient, requiring duplication of administrative and service delivery staff, it also undermines the effectiveness of necessary programming by subjecting children, who usually do not transition well, to two transitions in the span of 2-3 years (see Attachments 2 and 3).

Therefore, we recommend that the Department, working in conjunction with the Pennsylvania Department of Education and the State Legislature, seek to eliminate these transitions in favor of a more seamless service delivery system. As a first step, we recommend that the Department focus on eliminating the transition between Early Intervention and Ages 3-5. Furthermore, we recommend that the Department review the new provisions in the soon-to-be ratified Individuals with Disabilities Education Act of 2004 that purportedly afford states with greater flexibility in providing seamless service delivery to children aged 0-5.

5. Tailoring of Benefits - **[U]**

We recommend that the Department tailor benefits packages under the Autism Waiver(s) depending on the degree of disability. Benefits packages could offer premium support on a sliding scale depending on the severity of the disability. Cost savings should result from not delivering excessive or more expensive therapies while ensuring that more intensive options are available to those who need it. An example of such a construct could include, but is not necessary limited to:

1. Intensive, home-based services
2. Mobile and inpatient crisis services
3. Residential services (e.g., small group living, supervised apartments, supported living, cluster homes, and independent home living with support)
4. Specialized, family-based treatment
5. Specialized ICM/RC services
6. Specialized school support and consultative services
7. Group-oriented treatment options (therapeutic social groups, group discrete trial therapy)
8. Community inclusion activities
9. Parent competency training through positive behavior support
10. Specialized training for babysitters/respite providers
11. Person-centered planning for life transitions
12. Social/recreation opportunities for teenagers and adults
13. Transition guidance for families for a young adult
14. Short-term respite for children and adults (day or overnight)
15. Outpatient Services

B. Quality-of-Care Issues:

A. Outcome-Based Payment Structure - **[U]**

Abundant literature exists demonstrating that intensive early intervention using the principles and methods of applied behavior analysis ("ABA") can produce substantial benefits for many children with autism/PDD (Anderson et al., 1987; Birnbrauer & Leach, 1993; Fenske et al., 1985; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993)**(3)**. Further, emerging research indicates that similar intensive behavioral interventions can result in comparatively large cognitive, language, and behavioral gains in older children affected by autism**(4)**.

Investing in high-quality, early intensive behavioral interventions for children with autism is likely to yield significant, long-term cost savings for the various systems providing services to these individuals (see Attachment No. 1)**(5)**. The key to realizing such cost savings depends heavily on the quality of services being provided.

Therefore, we recommend that reliable and valid quality-of-care indicators be constructed and utilized that affect the distribution of total funds to providers. Three factors could be averaged to create a quality-of-care index: (1) complaint resolution, (2) customer satisfaction (i.e., based on surveys of patients and/or their guardians), and (3) changes in the severity in which an individual's disability impairs his or her functioning. A provider scoring 50 percent higher on this index than another provider would receive a 50 percent higher share of payments (per child/adult receiving services, adjusted for acuity)**(6)**. This would also incentivize providers to "go the extra mile" in providing professional development for its staff and, in doing so, allow the benefit of Pennsylvania's significant academic resources to trickle down to the consumer. Additionally, providers should be held accountable for providing outcome data that demonstrates that their work is yielding positive results. Failure to do so should result in the withholding of future payments until the provider does so.

Footnotes

(1) More information regarding the Education Improvement Tax Credit Program is available on the World Wide Web at www.inventpa.com/default.aspx?id=267.

(2) The Early Childhood Education Professional Loan Forgiveness Act (24 P.S. § 7103) and the Urban and Rural Teacher Loan Forgiveness Act (24 P.S. § 5194) currently enable qualified applicants who are selected for the respective Programs to be eligible for payment by the agency of a portion of the debt incurred by the applicant through the agency-administered Guaranteed Student Loan Programs for full-time professional in an approved Commonwealth child-care facility or for the education necessary to be certified to teach in Pennsylvania. For each calendar year or academic year that the applicant is a full-time childcare professional child care facility or a teacher in an approved Commonwealth urban or rural public school district, the agency may forgive a proportional part of the applicant's loan so that the loan may be entirely forgiven over four years of full-time teaching. Under the respective Acts, no more than $2,500 shall be forgiven in any year, and no more than $10,000 shall be forgiven for any applicant. The programs are funded and administered by the Pennsylvania Higher Education Assistance Agency ("PHEAA").

(3) Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. **Education and Treatment of Children**, 10, 352-366; Birnbrauer, J. S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. **Behaviour Change**, 10, 63-74; Fenske, E.C., Zalenski, S., Krantz, P. J., & McClannahan, L.E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. **Analysis and Intervention in Developmental Disabilities**, 5, 49-58; Lovaas, O. I. (1987). Behavioral treatment and normal intellectual and educational functioning in autistic children. **Journal of Consulting and Clinical Psychology**, 55, 3-9; McEachin, J. J., Smith, T., Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. American **Journal on Mental Retardation**, 97, 359-372.

(4) Eikeseth, Svein, Smith, Tristram, Jahr, Erik, Eldevik, Sigmund, **Intensive Behavioral Treatment at School for 4- to 7-Year-Old Children with Autism**, Behavior Modification, January 2002.

(5) Jacobson, John W., Mulick, James A., Green, Gina **Behavioral Interventions**, 1998, Volume 13, 201-226.

(6) Janet M. Corrigan, Jill Eden and Barbara M. Smith, eds., **Leadership by Example:Coordinating Government Roles in Improving Heath Care Reality** (National Academics Press: Washington, D.C. 2002).

Attachment 1

Attachment No. 1 is an abbreviated report available on the World Wide Web at www.behavior.org/autism/autism_consumers_guide.cfm. The full report, along with more detailed financial data is available in **Behavioral Interventions**, 1998, Volume 13, 201-226.

EIBI Saves Up to $2,500,000

SUMMARY: Cost-benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism

John W. Jacobson, James A. Mulick, and Gina Green In Behavioral Interventions , 1998, Volume 13, 201-226

Public and private spending for specialized human services has increased dramatically over the past two decades. So have concerns about the investment of public resources in these services. For example, research has shown that without effective intervention, most people with autism and other pervasive developmental disorders (PDD) require lifelong specialized educational, family, and adult services, at a total cost that is estimated at upwards of $4 million in some states. Every year, millions of dollars are spent on interventions for autism/PDD that have little or no proven efficacy. It is prudent, therefore, to ask how investments in services are likely to pay off in the long run, and how to make the best use of the limited resources available for educating and treating people with autism/PDD.

Research with children who have, or are at risk for, various disabilities has shown that effective early intervent ion can substantially reduce their need for specialized services later on. To be effective, however, Guralnick (1998) and Ramey and Ramey (1998) found that early intervention must be (1) comprehensive, (2) intensive, (3) extended over time, (4) individualized, and (5) delivered directly to children. Of course, such intervention is neither cheap nor easy, so it is important to determine how this kind of intervention is likely to pay off not only in benefits to particular children and families but also in financial savings.

Early Intensive Behavioral Intervention (EIBI)

Studies have demonstrated that intensive early intervention using the principles and methods of applied behavior analysis (ABA) can produce substantial benefits for many children with autism/PDD (Anderson et al., 1987; Birnbrauer & Leach, 1993; Fenske et al., 1985; Lovaas, 1987; McEachin, Smith, & Lovaas, 1993). Although there were some variations in procedures across studies, the interventions generally met the five criteria listed as essential by Guralnick (1998) and Ramey and Ramey (1998).

The interventions:

1. Emphasized skill development through positive reinforcement;
2. Started with an assessment of each child's current skills and deficits; instructional objectives, teaching methods, pacing, skill sequences, and reinforcers were all customized to the characteristics and needs of each child;
3. Addressed all skill domains;
4. Used frequent direct observation and measurement of individual performance to determine if progress was occurring, and adjust instructional methods accordingly;
5. Included parents as co-therapists; and
6. Were directed and supervised by individuals with postgraduate training in behavior analysis plus extensive hands-on experience in providing ABA intervention to young children with autism.

Among the studies published to date, the best outcomes – achievement of normal or near-normal functioning in all skill domains – were documented for children who received this kind of intervention for at least 30 hours per week year around for 2-3 years, starting before they reached the age of 6. In the longest and best-documented study, Lovaas and colleagues (Lovaas, 1987; McEachin, Smith, & Lovaas 1993) found that 47% of the children receiving EIBI were able to function independently and successfully

in regular classrooms. Another 40% or so made substantial improvements but continued to need some specialized intervention; and about 10% made minimal gains and continued to need intensive intervention. For a review, see Green (1996).

Cost-Benefit Analysis of EIBI

Given the emerging evidence on the effectiveness of EIBI, and the availability of detailed information about the costs of childhood and adult services for people with autism and related disorders, it is now possible to estimate the financial costs and benefits of EIBI. We conducted such an analysis using information from the state of Pennsylvania available to us at the end of 1996.

The major assumptions underlying the analysis were:

1. There is insufficient scientific evidence on which to base predictions about the likely outcome for any individual child.
2. In any group of children receiving EIBI, between 20% and 50% will achieve normal functioning and require no specialized services after entering elementary school. About 10% will make small gains and require intensive special education and adult services (minimal effect group). The remainder will make moderate gains and need nonintensive special education and adult services (partial effect group).
3. Without EIBI, most people with autism need lifelong special services.
4. The average annual cost of EIBI is estimated at $33,000 per child. The average duration is estimated to be three years.
5. Children who realize partial or minimal effects will use family support services to age 22, i.e. for 18 years.
6. During adulthood, those who achieve partial effects will use 18 years of Medicaid waiver (or equivalent) services and 15 years of supported work services.
7. During adulthood, of those adults for whom minimal effects are obtained, 80% will use waiver services for 20 years, 20% will use intensive community services for 23 years, and 40% will use supported work services for 15 years.

Calculating Projected Costs and Benefits

We summed the costs of all public entitlements to early intervention, education, family support, adult services, and Social Security benefits for people with autism. Then, we factored in earnings in adulthood using the 1996 median household annual income to estimate earnings by individuals who are diagnosed with autism or PDD as young children but achieve normal functioning by adulthood, and supported employment wages for those who do not.

Costs and savings were estimated for individuals who achieve normal range effects, partial effects, and minimal effects from EIBI and for differing proportions of groups of children with autism/PDD who achieve normal functioning (i.e., 20%, 30%, 40%, 50%). In the article we show projected present value, current cost, and cost with inflation. A great deal of additional information is provided regarding the exact methods used to project costs.

Summary of Results

Table 1 Estimated Net Costs and Savings of EIBI, Ages 3-55 years.

Net Savings/Cost	**Amount**
NET SAVINGS for typically developing person	$1,597,049
NET SAVINGS for child with autism/PDD who achieves normal functioning	$1,475,791
NET COST for child who realizes partial effects	$3,368,469
NET COST for child who makes minimal gains	$4,404,482
NET SAVINGS for child who realizes partial effects ($4,404,482. - $3,368,469)	$1,036,013

The net savings for a typically developing person shows the cost benefit of providing public education K-12 to a typically developing person through adulthood, i.e., career income minus costs of education. The net savings for a child with autism/PDD who achieves normal functioning has a similar basis, except that costs for early intervention and preschool age support services are included. The net cost for a child with autism/PDD who makes minimal gains is the cost of services for 52 years, less income from supported work. Net savings to age 55 for a child who achieves partial effects are the difference between "minimal gains" costs and "partial effects" costs. Below we show the range of average weighted cost benefits (savings) per child, based on differing levels of effectiveness of programs, per hundred children. For this reason, the savings we show below cannot be calculated directly from the costs shown in Table 1. The steps used to estimate these ranges are shown in the full article.

Estimated Savings Per Child, 3-22 Years. Average savings to the educational system range from $298,651 to $274,709 depending upon the proportion of children - 20, 30, 40 or 50% - who achieve normal functioning levels. Surprisingly, because children who achieve normal functioning continue to incur costs throughout the school years, i.e. the costs of regular education services, the largest savings actually come from the children who achieve partial or moderate gains from EIBI. This aspect of savings is not shown in Table 1 but is shown in the full article. The average cost savings are roughly equal to total regular education costs in Pennsylvania for a child from K-12.

Estimated Savings per Child, Ages 3-55 Years. The average savings per child to age 55, again depending on the proportions of effectiveness of EIBI, range from $1,686,061 to $2,816,535. There are a number of factors that cause the savings to be greater through adulthood. The most important considerations are that a person may use adult human services for a longer period of time than they attend school during their life span, and that some adult human services have annual costs higher than the annual costs of special or intensive special education.

Discussion

Investing in high-quality EIBI for children with autism is likely to pay handsome dividends for the various systems that are charged with providing services to these individuals. For the purpose of the present analysis, the initial investment was estimated at just under $100,000 per child ($33,000 per year for 3 years). This was the average cost in Pennsylvania in 1996. This figure probably is lower than present costs. Using $150,000, or $50,000 a year for 3 years, the estimated savings are still substantial. In either case, the overall average savings are estimated to range from well over $1 million to over $2 million per individual across the life span.

There are a number of potentially problematic features in the assumptions we made in conducting this analysis. These are discussed in detail in the published article, and involve assumptions about future costs, future service use, and levels of inflation, among other features. As indicated, a major qualifier is the rate of attainment of normal functioning, but it is important to note that moderate gains from EIBI result in substantial savings.

Another question is: "How do these costs and benefits of EIBI compare with other forms of early intervention for children with autism/PDD?" The question, unfortunately, cannot be answered, because, to date, comprehensive outcomes using nonABA interventions have not been documented. We simply do not know how many, if any, children who have received other forms of early intervention have achieved normal functioning, moderate (partial) gains, or minimal benefits.

Like effective treatments for other severe childhood disorders, such as cancer, early intensive behavioral intervention can be described as aggressive, intrusive, expensive, and necessitating a high level of specialized expertise for effective delivery. The decision to invest in intrusive, expensive treatment for childhood cancer is usually based on several factors, including the scientifically demonstrated efficacy of other treatments, and the probable consequences of pursuing other treatments or no treatment at all. If a child with a major disorder needs treatment, cost is usually not a major factor; various public and private resources are typically made available to cover the costs. Many parents and professionals are beginning to insist that the same considerations apply to the treatment of children with autism/PD. We should all recognize that the most expensive interventions are those that fail to produce meaningful, measurable, lasting benefits, regardless of cost.

References

[This is a partial listing of relevant references, some of which are cited above. A complete listing may be found in the original article.]

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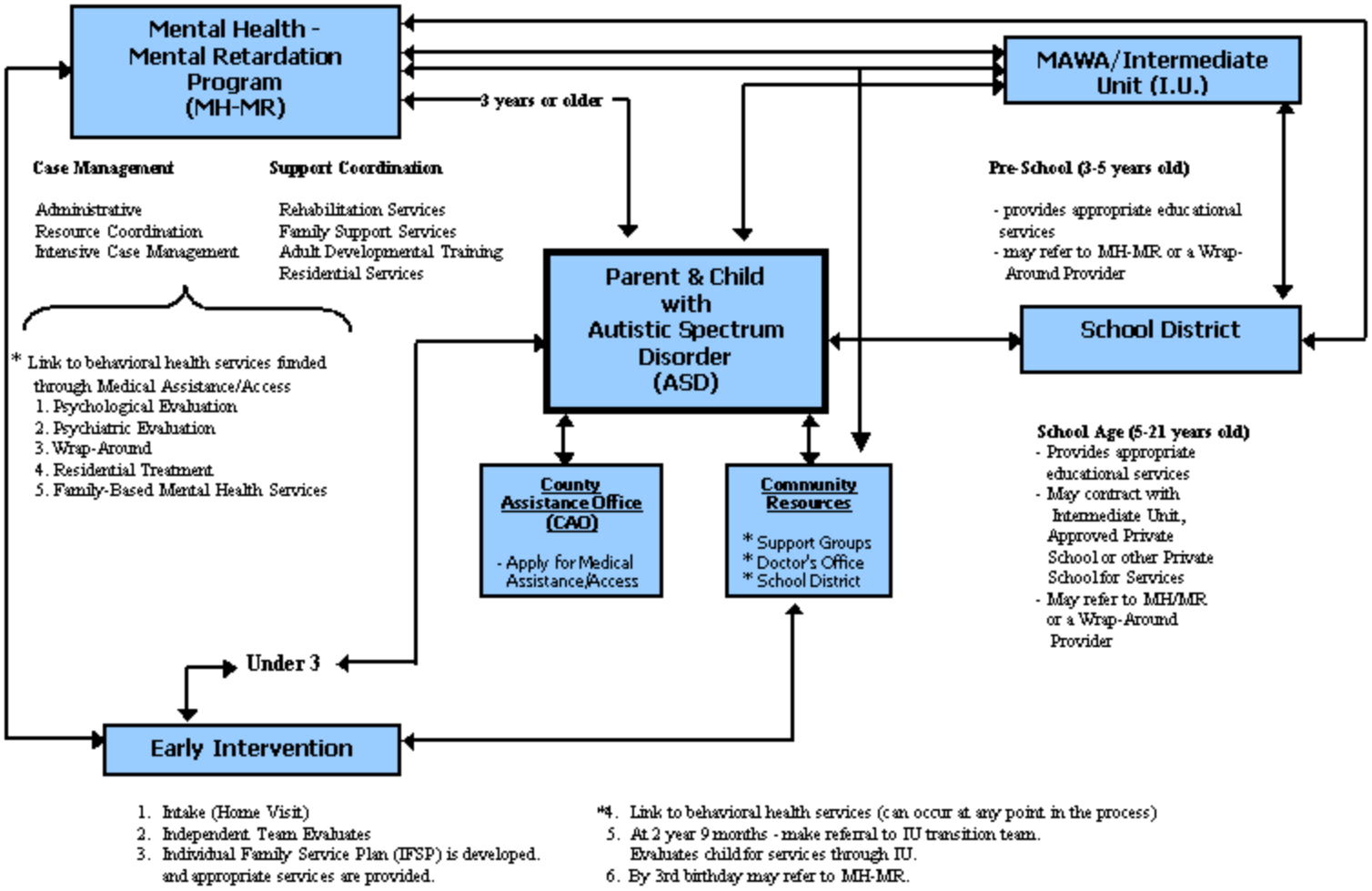
Attachment 2



The chart above shows the flow chart of services for the Parent and Child with Autistic Spectrum Disorder.

The Parent & Child with Autistic Spectrum Disorder (ASD) is in the center of all the services available and works directly with these areas:
Mental Health - Mental Retardation Program (MH-MR)
MAWA Intermediate Unit (I.U.)
School District
Early Intervention
County Assistance Office (CAO)
Community Resources

These areas are defined as follows:

Mental Health – Mental Retardation Program (MH-MR) for children 3 years or older Involves Case Management:
Administrative
Resource Coordination
Intensive Case Management

The link to behavioral health services is funded through Medical Assistance/Access and includes these services:
1. Psychological Evaluation
2. Psychiatric Evaluation

3. Wrap-Around
4. Residential Treatment
5. Family-Based Mental Health Services

The MH-MR Program is also involved with Support Coordination:
Rehabilitation Services
Family Support Services
Adult Developmental Training
Residential Services

The MAWA/Intermediat Unit (I.U.) is for Pre-School children 3-5 years old. It provides appropriate educational services and may refer to MH-MR or a Wrap-Around Provider

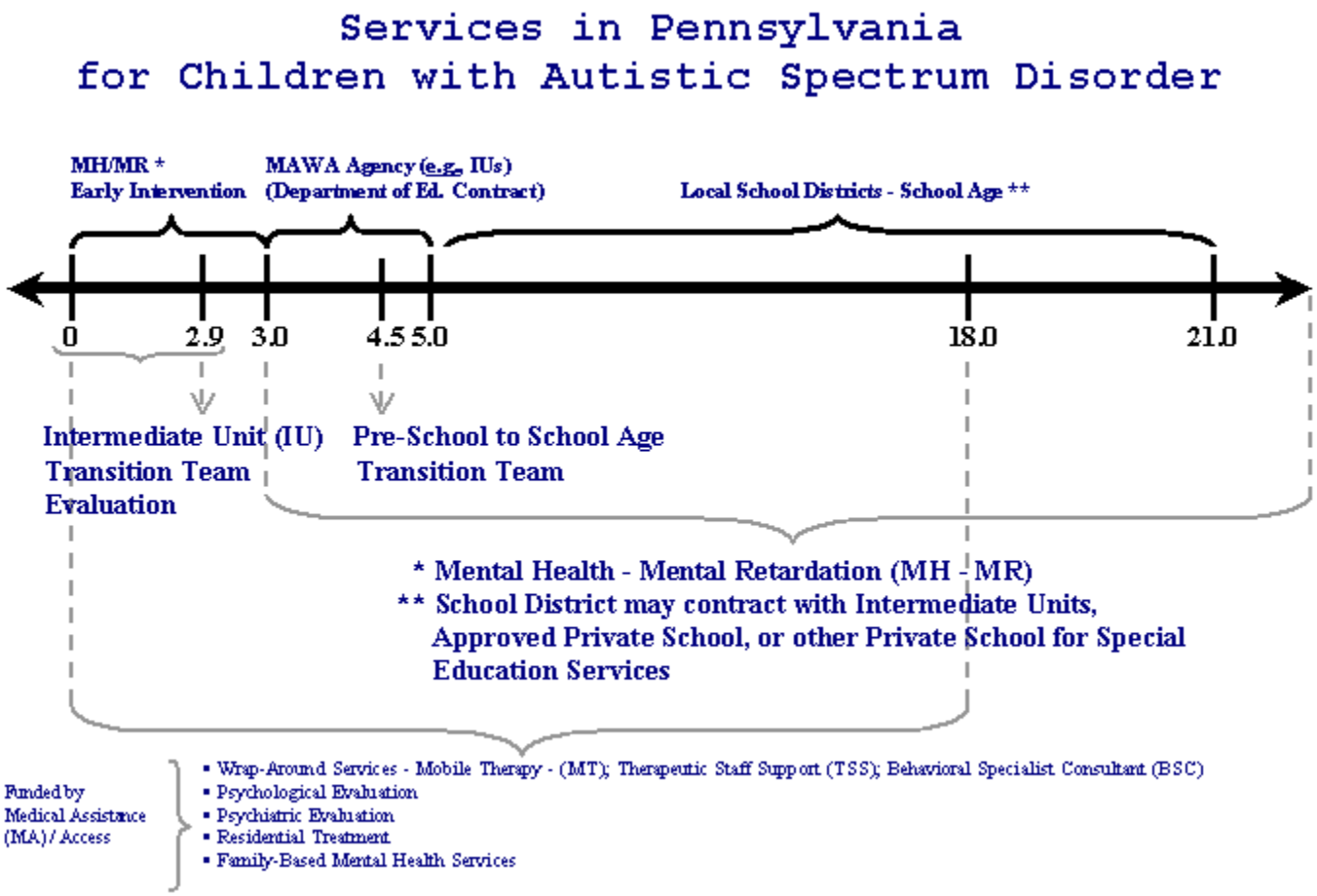
The School District is for School Age children (5-21 years old). It provides appropriate educational services, may contract with the Intermediat Unit, an approved Private School, or other Private School for services. It may also refer to MH-MR or a Wrap-Around Provider.

Early Intervention is for children under 3 years old and includes the following services:
1. Intake (Home Visit)
2. Independent Team Evaluates
3. Individual Family Service Plan (IFSP) is developed and appropriate services are provided
4. Link to behavioral health services (can occur at any point in the process)
5. At 2 year 9 months – make referral to IU transition team. Evaluates child for services through IU.
6. By 3rd birthday, may refer to MH-MR.

The County Assistance Office (CAO) provides services to apply for Medical Assistance/Access

Community Resources includes support groups, Doctor's Office services and School District services

Attachment 3



The chart above shows the time line of services for children with Autistic Sepctrum Disorder:

From 0-2.9 Years of age:
Intermediate Unite (IU)
Transition Team
Evaluation

Older than 3 years of age:
Mental Health – Mental Retardation (MH-MR)
School District may contract with Intermediate Units, approved Private School, or other Private School for Special Education Services

4.5 Years of Age:
Pre-School to School Age
Transition Team

0-18 years of age:
Services funded by Medical Assistance (MA)/Access:
Wrap-Around Services – Mobile Therapy (MT); Therapeutic Staff Support (TSS); Behavioral Specialist Consultant (BSC)
Psychological Evaluation
Psychiatric Evaluation
Residential Treatment
Family-Based Mental Health Services

MH-MR and Early Intervention services are for children 0-3 years of age.

MAWA Agency (e.g. Ius) and Department of Education contracts are for pre-school childrent 3-5 years of age.

Local School District services are for school age children 5-21 years of age.

07. Medicaid Waiver

Developing a Medicaid Waiver Subcommittee Report

Submitted to the Honorable Estelle Richman, Secretary of the Department of Public Welfare and Task Force Co-Chairs, Dr. Nancy Minshew, Dr. David Mandell, and Nina Cote, LSW, MSS

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Report Summary

Individuals with autism and their families face pervasive and complex challenges in finding services to meet their needs in Pennsylvania. This is due not only to the spectrum nature of the disorder and its complexities, but because of the less than optimal fit of Pennsylvania's existing mental health and mental retardation systems. Parents and individuals who have accessed these systems have described barriers such as IQ, treatment modalities for mental retardation or mental illness and the gate keeping and rigid medical necessity standards of managed care organizations. This report will examine the current state of barriers and recommend the following solutions in detail:

- A developmental disability department within the Department of Public Welfare to house an autism waiver;
- Two aggregate autism waivers, one designed for children and one designed for adults, with a transitional period from 14-21 in which children could apply for the adult waiver under certain circumstances;
- Eliminate eligibility barriers which are based on mental health or mental retardation criteria, particularly IQ, and replacement of eligibility criteria based on functional assessment of individuals;
- Regional, rather than county, administration of waivers;
- A caregiver and individual education component, developed by DPW and reviewed by stakeholders, for parents and individuals applying for an autism waiver;
- A housing component for adults, established with non-waiver monies;
- Establishment of an autism waiver workgroup at the time DPW begins the CMS application process, including members from the waiver subcommittee;
- Inclusion of the waiver services and definitions crafted herein within the CMS waiver applications;
- Consideration of the expansion of non-waiver services (such as the Medicaid State Plan or other services) for individuals who will not meet the eligibility criteria for a waiver.

Through these recommendations and the discussion that follows, we hope to fulfill our mission and begin the steps necessary to improve the lives of Pennsylvanians with autism.

Section One: Introduction

A. List of Subcommittee Members

JOAN BERGQUIST, Parent from SE Region
COURTNEY DONOVAN, Parent from SE Region
DAVID R. FINE, Parent from SC Region
JANEEN GASCON, Parent from SC Region
DAVID GATES, Health Law Project from SC Region
CHARLES HOOKER, III, Provider from SC Region
PAULETTE HUNTER, Parent from NE Region
STEVEN W. JEWELL, Provider from SW Region
JEFFREY R. LAWSON, Provider from SW Region
VIRGINIA LEONARD, Parent from SE Region
MARTIN J. LUBETSKY, Provider from SW Region
BRIAN LUZIER, Provider from SC Region
JEFF PETRACO, Administrator (OSP) from SC Region
NANCY C. RICHEY, Parent from SC Region
CATHERINE SCANLON, Provider from SE Region
GEORGE R. SHADIE, Parent from NE Region
ILENE SHANE, Disabilities Law Project from SE Region
JOHN A. STEVENSON, Parent from SW Region
DEE TAYLOR, Parent from SC Region
LISA C. VINCK, Parent from SW Region
KATHLEEN WEAVER, Parent from SE Region
MARY WILDMAN, Parent from SW Region

B. Mission of the Subcommittee

The mission of the Pennsylvania Autism Task Force Medicaid Waiver Subcommittee (the "Subcommittee") is to develop a Medicaid Waiver(s) for children and adults with Autism Spectrum Disorders. The waiver(s) will be specially designed to provide continuum of service options unique to the individual's needs, providing them lifelong supports and services to lead successful, healthy and safe lives integrated in their communities.

C. Meeting Times and Formats

The Subcommittee set up meetings at locations in Harrisburg, Philadelphia and Downingtown on the following dates:

Saturday, September 6, 2003 10:30 a.m. - 2:00 p.m.
Sunday, September 28, 2003 11:00 a.m. - 2:00 p.m.
Tuesday, October 28, 2003 11:00 a.m.-2:00 p.m.
Sunday, November 9, 2003 11:00 a.m. - 2:00 p.m.
Sunday November 23, 2003 11:00 a.m. - 3:00 p.m.
Sunday, January 11, 2004 11:00 a.m. - 3:00 p.m.
Sunday February 8, 2004 11:00 a.m. - 3:00 p.m.
Sunday March 7, 2004 11:00 a.m. - 3:00 p.m.
Sunday, April 25, 2004 11:00 a.m. – 3:00 p.m.
Sunday, May 16, 2004 10:00 a.m. – 12:30 p.m.

Through the Department of Public Welfare, facilitators arranged for speakerphone conferencing for members in Western Pennsylvania and others who could not attend in person. In addition, there were at least two members who could not attend meetings in person or by phone who contributed via emails to the facilitators. Facilitators attempted phone calls to members who had either no participation or low participation to advise them of upcoming meetings where decisions would be made.

Subcommittee members shared the responsibility of drafting agenda for each meeting, which were emailed to members for proposed additions or changes. Each agenda reviewed "Old Business" (such as reviewing points of consensus, discussing research results yielded from members' assignments, discussing input from the other Autism Task Force Subcommittees, etc.) under Old Business. Under "New Business," members discussed the following:

- Additional research steps necessary to understand waiver rules and requirements as well as existing waivers throughout the country;
- Presentation of research on waivers from other states and options for Pennsylvania in crafting an autism waiver;
- Practicality of one waiver (adults and children) or two separate waivers for children and adults;
- Priority of services to be included in a waiver;
- Service limitations;
- Administrative entity best equipped to house autism waiver services;
- Housing continuum options for adolescents and adults with autism;
- Funding sources and options for one or two proposed waivers;
- Other existing or potential services outside the scope of a Medicaid waiver for children with autism;

The Subcommittee also distributed research documents, minutes of meetings, meeting notices, drafts of the report and other necessary communication via email and fax. Members created a service list and completed a "Priority Form Survey" for children and adults to reach consensus on priorities for waiver services for children and adults. Work groups consisting of two or three members met with lawyers for the Health Law Project in Harrisburg and Disabilities Law Project in Philadelphia to create charts with various options, to outline the benefits and disadvantages of the various options and to develop working definitions of the services to be included in the waiver(s). The charts were sent via the Internet as well as discussed at Subcommittee meetings. The charts and survey also offered an opportunity to those unable to participate in person or by phone to voice an opinion via email if they so desired. Eventually, the priority lists served as a tool to determine which services should be recommended as unlimited within the waivers.

D. Report Formulation

Members proposed slight changes to the general format of the report in order to make it more relevant to the topic of waiver recommendations. Therefore, Section 2(C) was incorporated with 2(B) to read "Provider/Administrator Perspectives". Sections 3 and 4 categories (C) were also combined with (B) for provider/administrator perspectives. Various members wrote draft portions of the report for consideration, which were incorporated into a draft report distributed for further discussion. A number of members shared the challenges of single and low-income parents in fighting for services and systems for these families. Another group with access challenges is individuals with autism and another disability, such as hearing impairment or epilepsy. We include a brief section on "Access Challenges" to address these concerns.

There are two final issues to address with respect to the development of the Subcommittee's report. First, on some issues, there were significant divergences of opinion such that a report that included only the majority view would be inappropriate. In those cases, the report attempts to convey the minority view. Second, as noted above, some members of the Subcommittee were not able to attend all meetings, and others did not attend any. Because the Subcommittee did not wish to publish a report that included a person's name without insuring that the person had an opportunity to review and comment on the matters addressed in the report, the facilitators circulated this final draft by e-mail (or, where necessary, by United States Mail) to all those listed by DPW as members of the Subcommittee. All were asked to read the report and, if it adequately reflected their views. Those who indicated otherwise, or who did not respond, are not listed.

Section Two: State of Current Practice

A. Family Perspective

Education Services Group consensus was that education services alone are insufficient to meet the pervasive needs of children with autism, and many children will need additional services through Medicaid, whether it is through EPSDT **(1)** (the existing Medicaid state plan) or through an autism waiver. Problems with the education system mirror problems identified in other states. The education system in Pennsylvania for persons with autism spectrum disorder ("ASD") uses a service structure designed for individuals with mental retardation (e.g., with life skills classes) or mental health problems (e.g., with classes for those with social and emotional disturbances). Teacher training has not focused on autism and most teachers know little about autism. State initiatives have not reached down to staff (regular educators, bus drivers, cafeteria workers) who encounter children with autism daily. Since schools lack the resources, expertise and ability to serve students with autism, students are frequently in self-contained or out-of-district placements unless parents become the sustaining force for an alternative setting. In addition, slots in approved private school placements are few and children sometimes end up in inappropriate placements because appropriate placements are limited.

(1) Early Periodic Screening, Diagnosis and Treatment. Children with autism may currently access Occupational Therapy, Speech Therapy, Physical Therapy, and some medical services through Medical Assistance and school district funding. Behavioral Health Rehabilitation Services ("BHRS" or commonly known as "Wraparound") are heavily utilized through this portion of the Medicaid State Plan.

The Subcommittee gave consideration to Maryland's waiver model, one of only three states that have an "autism specific" children's waiver. Maryland's waiver is administered by the school system. The Subcommittee unanimously rejected the option of giving schools Medicaid waiver money to administer. No parents or providers expressed an interest in pursuing this system or delivery of waiver services in Pennsylvania.**(2)** The following points were considered in making this decision:

- The education system currently struggles with providing a free appropriate public education to the increasing number of children with autism. Therefore, to add significant additional responsibility would be imprudent;
- There are 501 different school districts in Pennsylvania, which could result in a lack of uniformity in waiver implementation;

- Traditional waiver services are outside the scope and responsibility of those the department of education provides. Therefore, members expressed concern that the education system lacks the administrative infrastructure to implement home and community waiver services. Moreover, most services encompassed within a waiver are outside the scope of the mission of education;
- The education system in Pennsylvania serves individuals to age 21. Adults with autism, therefore, are ineligible for services provided through this system.

(2) The federal Office of Special Education Programs (OSEP) cited Pennsylvania in 1998 for multiple violations of the Individuals with Disabilities Education Act. Pennsylvania is still in the process of implementing corrective actions for these citations. In addition, of concern of the Subcommittee was that there should be greater uniformity in service access across Pennsylvania. Having 501 school districts administer any new waiver(s) did not seem likely to meet that goal.

Mental Health/Mental Retardation Systems There was general agreement that Pennsylvania's existing Medicaid waivers in the mental- retardation system were nearly impossible for children or adults to participate in. The Subcommittee noted some of the deficiencies of employing the existing mental-retardation system to provide services to persons with autism:

- Persons with autism whose IQ is below 70 are considered to have mental retardation and referred to the Mental Retardation System where services are not appropriate and where decades-long waiting lists may make access to waiver services impossible while parents or other caretakers are still living; Persons with autism whose IQ is above 70, but who are nevertheless limited in living independently, are considered to have mental illness and end up in the Mental Health system **(3)** ;

No other disability labels are relevant to qualify for autism services as systems are currently configured, so persons with autism must seek to qualify as having either mental retardation or mental illness to receive services in Pennsylvania.**(4)**

(3) There are Medicaid waiver services in both the mental retardation system (OMR) and Office of Social Programs ("OSP"); there are no waivers in the mental-health system (OMHSAS) because there are no Medicaid ICF services to be "waived."
(4) One exception to this would be in the education system applicable to those under the age of 21. In that system, the federal overlay includes a category specific to autism.

The cultures of the Pennsylvania Office of Mental Retardation ("OMR") and the Pennsylvania Office of Mental Health and Substance Abuse Services ("OMHSAS") are not conducive to the needs of individuals with autism. Adults with autism in the MR system are considered to have the intellectual age of children and placed in group homes, or they might not receive services at all. Staff act as surrogate parents and provide care giving in homes owned by providers.

Adults and children who gain access to services through the mental-health system are given medical treatment. Adults and children served by MH are considered to have mental illness and are sometimes presumed to be in need of pharmacological and psychotherapy treatments. Members of this subcommittee reported that some managed care organizations ("MCOs") have recommended or, in some cases, demanded that elementary school children be placed on psychotropic medications rather than better-tested interventions. Currently, in the Southeast region, counties and MCOs such as Magellan are insisting nonverbal children have mobile or "talk" therapy in lieu of therapeutic staff and behavior specialist consultant services. Adults with autism in crisis are often placed into mental hospitals, some of which may not have staff equipped to treat developmental disabilities and, thus, mental illness medical treatment is applied. These services are costly, ineffective and waste resources that could be applied elsewhere to appropriate services.

Office of Social Programs Pennsylvania's Office of Social Programs ("OSP") has traditionally been a small agency to serve persons with disabilities not served by OMHSAS or OMR. The majority of those served have been persons with physical disabilities, although OSP has served as a "default" agency in state government for those who do not fit into existing systems. There is currently an autism pilot program (addressed in greater detail below), which is housed in OSP.

Although individualized applications of treatments within MH or MR categories may be helpful in some cases (e.g., teaching of life skills, individualized use of medication as an adjunct to other treatments), it is critical to regard autism as a distinct disability so that treatments can be appropriately tailored to individuals with ASD. Not only can inappropriate treatments designed for people with mental disorders or mental retardation be ineffective if not tailored to the individual, but in some instances they could be counter-productive or harmful. For example, individuals with autism are extremely sensitive to medications and do not always respond as expected. The needs of individuals with autism cross various systems domains and require additional services that are currently not anticipated or provided within existing systems. Therefore, autism needs its own specific system for those who do not fit into existing systems.

Although OSP does not require that services be based on IQ, Pennsylvania's IQ-driven culture has affected the pilot program in that persons participating with low IQ have been rejected during the second round of selecting participants for the autism pilot, contrary to earlier agreement in the autism pilot work group. In contrast to the caretaking culture of OMR and the medical- treatment culture of OMHSAS, OSP has primarily served persons with physical disabilities who were able to advocate for themselves. Therefore, OSP has fostered a culture of "independent living." Families of those served by OSP are not usually deemed to be stakeholders. Independent living agencies, which are governed by - and employ - a majority of consumers, direct some of the case management and service provision in this system.

Office of Vocational Rehabilitation Parents have reported that the Office of Vocational Rehabilitation ("OVR") generally provides short-term services (contrary to what most adults with autism require for success), and that the job coaches may not be well educated or trained in how to coach persons with autism. The service OVR provides has a long wait-time and is not well suited to the long-term kinds of job support persons with autism, pervasive developmental disorder ("PDD") or Asperger's Syndrome may require.

Office of Children and Youth No representative from this office participated in the Subcommittee. We recommend a representative be sought for input on systems coordination with respect to children with autism.

According to statewide meetings conducted by DPW in July and August 2002 involving the eastern, central, western and northeastern regions of Pennsylvania, there is great consensus among parents, providers and systems administrators that Pennsylvania's delivery of services to person with autism is:

Decentralized, fragmented, complicated, and difficult for parents to navigate…[with]…only the most skilled and aggressive parents…able to obtain proper service for their children. **(5)**

(5) Pennsylvania Department of Public Welfare, EIBI Public Meetings Report, November 2002, Executive Excerpts pp. 1, 7

B. Provider/Administrator Perspectives(6)

Services Across and in Coordination With Other Systems There is very little coordination of services across the systems. The lack of adequate case management has proven to be a barrier in effective communication and understanding of the roles and responsibilities of both providers and the educational system. This lack of coordination has caused mistrust between the systems at the ultimate expense of the clients.

Parents have been left without any direction with respect to whom to trust or what services to turn to for help. We are left with a system that spends more time pointing fingers and almost none seeking a common solution. There needs to be a bridge between the systems that would allow for full access of services for clients and their families. Both the educational system and behavioral health providers need to build a bridge of unity, which needs to be continually supported by the Commonwealth.

Circumstances Under Provision of Services BHRS, a.k.a. wraparound services, was first developed in Pennsylvania as a result of a lawsuit in which a child needed behavioral health care that would allow him

to receive services in the least restrictive environment. Residential treatment and hospitalization were deemed very restrictive and intrusive; the answer to this lawsuit was then to wrap the services around a child so that the child would not have to leave his or her home, school, and community.

In 1994, the Commonwealth developed specific regulations to help guide these services and the roles of the mobile therapist ("MT"), therapeutic staff support ("TSS"), and behavioral specialist consultant ("BSC") were defined. The intent of wraparound services was to follow the CASSP principles of least -intrusive, least- restrictive, child-centered, and family focused. The Commonwealth also defined the service as one based on medical necessity. In other words, the child needed to be at risk of being placed out of his or her natural environments before that child could be considered eligible to receive such a service. Wraparound services were also defined to be temporary in such a way that the clinical team would "get in and get out" as fast as "medically necessary."

In the years that passed, there had been accusations of abuse of the system by providers and of poor management of services by the Commonwealth. The Commonwealth, which set up the original regulations, did not have the ability to regulate the system properly due to the continual influx of children into the program. Thus the Commonwealth answered with the introduction of managed care and the oversight by each county.

On July 1, 2001, another lawsuit settlement brought about changes to the system. See Kirk T. V. Houstoun, No. 99-3253 (E.D. Pa.).. This settlement further defined the qualifications of staff, regulated staff training, and tried to deal with the issue of staffing cases.

If there is more oversight of the program, better guidelines for training, better guidelines for staff qualifications, and more accountability for the staffing of cases, why then are we still having so many problems? Why are so many families still not able to obtain the services so desperately needed for their children?

The answer to one of these problems is the term, "medical necessity," which has traditionally been defined as the needs of an individual with a condition that requires acute treatment. When we are addressing the needs of children with diagnoses such as autism, attention deficit disorder or obsessive-compulsive disorder, there is a need for flexibility in determining the most appropriate interventions and a need for long-term service provision. There are methods of intervention to guide us, but each child is unique and so are his or her environments. If the intent is to keep the child in his or her own environment, then it should be clear that we need to be tailoring services for each child instead of insisting that services look the same for each child. Thinking outside of the box does not mean we cannot have regulations to guide us; it does mean that we should not rely on regulations designed for other situations.

Another problem is the fact that every county and MCO has its own interpretation of the regulations. In some counties, the BSC can bill for writing the treatment plan, while in other counties the BSC may only bill for face-to-face services. Some counties have even gone as far as to limit the accessibility of services by the implementation of an initial extended assessment.

Though in theory, extended assessments could be a valuable tool, the reality is that it has been more of barrier to services and the cause of fear for some families. This inconsistent application of the regulations has proven to be confusing to both families and providers and one of the barriers in providing quality services to the children. There is inconsistent application across counties.

Ironically, in areas in which we need consistency, we have widely varying interpretations, and, in the areas where we need flexibility, we have rigidity. There needs to be clearly defined regulations regarding the structure of the service, but flexibility with treatment or methods of intervention. The Kirk T settlement did help to address some of these issues, but it did not go far enough. Training for TSS workers has been defined, but qualifications for TSS workers still need to be addressed. Now a TSS worker does not need a Bachelor's degree, but a TSS without a degree is required to have a minimum of 60 credits and three years full time experience working with children. It is actually easier for a provider to find a degreed individual rather than a junior in college who has worked three years full time.

It makes no sense to have a system developed for other situations but crudely tailored by lawsuits to address the needs of persons with autism. A panel of parents, providers, and administrators should be convened to develop a more consistent application of services and definition of terms such as "medical necessity". Additionally, we need to ensure that we do not box ourselves in a system that is inflexible. We need to be thinking outside of the box, this includes adding additional and more appropriate services to BHRS.

(6) Provider input was achieved via one conference call with providers/administrators and the input of the provider(s) most active in the Subcommittee.

Section Three: Problems with Existing Practices

A. Family Perspective

Barriers - As noted in Section 2, the configuration of Pennsylvania's systems presents the most barriers for both children and adults with autism.. Policy and funding at the Commonwealth level drive services and expertise at lower levels. Therefore, the configuration of a state that still considers itself as serving those with mental illness or mental retardation alone presents the following barriers:

- For persons with autism, only mental retardation and mental health services are available through county services. This adds to the de-centralized and fragmented nature of services for persons with autism. Although some counties have cooperative arrangements, this still creates dozens of different levels and qualities of service that vary according to a person's home county. As noted in DPW's EIBI Public Meetings Report, although there was general agreement about the systemic problems and need for solutions, the Southeast region participants had harsh criticism of the quality of and access to services due to the low quality of services in their region, while Western Pennsylvanians had some complimentary things to say about services in their region **(7)**.
- The education system in Pennsylvania has 501 different models of service provision, since school boards and districts create special education models and programs independently, with only cursory approval and oversight by the Pennsylvania Department of Education. Twenty-nine intermediate units ("IUs") also exist to assist school districts. However, school districts have the option of funding or utilizing IU programs. This makes for inconsistent regional availability of appropriate education programs for children with autism. For example, the Bucks County Intermediate Unit has more than 50 autism support classrooms. In contrast, the Delaware County Intermediate Unit has developed only a handful of classrooms for autism.
- **The MR Person and Family Directed Services Waiver** provides services for those who do not require a licensed residential program. It is capped at $21,225 per person per year. Generally this is used to gain Federal Financial Participation ("FFP") for services of sheltered workshops and day programs for individuals cared for by their parents. Persons with autism receiving services from this waiver must have mental retardation as a primary disability. Even if a person has significant functional limitations, if IQ is above 70, they are ineligible.
- **The MR Consolidated Waiver** provides services including residential services. This is an aggregate waiver. The aggregate cost of the waiver cannot exceed the cost of an Intermediate Care Facility for Mental Retardation ("ICF-MR"). A very small number of persons with autism are using this waiver and only if they have a primary diagnosis of mental retardation. Most people utilizing this waiver have no living parents or caregivers. Services in both MR waivers are specific to the needs of individuals with mental retardation. Clients who exhibit problem behaviors (common for persons with a diagnosis of autism) are placed in MH crisis services. **(8)**
- **The OBRA Waiver** is currently being used by persons in the 20-person Autism Pilot Program. This waiver is funding a range of services and hours of services for adults in the Autism Pilot Program, initiated by a joint OSP and Autism Living and Working, Inc. ("ALAW") working group.

* In order to obtain either the MR Person and Family Directed Waiver or the MR Consolidated Waiver, individuals must have:

1. an IQ under 70 **(9)**
2. Prioritization of Urgency of Need for Services ("PUNS") **(10)** classification of "Emergency" - no caregiver available;

3. Apply at County OMR office, document eligibility, and be placed on a waiting list; and
4. sometimes political "pull" is needed in some counties.

* In order to obtain the OBRA Waiver, an individual must:

1. be selected by OSP from information finders filled out and submitted to ALAW and forwarded to OSP;
2. demonstrate "three-functional limitations" federal eligibility standard;
3. have eligibility determined by OSP administrative entity (UDS of Lancaster); and
4. Develop individual service plans and budgets via UDS case management;
5. the pilot program is capped at 20 people.

Services Needed, But Not Currently Available - The attached survey and chart of results shows the subcommittee's development of service categories considered to be critical for inclusion in any Medicaid waivers for children and adults. The subcommittee met on November 23, 2003 to finalize the following categories of recommendations for Solutions (Part 4)

1. Administrative entity to house Autism Waiver and Medicaid Services;
2. Advantages to administration of one waiver (Child/Adult) versus two Waivers (Children's Waiver and Adult Waiver);
3. Funding recommendations regarding waivers;
4. Service descriptions to be included in waivers;
5. Services suited to limitations under waivers and those which should be considered for "unlimited" status;
6. Continuum of housing and other community service recommendations;
7. Recommendations for Medicaid services outside the scope of waivers.

The Subcommittee convened workgroups to write recommended service descriptions for inclusion in the development of any waiver. The full Subcommittee discussed and finalized these recommendations on Feb. 8, 2004 for the Report. The recommended service descriptions within this report were crafted from existing waivers. such as OBRA, Commcare, MR Consolidated and the Maryland Autism Waiver. The Subcommittee recommends strongly that DPW consider utilizing these in any application for an autism waiver and that housing funding be an additional component.

Access Challenges and & Differences

Under the best of circumstances, it is difficult for families to obtain services. There are cultural differences such as income, family configuration, regional and particularly families of children with multiple disabilities that make the challenges even more formidable.

The composition of the waiver subcommittee demonstrated the fact that it is difficult, if not impossible, for parents of differing cultural perspectives and socioeconomic status to access or impact systems. We had fewer minority parents participating, fewer low-income parents participating, fewer single parents, only one participant whose child had multiple disabilities and no participants from rural regions. The group had 100 per cent consensus that, although Pennsylvania systems are difficult to navigate,navigate; families with more education and income were more easily able to gain access to them because of the ability to sift through complex grievance and legal processes. We identified the following cultural factors that could affect a family's access to any potential autism waiver services:

1. Low Income: Many parents find the need at some point to seek legal counsel or advocates in order to deal with systems which are either non-responsive or lack compliance in order to obtain the appropriate services. If parents cannot afford to seek legal advice or counsel, they may obtain less appropriate services than parents who can afford these options.
2. Single Parents: It is recommended that single parents be considered for any additional task forces relating to autism. Family life for those with children with autism is difficult, even with two parents contributing to a child's well being. Single parents will have a unique perspective on how much more difficult raising a child with autism is in a single-parent family.

3. Rural Families: We echo the recommendations of the rural subcommittee report with respect to the challenges of obtaining services in a rural region and look forward to their comments for the Waiver Report.
4. Families in Major Cities: We recommend representation from Pennsylvania's major cities be sought in the future. Parents have unique challenges with schools and services in cities.
5. Families of Children with Multiple Disabilities: Some children with autism have additional co-occurring conditions such as blindness, deafness, physical disability, etc. The problems of access, training and appropriate services, in relation to children and adults in Pennsylvania with autism, are exacerbated when an individual also has another disability. One example of this is a child who has autism and is deaf. It is imperative that this unique subset of individuals be provided with professionals that are fluent in American Sign Language. This includes those that give assessments and provide direction interventions/support. It is an established fact that those with Autism Spectrum Disorder have impairments in language and communication. These difficulties often compound behaviors that result from frustration. These behaviors are accentuated when the individual cannot communicate because therapists/providers are not fluent in their native language.

Special consideration should be given to this and similar problems. For any person with autism, that difficulty will be compounded if the staff must also be fluent in American Sign Language. Perhaps, this skill could qualify for a higher rate differential. This may also be necessary for other subsets of children who have another severe co-occurring disability such as blindness, physical disability, etc.

(7) Pennsylvania Department of Public Welfare, EIBI Public Meetings Report, November 2002, p. 1
(8) See Joint OMHSAS and OMR Bulletin 00-02-16, issued December 17, 2002.
(9) Research has shown that IQ testing in persons with autism is often inaccurate and unreliable due to the verbal and social participation level necessary in taking IQ tests.
(10) The PUNS is a questionnaire developed by OMR and administered by the Counties in consultation with families. It is used for rationing of waiver services in an attempt to serve persons with the most critical needs first.

B. Provider/Administrator Perspectives

Barriers - Inconsistent support from some counties and managed care organizations as well as inadequate management by some providers are proven barriers in the providing of adequate services. Poor resources, lack of communication, insufficient training, and financial interests have continually been obstacles in determining "medical need" vs. budgetary concern. Antiquated evaluation tools, inadequate funding, and continually stereotyping have also been barriers to service.

It is difficult for families to secure the "medically necessary" services for their child when these services aren't available, inadequate, or being denied due to poorly trained staff. As a provider it is difficult to explain to a parent, who is desperate for help that the one such barrier to service is a lawsuit that has limited funds and shifted blame for the lack of services solely on the provider itself. Since Kirk T **(11)**, EPSDT providers have been asked to provide 39 hours of training, onsite supervision, weekly supervision with a supervisor that can only be responsible for 9 full time equivalent TSS workers, and ongoing training without any increase in the payment schedule. The State has also pushed the documentation of the monthly reporting of hours authorized and provided onto the already under funded and overworked provider. There has never been any training or support given to the providers to help with this "burden". The only requirement from the state has been that the current hourly rates should cover the cost. There are still many children not receiving services.

Regulations are important as they help to promote consistency and high standards of care. However, the results have been:

1. inequality and variability of services county by county and
2. requirements by some MCOs resulting in low authorization and barriers.

The family may be left with a prescription for service that is both inadequate and unstaffed as the providers have begun closing their doors.

Services Needed By Persons With Autism, but Not Currently Available - Services include, but are not limited to the following:

1. Respite services
2. Case management/Case coordination, including independent case management or brokerage
3. Life Skills
4. Social Skills/Social Competency Groups (both for children and for adults with Asperger's Syndrome and High Functioning Autism)
5. Housing **(12)**
6. Communication Skills.

For a more complete listing of waiver services needed, please see "Waiver Service Descriptions" within this report.

Problems with Existing Organization and Payment - Payment for services rendered can be adversarial. Providers have 60 days from the date of service to submit payment or be denied any payment at all. Providers are scrutinized if they do not provide all prescribed services, if they bill for all the services they provide and if they are willing to have larger caseloads even though the initial evaluation and authorization come through a BSU **(13)**. This may result in providers not getting paid.

Currently, there is movement in the State to reduce TSS hourly payments from $30/hr to $26/hr, which would be a hardship, especially for smaller providers. Limiting Behavior Specialist Consultants (BSCs) to face-to-face contact, having Mobile Therapists (MTs) writing behavioral plans, no reimbursement for travel and refusing to fund case management may save money, but it will do nothing to improve the quality of services.

Problems with System Coordination. - Counties are inconsistent in their views on how services should be implemented. Families face different barriers according to their county of residence. Families and individuals fear that financial interest may superced any "medical necessity."

(11) Kirk T., et al vs. Commonwealth of Pennsylvania, et al. is a legal action brought against Pennsylvania's Department of Public Welfare on behalf of children receiving Medicaid State Plan EPSDT services, specifically, behavioral health services, more commonly known as "wraparound." Part of the legal settlement agreement in Kirk T. was the provision that the Commonwealth require better training for staff working with children receiving this service and those providers and MCOs be accountable for delivering the hours of service approved for the child.
(12) Although housing is not a waiver service, it is a service necessary in order to live in one's community.
(13) Base Service unit, a part of the current County Mental Retardation Service System.

Section Four: Potential Solutions

Family Perspective

The members of the Waiver Subcommittee agreed that, while new systems are desperately needed, existing systems must remain available to persons with autism while waivers and other systems changes are under development. We recommend that DPW sustain oversight in this regard during what may be a lengthy transition to development of new systems for persons with autism.

Elimination of Barriers - There is consensus that the following activities should be conducted to eliminate barriers to services for persons with autism:

- DPW should develop an autism waiver for adults and an autism waiver for children as soon as possible;
- DPW should establish an autism waiver workgroup with representatives from the Medicaid Waiver Subcommittee for stakeholder input;

- DPW should, with help from the work group, and utilizing the service descriptions within this report, submit an application for an autism waiver with the Center for Medicaid Services (CMS);
- DPW should include a housing component for adults utilizing non-waiver monies;
- DPW should establish a bureau within an Office of Developmental Disabilities dedicated to the administration of an autism waiver or waivers with regional parent boards consisting of 51 per cent individuals or families of individuals with autism (See Administrative section below);
- DPW should give special consideration to ensure waiver services are as accessible to families with specific cultural issues such as low income, single parents, inner city families, rural families, families whose children have multiple disabilities, etc.
- DPW should strongly develop and define eligibility requirements for individuals with autism that are not tied to IQ.
- DPW should consider expanding the Medicaid State Plan to add services that could help maintain persons with developmental disabilities who do not fit into MH/MR and other groups in the community.

Administration of Autism Waiver

The waiver subcommittee has struggled with the issue of how an autism waiver should be implemented at the state and local levels. We explored various options and concluded that all options have both advantages and disadvantages. We have reached consensus on the following proposal.

Create an Office of Developmental Disabilities

We recommend that DPW create an Office of Developmental Disabilities alongside OMHSAS, OMR and OSP. We also recommend creating within that office a Bureau of Autism Services, headed by an individual highly knowledgeable about autism. Additionally, DPW should create six regional non-profit organizations each of which will be managed by a board of directors, 51 per cent of whom will be persons with autism or their family members. The responsibility of the regional entities would be to assure such things as intake, assessment, service management, service brokers, contracting for services and monitoring. It is the consensus of the families and advocates on the Subcommittee that the waiver model described here could not be properly implemented with a county based service delivery system. Flexibility should be considered in waiver development and it is recommended that the money follow the person in moving from one waiver to another.

Members struggled with the concept of creating a new bureaucracy. However, we feel it is the key element in fixing the current deficits in Pennsylvania with regard to misunderstanding of autism and appropriation of funds toward inappropriate services. Major themes emerged with strong feelings regarding why families of persons with autism object to being served in either MH, MR or OSP:

- MR eligibility is based on low IQ. Eligibility for autism services must be based on functional limitations; IQ is irrelevant.
- MR system lacks the capacity to accommodate any new group of individuals; many people are on the PUNS waiting list.
- The MR system's reliance on "natural supports" (person lives with unpaid family caregivers as long as possible) and on "family living" (services provided by a new family caregiver when parents die) does not provide adequate or appropriate supports for persons with autism and places them at risk of inappropriate crisis placements (i.e., mental hospitals).
- MR county-based service delivery system lacks understanding of autism and the needs of individuals with this disorder. Scarce resources are already stretched too thin and cannot accommodate new clients.
- Providers of basic MR services such as group homes, day programs, and sheltered workshops cannot accommodate most persons with autism since not all persons with autism handle group situations well; people with autism often get ejected or sent to psychiatric treatment programs.
- Autism is not a mental illness. Interpreting certain behaviors as symptoms of mental illness leads to inappropriate medical interventions.
- MH treatment models, involving inpatient stays alternating with periods of relative normal functioning, do not fit the chronic needs of persons with autism.

- MH community services tend to be larger residential treatment programs rather than self-determined living and working with supports; day treatment centers or clubhouses are too group oriented and unstructured to work for people with autism.
- MH county offices lack understanding of autism, lack resources to assist people with this disorder and lack programs that are helpful.
- MH models deny vital services related to treatment of autism's core deficits and restrict the very services which help ameliorate the behavioral difficulties (i.e., communication and social skill help, life skills training, sensory integration, etc.)
- MH providers offer therapies and other services that are governed by managed care models that restrict or terminate services unless improvement is occurring.
- OSP sees its constituency as physically disabled only. People with autism, who are seen as cognitively impaired, are outside its scope.
- The OSP service model, self-determination, is excellent, but the exclusion of families as stakeholders is not workable for the autism constituency at present.
- Some OSP regional administrative entities are Independent Living agencies who believe their funds are for physically disabled only.
- OSP administrative entities lack understanding of autism and lack familiarity with service delivery for those needing 24/7.
- OSP providers lack understanding of autism and are used to provide mostly ADL services. Billing system is cumbersome for clients needing around-the-clock services.

Rationale For a Developmental Disabilitites Office to Address Autism

The cluster of traits that are called autism result from neurological differences in a person's communicative, sensory, motor and social systems, which affect social interactions, communication, self-direction and executive function, interpretation of sensory input and capacity for living independently. Persons with autism can range widely in tested IQ, so low or high IQ is not a relevant measure in identifying autism or in determining a need for supports and services. Even persons of sufficient intelligence to attain college degrees can be severely challenged by everyday situations such as a sudden change in schedule or another person's offhand remark, requiring skilled assistance to successfully cope. Persons of high IQ may also have the intellectual knowledge of a subject, but not the executive function to manage their own life and social skills in order to maintain employment within their field of expertise.

Since autism includes persons along the entire IQ spectrum, a place in state government is needed where eligibility is not based on IQ, but on functional need. The federal category of Developmental Disability provides such a framework. Moreover, other persons with developmental disabilities such as cerebral palsy or spina bifida, whose families also have trouble accessing appropriate services in the current MH/MR system, could be accommodated in the DD office as well (if stakeholder concurrence from those disability groups is obtained from DPW).

The need for a cross-disability system in PA has been a topic of discussion for some 20 years, but these discussions have generally not included the autism community. Efforts at systems change have not succeeded due to resistance of some existing agencies and constituencies to adopting a new framework. Therefore, we suggest creating a new DD eligibility and service model alongside OMHSAS, OMR, and OSP and letting consumers sort themselves out, over time, among the various agencies.

In PA's MH/MR system, developed before the federal developmental disabilities language, eligibility is based on IQ: a disabled person with an IQ below 70 qualifies as MR. If the person has a higher IQ and has a disability, they must try to qualify for MH. Over many years, persons with autism have navigated this landscape by seeking to test low enough to qualify as MR or, failing that, trying to persuade the MH system to serve them. In recent years, the MH behavioral health system has provided some "wraparound" services and therapies to persons under age 21, though lately eligibility restrictions have limited access.

Consumers and families also attest to the fact that these services are not tailored to persons with autism, which contribute to inefficient use of funds, difficult systems, frustration among consumers due to inappropriate services and a risk for a higher and more costly level of care in institutions and hospitals.

As the default agency in PA, OSP's eligibility system screens out everyone who could qualify for MR or MH. As an example of this problem, candidates in the second phase of the Autism Pilot in OSP have been excluded if they have IQs below 70, despite the policy established by the Autism Pilot Program Working Group that the Pilot was to include persons along the full autism spectrum.

Not only do PA's current systems present eligibility problems for persons with autism, the existing service paradigms do not fit this disorder either.

The mental retardation system assumes a close correlation between IQ and functional deficits, so that anyone with an IQ much over 70 is deemed not disabled enough to need services. An adult with an IQ below 70 has the mental age of a child or adolescent, so MR services have a care-giving/custodial framework. However, a person with autism may have an IQ well over 70 and might need supports in order to function successfully, but these supports need to be accommodations and support independence skill building rather than caregiving.

The mental health (now behavioral health) system regards the behaviors of a person with autism as symptoms of mental illness for which therapies and medications are prescribed--but with the managed care requirement that improvement must take place. A person with autism may benefit from therapies or medication, but these will not cure autism or lead to a period of recovery. Indeed, reactions of individuals with autism to some medications can result in a worsening of symptoms. There is more recent information about the effects of psychotropic medications and autism, so this part should probably come out.

The Office of Social Programs main constituency is adults with physical disabilities who are mentally alert---people who can manage their lives and direct their staff, who mainly provide physical assistance with activities of daily living. A person with autism, in our view, does have a physical disability, but needs assistance with more than the basics of Activities of Daily Living.

Even the most challenged adults with autism see themselves as adults and want to be treated and respected as adults. All persons with disabilities deserve respect, particularly adults with disabilities. While adults with autism need assistance, some a great deal of assistance, that assistance needs to take the form of creating a prosthetic environment. The staff members are the wheelchairs, the sign language interpreters, the facilitators. They must maintain the agreed-upon schedule of activities through cues and prompts that are as unobtrusive as possible, so that the adult with autism feels confident--and in charge.

Minority Opinion: Utilize the Office of Social Programs to Address Autism

Some parents felt the Office of Social Programs, currently used to house the Autism Pilot program should remain as the office to serve autism for the following reasons.

The Autism Pilot Program (see "PA's Experience Using a Waiver Funded Program for Adults with Autism," Appendix E) has demonstrated the value of locating autism services for adults within the Office of Social Programs (OSP),rather than the Office of Mental Retardation (OMR) or the Office of Mental Health and Substance Abuse Services (OMHSAS), because:

- Eligibility for waivers in OSP is based on functional criteria, not the IQ criteria that apply to MR waivers. IQ is not relevant in determining the need for services to avoid institutionalization for persons with autism spectrum disorders.
- The model for adult services in OSP is independent living, which differs from the family caregiving model of OMR or the medical treatment model of OMHSAS. Adults with autism spectrum disorders want to be viewed as adults who can live and work in the community, not as children in need of continuing parental care, or patients in need of therapy.
- The administrative entities and case management system of OSP provide a contracted, performance-based system of determining eligibility and budgets, unlike the county-based political patronage system of MH and MR. Adults with autism have never been welcome at county MH/MR offices, where resources are scarce.
- The capacity of the OSP system supports the self-determination of adults to form households apart from parents, whereas OMR's limited capacity means long waiting lists for services, living with

family as long as possible, and then placement in group homes. Family and group living does not provide the structure and autonomy necessary for most adults with autism to live successfully in the community.

- The new policy of OSP-that everyone can live in the community-is in sharp contrast to that of OMR and OMHSAS where inpatient treatment and institutions are frequently used for persons, such as those with autism, who have behavioral challenges. Adults with autism must be free from cycles of crisis outplacements and the risk of institutionalization, which are inherent to the MH/MR system.

Section Five: Waiver Design Recommendations(15)

What is a Waiver?

Medicaid Home and Community Based Waivers are an important but limited part of a state's whole planned approach to helping citizens with various sorts of special needs. Waivers are state-federal contracts that "waive" certain requirements of federal Medicaid long- term care funding to provide community-based services as an alternative to institutional care. Many people seem confused about where waivers fit in relation to other services for children and adults, leading to the mistaken expectation that an autism waiver (or waivers) will be a far-reaching solution to getting necessary services for most people with autism. First, unlike EPSDT and IDEA services, waivers are not an entitlement. Second, waiver contracts are always for a limited number of persons who meet targeting criteria. Third, only people who require the level of care provided by an institutional setting can receive waiver services, which is a much stricter eligibility standard than for the IDEA or EPSDT services to which children up to age 21 are entitled.

The distinction between "eligibility" and "entitlement" is extremely important, particularly because that distinction is the reason some subcommittee members believe there should be wholly separate waivers for children and for adults. "Eligibility" means meeting the criteria to receive services. "Mental retardation" is an example of an eligibility requirement. However, having mental retardation is not an entitlement in the MR system. One could be eligible and still be on a waiting list indefinitely if funding is not available for everyone who is eligible, and others have more urgent needs. "Entitlement" means that if you meet the eligibility requirements you must be served promptly and not put on a waiting list. Being a child with a disability is an example of an eligibility criterion that is an entitlement to special education and related services, and to EPSDT.

(15) This section incorporates family and provider perspectives

Autism Waiver Service Definitions (16)

The subcommittee agreed that one of the most important components of any waiver are the service definitions. Members agreed that the subcommittee should examine existing waivers, approved by CMS. Based on this review, members recommend the following service templates for any proposed autism waiver.

For purposes of these definitions, the person directly eligible for waiver services is referred to as the "individual."

Most service definitions are equally applicable whether the individual is a child or an adult and whether the individual is eligible for the child waiver or the adult waiver. However, there are distinctions in some definitions, and some services that are not likely necessary for one set of individuals or another. Accordingly, those definitions for which a distinction is necessary will be noted. Otherwise, the definitions are broadly applicable.

1. Service Coordination

The service manager is responsible for development, coordination and ongoing monitoring of the provision of services included in the individual's program plan. Services assist individuals in gaining access to needed waiver and other state plan services, as well as needed medical, social, educational and other

services, regardless of funding source for the services to which access is gained. Service managers will also advocate for the rights of individuals in gaining access to appropriate home and community services.

The service coordinator is responsible for development, coordination and ongoing monitoring of the provision of services included in the individual's plan. Service coordinators will also advocate for the rights of individuals in gaining access to appropriate home and community services.

[MR Consolidated Waiver/OBRA Waiver]

2. Respite

Respite services consist of services that are provided on a short-term basis because of the absence or need for relief of those persons normally providing the care.

[MR Consolidated Waiver]

3. Family Training

Children

An individual's family may receive individualized, hands-on training in the treatment regimens, behavior intervention and modeling, skills training, and use of equipment specified in the individual's autism waiver plan and shall be provided with training updates as necessary to maintain the individual safely at home.

Adults

An individual's family shall receive training to assist the individual to acquire, retain, or improve skills in a wide variety of areas that directly affect the individual's development and ability to reside as independently as possible, including but not limited to habilitation, communication skills, self-direction; behavior shaping and management, daily living skills, socialization, mobility and money management.

4. Habitation

Habilitation means services provided in a home or community-integrated setting to assist individuals in acquiring, retaining and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based setting. Habilitation may be provided up to 24 hours a day based on the needs of the individual receiving services. Basic habilitation services may be provided by a qualified family member or relative, independent contractor or services agency.

[Consolidated MR Waiver]

Habilitation services shall include, but not be limited to, the following: attending; personal care; behavior shaping and management; communication training and enhancement; socialization; recreation; mobility; self-direction; survival skills; utilization of money; intensive behavioral episode intervention and medication management; monitoring and training. Habilitation services may be classified as basic, enhanced or intensive based upon the needs of the individual.

Consolidated [MR Waiver]

5. Pre-Vocational / Vocational

a. Pre-vocational

Children

Pre-vocational services not available under a program funded under Section 110 of the Rehabilitation Act of 1973 or Section 602 (16) and (17) of the Individuals With Disabilities Education Act, 20 U.S.C. § 1401, (16) and (17). Services are aimed at preparing an individual for paid or unpaid employment. Services include teaching such concepts as compliance, attendance, task completion, problem-solving and safety, work experience and training designed to teach job-related skills, as well as personal and work adjustment training designed to develop appropriate worker traits and teach an understanding of the expectations of a work environment. Activities included in this service are not primarily directed at teaching specific job skills, but at underlying habilitative goals such as attention span and motor skills.

[MR Waiver]

b. Vocational

Supported employment services which consist of paid employment for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting. Supported employment includes activities needed to sustain paid work by individuals receiving waiver services, including supervision, training and environmental adaptations reasonably necessary to accommodate the individual's needs. When supported employment is provided at a work site in which persons without disabilities are employed, payment will be made only for the adaptations, supervision and training required by the individuals receiving waiver services as a result of their disabilities, and will not include payment for the supervisory activities rendered as a normal part of the business setting.

Supported employment services rendered under the waiver are not available under a program funded by either the Rehabilitation Act of 1973, or P.L. 94-142, as amended by IDEA.

[Consolidated MR Waiver]

6. Planning, Intervention and Supports

This service is provided for individuals who, because of limited social skills, limited communication skills or impaired sensory systems require specialized behavior or other services. This service may include training, supervision, or assistance in appropriate expression of emotions and desires, compliance, assertiveness, acquisition of socially appropriate behaviors, and the reduction of inappropriate behaviors. Appropriate supports also include, but are not limited to, crisis intervention, the behavioral or environmental interventions necessary to stabilize and preserve the individual's living arrangements, thereby continuing to divert the institutional placement. Service may include psychiatric or psychological services provided by personnel provider qualifications.

7. Environmental Modification

Environmental accessibility adaptations are those physical adaptations to the individual's home, which are reasonable and necessary to do the following:

A. Prevent the individual's institutionalization;
B. Assure the following:
    1. The individual's health, welfare, and safety; and
    2. A safe, therapeutic environment;
C. Prevent the individual's self-injurious behavior; and
D. Enable the individual to function with greater independence in the home.

Environmental accessibility adaptations include, but are not limited to, the following:

A. Alarms or locks on doors, windows, or fences;
B. Protective padding on walls or floors;
C. Plexiglass on windows;
D. Outside gates and fences;

E. Brackets for appliances;
F. Raised electrical switches and sockets;
G. Safety screen doors;
H. Appropriate vehicle adaptations; and
I. Appropriate adaptations for those individuals who have physical disabilities.

The environmental accessibility adaptations shall be included in an approved, individualized program plan.

All construction shall:

A. Be provided in accordance with applicable state or local building and fire codes; and
B. Pass the required inspections.

Window locks may only be used if there is no other way to prevent an individual's rapid movement into a potentially dangerous situation. With the added safety precautions, it shall be assured that the house has enough exits, so there are not fire or safety concerns. Several rooms may be secured, but not the whole house.

[MD Waiver]

8. Community Integration

Community integration services are designed to assist individuals in acquiring, retaining and improving self-help, socialization and adaptive skills necessary to reside in the community. Community integration services and related training enable the individual to plan for and engage in meaningful age-appropriate activities including, but not limited to, domestic, work and leisure activities. Community integration can include, but is not limited to, cues, on-site modeling of behavior or supervision to assist the individual in maintaining maximum independent functioning. Community integration may include, but is not limited to, socialization with persons without disabilities, participation in age-appropriate peer-group activities such as sports and other group activities, money management, interpersonal communication, development of relationships, development of decision-making skills and awareness of civil rights and protections of those rights.

[OBRA Waiver]

Community integration includes provider training expenses, supervisory expenses, "purchases" personnel expenses and expenses of necessary supplies, equipment and adaptive appliances.

9. Personal Care Services

Assistance with eating, bathing, dressing, personal hygiene, activities of daily living. This service may include assistance with preparation of meals, but does not include the cost of the meals themselves. When specified in the plan of care, this service may also include, but is not limited to, such housekeeping chores as bed making, dusting and vacuuming, which are incidental to the care furnished, or which are essential to the health and welfare of the individual, rather than to the individual's family. This service may also include routine wellness services to enable adequate nutrition, exercise, making and keeping of medical appointments and proper taking of appropriate medications.

[MR Waiver]

10. Personal emergency response systems

Adults

Personal emergency response systems ("PERS") are electronic devices that enable certain individuals who would otherwise be at high risk of institutionalization to secure help in the event of an emergency. The

PERS include, but are not limited to, portable "help" buttons that allow the individual to be mobile. PERS are typically connected to the individual's telephone line so that they send a signal to a response center staffed by trained professionals. PERS services are limited to those individuals who live alone, those who are alone for significant parts of the day, those who have no regular caregiver for extended periods of time and those who would otherwise require extensive routine supervision.

11. Transportation

Transportation includes, but is not limited to, mobility services offered to enable individuals to gain access to waiver and other community services, activities and resources that are specified in the individual's program plan. This service is in addition to the medical transportation mandated at 42 C.F.R. § 440.170(a) (if applicable) and transportation services provided under the existing state plan as described at 42 C.F.R. § 431.53 (if applicable), and shall not replace them. Family members, friends, neighbors or community agents may provide transportation services without cost where appropriate.

12. Assistive Technology/Specialized Equipment and Supplies

Assistive technology/specialized equipment and supplies include, but is not limited to, devices, controls or appliances specified in an individual's program plan that enable the individual to increase his/her ability to perform activities of daily living or to perceive, control or communicate with the people and environments in which they live and work. This service also includes, but is not limited to, items necessary for life support, ancillary supplies and equipment necessary to the proper functioning of such items, and durable and non-durable medical equipment not available under the existing state plan. Assistive technology/specialized equipment and supplies reimbursed through the waiver shall be in addition to any medical equipment and supplies furnished under the existing state plan and shall not include those items that are not of direct medical or remedial benefit to the individual. All such items eligible for reimbursement shall meet applicable standards of manufacture, design and installation.

This service includes the expense of training the individual in the use of the assistive technology/specialized equipment and supplies.

13. Supports Brokerage:

Service/function that assists participating families and individuals to make informed decisions about what will work best for them, are consistent with their needs and reflect their individual circumstances. Serving as the agent of the family or participant, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. A family or person-centered planning approach is used. Supports Brokerage offers practical skills training to enable families and individuals to remain independent. Examples of skills training include providing information on recruiting and hiring personal care workers, managing personal care workers and providing information on effective communication and problem-solving. The service/function provides sufficient information to assure that participants and their families understand the responsibilities involved with self direction and assist in the development of an effective back-up and emergency plan. States may elect to fulfill the requirement of this service/function using a self-directed case manager or creating a distinct service. States may elect to fulfill this required service/function either as a service cost or an administration cost, but must clearly identify which method will be used. The services/functions included in Supports Brokerage are mandatory requirements of the template.

14. Fiscal/Employer Agent:

Service/function that assists the family or individual to manage and distribute funds contained in the individual budget including, but not limited to, the facilitation of the employment of service workers by the family or individual, including Federal, state, and local tax withholding/payments, unemployment compensation fees, wage settlements, fiscal accounting and expenditure reports, etc. States may elect to fulfill this required service/function either as a service cost or an administration cost, but must clearly identify which method will be used. This service/function, regardless of provider or method, must be delivered under a family or person-centered planning process and is a requirement of the template.

[Source: independence Plus]

[Note that OMR recently released a Bulletin regarding Fiscal/Employer Agents which they call "ISOs"]

15. Extended state plan services

The following services, available through the approved state plan, will be provided, except that the limitations on amount, duration and scope specified in the state plan will not apply. Services will be as defined and described in the approved state plan. The provider qualifications listed in the plan shall apply, and are hereby incorporated into this waiver by reference. These services will be provided under the state plan until the plan limitations have been reached. These services may include, but are not limited to, the following:

A. Physical therapy;
B. Occupational therapy (including sensory-integration therapy); and
C. Speech, hearing, signing and language services.

[Consolidated MR Waiver]

Additional Non-Waiver Services Needed

There was some consensus that expansion of the Medicaid State Plan to include "personal care" to persons without the current requirement of "mental alertness" would be advantageous. This would enable persons with autism and other disabilities to maintain some independence without the need for a waiver. Some individuals with Asperger's Syndrome may function well as adults and may not require a waiver, but need help organizing their lives and functioning day to day. The same might be argued about individuals on the mild end of other spectrum disabilities. Other consideration should be given to expanding Medicaid State Plan services for individuals with Asperger's Syndrome who will not qualify for a waiver and for whom mental health services are inappropriate. These might include social competency groups, drop-in centers for help with social skills and organization and cognitive therapy.

Other views expressed were that it might be cost-prohibitive since changing the State Plan would involve providing services proposed to all Medicaid recipients.

However, there was no disagreement that these services would be of benefit to Pennsylvanians with disabilities. Members also noted that when individuals with Asperger Syndrome (who may not qualify for waiver services) have periods of deterioration or require help, the lack of appropriate services may result in them entering inappropriate systems such as a mental hospital or correctional facility. It is for this reason that we recommend DPW proactively plan for thoughtful and appropriate services in order to avoid to preserve funds and maintain a good quality of life for persons with Asperger Syndrome and high functioning autism.

Housing Funding

The subcommittee also recognized that although its mission was not to make recommendations on housing per se, that no one can live a successful, healthy and safe life without an appropriate place in which to live. Therefore, some appendices addressing the housing issues have been attached as appendices. The recommendation of the subcommittee is that in the planning for implementation of an autism waiver for adults, additional housing allowances (using non-waiver funds) be anticipated and included in that planning.

(16) A smaller workgroup within the subcommittee drafted definitions for review and approval of the entire subcommittee. The workgroup used the following existing waivers as a template: OBRA waiver; MR Waiver; Commcare Waiver; and Maryland’s Autism Waiver. It is important to note, however, that the subcommittee tailored some of the definitions to meet needs specific to persons with autism, to take into account other proposed waiver provisions or to correct perceived inadequacies in the existing definitions.

Section Six: Waiver Structure

In drafting a waiver application, there are structural matters that must be addressed. The Waiver Subcommittee has done so.

One or Two Waivers

Subcommittee members have struggled intensely with the question of whether there should be one or two autism waivers. Some on the Waiver Subcommittee preferred a single waiver because, among other reasons, they have a concern that a two-waiver system would subject persons with autism and their families to an additional, often difficult, enrollment process.

In discussing the practicality of one waiver versus two, the subcommittee made the following assumptions:

- Among the people in Pennsylvania with autism spectrum disorders, there are many more children than adults.
- Most children with autism are covered by Medicaid's EPSDT and they therefore have an entitlement to services.
- Money is already being spent on children's services that could be redirected into a waiver.
- Adults have no entitlement and all new services for adults would require new money.
- In these tough budget times, it is not realistic to expect too much in the way of new money.
- As a legal matter, once a person is in a waiver that person has a right to all services covered by the waiver that the participant needs.
- If the Individuals' needs change, the waiver must continue to meet those needs.

In implementing one waiver for adults and children, DPW would need to limit the number of people who could enter the waiver because they would need to assure funding for each child as that child ages. In implementing two waivers - one for children and one for adults - a very large number of children could enter the child's waiver and a smaller number of adults (with this number increasing as new money becomes available.) The downside of two waivers is that there will be children who will age out of the first waiver and who will end up on a waiting list for the adult waiver.

In response to this downside, and in order to address the legitimate concern for families navigating two waivers as children neared the age of 21, the Waiver Subcommittee discussed the following options and recommendations.

- (Option One) Create two waivers - one child waiver and one adult waiver, but persons as young as 14 should be able to apply for available slots in the adult waiver program and, if they obtain those slots, be permitted to use them. The purpose of such a provision would be to allow those in the child waiver program significant time to seek available slots in the adult waiver program to insure that they do not reach adulthood only to find that there are no available slots in the adult waiver. While such a provision would not guarantee a seamless transition between the two waivers, it would help.
- (Option Two) Create two waivers, one child waiver and one waiver age 3-adult. The child waiver eligibility should be more flexible and available to children throughout the autism spectrum continuum. However, child eligibility for the waiver for age 3-adult should be restricted only to those children on the most severe end of the continuum. For instance, a child who can speak, dress, feed himself/herself, but still needs a great deal of assistance behaviorally, socially and with some life skills, would qualify for the child waiver only. A non-verbal or less verbal child with many physical care needs or additional disabilities (deaf, blind, MR, etc.) could be considered for eligibility in the 3-adult waiver. The restrictive eligibility would hopefully allow children with the most need access while still maintaining slots for adults who would not be eligible for any other services except the 3-adult waiver.
- (Option Three) Create two waivers, one child waiver and one adult waiver. The child waiver for children up to age 21 diagnosed with an autism spectrum disorder would function as a supplement to educational services and services available in the Medicaid State plan. (Currently EPSDT services, for example, are State plan services.) The adult waiver would be for people age 21 and

over with a primary diagnosis of an autism spectrum disorder who meet the federal functional eligibility criteria to receive community-based services as an alternative to institutionalization. (Entitlements to other services such as education and EPSDT stop at age 21.)

Majority Opinion on One Versus Two Waivers

The majority recommendation was for Option One - Two waivers - a child waiver and an adult waiver, but with the provision that children at age 14 may be eligible to apply for the adult waiver, enabling a "transition" period of up to 7 years.

Other Minority Opinions Expressed on One Versus Two Waivers

Parents Concerned About Two Waivers. Another opinion expressed was that because of the time and financial commitments involved in being a member, it sometimes felt like the concerns of families with fewer resources were not expressed. Some members were concerned that whatever Medicaid waiver or service mechanisms developed for individuals with autism be as accessible to poorer parents with less understanding of how these systems work as they are for parents who have greater resources and understanding of local and state systems.

For these members, the decision as to whether we have one or two waivers was an example. They worried that if parents have to negotiate one set of systems to get services when their child is first diagnosed and then another set when their child turns 21, it would create too much fragmentation and disruption of services.

Parents who have the resources to hire lawyers and advocate for their children ultimately will have greater access to adult services for their children than other parents. They proposed instead that we have one system that begins when children are diagnosed and ends when children no longer need services, regardless of their age.

They felt the mental retardation system offers an excellent example of how this could occur. Individuals with MR are eligible for services regardless of their age, and a system that plans for and provides those services. The only requirement to participate is that individuals have an IQ below 70. Currently, the MR Medicaid waiver serves many individuals with autism who meet that IQ requirement. The fact is, however, that most people with autism have IQs above 70.

One member asked why we could not set up a parallel requirement for individuals with autism that is not based on IQ and couldn't we base the criteria on the communication, socialization and behavioral deficits that are inherent in the diagnosis of autism? She felt it made no sense that an adult with autism with a verbal IQ of 90 and a functional IQ of 60 would not be eligible for the support services that he or she needs more than many people with mental retardation.

The argument against the "one waiver" position has been that the state would limit the number of slots available because of concerns regarding the expense of providing services as children age. One member felt was not an appropriate argument for two reasons. First, the state could do the same thing for an autism waiver specific to children. Second, the goal of the Autism Taskforce is not to second-guess what the state will or won't do, but rather to present what we consider to be the most effective reorganization plan for the delivery of services to individuals with autism. Even those in favor of a two-waiver system acknowledge that having one waiver would be more efficient and effective. This member felt we should not settle for what we know will ultimately cause problems for many families when we had not heard the state's response to our preferred plan.

Parents of Adults: Adult Waiver Applicants Should Be 21 and Over. Parents of adults with autism on the subcommittee felt it was inappropriate to consider entry of children prior to age 21 into an adult waiver. They felt that while children (up to age 21) have entitlements to education and related services as a result of IDEA, and to EPSDT through the Medicaid State Plan, adults are entitled only to services in an ICF (an institution). They felt as long as institutions exist, even though no one would prefer them, and as long as waiting lists exist, then some people, however few in number, will be forced into institutions when

they become emergency cases and no other placements are available, because they are entitled to institutional care but not to anything else. This is a great fear of parents whose children are now over 21, even fairly "high functioning."

These parents felt this inequity in entitlements between children and adults will not be solved by an adult waiver that begins at age 14, and certainly not by an adult waiver that begins at age 3. Astute families would soon learn to qualify their children at the entry age even if they did not feel an urgent need to use waiver services at that time, realizing that it would be "use it or lose it" in terms of access to the waiver at a future date. All the waiver slots thus would be allocated to children entering the waiver before age 21, leaving none for people to access after 21 when education and EPSDT services stop. The experience of the mental retardation system shows what happens with services, like a waiver, that are not an entitlement when all slots are filled--long waiting lists. Later applicants can be served only when they become crisis cases, at which point whatever placement has an opening--even an institution--will be used.

These parents felt the way to address the needs of the child or youth who needs an out of home placement, or more intensive services than education or EPSDT will provide is by reform of these existing systems.

Parents of adults felt if a waiver for adults started before age 21, adults over 21 would not be able to access this waiver because all the slots would be taken. Furthermore, they felt children would receive less benefit than hoped because a waiver is not an entitlement, and eligibility is more stringent than for other child services.

Aggregate or Individual Cap (17)

Funds available to waiver participants are subject to a monetary limitation or "cap." The design of a waiver can call for either an aggregate cap or an individual cap. An aggregate cap requires that the cost of providing services to all participants, considered together, not exceed the budgetary amount (generally the total cost of providing services to all of the participants in intermediate care facilities). An individual cap imposes a limitation on each waiver participant generally the cost of providing services to that individual in an intermediate care facility).

There are advantages and disadvantages to each. An aggregate cap can be helpful to consumers broadly in that it allows the cost of services rendered to those who need less expensive services to offset the cost of services rendered to those who need more expensive services. Accordingly, a person whose needs warrant more expensive services might well be able to fund those services under an aggregate cap when he would be limited by an individual cap. The primary benefit of an individual cap is administrative: it is far easier to determine that an individual has reached a funding limit than it is to determine that an entire diverse group has reached its aggregate limit.

The Waiver Subcommittee recommends an aggregate cap. As noted, that approach provides greater flexibility in a group in which some participants have more expensive needs than others. Because autism is a spectrum disorder and those with it are affected in so many different ways, the greater flexibility afforded by an aggregate cap is more appropriate.

(17) In the case of individuals with autism the cap would be based on costs associated with an intermediate care facility-other related conditions (ICF-OCR).

Waiver Education

Persons with autism and their families often have difficulty learning about services that are available to them. Education is often by word of mouth or through parent advocacy groups. Institution of autism waivers will add additional programming to the menu for persons with autism and their families, and it is critical to implement the waivers with appropriate education. The Waiver Subcommittee recommends that there be a comprehensive program to educate persons with autism and their families about a variety of matters related to the waiver, including:

- Participation in the waiver program is by choice, and that persons with autism and their families should be informed they may elect to continue receiving services solely from the state Medicaid plan. In addition, potential waiver participants and their families must be informed about the interplay between the waiver program and the state Medicaid plan so that they can meaningfully make an informed determination about whether to seek participation in waiver programs.
- Specific processes and steps to secure a slot in one of the waivers must be clearly outlined and easily accessible, perhaps including a checklist of necessary steps and paperwork. The complexity of the current system enables only the most knowledgeable and savvy parents to access those services.
- The organizational structure set in place to administer the waivers must be explained. Participants and their families must be provided with clear guidance about the agency with which they will interact, including information about case management, dispute resolution and the process for applying for transition to the adult waiver.

Finally, with respect to each of these issues, and any others for which the Department will provide guidance, there must be an effort to produce educational materials in the most simple and understandable language, also ensuring access for those who do not use English as their primary language. The recipients of those materials are people of various educational backgrounds, many of whom are contending with challenging and stressful circumstances that make it particularly difficult for them to study and decipher critical information. We recommend that drafts of such materials be reviewed by stakeholders.

Funding Considerations

The implementation of any autism waiver will take place against a backdrop of difficult economic times. As noted elsewhere in this report, the Waiver Subcommittee has attempted to make its recommendations with due regard for the economic landscape. One important issue is what happens with the funding currently provided to persons in other waiver programs (such as the mental-retardation waiver) who move into one of the autism waivers. As a matter both of fundamental fairness and budget considerations, the Waiver Subcommittee recommends that a provision be included wherever appropriate (perhaps in the Department's regulations) mandating that the funds currently designated for a person in another waiver follows that person into one of the autism waivers.

Section Seven: Conclusion

Only those who will risk going too far can possibly find out how far one can go. T.S. Eliot

Less than four decades ago, public mental health systems, doctors and sometimes families believed individuals with autism incapable of community life. In addition to being wrong about the psychological etiology of autism, about the commitment and love of mothers of children with autism and about the effective therapies for autism, the "experts" were wrong about the possible contributions to be made by persons with autism in society.

Today, we cite examples of adults with autism such as Donna Williams and Temple Grandin as important contributors to society, encouraging government to make an investment in autism services.

However, we forget that societies succeed and thrive not because of individuals who become famous for their extraordinary accomplishments, but because of millions who sustain the economy by performing day-to-day tasks that, while not celebrated, are no less important. Some of the contributors to this report have adult children who are doing just that. Others have children who are working each day toward the same.

Families keep dreams alive for their children and adults with autism. Not all individuals with autism will become the next author, artist, screenwriter or computer mogul. Developing a Medicaid waiver for autism, however, is one critical step in fostering independence and an opportunity for the kind of life our Mission Statement describes and every parent hopes for his or her child with autism.

Section Eight: Appendices

Appendix A: Waiver Services Priority Survey- Children

CHILDREN'S SERVICE PRIORITY LIST – Please Rank

SERVICE (Check One - Low, Med. Or High)	LOW	MED	HIGH	(Check one - Limited or Unlimited)	Limited	Unlimited
Case Management						
Respite						
Parent Training						
Complementary Therapies						
Social Skills						
Recreational						
Pre-Vocational/Vocational?						
Best Practice Evaluation						
Communication						
Behavioral						
Home Modifications						
Sensory						
Life Skills						
Community Integration						
OT/SLP						
In-Home Assistance						

Appendix B: Waiver Services Priority Survey- Adults

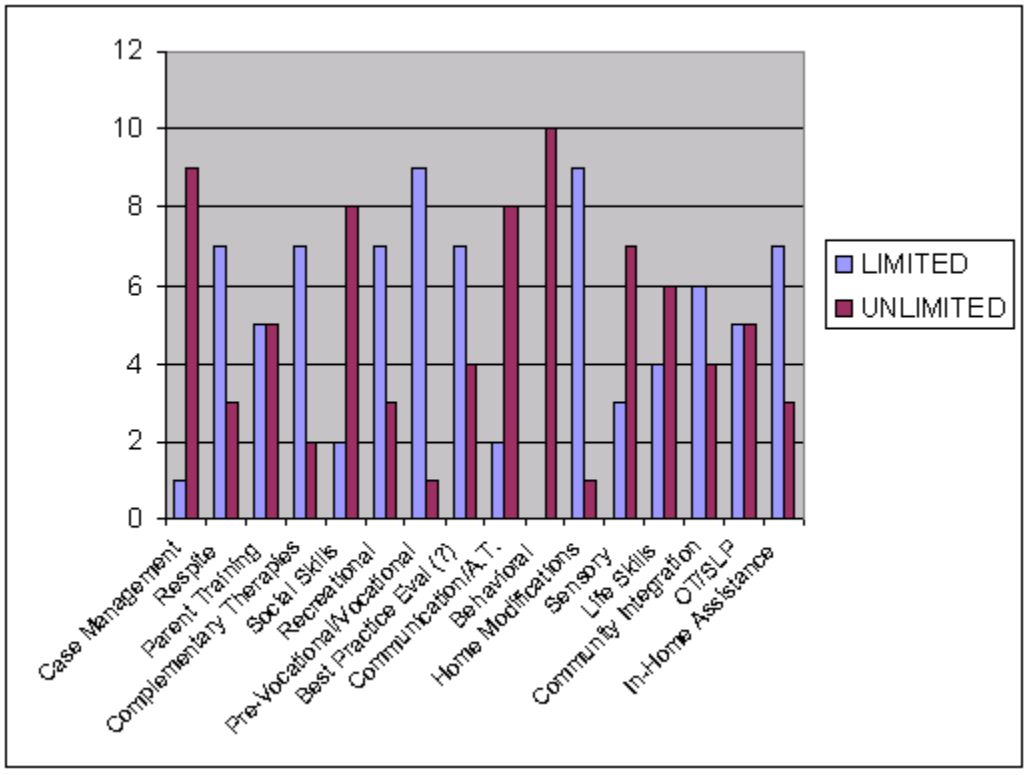
ADULT SERVICE PRIORITY LIST – Please Rank

SERVICE (Check One - Low, Med. Or High)	LOW	MED	HIGH	(Check one - Limited or Unlimited)	Limited	Unlimited
Case Management						
Respite						
Parent Training						
Complementary Therapies						
Social Skills						
Recreational						
Pre-Vocational/Vocational?						
Best Practice Evaluation						
Communication						
Behavioral						
Home Modifications						
Sensory						
Life Skills						
Community Integration						
OT/SLP						
In-Home Assistance						

Appendix C: Waiver Service Limitations Results- Children

Survey Results

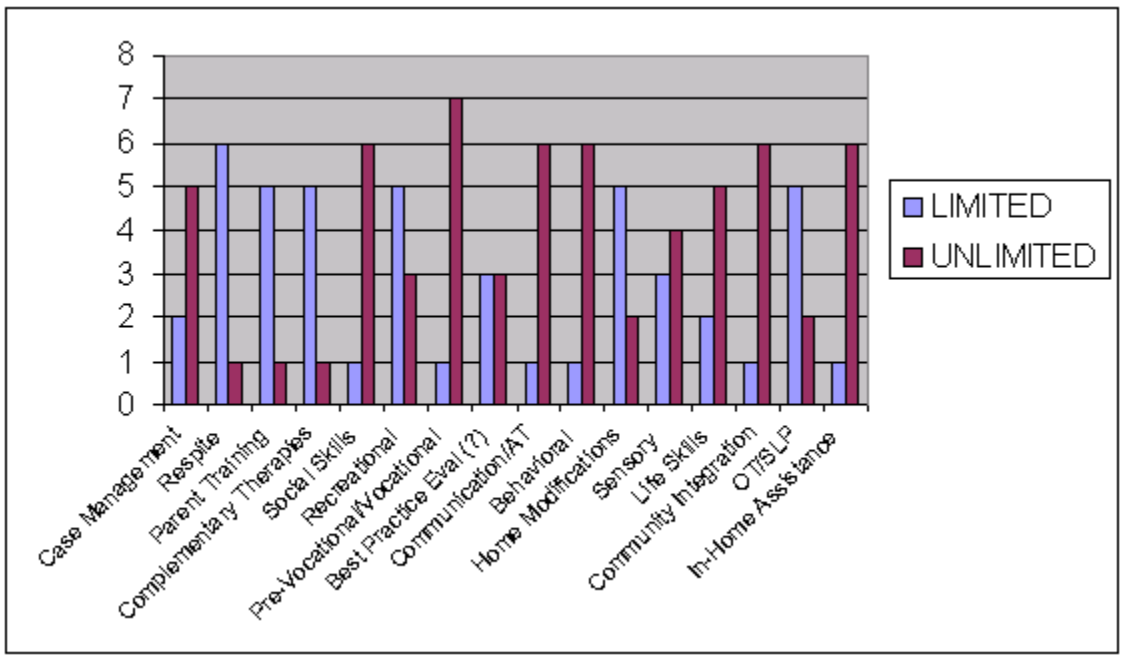
Child Service Limitation	Number Limited	Number Unlimited
Case Management	1	9
Respite	7	3
Parent Training	5	5
Complementary Therapies	7	2
Social Skills	2	8
Recreational	7	3
Pre-Vocational/Vocational	9	1
Best Practice Eval (?)	7	4
Communication/A.T.	2	8
Behavioral	0	10
Home Modifications	9	1
Sensory	3	7
Life Skills	4	6
Community Integration	6	4
OT/SLP	5	5
In-Home Assistance	7	3



Appendix D: Waiver Service Limitations Results- Adults

Survey Results

Adult Service Limitation	Number Limited	Number Unlimited
Case Management	2	5
Respite	6	1
Parent Training	5	1
Complementary Therapies	5	1
Social Skills	1	6
Recreational	5	3
Pre-Vocational/Vocational	1	7
Best Practice Eval (?)	3	3
Communication/A.T.	1	6
Behavioral	1	6
Home Modifications	5	2
Sensory	3	4
Life Skills	2	5
Community Integration	1	6
OT/SLP	5	2
In-Home Assistance	1	6



Appendix E: Pennsylvania's Experience Using a Waiver Funded Program for Adults

Submitted by: AUTISM LIVING AND WORKING, INC. (ALAW)

Pennsylvania's current Autism Pilot Program demonstrates the successful use of Medicaid waiver funding to provide appropriate community-based support services specifically for adults with autism spectrum disorder. Experience during the course of the Autism Pilot Program also shows that a waiver designed just for autism, rather than adapted from a more general waiver, will be more effective both for users and providers of autism support services. We believe that what we have learned about autism programming and waivers through the Autism Pilot Program, a joint DPW / ALAW project, offers valuable help in creating a better system and a better life for Pennsylvania's citizens across the autism spectrum.

BACKGROUND-- THE ADULT SERVICES SITUATION IN PENNSYLVANIA:

Since PA is not a "DD" state, there is no single place in the services system where adults with autism are served. Those with an IQ below 70 are referred to MR; those with a higher IQ are referred to MH. Neither system has appropriate services for persons with autism.

Adults with developmental disabilities, if served at all, get MR day programs, sheltered workshops, and respite care, as a supplement to family caregiving. Only when the last family caregiver dies or becomes incapacitated is an MR residential program possible, because only those with the most urgent PUNS category are considered for residential services.

Adult residential programs may be public or private institutions, or community-based group homes. Housing and services are operated by the same provider agency. To live in their own place, adults with disabilities generally must need less than 30 hours a week of support.

HOW THE AUTISM PILOT PROGRAM CAME ABOUT:

Though ALAW had held several meetings with the Secretary of DPW and with the Deputy Secretaries of OMHSAS, OMR, and OSP, ALAW's 1998 study of federal and state laws and regulations proved to be the turning point. We demonstrated that eligibility for Medicaid long term care services must be based not on state MH/MR categories, but on federal rules (which use functional need, not IQ, to determine eligibility). Furthermore, under federal rules, eligible persons are entitled to long term care services. After consulting their legal staff, DPW agreed they needed to begin serving adults with autism, and offered to establish a pilot program.

DPW / ALAW POLICIES FOR THE AUTISM PILOT PROGRAM:

- A joint DPW / ALAW working group would plan and implement the Autism Pilot Program.
- The Pilot Program would serve 20 adults with autism in the Southeast Region of PA.
- The Pilot Program would serve people across the entire spectrum of autism, regardless of I.Q.
- The Office of Social Programs, because it is not IQ-based, would administer the pilot.
- In order to be able to start as soon as possible, an existing Medicaid waiver in the Office of Social Programs would be used to fund services.
- Services would be community-based, and support individuals to hold jobs, seek higher education, or pursue other individual interests.
- Service providers would need to have a good knowledge of autism, provide ongoing training for staff, and hire sufficient supervisory and behavioral professionals to support direct care staff.
- Adults who desired to form households independent of their parents would receive funding for the individual staff supports necessary, including persons needing 24/7 support.
- Housing would not be owned or controlled by the service provider. ALAW would assist families as they seek regular houses or apartments for their sons/daughters.

WHAT HAS OCCURRED SO FAR IN THE AUTISM PILOT PROGRAM:

- Just under twenty people across the I.Q. spectrum of autism have been selected. Change in the intake form for the OBRA waiver led to exclusions of low-IQ persons during the second round of candidate selections, a violation of the intent of the pilot program.
- After the first round of candidates was selected, the DPW / ALAW work group stopped having regular meetings, also a violation of the intent of the pilot program.
- After the original case management agency failed to perform its task, OSP transferred the Pilot to a second case management organization which is willing and able to perform.
- After the first service provider abruptly dropped its autism program, a successor provider was found who is committed to implementing the necessary level of supports for these individuals. Conversations have been held by some families with an additional provider.
- The service rates, what program and staff costs can be reimbursed, and the billing system of the OBRA waiver continue to be a problem for providers.
- Hiring, retaining, and training capable direct care staff is an ongoing challenge.
- Initially two households, encompassing a total of five people, were formed with the assistance of ALAW. These families provided down payment money, obtained bank mortgages and received Section 8 housing subsidies. ALAW is purchasing two additional homes using PHFA grant money and small mortgages. Two people share the first house, and two more will occupy the second house by mid-2004. A Section 8 application is underway for the second house. Other participants are living in apartments or condos, alone or with a housemate, or with their parents.
- Participants and their families have expressed generally positive ratings in satisfaction surveys.

WHAT WE HAVE LEARNED ABOUT AUTISM PROGRAMMING AND WAIVERS:

ELIGIBILITY:

Waiver eligibility must be based on functional limits, not IQ. The OBRA waiver does this, but PA's MH/MR system diverts people with low IQ to MR, regardless of primary diagnosis. Autism is a spectrum disorder; IQ is irrelevant.

ADMINISTRATION:

Administrative structure must govern the entire spectrum of persons with autism, regardless of IQ.

Administration must have a self-determination approach to services for adults, not use congregate living and working models or medical treatment models, and must include families as part of the planning and oversight process.

Waiver cost caps need to be aggregate, and based on a fairly high-cost ICF program, not a NF.

Administrative entity must be accepting of the relatively high costs for persons needing 24/7 supports who wish to live apart from their parents.

CASE MANAGEMENT:

Case management must be knowledgeable and willing to schedule significant one-to-one staff hours during the day to permit jobs and other individually chosen activities.

Program plans need to make significant use of Community Integration waiver services during the day; the CI definition needs amendment to permit supports in work settings; the supported employment rate must be corrected, and must cover job finding. Home modifications may need to include soundproofing walls and climate control.

PROVIDERS:

Providers need to have accurate knowledge about autism, be willing to have ongoing training for staff, need to hire program directors and behavioral resource persons to support direct care staff.

Providers must be willing to work closely with families in directing the program and selecting key staff; providers need to meet regularly with families of persons sharing a household.

Providers need to be willing to have families or clients own and control their own housing.

The billing system is cumbersome for individuals getting residential supports; costs of program directors and behavioral consultants must be reimbursable.

CLIENTS:

Clients must be treated as adults, and enabled to exercise choice and control over their lives through the maintenance of a prosthetic environment.

Clients must be assured of an effective means to communicate at all times.

Clients need adequate and consistent staff supports and structure to participate in jobs and community life.

Clients must be provided with all necessary supports within the program, and not outplaced to MH or other settings if they have challenging behavior.

The Autism Pilot Program has produced significant lessons about serving adults with autism in the community and preventing institutionalization. All of the families of Autism Living and Working, and all of the adults with autism themselves who are pilot participants, are committed to carrying forward with these very promising beginnings. We hope that the lessons from the Autism Pilot Program, along with other recommendations of the Autism Task Force, can lead to a better system for serving adults with autism in the communities of Pennsylvania.

08. Early Intervention Subcommittee Report

I. Introductory Materials

A. List of members - See list attached

B. Mission of the subcommittee

To communicate the current state of early intervention services for children from birth to age of beginner as they pertain to early intervention, which includes screening, diagnosis, referral, education and intervention. In addition, the subcommittee will identify the gaps and problems associated with current screening, diagnostic, referral, education and early interventions practices. More importantly the mission for the subcommittee is to determine potential solutions to improve these practices.

Early Intervention is a mandate. Under IDEA, Individual with Disabilities Education Act, it requires children identified with a disability age birth to 3 be served under Part C of IDEA and 3 to the age of beginners under Part B of IDEA.

C. How and how often did you meet?

We have a "Yahoo" group for all participants to post comments and communicate with each other on the issues to be discussed and put in the report. A conference call was conducted for 3 hours on Saturday, November 8, 2003. Four EI subcommittee members participated in this productive meeting.

D. How was the report formulated?

This report was crafted from the flipchart notes from our meeting on Aug 26th and the comments and posts from the yahoo group from that date. The facilitator meetings were attended, and any comments, questions or suggestions were taken in to consideration and added to the report. The draft report was posted for comment by committee members, and was used for development of the final report. This final report does not have ‘all the answers’ but does summarize current obstacles and potential solutions.

NOTE: The subcommittee will be reviewing several reports from other states on Autism and also other reports from the state of Pennsylvania. Please refer to appropriate listed website for further information.

II. WHAT IS THE STATE OF CURRENT PRACTICE IN EARLY INTERVENTION?

Screening: The Academy of Pediatrics recommends developmental screenings at every well visit, yet there is no protocol for the screening of autism in the state of Pennsylvania. When screening tools are used, they may be non-validated tools and often miss children who are not classically autistic. Physicians comment they are too busy in their practices to administer screenings on all children.

There seems to be an overall lack of knowledge of developmental 'red flags' as well as the types of "red flags" that may signal ASD or other developmental disabilities. This is true across the board for physicians, preschools and other professionals that deal with young children. Pediatricians may not be trained to recognize the red flags and the need to identify children early for developmental delays or ASD. The earlier the intervention begins, the better the long term out-comes are for the individual, family and community.

Physicians often take a ‘wait and see’ attitude when children are young to keep from upsetting parents.

Diagnosis: Once the parent or pediatrician identifies red flags, a referral is usually made to a Developmental Pediatrician or other specialist. The waiting list for an evaluation by a developmental pediatrician or developmental neurologist in Pennsylvania is currently 6 to 12 months. There is a statewide and nationwide shortage of trained professionals that can diagnose autism. Pediatricians and physicians

may be aware of autism and may inform a family their child may be autistic, but will not be able to support the family until the diagnosis is confirmed. Parents are often then in the position of chasing a diagnosis, not knowing what to do in the mean time, until a diagnosis is obtained.

Currently in Pennsylvania, school psychologists can diagnose autism. In the Infant/Toddler Early Intervention, a diagnosis is not necessary to receive Early Intervention services; however a child must exhibit a delay that meets eligibility requirements. This becomes a problem in both areas because without a diagnosis, the intervention may not be specific to autism and children with autism who exhibit better academics and functioning will not qualify for services. The eligibility criteria for Early Intervention services as set forth in 55 Pa. Code * 4226.22 does not limit eligibility to children who present with currently-measurable developmental delays, but also includes those with "[a] diagnosed physical or mental condition which has a high probability of resulting in a developmental delay, including a physical or mental condition identified through an MDE that is not accompanied by delays in developmental areas at the time of diagnosis."

The professional that evaluates and diagnoses children with autism may not know what resources are available for parents of children with autism. In addition, the diagnostician may be lacking current information for recommendation of intervention and plan of care. It is important that pediatricians know who to refer parents to rather than prescribe a particular service or strategy. Also frequently, the professional may recommend services that are hard to obtain, unavailable or inappropriate to meet the needs of the child and family.

There are few if any supports for a family at the time of diagnosis, which many consider to be the most crucial time when support is needed. Parents may feel guilty and may be grieving their expectations for their child's life. They may be in denial and may not know how to effectively address the needs of their child because of their own lack of knowledge about autism.

Referral: In the Early Intervention System, there is no comprehensive information system or database for tracking, or for providing information to families. Currently, there is no system to coordinate screening, diagnosis and treatment, with no tracking system to monitor overall progress.

The Early Intervention system maintains a database in Penndata (preschool Early Intervention) with a category of autism. Children who are referred from Infant/Toddler EI are referred as early as 2 years to Preschool EI to coordinate service delivery. Unfortunately, transitions between the two systems are not always smooth for families. Even though there are Local Interagency Council agreements, a policy for coordinating transition, and guidelines for joint transition planning, the change from one system to the other causes confusion. The Early Intervention (Birth to 3 years, funded through OMR), and the MAWA (Mutual Agreed upon Written Agreement) holders (the 3 to age of beginners EI, IDEA funded), have difficulty with referral for services based on the focus of care from one system to the next. The Infant/Toddler system (Birth to 3) utilizes a family-based/developmental model while the Preschool Early Intervention system (Ages 3-5) utilizes educationally based driven interventions.

Additional confusion is caused by the lack of consistency across school districts in the process for referral or recommended services.

Wraparound services may not meet the needs of the family. The family may not be able to accept the services because of required intensity in certain settings that could cause hardship by forcing a family member to quit a job or hire in-home help in order to obtain services.

Intervention: Preschool age children can participate in Early Intervention if they have met the eligibility criteria for a delay or have a qualifying diagnosis such as autism. Children transition to school district-provided services at kindergarten. Higher functioning children with autism or Aspergers Syndrome may not be identified as having a delay or disability, and may not qualify for services. These children with high-functioning autism still need intervention for their autism, specifically in the area of social skill and pragmatic language development. These services are often available, but their cost is not covered by insurance or the education system. Many in the education system are not aware that the provisions of IDEA require them to provide such services. Even if they are trying to coordinate these services, there is a lack of professionals capable of carrying out these interventions.

There is no one intervention used or recommended across Pennsylvania. The various systems responsible for providing services to children with autism often do not communicate with each other. Funding systems and regulations differ across early intervention, school age and mental health systems. Mental Health service providers often do not know early childhood development and this lack of knowledge impedes providing adequate services to children with autism. At times in an autistic support class there may be more adults than children competing for space and providing treatment that is not coordinated.

The birth to 3 years Infant/Toddler Early Intervention Program is funded by the Department of Public Welfare through each county's Mental Retardation System. The Infant/Toddler EI provides only a few hours of service a week, compared to other states (NJ, NY) that recommend 20 hours a week. As the child transitions to Kindergarten, more difficulty can develop as each school district, county and region differs as to the types of interventions used for children with autism. Similarly, Mental Health services "Wraparound" provided across the state varies from provider to provider with various methods of intervention.

A. Family Perspective

1. General Group Consensus

What steps must parents take to access educational services? Parents must request an evaluation for their child. A physician or teacher can also refer a child to EI for an assessment. If it is determined the child is eligible, a plan is developed. The Individual Family Support Plan (IFSP) for Birth to 3 years and an Individual Education Plan (IEP) for 3-5 years and school age should identify what supports the child and family need.

The services available to families and their children in Early Intervention are based on those required to ensure a Free Appropriate Public Education (FAPE), according to the Individuals with Disabilities in Education Act (IDEA). Even though all schools are responsible for ensuring the provision of FAPE, services vary considerably across counties, IUs, school districts and private schools. The programs that are available in each district vary in their intensity and quality as well as the staff's knowledge of autism. While these services are mandated by law, often times it is difficult to obtain an appropriate education for children with autism. Children are placed in programming but often parent's involvement help the development of a program and placement that will allow for meaningful progress to take place. The IEP establishes the goals and objectives and should drive an appropriate program and placement for the child. In some cases, the school district has an autism support classroom or a range of placements available. It is important that within an autism programming there isn't a cookie cutter approach to programming. It is a challenge to do programming for kids who, despite having the same diagnosis, have very different strengths, needs, and abilities and the need for individualized interventions within the same classroom.

A child is eligible to receive medical assistance with a diagnosis of autism/developmental delay. Eligibility is not based on family income. Medical assistance provides services through wraparound and will pay for other related services through outside facilities, such as Easter Seals or a Rehabilitation Hospital. Again, just as education, the medical assistance and Behavioral/Mental Health Services are entitlements to a child with autism. Parents can experience great difficulty in applying for and accessing these services.

What steps must parents take to get Medical Assistance for their child with autism? Parents must file for the ACCESS Card through the County Assistance Office (CAO). They must complete a form and follow a process to receive the ACCESS Card. This process varies not only across the state, and across counties, but also from one individual to the next within the same county. Once the card has been obtained, the parent may go through a BASE SERVICE UNIT that will coordinate an assessment for the diagnosis and determination of hours, or the parent my be able to go directly to the provider. This also varies from county to county.

There are other available funds such as Family Support Services (FFS) funds through the Office of Mental Retardation (OMR) for persons who do not receive wavier funding, and funds for Mental Retardation (MR) diagnosis. A child with a dual diagnosis of Autism and MR is entitled to greater funds for materials, respite care and other support. FFS funds are supportive funds to augment existing services. Both of these funding streams are not well defined our coordinated. There are no publications readily available to

explain these funds or describe methods to access them. We were unable to obtain written criteria that explain how the money is determined or how it is distributed to families.

2. Other Views Expressed

- Wraparound looks different depending on where you are in the state. In some areas of the state Wraparound Services include in-home ABA services, yet in some areas of the state Wraparound services includes a TSS as a shadow for the child in a specialized program, etc. to address the behavioral health plan.
- Inadequate/appropriate training for wraparound staff in providing services to children with autism
- Lack of options of interventions- at the mercy of what provider wants to utilize; no clarity or regulations from DPW.
- Multiplicity of where services take place
- In many cases EI, IU and Wraparound systems do not communicate with each other or work together.
- MH/MR may not be qualified to deal with autism. Autism not Mental Health issue
- Some services cannot be given at required intensity in certain settings
- Limited communication between the clinical and educational systems
- Rules for wraparound are different for different services and vary by region and county
- Lack of current and comprehensive information for parents
- Need to define types of interventions, who provide and who pays
- Often an exclusion or not comprehensively covered under private/third party insurers
- Often considered mental health issue
- 'Hot Potato' between the education system and behavioral health system.

B. Provider Perspective

1. General Group Consensus

What services do they provide across and in coordination with other systems? Providers of wraparound services care for children across various systems and settings, but there is very little, if any coordination among these systems, especially with education.

What are the circumstances under which they provide them? If a goal is on the treatment plan, the child may have support at school, home, and community. The services provided by wraparound must be behavioral in nature, and are not to be educational. This creates a conflict when Therapeutic Support Staff (TSS), Behavior Specialist Consultant (BSC) or Mobile Therapist (MT) are involved in the support of a student in an educational setting. Frequently, the teacher does not know how to incorporate this support effectively within the child's program and placement. The TSS may not bill to attend IEP meetings for the child, and the level of support of a BSC and TSS are not even mentioned in an IEP. A discussion of how the wraparound staff should interface with the teacher rarely occurs. In addition, there are two documents for the same child, the treatment plan for the wraparound services, and the IEP to implement and measure educational goals. Each document may have their own Behavior Plan, and can cause great difficulty when a child has severe behaviors. Behavior strategies must be uniform across all settings and staff in order to support the child effectively.

2. Other Views Expressed - none

C. Administrative Perspective

1. General Group Consensus

How are services organized and paid for? Wraparound services are organized differently in every region, county and location. The funds come through DPW to counties, where some have managed care, and some are fee for service. Some counties have a Base Service Unit (BSU) that might conduct an extended assessment to determine the necessary level of care. Others have a case management system that will help make recommendations for services and providers. The system for billing for TSS, BSC, and

MT is confusing. There are certain rules for billing that seem to change based on interpretations of regulations and the Kirk T. lawsuit. Providers need staff to be able to do the billing and record keeping in order to be reimbursed. Reimbursement to providers is lacking.

The Birth to three EI is paid for through the IDEA funds in combination with State and Federal dollars through the Office of Mental Retardation and run out of the county office.

Preschool Early Intervention three to age of beginners EI is paid for through IDEA funds/State funds and is administered by the MAWA holder (School District/Intermediate Unit/Provider not for profit).

Which system are responsible for what services? The goal of the behavioral health system is to maximize functioning and reduce problem behaviors in the home, school and community. Providers funded through this system cannot work towards educational goals.

The funding of the 0-3 Infant Toddler Program causes a great deal of stress to families when they don't understand that their child isn't necessarily diagnosed with Mental Retardation. The services are provided in the home, and professionals work with the family to meet the IFSP goals.

The 3 to age of beginners program is responsible for providing a FAPE by addressing goals that are developed within the IEP. The transition from 0-3 to the preschool program can be difficult and confusing for parents. The shift from the Toddler program to the Preschool special education program is difficult in that the family is no longer the focus of intervention; the child and their needs become the focus for goals established in the IEP. Services are primarily provided in classroom settings throughout the counties in public schools and churches.

Each of these systems provides evaluations, and each has their own evaluation process. Both EI systems have multi-disciplinary assessments, but the team composition is different. The Preschool program may have a school psychologist who can provide a diagnosis, but this is not acceptable to the wraparound system. They require a licensed psychologist (not school psychologist) or psychiatrist.

2. Other Views Expressed - none

III. WHAT ARE THE PROBLEMS WITH EXISTING PRACTICES?

A. Family Perspective (What are the barriers to getting existing services? What services should be available but aren't?)

1. General Group Consensus

Screening: While the Academy of Pediatrics recommends developmental screenings at every well visit, there is no protocol for the screening of autism in the state of Pennsylvania. Physicians comment they are too busy to administer screenings to all children. If there are screening tools used, they may be invalidated tools with poor accuracy.

There should be a protocol for physicians to help screen children for developmental delays to refer for further assessment. It should be done early and frequently, for the earlier the diagnosis and intervention, the better the long-term outcomes are for the individual, family and community. There is an overall lack of knowledge of developmental ‘red flags.’ Healthcare professionals do not necessarily understand the importance of early identification of autism. This is true across the board for physicians, preschools and other professionals that work with young children.

Physicians often take a ‘wait and see’ attitude in the early years, to keep from upsetting parents if the delay is not major, thinking the child may grow out of it. Often times, also at this age, parents are not ready to receive a diagnosis and may be in denial. The need for public awareness of autism and the importance of early intervention must be made. Parents need to receive this information early, and often to be monitoring their child’s development, and what to do if there is concern.

Diagnosis: There is a statewide as well as a nationwide shortage of trained professionals that can diagnose autism. The developmental pediatrician, psychiatrist, psychologist or neurologist that diagnoses autism may be lacking current information for recommendation of intervention and plan of care. The information needs to be addressed in medical school curriculums in more detail. Also frequently, the professional that diagnoses the child may recommend services that are hard to obtain in the current system or inappropriate in terms of intensity. Medical providers in the state of Pennsylvania currently have waiting list of 6 to 12 months for a diagnosis.

There are few supports for a family at this point in time which is considered to be one of the most difficult times in dealing with a child with autism. The parents are feeling guilty, grieving what they expected their child's life to be, and are clueless on how to effectively deal with their child because of their own lack of autism knowledge. Parent support is needed for their own mental health needs with the acceptance of the diagnosis, and how it will have an affect on the family. There is a need for parent instruction of what autism is, what to expect, how to deal with the system to get services and how to learn to deal with their child with autism.

There is also a need for parent-to-parent support to help a family deal with daily struggle of living with autism. The state does fund a program called Parent to Parent which is a network created by families of children and adults with special needs. The connect families in similar situations with one another so that they may share experiences, offer practical information and/or support.

Referrals: In the birth to three system the Early Intervention Reporting System does record the referral source. In both the birth to 3 and 3 to 5 systems in PA they record the category children are eligible under, the intervention plan and do regular progress monitoring. Currently, there is a disconnect across serving systems in regard to screening, diagnosis and treatment, with no tracking system to monitor progress. Once a child has been identified as having delays, and the need for further assessment is determined, the steps that follow need to be hooked together so that no child slips thru the cracks and are missed because of a lack of follow through.

The birth to three system is governed by the same rules statewide and so is the three to five system, some of the federal and state regulations differ between birth to three and three to five. Even though, there is a lack of consistency and coordination across serving systems that should be statewide and a have a shared responsibility. With the lack of consistency and coordination is a lack of funding and major concern over how available funding is being used. There is little uniformity in wraparound for referral or the services recommended. Rules are different for different services and vary by region, county and service provider. The overall complexities of the paperwork and the need for assistance in navigating the system are overwhelming. There is a need for a united and uniform method of assessment, referral and provision of services across systems so if the Smith family moves from Philadelphia to Pittsburgh, their child and family will have little difficulty understanding the system and the services available and how to access them.

Services that family may be referred to as appropriate may not meet the needs of the family. The family may not be able to accept the services because of required intensity in certain settings that could cause hardship by forcing a family member to quit a job in order to access services. The services need to continue not to be determined by the level of income, but the need of the child for wraparound. These services should wrap around the family and support the child so as not to make hardships of any kind on the family.

The clinical and educational systems do not typically communicate to meet the needs of a child by blending funds and collaborating on treatment. If the child has wraparound, the need to communicate between EI, IU or school district and wraparound support staff is also of concern. This must be more functional and united. The services for children with autism need to support the child across settings by providing support to families and their child. A plan of care needs to be agreed upon by the Department of Public Welfare and the Department of Education to effectively support a child with ASD in any setting.

Some higher functioning children with autism may not be identified as having a delay, and may not qualify for services, while still having the need for intervention for their autism. There needs to be more specific and sensitive assessment and trained people to identify the higher functioning children that may be

missed by standard methods of assessment. These children with language skills and other skills intact have the potential to make very good progress with less intensive intervention.

Intervention: There is no one method of intervention used or recommended across the state of Pennsylvania. While there is no one method of intervention for all children with ASD, ABA is substantiated as effective, based upon the scope and quality of research. Other methods and interventions need to be explored and determined as acceptable methods for children. Methods such as TEACCH, PECS, and the Association Method need to be discussed, and in some instances, validated. Ideally, all research-proven methods should be available as options for youngsters with autism.

A child, birth to three years, or three to the age of beginners (age of beginners is 6 or age when a child can be admitted to the local school district K program) can participate in Early Intervention if they have met the criteria for a delay. The child then moves on to the school district until possibly the age of 21. Some higher functioning children with autism may not be identified as having a delay, and may not qualify for services, while still having the need for intervention for their autism.

Again, the split on funding streams also splits the intervention. The EI, IU, school districts and Wraparound system have a difficult time communicating and working with each other due funding issues and regulation differences. The birth to 3 years of age Early Intervention focus is family driven with a lack of hours that would provide a level of intensity for the child. The 3 years to the age of beginners Early Intervention is funded through IDEA and state funds and becomes more educational causing the focus to change from family to child. This causes difficulty in transitioning from one system to the next. As the child moves on to transition to school district, more difficulty can develop as each school district, county and region is different as to interventions for autism. The Wraparound service that is provided across the state also varies from provider to provider with a lack of choice in accessing interventions. This often leaves families at the mercy of what the provider wants to utilize.

2. Other Views Expressed

- Parents should have the option to hire their wraparound staff aids directly
- Not enough attention given to parents' need for respite
- Quarterly re-evaluations for wraparound services are an unnecessary burden for families, autism doesn't go away
- Looking at alternative treatments such as a biomedical approach as a part of the equation for a child with autism
- Treatments usually are not intensive or data driven to guide programming and report progress

B. Provider Perspective (What are the barriers to providing existing services? What services should be available but aren't?)

1. General Group Consensus

Providers have difficulty providing services for a variety or reasons, commonly, finding qualified staff. Once they find the qualified staff, they must spend the time training them, and very often the rate of turnover is high. So the providers may invest a great amount of time developing the staff only to have them move on to other positions. Providers also have difficulty with billing.

The rules and regulations for Wraparound cause a great deal of difficulty for providers. The demand for staffing may outweigh the availability of staff, causing the provider to be out of compliance with the Kirk T lawsuit. This, as well as regulations, can restrain services. Considerations such as the avoidance of double billing, lack of reimbursement from the State for staff billing for staff meetings, and strict timelines for training are just a few examples that are frustrating for providers. These providers feel it is almost impossible to provide quality care and meet all the regulations to remain in compliance with Medical Assistance.

In order for services that should be available to be in place, there needs to be staff that is available with appropriate training, starting at the age of diagnosis though to adulthood. Children are starting to be

diagnosed when they are 18 months old, and we need to have trained and knowledgeable staff on appropriate interventions. Providers would need to be flexible on how these services would be delivered and family's level of involvement.

There is a state and national shortage of trained professionals that can deal with autism. There is a shortage of trained speech therapists. Since communication deficits are the main focus of autism as a disability, this severe shortage of speech therapists is a major problem. Speech therapists that specialize in the pragmatics of speech, social group therapy and other language-based therapy are especially in need.

Funding for autism also makes it difficult for providers. There is need for a seamless system vs. the silo system of funding that is currently in place. The overall complexities of the paperwork and the need for assistance in navigating the system are overwhelming for all.

2. Other Views Expressed - None.

C. Administrative Perspective (What are the problems with existing organization of and payment systems for services? What are the problems with system coordination?)

1. General Group Consensus

There is a lack of consistency and coordination across systems that should be statewide and a shared responsibility. With the lack of consistency and coordination between systems, and with the lack of funding, there is a major concern over how available funding is being used. There is no uniformity for referral for the services recommended. Rules are different for different services and vary by region and county. The overall complexities of the paperwork and the need for assistance in navigating the system are overwhelming. There is a need for a united and uniform method of assessment, referral and provision of services so if the Smith family moves from Philadelphia to Pittsburgh, the child and family will have little difficulty understanding the system and the services available and how to access them.

There is a need for a seamless, coordinated system with braided funding. The funding should follow the child instead of each service being funded from its own individual system or silo. This would support an effort to collaborate and coordinate services for the individual with autism.

2. Other Views Expressed - None.

IV. WHAT ARE POTENTIAL SOLUTIONS FOR IMPROVING EXISTING PRACTICES?

A. Family Perspective (How could barriers to existing services be eliminated? What additional services should be provided?)

1. General Group Consensus

- Single point of entry into system
- Need for 'newly diagnosed' packet (STATEWIDE)
- Caseworker to help navigate systems with bilingual ability
- One form to access system
- Combining welfare, education, behavioral health, school systems
- Need for plan of care vs. IEP or treatment plan?
- Continuous progress monitoring
- Tailored to family needs
- Comprehensive, intensive, flexible
- Data driven, research based
- Parent support/grief counseling
- Options to choose between home/center-based settings

2. Other Views Expressed - None.

B. Provider perspective (What changes would improve the ability to provide high-quality services in a timely manner?)

1. General Group Consensus

- Widespread training/technical assistance across all entities
- County team for case management from diagnosis
- Collaboration between welfare, education, behavioral health, school systems
- Statewide physician training
- Single point of entry
- Agencies to network
- Continuous progress monitoring
- Data driven, research/evidence based such as with ABA
- Not one-size fits all approach; Individualized
- Research needed on best practices

2. Other Views Expressed - None.

C. Administrative Perspective (How could the organization of and payment for services be improved? How could coordination among different systems be improved?)

1. General Group Consensus

- Statewide physician training such as First Signs through the medical home project
- Alliances with American Academy of Pediatrics and County medical societies
- Combine birth to school age children systems (seamless system from diagnosis to age of beginners)
- Single point of entry into system
- Caseworker to help support program
- Combine welfare, education, behavioral health, and school systems
- Autism Caucus to educate policy makers
- House funding and information in one area such as PA Dept of Disabilities.

2. Other Views Expressed - None.

Early Intervention Recommendations
(Screening, Diagnosis, Referral, and Intervention)

RECOMMENDATION #1: SUPPORT THE MEDICAL HOME FOR CHILDREN WITH SPECIAL NEEDS

http://www.medicalhomeinfo.org/about/index.html

NEED: Collaboration and Form Alliance with the Medical Community

The (AAP) American Academy of Pediatrics' Committee on Children with Disabilities recommends the administration of standardized developmental screening tests at each of the 12 health supervision visits scheduled between 0 and 5 years of age and for every year thereafter.

The AAP is also working on the Medical Home for Children with Special Needs that supports these regular developmental assessments.

The medical home should be accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.

Please note the specifics for Comprehensive:

- A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient. · Care among multiple providers is coordinated through the medical home.
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.
- The medical home physician shares information among the child or youth, family, and consultant and provides specific reason for referral.
- Families are linked to family support groups, parent-to-parent groups, and other family resources.
- When a child or youth is referred for a consultation or additional care, the medical physician assists the child, youth, and family in communicating clinical issues.
- The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and family and, in consultation with them and sub specialists, implements recommendations that are indicated and appropriate.
- The plan of care is coordinated with educational and other community organizations.

RECOMMENDATION #2: PROMOTE STATEWIDEIMPLEMENTATION OF FIRST SIGNS

First Signs: www.firstsigns.org

NEED: Statewide Physician and Health Care Provider Training on Autism Identification

Approximately 50% of children aren't diagnosed until school age. This tells us that the physicians and pediatricians are in need of awareness and training for the early identification and treatment of autism. Several counties are currently working toward this goal of awareness and training with First Signs. First Signs is a wonderful resource and is a statewide program in New Jersey and Minnesota. Mary Barbera, our Asst. Facilitator has received a grant of $50,000 to implement First Signs in Berks County from CCBHO, the MCO. Other organizations across the state are working with First Signs for their area, such as Brenda Eaton with the Chester County Intermediate Unit for Chester County, SAFE in Wilkes-Barre, Sue Weir in Bucks, and others.

With the recommendation for First Signs as a statewide program, First Signs has a Screening Kit for physicians, which includes a 23 minute tape on developmental milestones and warning signs. It also has various developmental screening tools, the M-Chat and a protocol to follow once a development delay has been identified. Training with this tool would provide the necessary training and awareness for physicians and other professionals that identify children with autism.

The CADDRE (Center for Autism and Developmental Disabilities and Research and Epidemiology), a CDC funded group has met with First Signs to collaborate with implementations going forward with hope of statewide funding. Currently, a proposal is being formulated to submit to the Pennsylvania Department of Public Welfare and the Pennsylvania Department of Health to fund First Signs as a statewide program.

RECOMMENDATION #3: CREATE BIRTH TO 3 GUIDELINES FOR PENNSYLVANIA

Web links:

New Jersey - New York - Connecticut - North Dakota - Indiana - Educating Children with Autism

NEED: Develop Pennsylvania Birth to 3 Guidelines as Established in Other States

Topics to identify would be:

- Identification of what is considered to be "knowledge and experience" in autism
- Assessment Methods
- Intervention Methods
- Identification of level of service (i.e. 20 hours a week)

- Various Appendices for methodology, summary of evidence, tests and tools to be used such as the (ADOS), Autism Diagnostic Observational Schedule, The Assessment of Basic Language and Learning Skills (ABLLS).

This would allow for more consistency in the state, and raise the bar from a few hours a week of intervention to a more intensive intervention for better long-term outcomes. It should be considered for the Guidelines to extend to the age of beginners in the school system.

***Please see summaries for New York, New Jersey, North Dakota and Educating Children with Autism at the websites that are referred to above.

RECOMMENDATION #4: IDENTIFY A PROCESS OR PROTOCOL

NEED: A Process or Protocol

A process or protocol to be established for ease in referral and follow-up on a child would help support all professionals and families in the referral process. The following flow chart could be considered as a statewide procedure or protocol, followed by all professionals, and guided by the Medical Home for Children with Special Needs:

1. Birth
2. Medical Home for children with special needs
3. Developmental Screenings at every well visit per AAP (suggested PEDS)
4. Use of CHAT or M-CHAT for autism screening when developmental screening indicates
5. Refer to early intervention and specialist for further assessment (County Clinic)
6. Use diagnostic tool (along with the ADOS to use as a standardized assessment for autism)
7. Diagnosis if indicated
8. Assessment done on the child (suggested The ABLLS)
9. Plan of Care (education and behavioral health collaboration)
10. Refer to case management for coordination with family for selection of services and level of care.

RECOMMENDATION #5: IMPROVE TRANSITION FROM BIRTH TO 3 AND FROM 3 TO THE AGE OF BEGINNERS

NEED: More of a Seamless System for More Consistency

Early Intervention is a mandate under IDEA, Individual with Disabilities Education Act, that requires children identified with a disability age birth to 3 be served under Part B of IDEA and 3 to the age of beginners under Part C of IDEA. Part B implements a medical model while Part C implements an educational model. Each Part is funded through different funding streams to complicate the matter. Part B is funded through DPW then through county Mental Retardation, and Part C is funded through education.

The blending of this transition would allow for better support and services, reduced amount of lost time due to transitioning, and less confusion for the family.

RECOMMENDATION #6: COMBINE PLANS ACROSS THE LIFESPAN FOR A PLAN OF CARE

NEED: Collaboration Between Public Welfare, Education, Behavioral Health and School Systems to Provide Consistency

In early intervention, a child identified will have an IFSP, Individual Family Support Plan, School age, an IEP, Individual Education Program, and for Behavioral Health Services, a Treatment Plan. It would be ideal to be able to meet the needs of the child under one "Plan" and allow the funding to support the one plan, and would be followed by everyone providing services across their lifespan.

This would reduce the number of assessments the child would have to endure, and the various types of reports and assessments used on the child. Currently, in Wraparound, there is a psychological evaluation

every 4 months that is not need for autism (since it is a chronic condition and not a short term mental health issue), and the assessment for the education system as well as any other separate serving system.

RECOMMENDATION #7: COUNTY CLINICS

NEED: One Point of Entry with one Process to Access the System to Provide Consistency

To address the issue of long waiting lists for diagnosis, and to support a single process for the family to follow for assessment, diagnosis, referral and intervention, a county clinic is recommended to support each county. This clinic may be only a few days a month, but will provide the needed participants of a 'County Team' and have the level of expertise and knowledge to identify a child and get them into appropriate intervention as soon as possible.

County Clinics for assessment will consist of specialists from each of the following areas to follow the child through assessment, diagnosis, referral and interventions.

- Birth to 3 representative*
- MAWA – EI representative* (school psychologist)
- Speech therapist
- Occupational/ Physical Therapist
- Behavioral Health Representative (county or MCO)
- School District representative (school psychologist)
- Resource Case manager, social worker (independent party)

*Depending on the age of the child. If the child is not eligible for services due to their aging out of services, participation is not required.

Once a child is referred from a physician or pediatrician to the clinic, the professionals will develop diagnostic information (such as the use of the ADOS, not to be used alone but is a standardized assessment for autism) to aide in the development of interventions and programming. Currently, Pennsylvania school psychologists are able to provide the diagnosis. Prior to June 2001, there was a requirement of a medical diagnosis.

Case managers will have social work background to help parents through the diagnosis process and referrals for interventions and information of services and supports. They are to be employed by the state, so as not to show any bias for any one party. This would help to support a single Case Management System for a family to deal with instead of multiple providers and information systems.

RECOMMENDATION #8: SOCIAL SKILLS TRAINING, PLAY SKILLS GROUPS AND RELATED SERVICES

www.lekotek.org
http://PECS.com/playgroup/playgroup.html

NEED: Training for Professionals Specific to Autism and More of Their Services Available

The one common characteristic shared by all individuals with autism is impairment in Social Skills. There is a need for more opportunities for social skills training as well as play skill groups to develop play skills that will help lead to social skills. On top of this list is a need for professionals who are trained in this area to help support young children with High Functioning Autism.

RECOMMENDATION #9: DEVELOP A LEVEL OF CARE THROUGH ASSESSMENT

www.wpspublish.com
www.difflearn.com

NEED: Collaboration Between Providers for More Consistent Method of Assessment

There needs to be development of a Level of Care to support the screening, diagnosis and assessment for a '**Plan of Care**' to serve a child with Autism. As you progress though the identification of the child, the ADOS, Autism Diagnostic Observation Schedule could be a recommended tool to use as a clinical standardized assessment of the child. This assessment will provide valuable information that can better support the development of a plan of care for a child with autism. To implement the ADOS, there needs to be statewide training on the ADOS to a standard of reliability. The candidates for this training would be the County Clinic Teams.

Another known assessment tool that leads to more direct interventions is the ABLLS, The Assessment of Basic Language and Learning Skills. The ABLLS is an assessment, curriculum guide, and skills tracking system for Children with Autism or Other Developmental Disabilities. The ABLLS Tracking System provides the opportunity to see where the child is currently, what skills need to be worked on next, and the criteria to meet the skills. The ABBLS also works well with the Verbal Behavior (VB) Approach. VB is a way of developing language skills with a behavioral approach.

RECOMMENDATION #10: DEVELOP A LEVEL OF INTERVENTIONS

Educating Children with Autism- New York - New Jersey - MADSEC Autism Task Force - North Dakota- Connecticut

NEED: Identify Appropriate Interventions and Level of Service

The National Research Council, at the request of the U. S. Department of Education's Office of Special Education, reviewed current literature on educating children with autism and made recommendations. The NRC formed the Committee on Educational Interventions for Children with Autism to accomplish their task. The committee's recommendations are published in the book Educating Children with Autism, published by National Academy Press, 2001. Please refer to the website listed above for additional information.

The state of New York recommends a minimum of 20 hours of ABA a week with providers as reflected in the book Clinical Practice Guideline, Report of the Recommendations, Autism/Pervasive Developmental Disorders. (Sponsored by the New York State Department of Health Early Intervention Program, New York State Dept. of Health.)

The New Jersey report, "Service Guidelines, Children with Autism Spectrum Disorders," has information in Appendix form for the following:

- Appendix A- Knowledge and experience in autism
- Appendix B- Justification for services over 20 hours
- Appendix C- Applied Behavior Analysis

The MEDSEC Autism Task Force report, (Maine Administrators of Services for Children with Disabilities, Autism Task Force Feb. 2000), Applied Behavioral Analysis and other interventions should be reviewed and determined to be effective.

The North Dakota report, "Guidelines: Identifying, Serving, and Education Children and Youth with Autism" should be reviewed. The section on, "Interventions and Methodologies," can be found at the website listed above.

The Connecticut Report addresses approaches to providing services such as; terminology of behavioral approaches, behavioral approaches, developmental approaches and approaches used in the birth to three system.

Applied Behavior Analysis comes up as substantiated as effective, based upon the scope and quality of research. It is recommended that the various state reports given be reviewed and a list of acceptable and

not acceptable interventions be made. In addition to methods and approaches, the amount of hours of service and how that should be determined should be identified.

Other consideration should be taken into account as to current Pilot Programs in the state such as the Verbal Behavior Project through the Bureau of Special Education and SAFE, Serving Autism and Families Everywhere. Verbal Behavior is an approach using methods of ABA to develop language skills through the use of the ABLLS, and currently has 12 model sites.

RECOMMENDATION #11: AUTISM INFORMATION RESOURCE

NEED: A Clearinghouse for Gathering and Providing Information on Autism

There is a need for parents to be able to access information more easily. A 1-800- number and/or website for information and where to go in their area would cut down on the run-around time for information and services. For example: a 'newly diagnosed' packet, information on community support, grief counseling and other issues of dealing autism.

A data base system to track the number of children, referrals and other pertinent information would also help us understand where we are with autism in Pennsylvania.

RECOMMENDATION #12: BETTER PRESCHOOL AND CHILDCARE

NEED: Better Prepared Preschools and Childcare with Training on Autism

Preschools need to be educated to help identify children and refer to early intervention in a timely manner. They also need training on how to deal with the population in the classroom. Quality childcare is not available, and the need for training for childcare providers is vital for many families to be able to care for their child and still maintain a job.

09. Needs of Children (Ages 6-12) Subcommittee Report

I. INTRODUCTORY MATERIALS

A. List of Members

Co-facilitators:

Janet Formichella & Lori McMaster

Committee Members:

Jane Brown
Susan Coursey
Jan Cunningham
Deborah Delp
Amiris DiPuglia
Ted Fallon
Marla Jo Green
Randi Grimes
Theresa Harding
Marilyn Hendricks
Rose Huntzinger
Joe Hurd
Natalie Krebs
Rebecca Klaw
Gloria Lance
Annmarie Lynch
Marie McClay
Tara McHale
Wendy McSparren
Jaquelyn O'Flynn
Erin Olsen
Gwen Shoemaker
Michelle Spohn
Nicole Sturla
Carrie Todd
Sabra Townsend
Arleen L. Wheat
John Sportelli-Wright

B. Mission of the subcommittee

The mission of the subcommittee is to identify the current state of educational and behavioral health services in the Commonwealth of Pennsylvania as they relate to autistic children who are five to twelve years of age; to identify the problems with existing practices; and to identify potential solutions.

C. How and how often did you meet?

The subcommittee initially met on July 26, 2003. The subcommittee members have since held web chats, e-mailed, and posted summaries through a Yahoo group created via the Internet. Meeting in person has not been possible due to the geographical distance between committee members and time constraints. In addition, the Sub-committee held two 2-hour joint telephone conference calls on September 7, 2003 and June 1, 2004 to discuss all of these issues.

D. How was the report formulated?

Subcommittee members submitted draft outlines to the Subcommittee facilitators, who incorporated these written submissions, as well as the input received during the telephone conference calls, and prepared a Draft Report Outline. The Draft Report Outline was then distributed to the individual Subcommittee members for their review and approval. The report was then presented on October 11, 2003 at a facilitators meeting in Harrisburg. Comments and questions raised at that meeting were then presented to the sub-committee. Comments were then incorporated in the second presentation of the report in Harrisburg on November 22, 2003. All input from members was submitted, and the co-facilitators drafted the report and distributed it to the committee members for changes and approval.

II. WHAT IS THE STATE OF CURRENT PRACTICE FOR CHILDREN LIVING WITH AUTISM?

A. Family perspective

What services do they receive in education, Medicaid and other system? What step must they take to get them?

1. Education: Statutory Requirements of Special Education

The Individuals with Disabilities Education Act (IDEA), 20 U.S.C. 1400, et seq. and Chapter 14 of the Pa. Regulations govern special education.

A child's eligibility and need for special education and related services is first determined through an evaluation process which determines if a child is a "child with a disability". The definitions of disability categories specifically include "autism". Under IDEA, a "child with a disability" is entitled to a free appropriate public education (FAPE) if and only if, as a result of the disability, the child needs special education and related services to benefit educationally.

If the evaluation report determines that the child is a child with a disability and is in need of specially designed instruction, then the Individualized Education Plan (IEP) process commences. The IEP must be developed within 30 calendar days and a "Notice of Recommended Educational Placement (NOREP) is developed. Parents may approve or disapprove the NOREP. The IEP is to be implemented as soon as possible, but no later than 10 school days after its completion.

Children with disabilities are to have available to them "a free appropriate public education which is designed to enable them to participate fully and independently in the community, including preparation for employment or higher education."

To the maximum extent appropriate, children with disabilities are to be educated with children who are not disabled.

Related services (such as speech therapy, occupational therapy, physical therapy, transportation, etc.) must be provided if the child needs them in order to benefit from or access his special education program. Related services are often provided via the intermediate unit or outside contractors hired by a school district.

A child's reevaluation must occur every three years for disabled children other than MR (which is still 2 years).

2. Medical Assistance.

Medical assistance provides coverage of medical and mental health services for persons less than 21 years of age, and includes services such as mental health wraparound services, physical, speech or occupational therapy, shift nursing, in-home personal care services, diapers, pull-ups, prescriptions and transportation to and from medical appointments, and nutritional supplements for children less than 2 years of age.

Not all children with a disability or with an IEP qualify for Medical Assistance. The Social Security childhood disability standards, or the "Childhood Listings of Impairments" determine eligibility. Section 112.10 entitled "Autistic Disorder and Other Pervasive Developmental Disorder" provides that a child is eligible when there are qualitative deficits in the development of reciprocal social interaction, verbal and nonverbal communication and in imaginative activity; and a markedly restricted repertoire of activities and interests.

More information about Medical Assistance eligibility and how to apply can be found at http://www.dpw.state.pa.us/LowInc/MedAssistance/MAEligibility/003670295.htm.

Medical assistance is provided via a mechanism designed to serve children with mental illness or mental retardation. As a result, the medical necessity criteria, mechanisms for providing services, the definition and identification of covered services, service delivery criteria, reporting standards, and rate structures are grossly ill suited to meet the needs of children with Autism Spectrum Disorder (ASD).

Children with ASD may receive Wraparound services, which may include a Behavior Specialist Consultant (BSC), Mobile Therapist, or Therapeutic Support Staff (TSS). An evaluation is done every four months by a licensed psychiatrist or psychologist to determine the medical necessity of these services, and a prescription is written for a specific number of hours of service from a clinical professional. The provider must deliver the prescribed hours of service in a full and consistent manner. Once the need is determined a number of hours are approved by the state. Services must be deemed medically necessary.

If Wraparound services are provided in the school, and if a child's IEP team determines that such Wraparound services are necessary for the child to receive a free appropriate public education ("FAPE"), the district will become responsible for providing such services if the child's Wraparound agency withdraws their services. See Basic Educational Circular 22.

3. Other Related Services

Family Driven Support Services (FDSS)

Children who qualify as Mentally Retarded are eligible for Family Driven Support Services (FDSS) through their Base Service Unit. These funds are fixed annual amounts which are distributed to families to help pay for caregivers, home health, recreation, family education, adaptive equipment and camps, therapeutic materials such as weighted blankets, and safety equipment such as door alarms. Families are currently on waiting lists for these funds.

The annual amount of FDSS funds are subject to change, and seem to decrease annually. Parents pay for the services/items and are then reimbursed by the coordinator of FDSS funds. Even though a family is allocated a certain annual amount of FDSS funds, these funds are often depleted before the end of the fiscal year. Therefore reimbursement for qualified expenditures for families is not guaranteed after the funds run out, even if the reimbursement requests were filed in a timely manner.

Family Support Services (FSS)

Children who qualify as Mentally Retarded may also receive additional funds from Family Support Services (depending upon the County) for the services and items listed above.

III. WHAT PROBLEMS EXIST WITH CURRENT PRACTICES?

What are the barriers to getting existing services? What services should be available but are not?

A. Family perspective

1. Education

The major obstacles parents encounter in attempting to exercise their children's educational rights include the following:

Entitlement to Special Education Services

A child's eligibility and need for special education and related services is first determined through an evaluation process which determines if a child is a "child with a disability". The definitions of disability categories specifically include "autism". This definition could actually serve as an obstacle to some children (such as those with Asperger's Syndrome or Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS)) seeking special education services.

Inconsistency in the Availability and Quality of Special Education Services

While the "steps parents must take" to access special education services are legislatively determined, in reality, there are great differences between urban and rural areas, and among school districts in terms of how difficult it is to obtain and keep quality educational services. Districts often dispute the necessity of such services and attempt to limit the number of hours of services children receive. Although our children are entitled, to the extent appropriate, to be educated with children who are not disabled, there is great inconsistency throughout the state in terms of school districts' commitment to inclusion, and their capacity to appropriately effectuate inclusion through the use of qualified school personnel. Despite the legislative mandates, there is a continued cultural reluctance or even hostility to the concept of inclusion. As a result, many schools resist full compliance with the requirements of IDEA/Chapter 14, or attempt to minimize the type and level of educational and related services they provide.

Children with autism receive educational services in a multitude of ways that have resulted in services of inconsistent quality and in a lack of accountability. Many children are also inappropriately placed in behavioral support classrooms that are designed to serve children with psychiatric, emotional and/or behavioral problems. Some children are educated in "autistic support classrooms," "life skills classrooms", "support classrooms", and via dual placements where they receive academic instruction and/or related services from both the school district and the intermediate unit. Dual placements may result in power struggles, inappropriate shifting of responsibilities, and school districts failing to take "ownership" of our children. Parents of higher functioning Autistic children find that, due to large class sizes, lack of adaptation of curriculum, lack of teaching social skills, etc., it is difficult for this group of children to learn in the public schools.

Schools have difficulty addressing the entire Spectrum of Autism. Many school tend to use a "cookie cutter" approach to teaching children with autism instead of providing a truly Individualized Education Plan.

Parents are also more frequently reporting that school districts are requiring them to sign non-disclosure agreements which prohibit the parents from divulging information regarding the nature and/or quantity of services provided pursuant to their child's IEP. Presumably, such agreements are intended to prevent other parents from requesting similar services on behalf of their disabled child.

Required related services (such as speech therapy, occupational therapy, physical therapy, educational audiologists, etc.) are often not provided on a timely basis, if at all, due to the over-reliance on outside contractors who come to the school irregularly. Districts also consistently attempt to limit the number of hours of related services a given child receives. Many school districts contract with their Intermediate Units for these related services, and there is often a shortage of staff to cover many of these students.

Lack of Understanding of Autism Spectrum Disorder (ASD)

There is a lack of understanding by administrators and teachers regarding autism spectrum disorder and the need for instruction that is specially designed to fit the needs of children with Autism Spectrum Disorder (ASD). ASD is a very different diagnosis than many other diagnoses a school might encounter because symptoms do not always affect the cognition required to master content. Instead, ASD usually affects the process of mastering content and/or being successful in school. As a result, many regular education teachers are not equipped to serve autistic children and therefore overly rely upon the TSS or other third parties for the provision of educational services. The lack of understanding of ASD students actually instigates "problem behaviors". For example, many educators do not know that ASD children interpret language quite literally. For example, a teacher once complained that an ASD student treated her disrespectfully when she asked the class to proceed to the door and to "hop to it". The ASD child, naturally, did exactly what the teacher requested- he hopped to the door. What was perceived as an act of disrespect was actually an attempt to do exactly what the teacher requested.

Parents wishing to secure the best services for their children are sometimes compelled to accept a more restrictive placement (i.e., non-inclusive learning support classrooms) in order to access the more extensively trained special education teachers. Parents should not have to choose between inclusion and quality education.

In addition, children with ASD are frequent targets of bullies in school settings. It is imperative that school districts establish research-based "anti-bullying" policies to protect special needs students, and the general student population.

School Districts' Opposition to Services Which They Deem To Be "Community Based"

ASD children are entitled to "participate fully and independently in the community, and to be prepared "for employment or higher education." However, school districts lack the initiative and the vehicles necessary for our children to accomplish these goals.

Districts frequently object to any educational goal that they perceive as "community based." A catch-22 is created because the very deficits associated with autism impair a student's ability to integrate into the community. An autistic student will invariably possess qualitative deficits in the development of reciprocal social interaction, verbal and nonverbal communication and in imaginative activity; as well as a markedly restricted repertoire of activities and interests. This is especially true for students with Asperger's Syndrome, who frequently possess high IQ's, yet have significantly impaired social skills. School districts should not be permitted to resist providing services to address those deficits merely because they affect the child beyond the schoolyard.

Social skill groups and pragmatic language groups are almost non-existent. Schools are not offering opportunities for students with autism to learn social skills in a group setting. Parents have been told, "The school district cannot mandate non-IEP students to participate in these groups."

Lack of Interdisciplinary Cooperation and Accountability

Schools districts often either resent the input from third parties such as Behavior Specialist Consultants (BSCs), or they over rely upon the intermediate unit, parents, private therapists and Wraparound providers to address issues that, in fact, are the responsibility of schools. Schools alternately over-rely upon, or resist, the assistance provided by Wraparound providers. Although it is the legal obligation of schools (and not the mental health industry) to provide FAPE to autistic children, because schools are ill prepared, they continue to rely upon outside contractors and/or Wraparound providers to achieve inclusion and to provide qualified student aides. Many schools resist working cooperatively with private therapists and Wraparound providers to ensure consistency between the school and home programs.

Entry Into Kindergarten

Parents are often unaware that early intervention services may be provided until the age of 6, and are unfairly pressured to place their child in kindergarten at the age of 5. Parents are unaware that school age does not begin until age 8 and ends at age 17 or graduation. Chapter 11, Pa. Code § 11.13.

Extended School Year Services

Extended School year ("ESY") is provided inconsistently from one school district to the next. Many schools have limited funds for ESY, therefore the criteria for the services also vary. Children with significant deficits could use the summer to gain skills in academics, functional language and social skills – all things necessary for success in the classroom. Eligibility for ESY should not be dependent on a loss of skills for children who already significantly lag behind their peers. Services should not be limited to academic areas. Children with ASD need constant work on behavior, language, social training, and occupational therapy. Furthermore, many children with ASD do not transition well, and three months away from the classroom make the transition in September more difficult. Districts are also highly averse to providing transportation to ESY, or to accommodating the transportation needs of their children.

Procedural Safeguards Are Expensive and Time-Consuming

If a parent disagrees with the NOREP at the conclusion of the IEP meeting, they are permitted to pursue dispute resolution measures such as mediation, a pre-hearing, or a due process hearing. In most cases, parents require legal assistance to pursue the last two options. Many parents find that pursuing dispute

resolution is time-consuming, tiring and very expensive. If the parents need to pursue their case in court, this adds to the difficulty for families. The State Bureau of Special Education will audit for compliance with IEPs but does not become involved with disagreements between parents and the school district.

The Lack of Quality Educational Services for Children Living With ASD Often Forces Parents to Home-school

Lack of access to quality special education services forces many parents to home-school their ASD child, thereby denying them the free, appropriate public education to which they are legally entitled.

Additionally, home-schooling regulations are very restrictive in Pennsylvania. The parents of a child with an IEP must hire a special education teacher that the school district won't provide, to review the goals and objectives for the child with the IEP. The days and hours are rigid in that the student must be home-schooled for either 180 days or 900 hours, regardless of the type of days the child might be having. There are certain categories that must be taught, including Math, History, Science, etc. Sometimes, a parent must give more focus to lessons involving social skills, critical thinking concepts, etc. and the required classes do not fit the needs of the child. Finally, home-schooling presents a significant financial hardship as only one parent can work outside of the home. Single parents find it almost impossible to do so.

2. Medicaid

Medical assistance provides coverage of medical and mental health services for persons less than 21years-old, and includes services such as mental health Wraparound services ("Behavioral Health Rehabilitation Services" or "BHRS"), speech and occupational therapy, shift nursing, in-home personal care services, diapers, nutritional supplements, and prescriptions.

From a family perspective, the problems with existing practice include the following:

An Insufficient Number of Qualified Medical and Behavioral Providers

There are too few qualified medical and wraparound providers, particularly in rural areas, and the quality of services varies greatly from provider to provider and throughout geographic areas. Not all physicians or therapists accept Medical Assistance; therefore parents are unduly limited in terms of the availability of qualified providers.

While children with ASD are meeting the continued care medical necessity criteria, many children's prescriptions for Wraparound services are not being filled due to the lack of providers and qualified personnel required to fill the ever-increasing demand. Parents in some counties are contacting ALL of their county's authorized Wraparound providers and are being told to call back in three months because the provider does not have the staff to provide services.

There are an insufficient number of dentists who are both willing and able to treat autistic children, many of whom have heightened sensitivity in their mouths, and object to anyone else touching their mouth and teeth. Many dentists in Pennsylvania refuse to treat autistic children, and many of those will do not accept Medical Assistance.

Furthermore, most insurance plans specifically exclude treatments for autism.

Parents Are Not Effectively Informed of the Available Services and Treatments Which Are Available

Parents are often given little to no practical guidance at the time their child is medically diagnosed. Diagnosticians do not typically provide essential information regarding the behavioral and medical services provided via Medical Assistance, treatment options, and educational placement. Information regarding the various behavioral treatment modalities (e.g., Discrete Trial, Lovaas, Greenspan, Carbone, etc.) is frequently not provided, and parents are not advised that they have the right to choose whichever treatment approach they believe will most effectively assist their child. **(1)** Therefore, parents are forced

to educate themselves through informal channels in order to commence meaningful treatment and educational programs.

(1) Additional information regarding these treatment methods can be found at:
www.drcarbone.net
www.lovaas.com
www.stanleygreenspan.com

Many parents are unaware that they may access services via Section 529 on the basis of their child's diagnosis alone, and without regard to financial need. Parents are often unaware of, or do not understand the procedures necessary to access services via Medical Assistance.

Autism Services Are Currently Being Provided By A BHRS System That Was Never Intended To Serve Children With ASD.

The current system was designed to provide intensive and short-term treatment. This system does not properly serve the needs of an autistic population that requires long-term assistance that must change in intensity, methodology, setting, and hours as the child matures. The current system of MH/MR allows children with autism, many of whom are not mentally retarded, to "slip through the cracks". IQ is not an appropriate indicator of an autistic child's capacity to be educated, to interact with others, or to function independently. Yet the current system continues to use IQ as an indicator for eligibility.

Notwithstanding the fact that autism is a life-long, incurable biological disorder, the current system requires that a psychologist or a psychiatrist reevaluate the child every four months to determine their continued eligibility for services. Parents find this reevaluation requirement to be medically unnecessary, needlessly intrusive and demeaning. Parents' schedules are incredibly full coordinating their autistic child's BHRS, speech and occupational therapy, medical appointments and oversight of their child's educational programs. All of these demands are in addition to the typical scheduling demands which all families face. The 4-month reevaluation requirement is perceived by parents to be both unnecessary and needlessly onerous.

The current system creates an incredible amount of paperwork, and requires excessively frequent administrative interviews with parents.

When an individual is on the higher end of the spectrum, BHRS services become harder to obtain. Supports are inadequate for individuals with High Functioning Autism and Asperger's Syndrome. Many are banned from community and social programs unless an escort accompanies them.

Autistic children are often threatened with a discontinuation of service when they have made progress through Wraparound. "Progress should not be punished." Progress in some areas does not mean that progress has been made across the board, or that services are no longer required.

3. Other Related Services

Families Require Additional Funding Assistance

Families of children with ASD face substantial financial pressures as a result of having a disabled child. Many families have lost income as a result of one parent needing to stay home with the ASD child either full-time or part-time. Parents often face added financial burdens to keep their children safe, and many are also forced to alarm their homes so that their children do not wander. Families of children with ASD spend a large amount of their own money in purchasing: home alarm systems and specialized locks so that their children do not wander out of the home, or fall out of windows; special diets; nutritional supplements; educational seminars; non-reimbursable medical appointments; therapeutic materials, reinforcers, etc. Many of these services and items are not reimbursed, and those that are do not even come close to covering the cost of services.

Children who qualify as Mentally Retarded may receive extra funds from Family Support Services for caregivers, therapeutic materials (such as weighted blankets), parent education, recreation etc. The use of these funds varies from agency to agency, and there are waiting lists for FSS funds.

However, ALL families with ASD children, regardless of IQ and eligibility for MR services, need Family Support Service money. Children with ASD with higher IQ's are no less disabled and no less in need of services. Families with ASD children often require very specific types of therapeutic equipment and are subject to very lengthy reimbursement procedures, which often end in reimbursement denials.

Families of ASD children observe discrimination against their "invisibly disabled" children, who are often excluded from community-related activities to which those with visible handicaps are warmly welcomed.

Respite Services Are A Necessity.

Respite is NOT a luxury. Parents who have elected not to place their ASD children in residential treatment facilities and have instead chosen to have their children reside at home are subject to enormous stress and demands upon their financial and emotional resources. It is often impossible for parents of ASD children to secure babysitters. In order to provide on-going support to their children, these parents desperately need occasional respite services. Families who have not received adequate respite care have suffered from health impairments, depression, marital problems and other conditions directly related to the stress of raising an ASD child. Respite must be a reimbursable service.

B. Provider Perspective

What are the barriers to providing existing services? What services should be available but are not?

1. Medicaid

BHRS Service Delivery System is Ill-Suited to Treat ASD Children.

The current BHRS system was designed to provide intensive and short-term treatment. This system does not properly serve the needs of an autistic population that requires flexible, long-term assistance that changes in intensity, methodology, setting, and hours as the child matures. Autism is not a "short-term" disorder; therefore the treatment options ought not to be short-term only. There are no available services for children who have "graduated" from Wraparound. There are no established clinical standards for discharging children from Wraparound.

Autism must be redefined as a biological illness along the same lines as encephalopathy as these children often go without occupational therapy and other services because many providers do not accept MA, and those that do often have waiting lists. Children with ASD frequently have biological abnormalities such as metallathionein deficiencies, abnormal metabolism, food and environmental allergies, gastrointestinal problems, sleep problems and peripheral neuropathies.

Insufficient Number of Qualified Providers.

There are an insufficient number of qualified providers in the Commonwealth. Therefore, access to quality services is geographically inconsistent. The state does not recognize, nor does it offer proper incentives for improving the delivery of BHRS services. The current system makes no differentiation between highly qualified and experienced providers and Therapeutic Support Staff (TSS) persons and those with little experience in the delivery of autism services. The reimbursement rates are identical regardless of the qualifications of the provider. Moreover, BHRS providers are not reimbursed for staff training conducted outside of a client's home. A great deal of time and resources is spent on initial staff training and on-going staff support. This money is wasted when staff turnover is high due to low pay.

2. Other related Service

Money must be made available for non-medical services.

IV. What are potential solutions to improve existing practices?

How can barriers to existing services be eliminated? What additional services could be provided?

A. Family Perspective

1. Education

Entitlement to Special Education Services

A child's eligibility and need for special education and related services is first determined through an evaluation process that determines if a child is a "child with a disability". The term "child with a disability" is defined as including children with "autism". This definition actually serves as an obstacle to some children (such as those with Asperger's Syndrome or PDD-NOS) seeking special education services. A potential solution would be to change the definition of a "child with a disability" to instead refer to children with "pervasive developmental disorder", which would include those with autism.

Entry into Kindergarten

When the school district evaluates a child prior to starting kindergarten, they should discuss with the parents the option to start their child in school at the age of 6, instead of 5.

Quality Services Must Be Consistently Provided Statewide By Educators Who Are Properly Trained To Teach Students With ASD.

Administrators, special education teachers, regular education teachers, instructional aides and support staff must receive increased educational and cultural training relating to:

1. The assessment and educational needs of children with ASD; and
2. The non-delegable obligation and responsibility that districts have to educate their special needs students, including those with ASD.

Additional training is required regarding the preparation and enforcement of IEPs. The schools must remember that "I" stands for Individualized. School districts need to be open to greater flexibility in their teaching methods so that a child's unique learning style can be addressed. There needs to be more flexibility in doing what works for each individual child. Schools must be open to trying precision teaching, discrete trial, errorless learning, verbal behavior and other approaches that families have used with success.

Students studying to be teachers should be required to have some training in autism before receiving their teaching certificate.

The state should provide some type of "loan forgiveness" to college students who are considering a career in special education with a specialization in autism, and to established teachers seeking graduate degrees in the same area. This could create an influx of qualified teaching professionals into the state's school systems at a time when there is a veritable epidemic of autism diagnoses. An increase in professionals could mean an increase in appropriate placements.

Schools should be given grants or incentives for providing quality services to students with special needs. Districts could be rewarded for providing exceptional inclusion models, providing staff with continued education in autism related treatment, and raising the scores of the bottom 20% of students. Any incentive program would have to be applied for on a yearly basis, with parent feedback forms and unannounced inspections.

School Districts Must Cease Opposing Services Which They Deem To Be "Community Based"

Schools must focus upon the communication, language, and social skill needs of children with ASD. Extensive language training should be provided. Social Skills groups and pragmatic language groups are essential. Students must be afforded opportunities to learn social skills from typical peer models through programs such as "The Buddy System", "Circle of Friends", or extra credit or service projects. These programs should be offered during the school day. "Inclusion" must also mean support for all students to participate in extra-curricular and after school activities (i.e., music, sports, and drama). Incentives such as extra credit may be offered to regular education students who participate in social skills instruction.

Lack of Interdisciplinary Cooperation and Accountability

Schools need to work cooperatively with private therapists and Wraparound providers to ensure consistency among the school, home and community programs. Each IEP team should include an inclusion specialist and a representative to be designated by the parent who is involved with the child's private therapies (i.e., a BSC, case manager, etc.).

Related and Extended School Year Services

Each child with an autism/PDD/Aspergers label should automatically be evaluated by a Speech and Language Pathologist and an Occupational Therapist, as well as for social skills training, and a referral to an ESY that would also focus on all areas of need, including social skills, functional language, etc. Every school district should have appropriate related services programs for every age in order to avoid busing children long distances.

ESY services are often difficult to secure and/or inadequate in their delivery. Greater flexibility in ESY programs must be achieved in order that our children may receive appropriate academic, social and communication services in the summer.

ESY is funded with Special Education dollars left over from the school year. Often this money is limited. Separate funding for ESY could provide enough money for wide-ranging programs to meet the unique needs of the child with ASD.

Procedural Safeguards Are Expensive and Time-Consuming

The state should streamline the Procedural Safeguard system in order that the process not be so time-consuming and expensive for parents.

The state must provide parents with more information regarding their children's rights and about the educational and behavioral services available to children with disabilities.

A statewide "Autism Services Ombudsman" should be appointed who has the knowledge and authority to address parents' questions and concerns. The Ombudsman should have a toll-free number, and the ability to direct parents to the appropriate agency/person/provider.

Home-schooling Solutions

Home-schooling regulations should be amended to be more adaptable to the unique situation that each Autistic/ Asperger's child faces. Regulations should reflect an understanding of the scheduling and therapeutic demands placed on the ASD student and parent, including doctor's appointments, evaluations, speech and occupational therapies, meeting with caseworkers and Wraparound teams, etc. A child with ASD has more demands on his schedule than the typical child, for whom the regulations were designed.

The Department of Education and/or individual school districts should create resource networks and sample curriculums for use by home-schooling parents. The parent should still maintain the ability to carry out the home-schooling curriculum that they feel is the most appropriate for their child. Any resources would be advisory only.

The state must also insure that the child gets the related services to which he is entitled.

B. Provider Perspective

1. Additional Funding Streams

Additional funding streams, such as the Access System, may ameliorate some of the existing problems in education. The ACCESS program is a system that can be used by school districts, intermediate units, state-owned schools, or approved private schools (APS) to obtain funding for health-related services for special education students. These agencies can obtain funding for health-related services that are currently being provided to children. ACCESS is a method of gaining Medical Assistance (MA) reimbursements for the cost of the related services currently being provided to MA eligible students. Examples of services that are billable are speech therapy, occupational therapy, physical therapy, psychological services, etc. School districts must enroll as medical assistance providers to be eligible. They submit invoices to MA for the services they are providing to the eligible students. The funds received from MA are maintained in an account managed by PDE and must be used to enhance or expand special education programs. All requests for the funds must be approved by the Bureau of Special Education.

2. Medical Assistance

What changes would improve the ability to provide high quality services in a timely manner?

A. Family Perspective / General Group Consensus

Service Delivery System is Ill-Suited to Treat ASD Children.

A Department of Developmental Disabilities ("DDD") must be designed to oversee Medical Assistance (MA) to children with ASD. In order for the state to determine the size of the population to be served by the DDD, a statewide census is required to determine the number of persons in Pennsylvania with pervasive developmental disorders, including autism, Asperger's Syndrome, etc.

Entirely new medical necessity criteria must be developed which accurately reflect the behavioral and medical aspects of ASD. IQ alone should not be a criterion for services. The system must provide for the delivery of a full-range of flexible, long-term services for persons with ASD.

At the time when a child is diagnosed, a "Case Manager" should be assigned to the family. The Case Manager will have the responsibility of providing parents with information regarding: the educational rights of their child; how to obtain Medical Assistance; the availability of Wraparound, speech therapy, occupational therapies and other therapeutic assistance; and a list of medical and therapeutic providers in the family's area. One model to consider is the program established by the American Academy of Pediatrics entitled the "Medical Home Project."

Wraparound should be more culturally sensitive and more easily accessed. There should be an option for the bulk of TSS hours to be delivered in a community-based center for families that cannot open up their homes to therapeutic work. In areas where TSS are not readily available, parents should be given the option of hiring their own Wraparound aides directly, with all costs paid by the state.

Confidential feedback surveys should be administered by organizations other than the providers to monitor the quality of services offered and to gauge parental satisfaction with the services their child is receiving. Providers who are doing excellent work should be paid more, or given some type of incentive to provide a higher standard of care.

The insurance industry must include autism as a covered condition.

Although according to CAASP principles, parents are supposed to be equal members of the treatment team, there are certain providers that do not consult with parents when developing the treatment team, communicate with schools, etc. Also, certain MCO (Managed Care Organization) representatives sometimes do not take the parents' opinions as seriously as those of the wraparound providers.

Insufficient Number of Qualified Providers

Wraparound providers who serve individuals with autism must have a minimal degree of proficiency and education regarding the autism spectrum. Providers must understand the differences between the causes of behaviors from those clients with emotional disturbances vs. those with autism.

Additionally, Wraparound for autism must focus on finding the core causes of behavioral issues of children with autism rather than quelling the behaviors themselves, which is akin to putting a band-aid on a serious illness. They must address social skills, pragmatic, self-regulation and other issues that lead up to the negative behaviors associated with autism and Asperger's syndrome. Parents have been unfairly told that if their children cease to act out inappropriately, they will not be eligible for continued Wraparound services. Also, due to the complexity of the diagnosis, children who regress when encountering new situations should not be terminated from Wraparound due to "failure to progress".

Additionally, there must be an explicit provision that if the client or parent of the client files a grievance or complaint that the Wraparound provider cannot retaliate against the complainant by dropping them from the provider's services, or by any other means.

In areas where TSS is not readily available, parents should be given the option of hiring their own Wraparound aides directly.

Other Views Expressed

An autism waiver should be established to serve the needs of Pennsylvanians from the date of diagnosis until death. Families must be given the right to choose which therapies they will utilize for their children, using a "toolbox of therapies" which recognize the diverse needs of autistic children.

B. Provider Perspective

1. Medicaid

Service Delivery System Must Be Reconfigured to Properly Serve Children With ASD

Wraparound should be provided in "phases" which acknowledge the varying needs of children as they mature. The needs of autistic children do not diminish with time- they only change. Yet Wraparound providers are not currently equipped to provide services for a ten-year period. The delivery system should be revised to reflect the different needs of children as they develop and mature. Each phase could provide different and age-appropriate therapy options.

For example, the first phase of Wraparound could serve the preschool population and involve an intensive 30-hour per week at-home program with reauthorization occurring every 4 months. The second phase could address the needs of school-age children, which often include playgroup therapy, and require reauthorization every nine months. The third phase could require only annual re-authorizations. More service programs are needed for children who have "graduated" from Wraparound. Currently, there is nothing for our children to "graduate to."

Wraparound should provide greater flexibility in terms of the nature of services that could be provided. For example, some families would greatly benefit from a "BSC only" program in which a BSC provides a variety of services to the child in a multitude of settings. For example, at the beginning of the school year, the BSC could assist with the transition process at school and provide advice and assistance to the family and to school personnel. If the child were in crisis one week, then the BSC would have the flexibility in terms of hours to properly assist the child. Some weeks would require 10 hours of BSC assistance, while the next week would only require 2 hours of BSC assistance.

The system should be reconfigured to provide for a tiered reimbursement schedule with different recognized levels of therapeutic staff support.

The system needs better quality control and should reward superior service.

Retention bonuses should be granted to providers who achieve greater longevity with support personnel.

There should be more of an effort to reach ALL families and not just the squeaky wheels. Outreach workers and free transportation are required in some instances.

10. Needs of Adolescents Subcommittee Report

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I. Introductory Materials
II. State of Current Practice
III. Problems with Existing Practices
IV. Potential Solutions
Glossary

I . INTRODUCTORY MATERIALS

A. List of Members

Co- facilitators:
Claire Choutka and Amber Mintz

Original Committee Members:
Judy Baker, Diane Carroll, Diane Catterall, Anne Coppes, Sheila Fabrizio, Heather Firkenworth, Karen Cribbin Fitzpatrick, Stephanie Gerglielmo, Elaine Gilbert, Giannina Griffin, Pamela Haines, Kathy Irving, John(Ed) Kaneday, John Lovelace, Marie Mambuca, Mary Maurer, Suzanne Mentzer, Elvei Newbern, Louise Saruk, Beverly Smith, Tara Walsh, Paula Dell Ward, and Karen Woodings

Members added as of May, 2004:
Michael Christian, Kristin Phillippe-Yerger, Fran Serenka, Joan Taylor, Jean Stauffer, Sherry Sterling-Holt, and Tee Decker

B. Mission Statement

The mission of the adolescent subcommittee is to shape solutions to improve the lives of adolescents with autism, their families and caregivers across the Commonwealth of Pennsylvania.

C. Where and how often did we meet?

We met initially in person on 7/27/03 in Harrisburg and have since held web chats, emailed and posted summaries through Yahoo groups created via the internet due to geography and time constraints for the participants.

D. How was the report formulated?

The group approached each section of the report, shared opinions and philosophies and came to a consensus agreement. The co-facilitators crafted the report and distributed it to the group members for changes and approval.

Please note:

- We received five comments during the public response period and have addressed these in this final document.
- For Autism Task Force report purposes an adolescent is between the ages of 13 and18, although most of our committee input was based on behaviors and growth stages that can occur earlier.
- Autism has been for several years now the most common developmental disability, and has been acknowledged an ‘epidemic’ (1) (1 in 166(2) students). The growth rate for autism in Pennsylvania from 2002- 2003 was 22% whereas the ‘growth’ rate for all other disabilities defined by IDEA remains at 5%(3).
- Adolescents with autism in PA served under IDEA in 2002-2003: age 10-12: 1,365 age 13-18: 1,150.

- It is especially crucial that PA address adolescent issues now; there are an even greater number of children in the age 3-9 group(3,283) who will age into adolescent years in the next 7 year span, and an additional 9,889 students age 3-9 with 'developmental delays'(a term and category exclusive to PA Chapter 14 and Federal IDEA Special Education Law, not recognized as a medical diagnosis.

(1) House Committee on Govt. Reform, November 20, 2003, "The Future Challenges of Autism: A Survey of the Ongoing Initiatives in the Federal Government to Address the Epidemic " chaired by Rep Dan Burton(R-IN), http://reform.house.gov/WHR/Hearings/EventSingle.aspx?EventID=635.
(2) Center for Disease Control and American Academy of Pediatrics, Autism Alarm, www.medicalhomeinfo.org/screening/Autism%20downloads/AlarmFinal1.jpg.
(3) Table 10, Revised Child Count of Students with Disabilities, Ages 6-21 Receiving Special Education Services, page 8 of Special Education Statistical Summary, 2002-2003.

II. WHAT IS THE STATE OF CURRENT PRACTICES FOR ADOLESCENTS LIVING WITH AUTISM?

A. Family Perspective

What services do they receive in the education, Medicaid and other systems? What steps must they take to get them?

1. General group consensus

Issues Unique to Adolescents and Issues that Linger:

1. Education: to access the system, families first need prior knowledge of successful potential therapies, case law, and school district options. In the education system many therapies and options are hidden. Most learners have a diagnosis by adolescence unless very high functioning. High functioning students need a 504 Plan(4) or fit into the discrepancy category, or are covered by the autism category of IDEA and Chapter 14 of PA Code.

Education services are very much a function of the school district, especially ESY.

1. Medical Assistance(MA): one must still apply and be rejected by Social Security(SSI7) as one of the contingencies of eligibility for MA. Discrepancies exist from county to county and office to office as to how strictly they follow procedural formalities, (i.e., phone or in person appointment). Wraparound services require a quarterly re-evaluation by a psychologist and an Interagency Team Meeting(ITM) for the treatment plan and redundant paperwork. The MA system requires a yearly reapplication plus mandatory notice of any changes to income. Having four caseworkers whom the family rarely sees is not uncommon(MR, MA, BHRS and a BSC).
2. Some children may be eligible for Supplemental Social Security Income(SSI)(5).
3. Mental Retardation(MR) system requires an evaluation and IQ testing by a PA licensed psychologist for a MR waiver. If eligible, funds may be available for respite, medical supplies and summer activities.
4. Private pay to include (a) private insurance may be and often is used for speech, occupational therapy(OT) and counseling services; and (b) out-of-pocket payments also often used for the above listed therapies as well as biomedical testing, social skills, medical needs, respite and aides.

2. Other views expressed

Behavioral Issues:

1. Education concerns: several members were concerned that education is such a large part of the life of an adolescent but may be beyond the purview of the task force. Additionally, members felt that a Developmental Disabilities Program, as seen in 48 other states would resolve many issues.

(4) Through Section 504, some students not eligible for special education may be entitled to accommodations that may help them learn(see glossary for details).

(5) SSI is a Social Security program that pays monthly checks to people with disabilities who meet low income requirements and work related disability specifications, http://www.ssa.gov.

B. Provider Perspective

What services do they provide across and in coordination with other systems? What are the circumstances under which they provide them?

1. General group consensus

1. Education: provided within the school and some children may receive supplemental home hours for social skills or academic work but, as always, quality depends on the area and the child. Older students who may be included for part of the day are with regular education(content area) teachers who have no idea how to teach learners with ASD and have no time to make adaptations. Aides in school are poorly paid, and in some areas unions prohibit physically prompting students. There are few alternative Approved Private School(APS)(6) placements available, and these are not inclusive settings. There are no referral programs available for many issues faced by adolescents with ASD.

2. Wraparound: re-evaluation/ITM requirements every four months are a burden for families. Wraparound TSS personnel are scarce and often not trained on ASD. TSSA's are no longer an option for most, if not all agencies working with MCO's. Low pay scale(comparative to working in privately or with district perks) results in few experienced/skilled BSC's. Supervision requirements(to increase competencies) are paid at the hourly rate for TSS; the reality is often 10 minutes, or an article to read and comment from the director. Supervision time and Daily Progress Note work are done during 'service' time for families.

2. Other views expressed
None.

(6) APS is a private school licensed by the State Board of Private Academic Schools approved by the Secretary and thus eligible to receive payments for tuition or tuition and maintenance from funds of the school district and/or PA Department of Education(see glossary).

C. Administrative Perspective

How are services organized and paid for? Which systems are responsible for what services?

1. General group consensus

1. Education: much of the funding stream for adolescent services is local school districts.

2. Federal ACCESS program funds are used for billing for PT, OT, speech therapy, etc. and reimbursed through PA DPW. However, reimbursements have been used by schools for educational purposes other than Special Education(7).

3. MA is state funded through DPW.

4. The Court system is state funded. Schools do call 911 for severe behaviors, some adolescents end up in psychiatric units for evaluation, as suspending a child with MR or suspected MR is not allowed in PA per PARC Decree(8).

5. Private insurance: there are some providers that still cover services such as counseling and speech or OT.

2. Other views expressed
None.

(7) ACCESS funds are reimbursed from the Federal Medicaid School Based ACCESS Program(SBAP) for direct health-related services(see also glossary).
(8) Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania(PARC) 343 F. Supp. 279 (1972). Also PA Chapter 14 , Section SS 14.142; suspension for students with MR is considered a change of placement and thus disallowed(see also glossary).

III. WHAT ARE THE PROBLEMS WITH EXISTING PRACTICES FOR ADOLESCENTS LIVING WITH AUTISM?

A. Family Perspective

What are the barriers to getting existing services? What services should be available but are not?

1. General group consensus

Education concerns:

a. A major concern lies in the fact that the education system and the MA system are often antagonistic and each points to the other when a parent needs services for a child. The 'best' used in the medical therapeutic model does not mesh to the 'appropriate' educational model-- the "serviceable Chevy vs. Cadillac" disparity.
b. If TSS services are delivered in the schools for behavioral issues, many schools use them in lieu of classroom aides because they are more skilled(TSS requires 60 college credits, teacher's aide requires only a GED). However, some schools discourage TSS in school.
c. There are few teachers or TSS's that can teach (a) social skills or (b) sexuality and few places for teachers to learn the skills to teach adolescent students.
d. The majority of Special Educators have never had a college credit course in autism. Current education students receive only cursory coverage of autism, an Introduction to Special Education class only.
e. For many parents there is the perception that schools are not accountable: no compliance efforts to ensure that IEP services are being delivered. The school system is not designed to facilitate progress and communication across a student's environments because of many with compartmentalized mentality.
f. There are few openings in PA at Approved Private Schools(APSs) with an autism specialty. This becomes especially crucial as behaviors often escalate or intensify in adolescence and the IEP team may determine that the district school now has no appropriate placement.
g. Many schools have a culture of nonreferral for new issues the adolescent may be showing, such as: depression, bullying, low self-esteem, suicidal ideation and social issues.
h. Schools consider leisure activities beyond their responsibility(e.g., swimming, gymnastics, etc.) although it is outlined in IDEA under "Related Services"(9).
i. Parents seldom win a due process without an attorney, and even then only 50% of the time will they prevail. It is expensive to hire an attorney($1,500-$5,000 retainers). Parents are not allowed to have an advocate speak for them at a due-process hearing(Chapter 14 of PA Code, 2002, specifically bars advocates from representing families in due process hearings).
j. There is a growing perception perpetuated in the media that special education budgetary issues and discipline are major sources of school problems.
k. Parents are afraid 2004 IDEA ratification will further reduce potential for successful special education experiences as the loss of short-term goals will reduce accountability.

Medical assistance:

a. There is great variability (a) in applying eligibility criteria between HMOs and (b) in the quality of behavioral-health-services providers(e.g., TSS and BSC training and TSS availability).
b. There is no cradle-to-grave, seamless delivery system to manage all the systems that children and families need.
c. The MA behavioral health system does not acknowledge nor serve the pervasive nature of autism or pervasive developmental disorder(PDD). The behavioral health system operates as if autism were a short-term medical condition.

d. Per MA regulations, a child must consent to treatment beginning at age 14. However, many ASD students are incapable of giving informed consent; therefore, some parents must declare their child incompetent in court(requiring an attorney, day off from work with a child with problem behaviors), or get a power of attorney(POA), as Wraparound agencies do not have to talk to parents/caregivers about their now-adolescent children.
e. In the MR system there must be a diagnosis of mental retardation(IQ below 70). This presents a problem for high functioning learners and those with Asperger's Syndrome as they may test higher than 70, but still need extensive supports to achieve basic life goals.
f. MR, MA and BHRS caseworkers are overloaded and offer no meaningful help, so parents end up as caseworkers for their child across all the agencies.
g. MA services do not appropriately address social skills, depression, anxiety, bullying, self-esteem, school culture or emerging sexuality.
h. Interventions are based only on what is currently available, as there is a paucity of creative, person-centered solutions for learners.

Other issues:

a. SSI allows child very limited 'assets' in their name to qualify.
b. Children who receive Social Security Survivors income before applying for MA(10) are ineligible for MA.
c. 3a. Physicians encourage pharmacological interventions rather than behavioral interventions because the medical model autism is wedged into is in the mental health category and mindset. 3b. Physicians are not knowledgeable on the extent of family needs.
d. Law enforcement and Court systems do not understand challenging behaviors exhibited by persons with ASD. A 2003 government report found a disproportional number of teens with learning or behavioral problems end up in juvenile court. "There is plenty of anecdotal evidence that schools tend to want to deal with problems by removing kids"(11). Additionally, with the closing of Philadelphia's Children's Hospital(CHOP) Bio-Behavioral Unit, there are even fewer psychiatric units specializing in autism that schools can refer students to in an emergency. Some families have spent days in an emergency room until an appropriate placement has been found for a child.
e. Private insurance: families must hide the diagnosis of ASD in order to obtain services. This places an unreasonable and ethical burden on families. There are annual caps(such as 10 speech sessions per year) and facilities tend to prefer younger clients because of a better prognosis.
f. Private pay: even if parents are able to pay for services not offered elsewhere, they are often nonexistent(e.g., social skills) or have 6-9 month waiting lists(e.g., speech, OT).

2. Other views expressed
None.

(9) IDEA: §300.24 Related Services. Section B Definitions specifically includes 'recreation' and 'leisure skills'(see glossary).
(10) Medical Assistance Eligiblility Policy change 2/2004, as recorded in "Operations Memorandum OPS 040107" exempted existing MA recipients.
(11) National Council on Disability, 9/2003, www.ncd.gov.

B. Provider Perspective

What are the barriers to providing existing services? What services should be available but are not?

1. General group consensus

a. It is hard to serve the many different students with the appropriate services, given budgetary constraints.

b. Many TSS and school staff do not want to work with adult-sized children that may pose a physical threat to them.

c. Few providers are willing to work during afternoons and evenings, when adolescents could participate in after school or community activities and practice social skills.

2. Other views expressed

a. Routine medical care: few providers are willing to treat adolescents who may need extraordinary services(e.g., anesthesia for routine teeth cleaning) and who may not be covered by private insurance.

b. If TSS or family are uncomfortable with connection/relationship between client and TSS, TSS's only recourse seems to be to quit. Provider agencies may limit or discourage transfers.

c. Allowable goals/language in treatment plan continually become more restricted(e.g., speech or OT goals no longer allowed).

C. Administrative Perspective

What are the problems with existing organization of and payment systems for services? What are the problems with system coordination?

1. General group consensus

a. There is no universal system for finding or providing appropriate services.

b. Many schools eligible to access the ACCESS funding stream do not.

c. Families are not privy to ACCESS billing by schools for eligible services and thus have no proof that their child is benefiting from billed hours.

d. Due to lack of local competent psychiatric units able to serve learners with autism, students referred by schools in an emergency can easily end up spending several days in an emergency room(restrained) until a Texas or Pittsburgh facility has an opening available.

2. Other views expressed

a. Paperwork is cumbersome, redundant and different for each DPW HealthChoices subcontractor(e.g., CCBH, Magellan, Americhoice).

b. Allowable Daily Progress Note training for TSS lags behind updated criteria. Providers learn new ways by failing audits/returning reimbursements.

IV. WHAT ARE POTENTIAL SOLUTIONS TO IMPROVE EXISTING PRACTICES?

A. Family Perspective

How could barriers to existing services be eliminated? What additional services should be provided?

1. General group consensus

a. There should be a separate delivery system for learners with ASD within the Wraparound system. We look to the Waiver Committee to flesh this out.

- Standards of service should be transparent, mandated and enforced across the state with rewards, sanctions and fines.
- Create a Developmental Disabilities Council(DDC) to provide services and manage the process for providing specific information to parents/caregivers(e.g., information given to the parent detailing the process to access services for transitioning adolescents prior to transitions taking place).

2. Other views expressed

a. Develop physician sensitivity to family issues, beginning in medical school such that they would be willing to help support alternate therapies, medical paperwork, and family support.
b. Develop statewide transition services model:

- Require school districts to report on the status of transition students on predetermined progress points with caregiver/client feedback and a corresponding quality feedback instrument completed by caregivers/parents/client.
- Provide technical support and the resources to allow districts to provide early(before 18 years of age) local choices of internships suited to the learner's interests rather than place an adolescent into an open job slot later which may not match his or her abilities or interests.
- Collaborate with Vocational Rehabilitation Services and district to provide a transition plan to (a) identify potential job opportunity options early in client's community, (b) develop job opportunities that take advantage of client interest and skills, (c) train job coaches to support ASD behaviors that ordinarily disqualify them from similar Vocational Rehabilitation-funded supports, and (d) promote local employer support of job placements for ASD students.

3. Require private insurers to remove autism spectrum disorders from a mental health category and place it in a separate developmental disability category(as it is not a mental health disorder), and remove capitation(limits) for service units; especially, speech, OT and PT.

B. Provider Perspective

What changes would improve the ability to provide high-quality services in a timely manner?

1. General group consensus

a. Interventions should emphasize building early competencies in social skills and self-esteem and addressing puberty issues before they become problematic.
b. Eliminate variability of service components by (a) providing consistent, appropriate training for staff: BSC and TSS; (b) applying criteria for eligibility consistently; and (c) having all systems match semantics/language on forms.
c. Help agencies/providers fill hours by aggressive recruiting campaigns and training with marketing and training support from the state and collaboration with PA Department of Education through colleges.
d. Crisis teams of BSC and TSS highly trained in Positive Behavior Support and Functional Assessments would (a) respond in crisis situations and (b) train first responders(state/local police/fire/EMS) in appropriate interventions.

e. The Commonwealth of Pennsylvania would move the requirement for 'consent for treatment,' which is designed for mental health issues of which autism is not, to age 21 from age 14.
f. Expand awareness of issues facing single parents, of multicultural issues, and of siblings of adolescents. Provide ongoing training opportunities on these topics through the recommended DDC.
g. Expand respite care to support working families and provide day care for teens who may continue to need supervision and assistance through their teen years. Enlist service learners and volunteers from existing respite care provider organizations(i.e., college work study programs, HS Senior Project Buddies, etc.).
h. Expand loan forgiveness programs to include any therapist working with a child or adult with ASD, such as current bill PA HB 1530.
i. Require educators to receive training related to the assessment of children with ASD.
j. Expand grassroots support of ASD families by connecting supportive physicians, disability advocacy groups and nonprofits with ASD families through a DDC website and printed materials.

2. Other views expressed

a. Require psychosocial testing during the transition process(age 14 in PA) because of burgeoning issues with dual diagnosis and 'typical' adolescent issues.
b. Parents would be required to notify schools/providers of prescription medicine changes, regardless of where administered.

C. Administrative Perspective

How could the organization of and payment for services be improved? How could coordination among different systems be improved?

1. General group consensus

1. Develop one standardized, automated system for developmental disabilities with competencies rewarded by levels. Competencies would include training, use of science-based interventions, end-user satisfaction results, etc. Rewards would include access to simplified or reduced/less frequent paperwork requirements, demonstration or startup grants and bonuses for innovative service delivery. The developmental disabilities system would (a) serve as a public, accessible clearinghouse of best practices(a database available to caregivers, educators and providers through an on-line and in-print system) with reports on 'innovative service delivery' rewards being made public; (b) provide objective information about lifespan care to consumers, their families, persons working in the field of autism care, legislators, the Governor and the general public; (c) expand the concept of DPW's COMPASS Community Partners to include case management and advocacy(12); and (d) provide information and training to parents on the changing needs of adolescents regarding medications and provide information to assist in the management of the behavioral issues that may arise due to the changing neurology of teens(e.g., mood disorders, changes in seizure disorders, hormonal shifts, etc.).

2. Develop alternatives to APSs, partial hospitalization programs and psychiatric units when schools cannot serve students with severe aggression based upon a least restrictive environment.

2. Other views expressed

a. Utilize the antecedent interventions listed in behavior plans to prevent inappropriate behaviors.
b. Exploit Opportunities of Service Learning Concept by (a) collaborating with PA Department of Education to develop a college-level service-learning component, internships in school and home settings, as a graduation requirement for paraeducators and educators(e.g., Syracuse University's Service Learning Model through the Center for Public and Community Service (CPCS)(13) or a tuition-for-service model like Lehigh University's Masters Level Community Fellows Program(14), or University of Pittsburgh's Gerontology Service Learning Model(15)); (b) tapping existing service-learning grant recipients(16) to develop/incorporate opportunities that help support autism families, such as 2004 PA Grantee PDE grant, $793,404: "States use the funds to make service

learning part of the academic curriculum and to support training of teachers and service-learning coordinators, who incorporate service into academic settings."; and (c) providing technical support to providers to obtain national grants such as the Learn and Serve program(17) to support service-learning opportunities: "Funds are awarded to national, statewide, or regional nonprofits, which support local youth service and service-learning programs, primarily during afterschool, weekend, and summer hours."

c. Enlist legal aide societies to provide help for parents needing due process, health law or criminal justice system legal assistance.
d. Raise awareness within the criminal justice system: develop and carry out annual training on autism-caused aggression or elopement behaviors.
e. Provide universal paperwork templates for all HealthChoices subcontractors.
f. Establish similar training and academic experience requirements for TSS and paraeducators.
g. Utilize guidance counselors and 'mentor' programs to support teens and foster friendships in middle and high school.
h. Encourage teachers to refer teens with ASD for expanded services that might be come necessary during teen years.
i. Insist on and promote dentists' willingness to accept MA reimbursement.
j. Include 'community supports' in treatment planning and improve services to build true communities and quality of life for adolescents.

(12) COMPASS: Commonwealth of Pennsylvania Access to Social Services is DPW's on-line MA application portal. Organizations, such as hospitals, church groups and other community-based groups that help Pennsylvania residents apply for social services, can apply to be a COMPASS Community Partner, which allows them system access to help families to initiate and actively track MA applications they submit, https://www.humanservices.state.pa.us/COMPASS/PGM/ASP/SC002.asp?hdn_SessionId=5458288464848052804100512.

(13) http://students.syr.edu/depts/cpcs/.
(14) http://www.lehigh.edu/~infellow/description.html.
(15) http://service.gt.pitt.edu/publications.html.
(16) Corporation for National and Community Service, PA list of grant recipients of Learn and Serve program, www.nationalservice.org.
(17) Corporation for National and Community Service, Learn and Serve program, www.nationalservice.org.

Glossary of Terms

ACCESS: funds that are reimbursed from the Federal Medicaid School Based ACCESS Program(SBAP) for direct health-related services are kept in LEA specific accounts at PDE. To receive these funds, each LEA must apply to the PA Bureau of Special Education(BSE). "Funds may be used to support the education of any special education student, not only those who are Medicaid eligible." See http://www.pde.state.pa.us/k12_finances/cwp/view.asp?a=11&q=94006.

Allowable Daily Progress Notes: notes taken in specific format for the express purpose of justifying continuing TSS or BSC services. Outline of actions taken to meet goals of treatment plan.

Approved Private School(APS): a private school licensed by the State Board of Private Academic Schools when the specific special education program for certain exceptional handicapped persons is approved by the Secretary and is thereby eligible to receive payments for tuition or tuition and maintenance from funds of the school district, the Commonwealth of Pennsylvania or both(from Chapter 14 of PA Code; § 171.11 Definitions., found at http://www.pacode.com/secure/data/022/chapter171/chap171toc.html).

Autism: in Federal law, this term is found under §300.7 Child with a disability.(c)(1)(i). "Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3, that adversely affects a child's educational performance."

BHRS: Behavioral Health Rehabilitation Services.

Community Care Behavioral Health Organization(CCBH): a behavioral health agency that has been contracted by some PA counties to provide MA-funded health services to children with ASD. See also Magellan.

Chapter 14 of PA Code: regulations detailing the Special Education Rights, changed in 2000, one of which disallowed advocates from representing families in due process hearings. http://www.pacode.com/secure/data/022/chapter14/chap14toc.html.

Child Find: a term and Section 300.125 in Federal IDEA law that identifies the obligation of educators to take action to refer students they suspect may have a disability through the IDEA screening process. Further, PA Code on Identifying Exceptional Children states, "The primary responsibility for identifying all exceptional children and developing educational programs to meet their needs rests with the local school district. Veschi v. Northwestern Lehigh School District, 772 A.2d 469 (Pa. Cmwlth. 2001)."

DPW: Department of Public Welfare, Commonwealth of Pennsylvania. http://www.dpw.state.pa.us.

Extended School Year(ESY): see § 14.132. ESY of PA Code. "At each IEP meeting for a student with disabilities, the school districts shall determine whether the student is eligible for ESY services and if so, make subsequent determinations about the services to be provided." The IEP team shall consider the seven listed factors, of which autism is one. Federal IDEA covers this in § 300.309.

Health Maintenance Organization(HMO): for the purposes of this report, this means county-contracted providers of medical and behavioral health services for students with autism.

Individuals with Disabilities Education Act(IDEA): Federal law guaranteeing the right of all children to an appropriate education. Chapter 14 refers to special education rights specific to Pennsylvania. The Individuals with Disabilities Education Act or Public Law 105-17 was signed into law June 4, 1997. The final IDEA '97 Regulations were released March 12, 1999. Access IDEA law on-line at http://www.ideapractices.org/law/index.php. The sister part of the law detailing Special Education in Pennsylvania is referred to as 'Chapter 14.'

Interagency Team Meeting(ITM): a term for the team that determines goals, progress and treatment for a client eligible for Wraparound services and that meets every 3 months. It can include MR caseworker; family members; BSC; and, if the learner(client) is school age, school staff and the client himself/herself, if age 14 or older.

Leisure Skills: found in IDEA, §300.24 Related Services. "(a) General: as used in this part, the term related services means ... recreation, including therapeutic recreation...; (b) Definition: (10) recreation includes (i) assessment of leisure function, (ii) therapeutic recreation services, (iii) recreation programs in schools and community agencies, and (iv) leisure education."

Magellan: a behavioral health agency that has been contracted by some PA counties to provide MA-funded health services to children with ASD.

Mental Retardation (MR): generally accepted as having an intelligence-quotient(IQ) test result of 70 or lower.

MR Waiver: funding for specific services available to those with a diagnosis of mental retardation.

No Child Left Behind Act(NCLB): visit http://www.ed.gov/nclb/landing.html.

Office of Mental Health and Substance Abuse Services (OMHSAS): a deputized office of the Department of Public Welfare, Commonwealth of Pennsylvania. OMHSAS handles MA coverage for behavioral health services.

The Office of Special Education and Rehabilitative Services(OSERS): http://www.ed.gov/about/offices/list/osers/index.html.

Pennsylvania Department of Education(PA DOE/ PDE): whose Bureau of Special Education in the Office of Elementary and Secondary Education serves eligible children of the Commonwealth of Pennsylvania with IEPs.

PARC Decree (Pennsylvania Association for Retarded Children v. Commonwealth of Pennsylvania (PARC) 343 F. Supp. 279 (1972)): this landmark special education case began as a civil-rights class action suit brought by thirteen mentally retarded children against the public schools for excluding the children from a program of education and training and ended in settlement. The PARC Decree led directly to the enactment of Public Law 94-142, the EAHCA. In this suit, the Court ruled that schools may not exclude students with mental retardation. See PA Chapter 14 , Section SS 14.142 ; suspension for students with MR is considered a change of placement, and thus disallowed.

Pervasive Developmental Delay(PDD) and Pervasive Developmental Delay-Not Otherwise Specified(PDD-NOS): these medical terms are found in the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition(DSM-IV), published by the American Psychiatric Association, Washington, DC, 1994, which is the main diagnostic reference of mental-health professionals in the US. 'Developmental delay,' however, is solely an educational system term, found in Section 300.7 and 300.313 of Federal IDEA. States and Local Education Areas(LEAs) may adopt and use this term.

Service Learning: a program that places a college or high-school student in a position to learn from hands-on experiences. In Pennsylvania, many colleges have this option, and a growing number of high schools have a service-learning requirement in order to graduate.

§ Section 504 - Vocational Rehabilitation Act of 1973: a civil-rights law that prevents discrimination against all individuals with disabilities in programs that receive Federal funds. This includes educational programs. Through Section 504, some students not eligible for special education may be entitled to accommodations that may help them learn. For the purposes of this report, this means students with Aspergers Syndrome(AS), not one of the IDEA eligible categories. Though AS students may have no discrepancy between intelligence and performance, they may have other issues that interfere with their learning.

Social Security: for the purposes of this report, income received by a student with autism due to the death of a parent. As of 2004, this income no longer affects eligibity of MA recipients.

Transition: specifically outlined in IDEA in 'Transition Services,' Section 300.29. For the purposes of this report, "transition" refers to adolescents reaching age 14 as opposed to children transitioning to preschool- or kindergarten-age services. In Pennsylvania, school districts begin this process at age 14.

11. Transition to Adulthood Subcommittee Report

Members: Carol Calloway, Karen Senft, Linda Christie, Margaret Skrovanek, Cindy D. Slout, Marie Fairman, Bill Stillman, Frank F. Hightower, Stu Symons Kevin Muszynski, Andrea Temple, Mary Pritchard, Geoffrey Temple, Jay Purdy, Dan Torisky, Kim T. Rhodes, Shelly Washington, Mara Winn

Facilitators: Courtney Donovan, Jean Ruttenberg

INTRODUCTION

The Transition to Adulthood Committee first met after the Autism Task Force organizational meeting on July 26, 2003 in Harrisburg; our committee met a second time September 6 in Harrisburg with additional face-to-face meetings on September 20 and October 11 in Lancaster, plus numerous phone and written communications among us.

All of us on this committee are grateful for the enabling opportunity that Department of Public Welfare Secretary Estelle B. Richman has provided to parents and families with ASD family members, and the caring professionals who work with them. We look forward to integration of our report with those of other committees and with the final recommendations of the whole of the Pennsylvania Autism Task Force, and ultimately, to better tomorrows for Pennsylvanians with autism and their families.

It is to be noted that the action by the current administration's Secretary of the Department of Public Welfare, Estelle B. Richman, in creating and energizing this Autism Task Force, is without precedent in this state. Not since 1969 has there been the slightest attempt to direct appropriate attention to the needs of Pennsylvanians with autism, the highest incidence developmental disability in our State and in our Nation.

Two attempts failed in the intervening years: (1) Implementation, in 1970 in Pennsylvania, of the all-inclusive mandates of the Federal Developmental Disabilities and Bill of Rights Act, and (2) the findings of the Pennsylvania House Select Committee on Autism in 1988, both of which were stifled by entrenched state :"stakeholders" that were allowed by previous administrations to dictate rather than serve.

That is why today, with an unusual admixture of pride and humility, the 24 autism-focused members of our Transition to Adulthood committee acknowledge the unswerving commitment of Secretary Richman. Never has a Department of Public Welfare (DPW) secretary done such a thing. Never has a PA DPW secretary allowed challenge of the discriminatory status quo that deprives Pennsylvanians with autism of appropriate services. Never has a DPW Secretary stated publicly, as she did on November 22 in Harrisburg at the facilitators' meeting, "**Tell me what in existing policies, mandates and practices is wrong, doesn't work, or is just plain stupid, and I'll check it out and do what can be done to fix it…**"

Inspired by her words, in no way have we felt constrained in our recommendations by existing systemic traditions and turf-protecting mind-sets. Our turf the "stakeholders" have never walked upon. We thank Secretary Richman and the present Administration for this trust, and this opportunity.

OBJECTIVE

In line with DPW Secretary Estelle Richman's charge to the assembled Autism Task Force members on July 26: **To produce an action plan that will increase the likelihood of successful transition to incrementally higher qualities of life for adult aged Pennsylvanians with autism spectrum disorders.**

PROCESS

Our Committee has enumerated and examined needs and considerations for successful transition as can be addressed in the following areas: education, pre-vocational assessment, classroom and on-site training, training of professionals in autism, family training and involvement, business and community outreach, respite, out-of-home residential settings, job counseling, placement, guardianship, estate planning, continuing intervention after age 21, including monitoring and follow-up retraining when necessary.

We have also listed factors that currently make "transition to adulthood" difficult to impossible for many with autism spectrum disorders. These factors range from a lack of sufficiently trained-in-autism professionals; general public and professional misunderstanding of autism, the individuality of each person in the autism spectrum; the manner in which existing funds are used to address this transitional developmental aspect; and finally, the absence of autism-appropriate state mandated standards and options for individuals with autism spectrum disorders, their families and those who provide services relevant to their needs.

Pennsylvania has no system for providing appropriate supports for young adults with autism. The current eligibility and funding systems under MHMR are not required to serve those with autism. I.Q. requirements add additional barriers to accessing of services. For example, the OBRA Waiver, sometimes used to access supports for those with autism, does not have I.Q. limitations, but it is specially designed for physically handicapped, slots are capped, and families have little or no awareness of its existence nor how to utilize it.

- Our field of vision had to be dynamic. Accomplishing "transition to adulthood" is more than intervening intensively and appropriately during adolescent years and expecting the outcome to be a full-fledged, functioning, independent adult at age 21, when education mandates and funding ends. For many, "transitioning to adulthood" supports are a lifetime requirement.
- For some, we recognize also that desired levels of adulthood "copeability" may never be achieved or even be achievable, but can only be pursued. Yet this must be pursued, and to the fullest possible extent.
- Consideration must be given to the often more complex interventions and approaches necessary for those individuals in whom autism exists in conjunction with other developmentally disabling characteristics, i.e., sight and hearing impairments, and other physical or medically complex conditions.

RATIONALE

We have determined many of the obstacles to successful transitioning for most of those with autism spectrum disorders in Pennsylvania. This led to our proposing realistic, clearly practical measures to overcome them.

Along this line, we examined existing models (programs, approaches, services) both in and out of Pennsylvania wherein the various needs are being addressed appropriately, or appear to be.

Our recommendations, therefore, include combinations and adaptations intended to ensure linking of a continuum of service options appropriate to individuals' transitioning needs across the autism spectrum.

Our final recommendation is one that we share with the other committees of the Autism Task Force: the establishment of a State Office of Developmental Disabilities. Within this Office there should be a single responsibility center established – be it division, bureau or section – with oversight in this area and specifically dedicated to addressing appropriately the needs of Pennsylvanians with autism spectrum disorders.

Without such an Office, sustained implementation of any of these recommendations will never happen in Pennsylvania.

Summary of our recommendations follows. In each numbered problem/solution category, see the corresponding numbered segment in the APPENDIX for details.

Problem Number 1:

Lack of relevant assessment models for adolescents and young adults. (This would help determine the range of needs and services required. Existing pre-vocational and vocational assessment tools are not widely used due to expense, complexity and the lack of trained evaluators.)

Short-Term Solutions:

Require that IEP's include an assessment component beginning at age 13 and progressively expanding in the adolescent school years depending on the readiness of each individual.

Include ongoing monitoring, evaluation and assessment on into adult years for Adult Basic Education and OVR case management.

Involve OVR at the earliest point in IEP development.

Along with these assessments require multiple trials that do not end at age 21 but continue until the individual is successfully employed.

1. Participants must be representative based on original design of interagency planning.
2. Existing range of career preparation supports must be available at the high school level and post graduate or accessible to individuals with autism: technical programs, mechanics, food services.
3. Current career development (job development and job coaching) supports provided OVR are severely limited. Staff of OVR must be trained in testing autistic individuals.
4. Employment support duration must be extended.
5. OVR must link from employment supports to long-term employment opportunities.
6. OVR job coaching must address the social cognition challenges that interfere with job performance and sustainment that are particular to individuals with autism.
7. There must be an enforcement person/entity to insure implementation of the transition. Plan developed by the interagency agreement.

Long-Term Solutions:

Assign a team of special education/OVR practitioners who are currently involved with vocational and pre-vocational assessments and direct that they study existing assessment instruments such as the Brigance Inventory of Essential Skills and Brigance Employability Skills Inventory, and direct that they develop a protocol and standardized procedure that could be adapted for IEP and post-21 OVR to use with this ASD population.

Prepare a curriculum for training OVR rehab counselors and school district transition coordinators in this standardized assessment method, requiring certification.

Although there are numerous pre-vocational and vocational assessment instruments, they are exceedingly expensive; hence intermediate units should be required to arrange to purchase and make available these instruments, e.g., Brigance, for training practitioners to conduct pre-vocational and vocational assessments.

Develop and organize directory of assessment tools to be used with adolescents and young adults. In addition to academic and work readiness skills this assessment resource directory would include assessment of social cognition/interaction skills, functional language, neurological challenges, behavior challenges, and special interests and talents.

Problem Number 2:

Insufficient employment, career development.

Short-Term Solutions:

Explore "e-mentoring" website available in other states and not yet in Pennsylvania – it is a program wherein corporations dedicate time via email with developmentally disabled students. This website could also be expanded to include post-21 year olds. (The website for "e-mentoring" corporate program is currently available.)

Immediately begin linking seniors and post-21 year olds with rehabilitation counselors of the Office of Vocational Rehabilitation (over 350 statewide) to enable employment development, training, monitoring and general oversight for individuals with autism.

Provide succinct instructions for parents regarding to how to access OVR rehab counselor linkages.

Immediate implementation of the state DPW/PDE/L&I (OMR) interagency agreement to work with students prior to graduation on vocational assessment, training and subsequent placement recommendations – including same in the IEP as an "ITP" individual training plan – from age 13 through age 21 and beyond.

Assign a qualified person in every secondary school to be a "Transition to Adulthood Coordinator," available to students as necessary.

Cross-system collaboration, with OVR, beginning assessments as soon as prevocational readiness is determined via the IEP for given students. (Note: IEP's now call for an indication of a given student's readiness for and implementation of transition plans based on readiness.) Be it age 14 or older, currently it must be addressed, but it is not being done well.

Revise Office of Mental Retardation (OMR) measurement criteria to ensure that any given OMR case worker or rehab counselor can work with eligible ASD students upon graduation and beyond – as long as it takes to get them into a job.

Training in social and life skills beginning in middle school as well as on the job training in the community with staff in schools to be appropriately trained in job coach skills.

Invest time/energy into how other states conduct vocational assessments. Focus on individual's true interest areas; foster passions early on – people/employers respect talent. Offer more computer-related employment opportunities.

Immediate correction of the obstacles to implementation of the Interagency Collaboration Plan (agreement between DPW/PDE/L&I-OVR).

1. Participants are not representative based on original design of interagency planning.
2. Existing range of career preparation supports are not available at the high school level and post neither graduate nor accessible to individuals with autism: technical programs, mechanics, food services.
3. Current career development (job development and job coaching) supports provided OVR are severely limited. Staff of OVR is inexperienced in testing autistic individuals.
4. Employment support duration is too short.
5. OVR provides no linkage from employment supports to long-term employment opportunities.
6. OVR job coaching does not address the social cognition challenges that interfere with job performance and sustainment that are particular to individuals with autism.
7. There is no enforcement person/entity to insure implementation of the transition. Plan developed by the interagency agreement.

Long-Term Solution:

Establishment of more charter schools and educational programs such as the Spectrum Charter School which integrate vocational training with classroom education at job sites in the community from age 13 to 21.

Establishment, by Intermediate Units, of regional public school programs similar to Spectrum for individuals ages 13 to 21, using PDE Adult Basic Literacy Education (ABLE) funds.

Establish a "road map" for parents to enable them to access the interventions described here and above.

Implementation of individualized vocational assessment. Use Pennsylvania Training and Technical Assistance Network (PaTTAN – Bureau of Sp. Ed's training/tech. assistance arm) as clearinghouse for technical support.

Identify additional long term funding streams other than MH/MR/OVR.

Problem Number 3:

Insufficient funding for necessary programs.

The problem can be reduced greatly by proper allocation of existing funds that are now used to provide services of questionable appropriateness to individuals with autism under the MR and MH umbrellas

Short-Term Solution:

Obtain and review all existing MR and MH memorandums and bulletins that have emanated from DPW that specifically mention or address autism issues within the MH or MR rubric. For those that prescribe funding of any kind, see what can be accessed immediately and directed toward service recommendations of this Task Force. Current bulletins and memorandums now address such things as housing, CLAs, home and community based waiver, ICFMR eligibility, estate planning and guardianship.

Examine the existing pot of money (Federal and State) and utilize it better, i.e. outpatient funding could be adapted if location requirement was removed and rate increased.

Long-Term Solution:

With the creation of a Developmental Disabilities office and an autism responsibility center within same, additional federal funds can be accessed under the Developmental Disabilities and Bill of Rights Entitlement as well as IDEA/OSEP programs.

Over time, the Department of Public Welfare can authorize autism-specific memorandums and bulletins that specifically allocate existing funds as well as federal funds to appropriate autism service programs.

Changes in the Pennsylvania Education Code, in line with IDEA mandates and options, will enable Pennsylvania to access additional education and vocational funding as well as facilitate the efforts of those soliciting foundations for autism-specific project funding.

Look at how federal funds flow down to states and how Pennsylvania disperses funds on a local level for ASD, and not MH or MR.

Problem Number 4:

Insufficient or no services past high school.

Short-Term Solution:

Programs should include opportunities for social and recreational activities and interaction. Establish programs of continuing educational or vocational training intervention after age 21, since individuals with autism sustain learning readiness indefinitely.

Create a structure of daily life post high school that enables the ASD individual to maintain current developmental levels and improve upon them (volunteer jobs, part-time **temporary** employment.

Tapping into already existing non-DD recreational programs that can be tolerated by, or appropriate for, the ASD individual with accommodation of the ASD persons being acceptable to the existing program participants.

Provide MT or TSS to mentor individuals as needed.

Long-Term Solution:

Assess vocational potential, one on one.

Feedback from ASD individuals themselves.

Long-term job coaching arrangements with local OVR rehab counselors.

Establish liaisons with churches and faith-based organizations in providing recreational programs and activities.

Ongoing monitoring by a job coach or supervisor employed by the county, or as an extension of the school district or as a special funded project of a relevant advocacy organization.

Problem Number 5:

Little or no information about what the continuum of services would look like.

Short-Term Solution:

Extract, from the conclusions of this Task Force, which services appear most reasonable and appropriate and compare them with what appears to be working in states like West Virginia and Michigan where single autism responsibility centers exist and services as well, and see how they are working.

Ensure that transition services in the IEP are in sequential/attainable steps. Identify key team members to implement transition plan beyond school. Encourage Advocacy Groups to monitor, follow up, assist post grad ASDs.

Long-Term Solution:

Match the best of what our committee comes up with those services in these other states, and combine them with the improvements and additional services our committee recommends, and then see how they might be implemented at little or no extra cost within the rubric of our current state funding policies and mandates.

Make consistent the practice of person centered planning with self-determination to the fullest extent practicable.

Problem Number 6:

No social and recreational programs.

Short-Term Solution:

Create social clubs for teens/young adults.

Ensure that extended school year (ESY) programs include social skills awareness and training to the fullest extent appropriate for given students. Recreation activities and community-based field trips are perfect enhancement vehicles for this. Model programs do exist – SPEAK and PEACE programs in Western Pennsylvania – and should be replicated in every county.

Encourage churches, fraternal and civic groups and organizations to facilitate inclusion of ASD young people in their regularly scheduled holiday and seasonal events and parties.

Urge advocacy groups to get their members to speak at meetings of such groups to do the above, as well as create new programs, such as transporting ASD individuals to community-wide activities, i.e., light-up nights, hayrides, parades, picnics, sports events.

Use computer games as a tool to stimulate and sustain social and recreational interaction.

Long-term Solution:

Advocacy groups prepare and disseminate draft homilies for faith-based organizations, direct mail and email appeals to relevant civic and fraternal organizations, to include such programs in their yearly planning.

Feature news releases from Governor's office urging such activities on the part of such organizations.

News announcements praising such programs as they are initiated.

Problem Number 7:

Insufficient travel support.

Short-Term Solution:

Adapted driver’s education courses provided by the school district

Assessment of who might have potential for becoming licensed drivers or the potential to learn to travel independently.

Initiate specific travel training for ASD individuals; include driver’s ed or travel training programs for higher-functioning and Aspergers level individuals who might be eligible otherwise for distant employment; also create awareness on the part of transit drivers as to the needs of individuals with autism.

Note: It is imperative that parents and advocates demand no less of a degree of demonstrated competence by professionals providing training to these individuals.

For individuals who have been diagnosed within the autism spectrum, having a qualified special education teacher with additional competence as a travel instructor is extremely critical.

Provide and implement mobility training on transportation systems present in the community. Look at natural transportation systems to see if they would function given additional supports such as rider to go along with parent/community volunteer, etc.

Long-Term Solution:

Western Michigan University currently is the only university offering a BS degree in the field of travel instruction. This includes developing competencies and standards applied to those who are "orientation

and mobility impaired." Within Pennsylvania, there are three programs based on the Western Michigan University program – one in Pittsburgh School District (since 1973), one in the Delaware Intermediate Unit (since 1985) and the Allegheny Intermediate Unit (since 1997). The Delaware Intermediate Unit has had tremendous success with its program.

Based on the above, it is recommended that every intermediate unit create similar programs for individuals with developmental disabilities enabling them to travel independently within their communities.

This training should begin as early as possible in the school system and extend beyond age 21 as part of Adult Basic Education programs.

Parents and families as well should be given fact books and how-to information to reinforce what their children and adult-aged individuals are learning in these programs.

Pennsylvania Department of Transportation (PennDOT) must provide for education of its drivers in much the same way as police are trained to be aware of the characteristics of special needs populations such as ASD.

Travel training should be mandated and included in IEP's of individuals beginning at age 13.

Training should be made specific to urban, suburban and rural circumstances.

Increase public transportation options in suburban/rural areas. Develop an informal network of drivers to provide ride options, such as school bus/car drivers looking for work after hours, jitney service, volunteers, etc.

Problem Number 8:

Insufficient medical support, medical and dental, psychiatric (There is an insufficient number of trained doctors to handle cases involving ASD; many trained doctors don't take Medicaid payments; most doctors are unaware of community resources, i.e., behavior interventions; diagnoses are often delayed for individuals with Asperger's and high-functioning autism disorders.)

Short-Term Solution:

Have all autism advocacy organizations in the state provide from their files names of doctors and dentists and psychiatrists they know are willing and qualified to work with individuals with autism and from this compile an interim state-wide directory.

Have state and county medical and dental associations scour their files and provide information from which a more comprehensive state-wide directory can be compiled.

Communicate through the medical and dental associations the need for doctors to allow a percentage of their practice time to those with ASD disorders.

Provide through county MH/MR programs, schools, and agencies these directories of medical and dental resources.

Long-Term Solution:

Require ASD curricula on autism for medical students.

On doctors continuing medical education programs, require familiarization with autism as a component.

Explore inducements for doctors and dentists that might make them willing to take on individuals with ASD.

Payment structure must change – it must be resolved at the state level to eliminate the split between "medical" and "mental health" funding and reimbursement streams.

Malpractice issues must be resolved.

Develop a curriculum for medical and dental school instruction to educate medical/dental practitioners, including nurses (RN, LPN) with training also in the ASD spectrum and medications - with funding for such training provided through HCQU.

Such training should be extended through CME involving primary care, internal medicine and family practice so that new physicians and dentists coming on stream are comfortable with and understand the implications of the diagnosis and care of late teens and adults with autism.

Education support staff and individuals with ASD to communicate accurate symptoms – sensitivity training issue.

Appropriate reimbursement rates especially in dental to encourage more dentists to treat ASD individuals.

Problem Number 9:

Insufficient Education Support.

Short-Term Solution:

Use every means possible, legislative and regulatory to see that teachers are trained in ASD and regular education teachers are made aware of ASD characteristics.

Require administrators to become aware of ASD considerations.

Address social skills training in all IEPs.

Encourage inclusion of ASD in schools with field trips with regular ed students and other community integration opportunities should be provided.

Enforce current inter-agency agreement. Collaboration of agencies with increased allocation for trained staff, i.e. support coordinators, re: transition planning education and training for all systems. Training must be provided to paraprofessionals as well.

Transition coordinators should be functioning in every school district.

Pre-vocational and vocational assessments appropriate to ASD individuals must be a key point in every IEP beginning as early as readiness of the individual can be determined.

Outside members such as OVR rehab counselor, transition coordinator, vocational counselor must be included in the transition plan as part of the IEP.

Make better use of PaTTAN and other training resources for staff.

Long-Term Solution:

Require that certification in special education include ASD training.

Mandate yearly inservicing on ASD for regular, special education, as well as administrators to be in attendance.

Loan forgiveness for teachers in ASD.

Development of prevocational tools.

Development of transition coordinators capability to deal with ASD individuals.

Include school directors association as well as individual school directors in awareness building publications and advocacy newsletters concerning ASD issues.

Publish regulations that expand individual transition planning to include multi-agency participation and accountability.

A social skills curriculum needs to be developed.

Require each school district to submit yearly autism special education plan to include the manner in which ASD needs will be addressed.

Expand educational placement options for ASD individuals within school districts to enable parents to have a choice as to where their child might be better served educationally.

Create one entity that has enforcement for interagency collaboration along with education for families to understand their rights and assistance when a family needs help.

Problem Number 10:

Insufficient legal support.

Short-Term Solution:

Make available to parents a directory of the contact individual in every county bar association – every bar association is required to provide pro bono assistance to individuals having human service problems of all kinds, hence provide each contact with information on ASD, plus legal consultation for parents on guardianship, estate matters, as well as assistance when an individual with autism is in trouble with the law.

Provide information on guardianship to all parents as a part of the IEP process.

Provide families through various advocacy and public service publications information on attorneys who specialize in developmental disabilities law, i.e., Herbert Hinkle and Paul Prior's "Disability and the Law Bulletin" provide parents with checklists of information required for any lawyer to set up wills, special needs trusts, financial planning safeguards – virtually any law firm is able to do this work, but information assembled by parents in advance can save families much money.

Promulgate information to all state and municipal law enforcement agencies on the manner in which to deal with individuals apprehended who have ASD, specifically, the MPOETC (Municipal Police Officer Education Training videotape and curriculum) prepared in 2001 currently in use in several states, including Pennsylvania.

Prepare a guide book for parents on how to access legal services when necessary.

Provide detailed guide lines on accessing Social Security and disability payments for ASD individuals (see long term solution below).

Long-Term Solution:

Constant promulgation of police training ASD video tape and curriculum to local and municipal police by autism advocacy organizations.

Prepare a comprehensive guide book to making life decisions for autism under Social Security covering the following items:

- Types of benefits and entitlements under SSA and SSI; benefit of early attempts at employment for entitlement to ensure disabilities benefits and Medicare; differences between Medicare and Medicaid; effect of stopping work and the career parent and their insured status for SSA. Note: high functioning individuals (such as Aspergers) may not possess the degree of disability that would qualify them for such benefits.

Ongoing publication through advocacy and public service organizations of the information listed in short-time considerations above.

Problem Number 11:

Insufficient support for parents and families of people living with autism.

Short-Term Solution:

Everything within reason must be put in place to enable parents and families to sustain loving contact with their family member with ASD.

This includes short-term, emergency, and longer term respite. This includes a referral system to hook parents up with other parents through support groups and advocacy organizations.

This includes developing "chat rooms" for parents to converse from their own homes with one another.

This includes promoting use of the Parent-to-Parent in Pennsylvania 800 number; parents have said it's their single greatest resource – advertise it! Online directory of local/state autism support groups.

Schools themselves should be required to make available meeting rooms for parent support groups during the school day.

Parents should be assured by the state that they have a right to learn about all options and make the choices they feel are most appropriate for their individual dependent with ASD. No parent should ever be made to feel guilty for choosing an option another might disagree with.

Long-Term Solution:

The Department of Public Welfare should make available to all parents and providers involved with individuals living with ASD lists of active autism advocacy organizations in the state providing information relevant to the needs of individuals with autism. This includes local as well as national organizations providing such information, including access to website of these organizations.

Website and contact information on relevant professional organizations should also be provided or made available for parents and other providers to access as they choose. Mentor should be provided to parents.

Expand sibling support groups among existing advocacy organizations and schools.

A guide book should be prepared that comprehensively enumerates all rights of families as they involve care, service and treatment of individuals with ASD. This guide book must also include the state and legal bases establishing these rights.

The Department of Public Welfare must purge from its policies, bulletins and memorandums all references and philosophies that reflect restrictive opinions or practices that tend to reflect "one size fits all" mindsets that put parents and providers at a disadvantage when seeking to provide services appropriate to individual needs.

When an Office of Developmental Disabilities is established with an autism responsibility center as a component, dissemination of information such as above will be facilitated.

Stop requiring that parents declare their ASD individual as "mentally retarded" or "mentally ill" in order to qualify for funding for services – make whatever amendments must be made in order to eliminate this requirement in state regulations, codes, and Department bulletins.

Problem Number 12:

Inappropriate categorization by MH/MR/IQ statuses that limit or prevent service delivery to individuals living with autism who would otherwise benefit from certain services that are currently restricted due to specified regulations and policy criteria.

Short-Term Solution:

Recognize autism as a developmental disability separate and apart from mental health or mental retardation.

Incorporate the DSM-IV definition of autism in current state regulations, mandates, and legislation amending the education code.

Eliminate IQ entirely from any determination of autism diagnoses, replacing it with a functional or adaptive assessment that would dictate level, intensity and appropriateness of services for given individuals. (see note below)

By DPW departmental fiat, immediately create an Office of Developmental Disabilities (ODD), which would house a center of responsibility for autism, either as a bureau, division or section. Creating this "on paper" now, separate and apart from OMH and OMR – even though fleshing it out and structuring it would be done over time, as was done with OMH and OMR back in the 70's – would send a clear message of intent and commitment of the present Administration to better serving those with ASD.

Immediate establishment, if only on paper, an Office of Development Disabilities with an Autism Spectrum Bureau, with framework for a county level service system.

Provide outpatient services removing location requirement with increased rates.

Long-Term Solution:

Legislation if necessary, affirming the above, with attendant amendment of the existing MH/MR Act, but again only if necessary.

Structuring an autism responsibility center adapting existing regulations and creating new regulations specific to autism.

Consistent approach to assessment of intellect/capabilities of individuals with ASD, use of alternative assessment tools.

Development and implementation of strategic plan for staffing and scope of D. D. office with Autism Spectrum Bureau.

Note: For example, consider a Verbal IQ (VIQ) – Performance IQ (PIQ) split in which one score falls above a standard score of 70 and the other falls below 70 for the determination of mental retardation. The Full Scale IQ (FSIQ) in this case would hover around 70, the accepted cut score for the psychometric determination of mental retardation. The Full Scale IQ is basically an average of the Verbal and Performance scores and therefore will fall above or below the cut score of 70 based on the distance of the VIQ and the PIQ from 70. For example, if the person has a VIQ of 65 and a PIQ of 80 the FSIQ will be

about 73. On the other hand if the VIQ was 72 and the PIQ were 55 the FSIQ would be about 64. There are intelligence tests that use more sophisticated algorithms to combine scores into composites (e.g., Woodcock-Johnson Tests of Cognitive Ability), but in general the above principle holds. With autism the VIQ/PIQ split could be even more disparate.

So this raises the question whether one should use the FSIQ in such cases. First, the determination should not be made using the IQ data in isolation. The American Association on Mental Retardation provides the most comprehensive definition of mental retardation. According to the AAMR the diagnosis should also include significant limitations in adaptive functioning (see http://www.aamr.org/Policies/faq_mental_retardation.shtml for a complete description of the definition.) Second, tests do not diagnose, professionals do. In the case of large VIQ-PIQ splits, there should first be evidence of significant limitations of adaptive functioning (there are several tests that measure this) and the professional will have to make the determination if the VIQ-PIQ scores are indicative of mental retardation or not.

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Problem Number 13:

Insufficient housing; insufficient residential options.

Short-Term Solution:

Provide guidelines for parents on how to access dollars for and funding streams for housing for their ASD individual.

Website publication enabling parents of individuals of the same age and in the same geographical area to link up for purposes of pooling individual resources to create their own CLAs (ALAW model).

Familiarize parents with relevant areas of waiver program wherein housing can be accessed.

Encourage families to develop a network of allies for their children (potential roommates/housemates).

Review what's "out there." If parents are providing the program at home because necessary services are not available, reimbursement should be provided. Increased range of housing options and supports in the community are needed. An 800 number that matches people with housing needs on local levels to partner/share apartments, etc.

Equalize wages of CLA direct service workers, thus enabling improvement of care in CLAs and making expansion of existing CLA programs more feasible for providers.

Eliminate the limitations on 3 residents for HCBW group homes and 4 residents for ICF group homes.

Immediately make all residential care and treatment options – ICFMR and Home and Community Based Waiver – available.

Address funding streams to minimize waiting lists and develop increased capacity.

Long-Term Solution:

Link urban homesteader's model for purchase of homes by individuals with ASD similar to program now existing for mentally retarded individuals.

Assisted mortgages from the state for such purchases.

Comprehensive reform of all state centers converting them into intake facilities for differential diagnosis, evaluation, assessment and transitional planning for outplacement into CLA group homes, supervised apartments, or other community-based residential facilities.

Making provisions for training and retraining as necessary to effect successful community placements.

Maintain private and public residential care and treatment centers for those for whom (in line with the provisions of the Olmstead Supreme Court decision) are not likely to ever be appropriately served in a community-based residential program.

Expansion of "wrap-around" services for individuals into early adulthood.

Managed care companies do not serve this population well. Disparities county to county must be eliminated in training and availability of staff. Consider expansion of, if not exclusive fee-for-service to achieve equity.

Problem Number 14:

Little or no respite for family members or guardians who care for individuals living with autism.

Short-Term Solution:

Make respite dollars a set figure exempt from reduction by county administrators.

Provide a directory in each county of trained and qualified respite providers.

Eliminate all allocation of funds based on IQ of respite subject (see note in "Inappropriate Categorization by IQ, etc." section of this report).

Require that existing group homes and other residential service providers review their total operation to determine if they can make available respite bed or beds in their facility (for example, if a resident visits his home every weekend, that bed can be made available for weekend respite; precedent: hotels do this every day); or depending on the size of the facility a specific bed or beds could be permanently set aside for temporary or emergency respite residential placement.

Require that every contractor for day program services review their total operation to determine if they can make available additional slots for temporary or emergency respite, and what this would involve in increasing their overall operations or if it can be accommodated within their existing operation.

Require that existing state centers and private residential care and treatment facilities set aside a certain number of respite beds.

Eliminate the 3-4 resident limitation on group homes and respite slots would become immediately available.

Long-Term Solution:

Establish guidelines for training to enable individuals and organization – including church groups and fraternal organizations – to qualify and be licensed to become providers of respite services.

Enable autism advocacy groups to solicit members and friends who wish to become "bonded" "sitters" for short term in-home respite.

Problem Number 15:

Limited number of service providers.

Short-Term Solution:

Enable current providers to diversify into ASD given technical support. It may not require extensive/expensive/specialized approach. All MH/MR funded providers are currently serving people with autism (they may not realize it). Validate this but support them to do it better.

DPW must announce statewide to all providers of services relevant to developmental disabilities, such as mental retardation, cerebral palsy, epilepsy, etc., first that there is no longer a need to disguise or improvise services for ASD individuals under the mental retardation umbrella or that of any other, and second that the Department is committed to providing appropriate services for ASD individuals and is looking forward to seeing providers expand their capabilities in this regard.

Creating an Office of Developmental Disabilities with an autism responsibility center as a component – even though it can be done at this point only on paper – the intention of the Department will trickle down steadily and affect the policies and programs of many providers for whom expansion into ASD services can be easily and willingly accomplished – without fear of reprimand or criticism from DPW/OMR.

Long-Term Solution:

Currently there are financial disincentives for potential providers to provide services. System issues of recruitment/retention must be addressed, as well as adequate reimbursement rates, career paths, full-time positions with benefits.

Review of all existing regulations, mandates and laws, bringing them into compliance with Federal mandates in order to facilitate the direction and re-direction of funding appropriately into areas involving services for individuals with autism spectrum disorders.

DPW statement to all county administrators and all its regional offices that autism spectrum disorders are now an equal priority with the Department in so far as providing appropriate services is concerned.

Reinforcing the above, the Department of Public Welfare should publish statistics on incidence of autism and numbers of individuals with autism in various state-funded programs, services and residences or in private residences funded by public dollars. This will further reinforce the need for refocusing attention in the regions and in the counties on serving the huge autism population appropriately.

The Department of Public Welfare should also publish information on the economies that can be realized by serving individuals with autism spectrum disorders appropriately as early as possible in life and throughout their school years so that transition to adulthood levels of living can be more easily accomplished and that such individuals successfully transitioned will result in enormous tax savings that otherwise would be required for their ongoing care and treatment.

Problem Number 16:

Untrained staff, schools, OVR, county offices, medical, funding sources, case managers

Short-Term Solution:

Get current providers to diversify into ASD given technical support. It may not require extensive/expensive/specialized approach.

Urge Intermediate Units and County MH/MR programs to sponsor autism training workshops and seminars for practitioners in all relevant disciplines in agencies and organizations providing services relevant to autism, using in and out-of-state autism specialists.

Encourage advocacy groups to sponsor "singe-issue" training workshops along with relevant Act 48 and/or continuing education credits for attendees.

Provide informational handouts for health and medical offices and clinic waiting rooms.

Shared training amongst providers. Consider having existing specially trained management and program staff who could train others. Examine good training models, such as Allegheny Valley School (PA) and Autism Services Center (WV) – to become more effective and efficient, or contract with such providers to conduct training.

Long-Term Solution:

Include those serving ASD individuals specifically in House Bill 1530 provisions for the "staff Member Loan Forgiveness Program for those who graduate for institutions of higher learning who apply their degrees to careers in MH/MR."

As a requisite for continued state funding, require that PA colleges and universities include sequences in autism in all human services programs of instruction, i.e. special education, psychology, social work, etc.

High school and up – need more education curriculum addressing this disorder. Time release and compensation must be available to staff to inspire career development in this field.

Problem Number 17:

Untrained staff, schools, OVR, county offices, medical, funding sources, case management.

Short-Term Solution:

Other areas of this report such as "limited services providers", "education support," and "legal support" all contain recommendations that will accelerate training and awareness-building among individuals and organizations throughout the Commonwealth in the area of ASD. Subsequent action will result in limited short and long term objective achievement. However, it all depends on the intensity and degree of commitment that the relevant departments of state and the Governor's office give to encouraging such training among the various disciplines involved.

Long-Term Solution:

Of primary importance: tie state funding to the requirement that colleges and universities, medical schools and law schools, offer courses of instruction in human services. This will do more than anything to build awareness and training of present and future practitioners and service providers in these various fields of importance to transitioning individuals with autism spectrum disorder to incrementally higher levels of adult-aged "copeability."

Problem Number 18:

Insufficient system collaboration.

Short-Term Solution:

Immediate implementation of the 1971-74 DPW/PDE/L&I (OVR) interagency agreements to facilitate pre-vocational assessment, job training, education and placement beginning at age 13 and continuing through age 21.

Use of applicable CASSP model/principles to bring systems together on the state level with spin offs for each county.

Major address by the Governor describing the value of system collaboration in order to convert unemployables and tax consumers into gainfully employed taxpayers with enormous savings of all relevant tax-fed entitlements.

Promulgating departmental regulations, written clearly and succinctly, leaving no doubt that departments and offices involved **will** work together.

By DPW departmental fiat, create immediately a **developmental disabilities office**, (DDO) within which would be an autism responsibility center as a bureau, division or section. Creating this "on paper" now, separate and apart from OMH and OMR – even though fleshing it out and structuring it would be done over time, as was done with OMH and OMR back in the 70's – would send a clear message of intent and commitment to better serving those with ASD.

Long-Term Solution:

Implementation of the official model for system collaboration.

Legislation if necessary, affirming the above, with attendant amendment of the existing MH/MR Act, but again only if necessary.

Structuring an autism responsibility center adapting existing regulations and creating new regulations specific to autism.

Develop Disability Office with autism-focused component with mandate to implement and enforce interagency collaboration.

Problem Number 19:

Insufficient information available to families and providers on what services exist in their area

Short-Term Solution:

Ensure that transition aspects are clearly defined in the IEP and are described in sequential/attainable steps.

Urge that advocacy, information and referral organizations – such as existing autism-focused organizations – immediately publish for their constituent areas such information as they know is available. IU's, county MH/MR programs, and Labor and Industry OVR offices can provide this to these organizations for promulgation in their communications.

Television/radio, public service announcements that are positive. Use of self-advocate parents to educate/demystify autism for public through promulgation of positive testimonials.

Promote use of Parent-to-Parent 800 number.

Long-Term Solution:

Prepare and disseminate resource directory of existing services by individual county.

Develop a website clearly identified for families with ASD individuals that contains county by county and statewide information on all services available relevant to the needs of ASD individuals. DPW should contract with a web master with authority to extract this information and organize it for promulgation over

and through this new web site. Maximum publicity should be given to this intent by the Department of Public Welfare to provide this information.

The above cannot be done unless the departments are directed to do so by the Governor's office – hence mandates should be delivered to the office of the Department of Public Welfare, Office of Vocational Rehabilitation, Department of Commerce and Travel and the Department of Education that they are to provide such information to the web master working under state contract to provide same.

Website information should be converted to brochures and data sheets, and be made available to consumers and affected families and relevant providers through all state agencies with responsibility, relevance or mandates concerning services for those with autism spectrum disorders.

APPENDIX

Transition to Adulthood Subcommittee of the Pennsylvania Autism Task Force

Area of Deficiency	Action That Can Be Taken Now	Change Agent
I & II Assessment,Employment	A. Require assessment in IEP's beginning at age 13.	PDE, L&I (Our)
	B. Extend duration of OVR counseling of ASDs	L&I (Our)
III Funding,Regulatory	A. Create an Autism bureau within a department;of the state use Task Force Committee to set up	Admin, DPW
	B. Examine existing regs, bulletins; re-route funds now used for inappropriate services for ASDs	DPW
IV. Post-High School	A. Establish continuing intervention programs- ed/voc/social community based.	DPW, PDE
V. Service Continuum	A. Examine what is working for ASDs in states that have Autism responsibility centers	Admin, DPW
VI. Social Recreational	A. Require that all ESY programs include such social/recreational components as in SPEAK, PEACE, etc.	PDE
VII. Travel to Jobsites	A. Travel training for ASDs and transit drivers	L&I, DOT
	B. Training of the trainees, using Delaware County	PDE
VIII. Medical,Dental, Psych	A. Have County/State Medical/Dental Assns, Advocacy groups compile local/state roster of trained practitioners	DOH
IX. Education Support	A. Require special ed, regular ed students, teachers and administrators be made aware of ASD	PDE, Legis.
X. Legal	A. Director of names from each Bar Assn. required to provide counsel to DD	ATTY G., PBA
	B. Provide guidelines on guardianship, wills and trusts to to families	PBA
XI. Parent Support	A. Provide emergency, short & long term respite within existing system's network of public and private providers	DPW
XII. Categorization	A. Recognize autism as distinct from any other DP	Legis.,DOH,DPW
	B. Eliminate IQ as a factor in ASP diagnosis	Legis.,DOH,DPW
XIII. Residential	A. Equalize wages of public and private direct care workers	DPW
	B. Eliminate limitation of 3 residents per HCBW homes	DPW
XV. Stifled Providers	A. Authorize all providers to expand to serve ASDs openly without fear or strictures of OMR	DPW
XVI.& XVII Untrained Workers	A. Require IU's to conduct ASD training workshops for practitioners in all relevant disciplines	PDE, IUs
	B. Contact with proven-effective private providers to conduct training	PDE, IUs
XIX. Awareness of Services	A. Require that transition aspects are clearly defined in sequential, measurable steps	PDE
XVIII. System Collaboration	A. The Governor himself must direct that relevant departments of the State will work together on this.	Admin.
	B. Creation of a single autism responsibility center (bureau, section, division, office) within state government	Admin.

NOTE: ONLY the DPW's commitment and the Governor's demonstrated strong endorsement of these common sense recommendations can enable Pennsylvanians with Autism Spectrum Disorders to be served appropriately.

12. Needs of Adults (Ages 21 and Older)

I. INTRODUCTORY MATERIALS

A. List of Members

Barbara Addison, Mary Ann Belesario, Jerry Brucker, Karen Clark, Becky Cook, Roy Diamond,Ed Fersht, Carol Freeman, Abby Harris, Joe Leonard, Linda McCullough, Sylvia Mishalove, Mary Nau, Bernadette Obermeier, Michael Powanda, Carol Roarabaugh, Marsha Rothman, Michael Southwell, Barbara Thackery, Rae Unger, Doris Washington, Paula Smith.

B. Mission of the Subcommittee

Develop recommendations for the creation of a new system for the provision of services to adults with autism within the Commonwealth of Pennsylvania.

How and how often did the subcommittee meet?

Following our first face to face meeting in Harrisburg, sub-group one met once by teleconference on September 13, 2003 at 1:00 p.m. and sub-group two met once by teleconference on September 15, 2003 at 5:00 p.m.

How was the report formulated?

Sub-groups met by conference call to compose responses for the report on September 13 and September 15, 2003. Notes from both conference calls taken by the facilitators were formulated into a draft report, which was circulated to the entire Adult Needs Sub-Committee for comments. Revised drafts were circulated on October 9 and November 20, 2003. Following circulation of the second revision, the Adult Subcommittee made final changes and approved the report.

II. WHAT IS THE STATE OF CURRENT PRACTICE IN SERVING ADULTS LIVING WITH AUTISM?

A. Family Perspective

What services do adults with autism receive in the Office of Vocational Rehabilitation (OVR), Mental Health/Mental Retardation (MH/MR), Office of Social Programs (OSP), Medicaid and other systems? What steps do adults with autism take to get them?

<u>General group consensus-</u>

Simply stated, Pennsylvania has no statewide system of appropriate supports for adults with autism. Pennsylvania has a Mental Health/Mental Retardation (MH/MR) system, but by law, MH and MR programs are not obligated to provide services to this population **as individuals with Autism Spectrum Disorder**. In the MR system, eligibility is determined by an IQ test (tested IQ less than 70), and even when persons with autism are deemed eligible, all of the services are defined for persons with MR, and are therefore not an appropriate or useful fit for persons with autism. Moreover, Pennsylvania¹s approach to providing MR services is characterized by a "caretaker" sensibility, rather than a skill-building or supportive approach that would enable participants to continue to achieve social, employment or cognitive gains. The inadequacy of these MR services for persons with autism is demonstrated by the fact that frequently these individuals are referred for Mental Health services following an episode of distress. It is the experience of families that such episodes are the consequence of inappropriate services by providers who do not have experience with Autism Spectrum Disorder. The only exception to this general picture is the Autism Pilot Project in southeastern Pennsylvania. Twenty-four individuals with Autism Spectrum Disorder are approved to receive autism-specific supports enabling them to live and work in the community. Half the individuals in the project are living in their own homes independent of their families. This program is explained in detail below.

The following sections describe current practices in several systems that sometimes serve adults with Autism Spectrum Disorder.

A. Office of Vocational Rehabilitation:

Some adults with autism receive limited help from the Office of Vocational Rehabilitation (OVR). Staff from some OVR offices participate in transition planning meetings as persons with autism age out of the education system. OVR will provide very limited job development-job coaching assistance for adults with autism. However, frequently this means little more than aptitude testing and readiness activities and no actual job placement. If the individual with autism is able to demonstrate an ability to function in the job with minimal job coaching and the individual has MR funding for follow along coaching at a cost no more than the cost of a day program or sheltered workshop, then OVR will fund up to 1200 hours of job coaching support. Individuals must have a label of mental retardation to be eligible for MR follow along support. Even if a provider knows how to support an individual with autism in a job situation, it is the MR label that must be in place for services to be offered. Individuals access these services because family members persist in seeking them and sometimes through OVR follow up to transition planning meetings.

B. Mental Health/Mental Retardation:

A few adults with autism who are also determined to be MR-eligible receive residential and employment services from MR providers. The inadequacy of these services to meet the needs of individuals with Autism Spectrum Disorder typically leads to hospitalization under the MH system in a cyclical pattern of movement from MR to MH and back to MR again. Access to such services depends on persistent advocacy by families. In a few cases family members have succeeded in modifying MR provider practices to better meet the needs of the individual with autism. Funding for the services is through the Consolidated Waiver.

C. Office of Social Programs:

The Office of Social Programs (OSP) has been the Department of Public Welfare (DPW) partner in creating the Autism Pilot Project with Autism Living and Working, Inc. (ALAW), a consumer and family driven advocacy organization. OSP administers the Autism Pilot Project. Funding for the individuals in the project is through the OBRA (Omnibus Budget Reconciliation Act) Waiver. The goal of the project is to demonstrate that individuals with Autism Spectrum Disorder can live and work in the community if they are provided appropriate supports.

Under the agreement between ALAW and OSP, 24 individuals with Autism Spectrum Disorder receive supports, mainly community integration services. Eleven of the individuals are currently living in their own homes independently of their families. Others in the program live with their families. Supports range from a few hours a week to 24/7 staffing of shared homes where two or three individuals with autism live together. In all cases, staffing patterns allow individuals to hold jobs in competitive employment (half the pilot group are currently employed in sheltered workshops, retail, food service, office work, farming and volunteer activities) and to pursue their individual goals and plans. One individual in the program graduated from a residential college with the support of peer assistants in socialization. It is the observation of the families involved in the pilot project that their member with autism experiences personal growth, greater self direction, improved communication, vocational development and better mental health when supports are provided by helpers who have received autism specific training and are backed up by trained supervision and behavioral therapists experienced in working with individuals who have Autism Spectrum Disorder.

One individual in the Pilot Project is in his 50's. This person represents one of the few middle-aged people with autism who were not [3]disappeared[2] into the MH/MR system, and whose parent was successful in avoiding an institutionalized placement during a time when 90 percent of adults with autism were routinely institutionalized. The major challenge that faces older adults with autism is transitioning to a time when they will not have the benefit of parental oversight, support and advocacy but will continue to need autism specific supports to live and work in the community.

An evaluation/review of the project by the DPW Office of Policy Development has been completed. It is anticipated that what has been learned from the pilot will provide the basis for developing a state wide service system for adults with Autism Spectrum Disorder.

Other views expressed- None

B. Provider Perspective

What services do they provide across and in coordination with other systems? What are the circumstances under which they provide them?

General group consensus-

Providers of both residential and day program services typically have no training specific to serving those with Autism.

Typically, an individual with Autism in the MR system presents with problematic behavior either at the day program or in his community living arrangement, or both. This consumer is then likely to be labeled "problematic" and the course of action would likely be a psychological evaluation where an uninformed psychiatrist with uninformed social workers conclude with a misdiagnosis of something like: Atypical psychosis, Intermittent Explosive Disorder, Impulse Control Disorder Not Otherwise Specified, Generalized Anxiety Disorder, some type of mood disorder, or any number of Diagnostic and Statistical Manual diagnosis options. All of which would be inaccurate and lead to treatment that may be quite inappropriate and very, very expensive.

Additionally, a behavior specialist may be requested to apply some type of Behavior Therapy to address the maladaptive behavior. The therapist may, or may not, be informed of the nature of Autism. If not operating with a trained eye, s/he is likely to accept an inaccurate diagnosis of one of the DSM variety, and develop interventions based on a false premise of mental illness. This results in a compounding of problems rather than a lessening of them.

A specific case referred to a Behavior Specialist on the Adult Sub-committee is illustrative:

A consumer had a diagnosis of Atypical Schizophrenia and a reputation for severe problematic behaviors. Someone had even suggested he was "evil". After spending time with this individual, it became obvious to the specialist that he was autistic. There was no diagnosis of Autism in his records. (Many over the age of 40 did not receive this diagnosis early in life due to lack of knowledge or family physicians didn't want to stigmatize families due to the prevalence of the idea that autism was caused by "cold parenting". There are a large number of those with autism who don't have the diagnosis and are treated as having a mental illness.) In this particular case, a licensed psychologist confirmed the diagnosis of autism. An informed plan was developed that outlined an entire program sensitive to this individual's need for sameness, routine, sensory sensitivities, and social training through use of social stories. A mixed reaction took place when this was done. A day program provider was excited and wanted to create a program for those with autism; the treating psychiatrist stated that "everyone is getting this diagnosis; it's the fad," and the direct care staff thought it was an attempt to excuse problematic behavior. This scenario is probably quite common.

What is needed is an informed and respectful treatment of individuals with autism that is not currently found in the MR system. With a great deal of advocacy, this particular individual received more informed treatment, but with a significant amount of resistance and skepticism. With the passage of time and staff turnover, this person will quite likely lose the gains that were made. Many other individuals haven't even been identified, let alone are being provided with informed and effective treatment.

Other views expressed- None

C. Administrative Perspective

How are services organized and paid for? Which systems are responsible for what services?

General group consensus-

The Act of 1966 put into place a categorical system in Pennsylvania. It created Offices of Mental Retardation and Mental Health plus regional administrative entities which must be paid for prior to the delivery of any services. The key administrative entity is at the County level, which drains a significant percentage of the $1.2 billion spent annually. The County offices and employees are effective as employment programs, which local legislators will defend strenuously.

Other views expressed- None

III. WHAT ARE THE PROBLEMS WITH EXISTING PRACTICES FOR ADULTS LIVING WITH AUTISM?

A. Family Perspective

What are the barriers to getting existing services? What services should be available but are not?

General group consensus-

Barriers to getting existing services are several. First is funding. Families have observed that the State¹s rules on funding providers are a serious part of the problem. Payment restrictions (1), make it very difficult for providers to recruit and retain excellent staff, and (2), do not reimburse providers for staff training. This is a particular ironic tragedy for Pennsylvania¹s citizens with autism, because nationally, advances in understanding and working with persons with autism have attracted an increasing number of talented professionals and new educational and socialization techniques are continuously being reported. As a consequence, Pennsylvania does not attract the best and the brightest in the field and discourages existing staff persons from remaining in this field in Pennsylvania.

Second, for those being served in MR programs, there is no coordination among services. For example, an individual may be served by a group home provider and a day program provider. Little communication and no coordination exists between the two providers and so the individual with autism is confronted with inconsistent expectations and supports. It falls on families to provide the communication and coordination between the two providers.

A third barrier that is preventing persons with autism from accessing services under the OBRA Waiver is an eligibility form that is designed to divert people with autism into the MH/MR systems. Sophisticated knowledge of the OBRA waiver and its provisions for services to persons with ³other related conditions² is required on the part of consumers and families in order to survive this screening instrument.

A fourth barrier is the short time OVR will fund supported employment. While adults with autism can learn job tasks, often speedily, they continue to need continued coaching to navigate the social environment of the workplace. In the Autism Pilot Program, under the OBRA Waiver, funding for supported employment services and community integration services are distinct. Neither OVR nor OSP is prepared to accommodate the linkage of these services so that adults with autism can be sustained in employment.

Adults living with autism spectrum disorder present a range of needs and strengths. Effective support services must be tuned to this range. Adults with autism need supported living services ranging from a few hours a week to 24/7 in homes and apartments belonging to and chosen by them; supported employment services in real jobs linked to community integration supports which will enable individuals with autism to continue in employment; and supports that will enable adults with autism to socialize, recreate, and continue their education both at the level of skill learning and to satisfy their intellectual needs. Key to effective community integration is helping adults with autism to link with community interest groups (e.g. a railroad club, a religious congregation) and community educational programs (e.g. community colleges and adult learning programs). Opportunities for vocational development, and to

socialize and continue learning are central to preventing the frustration and despair that underlie acting-out episodes leading to hospitalization.

Other views expressed-

Either State rules or insurance for providers prevent many providers from taking adults with autism out into the community in order to improve their social skills and broaden their worlds.

B. Provider Perspective
What are the barriers to providing existing services? What services should be available but are not?

General group consensus-

Barriers include a lack of trained staff; a lack of focus on autism as truly distinct from mental retardation; and a complete lack of services specific to training, teaching, and serving those with Autism.

Other views expressed- None

C. Administrative Perspective
What are the problems with existing organization of and payment systems for services? What are the problems with system coordination?

General group consensus-

The major barrier to providing high quality, Olmstead compliant support services is the high turnover of staff and lack of a pool of well prepared candidates for direct service positions due to chronically low wages, lack of opportunity for advancement along a career track and lack of funded training opportunities for worker skill development. Pennsylvania lacks a coordinated long-term care system. The percentage of wage increase for direct service workers is well below trends in comparable job categories; yet direct care is among the 10 fastest growing occupations. These facts and others, plus an analysis, are available in a draft report to be circulated to the General Assembly by the Community Imperative Coalition (composed of advocacy organizations).

MH/MR funds services for people with a diagnosis of mental illness or mental retardation with a combination of money from Medicaid and the Commonwealth budget. Approximately 55% of MR funds are provided by Medicaid, 45% by the state budget. A waiver is written to allow services typically given in an institution to be given in a community setting. Waiver services qualify for payment by the federal government Medicaid program at a 55% level of federal participation. The Office of Social Programs (OSP) funded the Autism Pilot Program with the OBRA Waiver, which was used because it has no IQ limitations. The OBRA Waiver is typically used by persons with physical disabilities. The other advantage of the OBRA Waiver is that it had ³slots² left. DPW establishes the ³number of slots² with the approval of CMS/HCFA, the federal oversight body that approves the slots. The MR budget in PA is $1.2 billion, of which 55% of waiver funded programs is federal dollars. See additional comments above.

Other views expressed- None

IV. WHAT ARE POTENTIAL SOLUTIONS TO IMPROVE EXISTING PRACTICES FOR ADULTS LIVING WITH AUTISM?

A. Family Perspective
How could barriers to existing services be eliminated? What additional services should be provided?

General group consensus-

A statewide program of services for adults with autism needs to include the following:

1. **Community integration**- Meaning staff supports to assist individuals with autism to acquire, retain and improve communication, self-help, socialization and adaptive skills necessary to reside and work in the community. Community integration supports enable adults with autism to plan for and engage in meaningful adult activities, including domestic and leisure activities, volunteer work and continuing education. Community integration supports involve the use of cues, on-site modeling of behavior and assistance in maintaining maximum independent function.
2. **Supported employment**- Meaning staff supports, training and supervision that enables adults with autism to find, secure and maintain employment in a community work setting in which persons without disabilities are employed.
3. **Environmental adaptations**- Meaning modifications to an individual¹s home to accommodate their disability (e.g. soundproofing, additional bathrooms, and climate control).
4. **Transportation**- Meaning supports that enable adults with autism to access community activities, such as work, leisure, domestic errands, continuing education, and religious / spiritual life.
5. **Assistive technology**- Meaning devices and methods that enable adults with autism to communicate, manage sensory and motor challenges, and control the environment in which they live.
6. **Behavioral specialist consultant**- Meaning consultation services by professional behavior management specialists trained in assisting adults with autism, available to staff supporting adults with autism on both a periodic and as needed basis.

A statewide continuum of services for adults with autism would have to be funded with money from a new waiver. The group reached this consensus after reflecting that any redirection of funding currently used in the system would be opposed by the County-dominated existing MH/MR system, their employees, and most importantly, the legislature that defends these jobs for its constituency. Accordingly, the only feasible tactic would be to write an autism waiver, next have it approved by CMS, and then funded by the Legislature. Realistically, this will take a year to write and a year to implement. CMS will look to comparable programs in other states (particularly where MH/MR programs do not exist), and the comparison will lead it to agree that Pennsylvania is substantially lacking. The difficult part will be persuading the legislature to approve its 45% of the funding.

The Subcommittee proposes that the autism waiver must have the following elements in order to win the legislature¹s support:

1. **Accountability**
2. **Demonstrable Outcomes**- This will be tough. Current services are so far from using meaningful measures (vs. teaching adults to set the table)
3. **Quality of Life / Integration in the Community**
4. **Cost-Benefit**- The traditional comparison will be with the cost of institutionalization. In addition, the multiplier effect of employing provider staff, etc.

In order to avoid confrontation with the existing MH/MR system, and in order to maximize the % of money which actually reaches providers, the funding could flow through OSP and its regional administrative entities.

An autism waiver must NOT utilize IQ as a determiner of eligibility. It is the view of the Subcommittee that IQ is irrelevant to determining the needs for supports of adults with Autism Spectrum Disorder.

An autism waiver must provide reimbursement for training direct support staff and for the services of behavioral therapists/specialists who can problem solve with direct support staff, devise behavioral plans, train staff in carrying out such plans, and hold staff accountable for implementing the plans.

<u>Other views expressed-</u>

So-called "lower functioning" individuals may need some kind of alternative to traditional supported employment. Such alternatives might be autism specific training programs that prepare individuals for employment, that find jobs both paid and volunteer, that train job coaches in working with individuals who have autism spectrum disorder and that can serve as a fall back when individuals lose a job or need

further vocational training or need to withdraw from employment for a time. One member expressed a desire for workshops and day programs.

B. Provider Perspective
What changes would improve the ability to provide high-quality services in a timely manner?

General group consensus-

In addition to an autism specific waiver, there needs to be legislation, something like an Act 150, to enable people with Autism Spectrum Disorder who are not Medicaid eligible to receive needed supports while earning a living. The Autism Accommodated Living Act (SB 881 and HB 1265), introduced this session in both houses, would accomplish this.

Under the terms of an autism specific waiver, there must be per diem rates available to providers of 24/7 supports. The rate system (hourly and per diem) needs to be structured so that it fits the varied range of consumer needs across the autism spectrum. Either rates must be adequate or specific funding must be provided for ongoing staff training and supervision.

Coordination of services for adults with autism spectrum disorder needs to begin during transition from school to adult life, linking OVR services with waiver-funded community integration services so that young adults can move into employment with the assurance they will receive the ongoing supports they require to stay employed (in paid or volunteer positions) and to reenter the job market when needed.

Additionally, a comprehensive training program that offers credentials to those staffing the programs that serve individuals with Autism would help to assure that qualified staff are working with this special population. Training would not need to be cumbersome. A training course of two weeks, three hours each day would be sufficient, followed by quarterly meetings of staff to refresh knowledge/understanding and consider challenges and how to address those challenges. During the initial 3-6 months of actual work new staff should work side-by-side with a qualified, experienced, staff person who has demonstrated a solid understanding of effective service. As trained staff become more experienced, a mentoring/ apprenticeship program for newer, less experienced staff should be formed and provided by those who have successfully gone through the initial training. Oversight by a council of parents, experienced professionals and advocates might also prove to be quite useful.

Other views expressed- None

C. Administrative Perspective
How could the organization of and payment for services be improved? How could coordination among different systems be improved?

General group consensus-

Coordination and case management functions/resource management functions/eligibility determination points of entry to services should be located throughout the state, each with jurisdiction over a defined geographic area and staffed with sufficient personnel that case managers/resource managers need deal with no more than an average of 25 cases. Entities providing these functions need to be (1) consumer controlled; (2) independent of service providers; (3) accountable to DPW (not counties).

Other views expressed- None

V. SUMMARY RECOMMENDATIONS OF THE NEEDS OF ADULTS SUBCOMMITTEE

1. Services to adults with autism do not exist in Pennsylvania. The proposed Autism Waiver and other sources of funds (hereinafter [3]combined sources) must define the nature and quality of services that will be funded, the eligibility criteria for services, and an effective administrative system for monitoring those services that ensures that the system is a national, innovative leader, not a static, uninspired bureaucracy.

Currently, the bureaucracy is almost as hostile to providers with innovative ideas in supporting persons with autism as it is in its treatment of persons with autism themselves.

With no other choice, some persons with autism participate in the MH/MR system where they are ill served, rarely understood, barely maintained and never effectively encouraged to strive to be full human beings.

2. In order to be eligible for payment by DPW, services to adults with autism must strive to help the participants to live increasingly enriched lives rather than simply to ensure their maintenance.

The communicational, social, educational, employment, and recreational skills of adults with autism will improve over time with supports that set such goals and expectations.

To simply terminate the supports for improved communication, management of sensory/movement challenges, educational opportunity, social and community integration, occupational and speech therapies and behavioral consultation services (and therefore gains made by children with autism) available through the high school age years to persons with autism because those persons have reached age 21 is cruel, cost ineffective, inappropriate (as adults with autism, if supported, continue to make gains in all areas), and even discriminatory in light of the Commonwealth¹s strong commitment to the continuing education of non-disabled adults through its public university education system.

It is not enough for Pennsylvania to simply expand the maintenance approach of many MH/MR providers and programs to persons with autism. In order to encourage providers who are committed to excellence and continuing innovation to work within Pennsylvania, the proposed system must be characterized by (1) strong payment levels which support professional training time, (2) encouragement to providers to learn and implement state of the art techniques, (3) avoidance of unnecessarily, burdensome paperwork and participant certifications, and (4) oversight by DPW staff with specific knowledge, experience and interest in this field. Nationally and internationally, breakthroughs in services for persons with autism are now experiencing a revolution, attracting talented professionals and young persons into the field.

Pennsylvania¹s system of licensing and paying providers must be redesigned in order to enable the State to attract, not (as it presently does) repel, these skilled persons. Provider staff persons all too often have neither the desire nor the skill to understand the behavior of adults with autism. Accordingly, staff persons fail to detect or are indifferent to the antecedents of expressions of frustration by adults with autism. In response to these behaviors, the system is, however, funded to respond with hospitalization and/or institutionalization the infrastructure of the old but surviving view that adults with autism are dangerous and only partially human.

3. The cost of a wide range of housing types must also be covered by the combined sources. Like typical Pennsylvanians, adults with autism will choose a variety of housing types, including continuing to live with their parents or other relatives, independent housing, group housing, or living within communities that are defined by educational or therapeutic approaches. Collaboration with other State and local funding sources is recommended. However, realistically, the promise of quality housing choices for adults with autism will only be realized if DPW collaborates aggressively with affordable housing funding streams (PHFA, HAs DCEDs, and HUD).

The Autism Pilot Program is indicative of this broad and flexible approach, accommodating persons who live by themselves, with their families, or with other adults with autism.

However, the provision of shelter chosen by consumers must be planned in conjunction with the provision of services tailored to the aspirations and potential of the participant.

In order to preserve consumer choices of where to live and with whom, services must be provided in all such consumer chosen settings.

4. Vocational services must be defined and offered in a manner that is appropriate to persons with autism, not predetermined by OVR’s practices with respect to persons within the MH/MR system.

Providers must be knowledgeable regarding the range and type of behaviors and challenges faced by persons with autism in the workplace and be capable of designing supports that enable participants to negotiate those challenges.

The length of time in which those supports are in place, the frequency of contact, and the eligibility for the services must all be redefined in order to be effective for adults with autism.

Autism Task Force - Abbreviations and Acronyms List

Abbreviations and Acronyms are used throughout the Autism Task Force Report (December 2004). The following table contains an alphabetical compilation of many of the abbreviations, acronyms, and corresponding meanings, which are found in the subcommittee reports.

Abbreviations and Acronyms	Words, Phrases or Meanings, assigned to each listed Abbreviation and Acronym
ABA	Applied Behavior Analysis
ABLE	Adult Basic Literacy Education
ACC	Autism Coordinating Committee (NIH)
ACCESS	Plastic identification card issued to Medical Assistance recipients; used by Medical Assistance providers to verify client eligibility.
ADA	Americans with Disabilities Act
ADDM	Autism and Developmental Disability Monitoring
ADHD	Attention Deficit Hyperactivity Disorder
ADL	Activities of Daily Living
ALAW	Autism Living and Working
APS	Approved Private School
ASA	Autism Society of America
ASD	Autism Spectrum Disorder
ASHA	American Speech & Hearing Association
BCBA	Board Certified Behavioral Analyst
BHRS	Behavioral Health Rehabilitation Services
BSC	Behavioral Specialist Consultant
BSE	Bureau of Special Education (PDE)
BSU	Base Service Unit
CADDRE	Center for Autism & Developmental Disabilities Research & Epidemiology
CAN	Cure Autism Now
CAO	County Assistance Office
CASSP	Child and Adolescent Service System Program
CBH	Community Behavioral Health
CCBH	Community Care Behavioral Health
CDC	Center for Disease Control and Prevention
CHARGE	Childhood Autism Risks from Genetics and the Environment
CHOP	Children's Hospital of Philadelphia
CI	Community Integration
CLA	Community Living Arrangement
CMS	Center for Medicare and Medicaid Services
CMS	Center for Medicaid Services
COMPASS	Commonwealth of Pennsylvania Access to Social Services
COSAC	New Jersey Center for Outreach & Services for the Autism Community
CPEA	Collaborative Programs of Excellence in Autism
DDD	Department of Developmental Disabilities
DHHS	Department of Health & Human Services (Federal)
DOD	Department of Disabilities
DPW	Department of Public Welfare (Pennsylvania)
DSM-IV	Diagnostic and Statistical Manual, 4th Edition

DV	Domestic Violence
EI	Early Intervention
EIBI	Early Intensive Behavioral Intervention
EMS	Emergency Medical Services
EPSDT	Early & Periodic Screening, Diagnosis & Treatment Program
ESY	Extended School Year
FAPE	Free Appropriate Public Education
FDA	Food and Drug Administration
FDSS	Family Driven Support Services
FFP	Federal Financial Participation
FSS	Family Support Services
GED	General Equivalency Diploma
HCBW	Home and Community Based Waiver
HCQU	Health Care Quality Units
HRSA	Health Resources and Services Administration
IACC	Interagency Autism Coordinating Committee
ICF	Intermediate Care Facility
ICF-MR	Intermediate Care Facility for Mental Retardation
ICF-ORC	Intermediate Care Facility/Other Related Condition
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
ISO	Intermediate Service Organization
ITM	Interagency Team Meeting
IU	Intermediate Unit (PDE)
L&I	Labor and Industry (Pennsylvania)
LEA	Local Education Agency
LRE	Least Restrictive Environment
MA	Medical Assistance
MCO	managed care organization
MH	Mental Health
MPOETC	Municipal Police Officer Education Training
MR	Mental Retardation
MT	Mobile Therapist
NAAR	National Alliance for Autism Research
NICHD	National Institute of Child Health & Human Development
NIDCD	National Institute on Deafness & Other Communication Disorders
NIEHS	National Institute of Environmental Health Sciences
NIH	National Institutes of Health
NIMH	National Institute of Mental Health
NINDS	National Institute of Neurological Disorders and Stroke
NOREP	Notice of Recommended Educational Placement
OAR	Organization for Autism Research
OBRA	Omnibus Budget Reconciliation Act
OCD	Obsessive Compulsive Disorder
OCD	Office of Child Development (DPW)
OCYF	Office of Children, Youth and Families (DPW)
OIM	Office of Income Maintenance (DPW)

OMAP	Office of Medical Assistance Programs (DPW)
OMHSAS	Office of Mental Health and Substance Abuse Services (DPW)
OMR	Office of Mental Retardation (DPW)
OSEP	Office of Special Education Programs
OSP	Office of Social Programs (DPW)
OT	Occupational Therapist
OVR	Office of Vocational Rehabilitation (L&I)
PARC	Pennsylvania Association for Retarded Children
PaTTAN	Pennsylvania Training and Technical Assistance Network (PDE)
PDC	Pittsburgh Development Center
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder Not Otherwise Specified
PDE	Pennsylvania Department of Education
PERS	Personal Emergency Response Systems
POA	Power of Attorney
PT	Physical Therapist
PUNS	Prioritization of Urgency of Need for Services
RO1	(Type of research grant)
SLP	Speech and Language Pathologist
SSA	Social Security Administration
SSI	Supplemental Security Income
STAART	Studies to Advance Autism Research and Treatment
TEC	Transitional Employment Consultant
TSS	Therapeutic Staff Support (Bachelor's degree required)
TSSA	Therapeutic Staff Support Assistant
UDS	United Disabilities Services
UMDNJ	University of Medicine and Dentistry of New Jersey
UPENN	University of Pennsylvania
Wraparound	Behavioral Health Rehabilitation Services

Autism Task Force - Public Comments

Family and Social Issues

Subject = Family and Social Issues
Name =
State = PENNSYLVANIA
County = MC
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = Family, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 9

Comments: After reading the report, my husband and I felt that a part that should be taken into consideration is the impact that a child with ASD has on the family and their employer. My husband is currently in limbo with his employer of nine years because they are unwilling to understand his need for a consistent work schedule do to our child with ASD. This alone is frustrating to us because even though he has discussed this issue with his employer numerous times they fail to acknowledge his need as a responsible parent in wanting and needing the consistency to prevent our child with ASD from having numerous seizures due to the fluctuation in his father's work schedule. He is looked down upon and has even been reported to be a problem employee due to the fact that he will and always put his families needs first. For us it is the need of a consistent schedule for our child. We like the ideas for running commercials and for informative information to be passed for public awareness. Living in rural PA, the awareness for the general public is limitted. Please feel free to contact us at any time regarding this matter. In our area we strive to be advocates for our child and inform people the best we can on what is needed. Thank for developing the Autism Task Force, it provides some encouragement to keep enduring for our child's sake.

Subject = Family and Social Issues
Name = Delaware County Department of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 9
Overall Rating = 9

Comments: The Delaware County Department of Human Services gives this subcommittee’s report a 9. It does an excellent job of outlining the lifespan needs of the individual and effects on the family as well as pointing out the fragmentation that currently exists. There is only one factual discrepancy that was noted by our staff: on page 25, next to the last paragraph refers to the Medicaid system as a physical health

system, which cannot provide services in the home. In fact, the Medicaid system is not only a physical health plan. Medicaid is also a source of funding for Behavioral Health Rehabilitative services for Medicaid eligible children. These services are provided to the child and family in the home, school and community. We agree with the statements and examples of how the current systems of mental retardation, mental health, and education cannot meet the needs of persons with autism. We commend the authors of the report for understanding that those service systems may well meet the needs of the population they were designed to serve and so should not necessarily be expected to change registration and service criteria. It is true that a means of coordinating services across the DPW, OVR, and Educational systems would assist individuals and families affected by autism. We agree that a "home" on a statewide level to coordinate services, seek funding, and design appropriate services is necessary to achieving the desired changes.

Subject = Family and Social Issues
Name =
State = PENNSYLVANIA
County = CHESTER
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10

Comments: Response to Autism Task Force Reports (response to all reports) The Autism Task Force did an incredible job on developing their 12 reports. It is obvious those involved were dedicated to this project professionally and personally. There are a few comments that I have in regards to the reports. 1) In the report on school aged children there is advocacy for both inclusion in ones home school and segregation in Approved Private School specifically for children with Autism. These arguments seem counter to one another. It is not clearly written in the report that there is advocacy for a continuum of educational services due to the varied presentations of ASD. 2) The request for student loan forgiveness for individuals who choose to work in this field for a specific number of years is a positive idea. This would increase both recruitment and retention of qualified staff. 3) The committee's request for training is fundamental. Assurance must be given that providers will be adequately reimbursed for providing this training. Some consensus must also be determined in regards to the appropriate amount and type of training that would be acceptable. The fact that there are multiple treatment modalities for ASD and each child responds differently must be taken into account when making this decision. 4) The committee on Services for Adults with ASD outlined the need for supported community living arrangements of various intensities. This is needed. I am concerned that the committee was negative about Community Living Arrangement through OMR. It is clear that adults with ASD may need something different from these services. However, OMR has supported many people with Autism and the committee should be conscious of not loosing any support from any organization that has provided services to this population. 5) A Department of Developmental Disabilities is an obvious route to begin to develop services for people with Autism. Perhaps people with other concerns that are not clearly responded to via OMR of OMHSAS like Traumatic Brain Injury and Fetal Alcohol Syndrome can be served by this department once it is developed.. 6) The Early Intervention Committee recommended the use of the "First Signs" by Pediatricians to identify children with ASD early on. This is also able to identify children with other delays. The use of this protocol should be supported. I thank the committee again for the opportunity to respond to these reports.

Subject = Family and Social Issues
Name = Employee, Family-Child Resources
State = PENNSYLVANIA
County = YORK

Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = , Family, Advocate, Other (Please specify)
Interest category Other Description = Former Director of Asperger Syndrome Coalition, Current Development Director Family-Child Resources
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8

Comments: Family-Child Resources (FCR) is in agreement with much of the information contained within this report. Clearly illustrated are the challenges and emotions faced by individuals and families dealing with ASD's. Anecdotal as well as research based evidence for PDD and AS fully supports statements made that discuss the financial drain and isolation caused through insufficient, sporadic service delivery systems. Most importantly, the statement regarding the observation that the PA services are inappropriate and inconsistent with the needs of these individuals is both accurate and brutally honest. Children with PDD and AS are not able to sustain gains after wrap services are terminated under the current model. Once placed in these systems they should be allowed to stay for life with only those changes in services that reflect the individual's growth and developing needs at their current age or level of function. We would also suggest that the discussion regarding ASD adults being able to to perform will on the job once being trained my be limited in its vision. While this could be true for some, most adults with PDD and AS have exceptional difficulty interviewing well and negotiating the hidden curriculum or office politics on the job making it almost impossible to maintain employment without sustained supportive services. FRC would respectfully suggest that there are a number of identified and unidentified adults with PDD or AS that would benefit from more thorought inclusion in services that are designed or implemented in the future. Family-Child Resources would support any effort toward this end in the future and happily contribute to its successful implementation.

Subject = Family and Social Issues
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10

Comments = Amazing report.

Subject = Family and Social Issues
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =

How found out = From a meeting
How found out Other Description = DPW action alert
Report being commented on = Family and Social Issues
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 9
Overall Rating = 9

Comments: This report was very comprehensive and enlightening. It would be useful for provider education as well as a map for how to change the system to better serve children and their families. Adequate and flexible funding is needed so that providers can tailor their services to meet the very diverse needs of this population as opposed to only offering those services that are reimbursable whether that fits the child and families needs or not.

Subject = Family and Social Issues
Name =
State = PENNSYLVANIA
County = BUCKS
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Family and Social Issues
Interest category = Advocate
Interest category Other Description =

Comments: In each of these reports the word "autism" can be replaced with "various disabilities". The MH/MR system, education, and other agencies create the same challenges for all individuals with disabilities, and specifically for all individuals that don't fit into the MH/MR criteria, but who have significant needs in functioning. In reading the reports there are not things unique to individuals with autism that doesn't apply to any person with a disabilty where the disability ithat s not a common cause for mental retardation or mental health. Whether the diagnosis is autism, undiagnosed, or some other neurological cause, the same issues arise in gaining supports, battling education, not fitting into the systems, not having trained and knowledgeable supports, when the person has sensory/behavioral and developmental delays that affects their level of functioning. Even for those that do fit into the system it doesn't meet their needs, but for those with multiple disabilities, a variety of syndromes and conditions the experience is the same as those happen to have the label of autism. I hope that this effort will help to expose the inadequacies that many many families face, and tht it will move the state toward a developmental disabilities state, not focused on paperwork and eligibility and figuring wasting resources figuring out where a person fits or doesn't, but a state that simply looks at the individual's needs regardless of cause or the label of the needs, and then focuses on supporting the person because there is a documented need for support.

Education and Certification

Subject = Education/Certification
Name =
State = PENNSYLVANIA
County = LEBANON
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = State College Autism Conference
Report being commented on = Education/Certification
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: Wow, this draft is wonderful!! Thank you everyone for your hard work. I feel that our concerns will finally be heard. I am still reading the different subsections so I may have further comments but I have one question now. I've read in one of the subsections that there is a tuition loan forgiveness program for professionals (teachers, OTs, etc.) that work in education. Is there a similar program for parents that further their education in an autism related field I order to help their child?

Subject = Education/Certification
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = e-mail
Report being commented on = Education/Certification
Interest category = Family
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating = 9 Comments: All professionals, especially teachers should be trained (perhaps using an in-service) to consider the use of assistive technology (AT) for students with autism. Most times, when assistive technology is mentioned, people automatically think of communication devices and systems. That is only one type of AT.

AT should be considered for students who need help with reading, writing, note taking, executive functions, mathematics, and money, among other things. Also, there are some types of AT that can be used when making accommodations for testing.

Subject = Education/Certification Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Education/Certification
Interest category = Provider
Interest category Other Description =

Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating = 8 Comments: Core Elements…

To the core elements, it seems that you might want to add:

- Typical development versus the development of a child with ASD, beginning as early as age 1.
- Developmentally appropriate adaptations to intensive 1:1 therapies, especially for the child age 1 to 4.
- Measuring progress by taking and analyzing valid data for all models of intervention: Discrete Trial Intervention; Play-based Intervention; Community Support; School support; Home Support

Barrier C-2

Re: incentives to hiring TSSs with previous ASD experience….What will prevent large agencies from pilfering the experienced staff of a smaller agency? Someone has to begin the training, which is costly. We have to make sure that we design a system that supports the costly training as well as provides tiered levels of reimbursement so that the experienced staff can be rewarded.

Barrier C-4

To accommodate these training requirements, perhaps you can have a BSC I (working on certification, etc.) and a BSC II (completed). Currently there is a different reimbursement rate for Master's level and PhD level BSCs but it might be advisable to reimburse the highly educated BSC differently than the beginning BSC. The additional payment for the BSC II can go both to salary increases and the training of a BSC I. The recommended curriculum (Core elements and ABA certification) needs to be on-line and affordable.

Section D-1

Recommendations…

5. BHR services are designed to support family member in the management of their child's behavior and their ongoing growth and development. For young children with ASD and for many HFA/Aspergers children, the issues may not be about managing behavior, but about promoting new and more adaptive skills. It might be important to emphasize the BHR services are not meant to "cure autism" but to assist families in helping their child or children reach his/her potential, whatever that may be.

Subject = Education/Certification
Name =
State = PENNSYLVANIA
County = CHESTER
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Education/Certification
Interest category = Provider, Advocate, Researcher, Public Health Professional
Interest category Other Description = The last box in the form is set-up wrong.... Comments: Requiring all Behavior Specialist Consultants, by 2013, to have acquired certification as Applied Behavior Analysts is an unwieldy stipulation that will cause an unnecessary restriction in the pool of professionals who are allowed to treat children with Autistic spectrum disorders. Many professional psychologists with lengthy track-records of excellence as providers will be excluded because they do not NEED such certification in order to provide excellent services to children on the Autism spectrum. There should be a "grandfather" clause that allows such professionals (those with 20+ years' experience and excellent references from parents, for

example) to be "certified" as appropriate providers of Behavior Specialist services WITHOUT having to obtain "ABA certification."

Subject = Education/Certification
Name =
State = Pennsylvania
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Coworker
How found out Other Description =
Report being commented on = Education/Certification
Interest category = Provider, Advocate, Researcher, Medical Professional
Interest category Other Description =
Draft Report Rating =
Nature and Scope Rating =
Presentation Rating =
Overall Rating = Comments:

Comments on Pennsylvania Autistic Taskforce Report

It is an extraordinary undertaking for Pennsylvania to organize toward the enhancement of services to autistic children and their families. We rallied in the enthusiasm felt as Secretary Richman and our chairpersons, Nancy Minshew, Nina Wall-Cote, and David Mandell kicked off the Taskforce with their sincere commitment to do whatever it takes to provide quality services to Pennsylvania's children and their families. And now each of the Taskforce Committees have submitted the collaborative efforts of their groups to comprise the Pennsylvania Autistic Taskforce Draft Report. The energy of these 200+ people is clearly felt in this report.

Two important points have been made in this report. First, working with Autistic Spectrum Disordered children and their families and the service providers requires specialized knowledge and expertise and must be ready to integrate new knowledge and gained insights. Second, children with relating and communicating vulnerabilities often have life long developmental challenges and we, as caregivers, with respect and dignity must anticipate their needs and support them in their important relationships. This means supporting the children and their families as well as their service providers.

Specialized knowledge and a value for interrelated lines of development must start with prevention so that providers working on the front lines of daycare, in healthcare and in homes, know enough about development and human relationships that they do not take a wait and see approach to children's functional capacities or vulnerabilities. Front-line caregivers as well as parents need more training and support in understanding typical development and red flags as a child's functional developmental capacity begins to compromise.

We now have the opportunity to redefine the standards of care in children with severe developmental challenges. This letter will set forth a model for early identification, early intervention and ongoing treatment approaches for children on the autism spectrum and their families called DIRTM. It is based on a modern reconceptualization of these disorders from a functional developmental and relationship perspective which takes individual differences into account. My comments below are made in collaboration with Stanley I. Geenspan, M.D., Chair, ICDL, Clinical Professor of Psychiatry and Pediatrics, George Washington University Medical School, and Serena Wieder, Ph.D., Associate Director ICDL, Director, DIRTM Institute, ICDL. I currently implement this model extensively in the state of Pennsylvania and elsewhere as well as provide training as a member of the faculty of the DIRTM Institute.

In the past, two models guided interventions. One, the behavioral model, did the best that it could under the circumstances and worked with surface behaviors. Much of the behavioral work was geared to just modify how children behave. In its time, and for a long time, the behavioral approach was the only intervention approach available. While the early report on this approach from non-clinical trail research

study (Lovaas, 1987) was encouraging, a more recent study, the only clinical trial study of this method (i.e., with random assignment to the intervention group), showed very modest educational gains (13% had good educational progress) and little to no social and emotional differences with a control group (Smith, Groen, & Wynn, 2000). The fact is that this approach pioneered the intensity of working with the child with special needs was a promising development. Now, however, we can go beyond working on circumscribed cognitive skills, taking lessons from older children. For example, if an older child is supposed to learn how to identify shapes, then take a three year old who has no language and work on matching shapes in a rote and repetitive way. But this approach was piecemeal and worked with isolated cognitive skills.

Now with our understanding of how the mind and brain function, we can go beyond these two older approaches of modifying surface behaviors and/or working with isolated cognitive skills. We can now systematize a developmental approach that synthesizes and integrates all the best information we have about how the mind and brain grow.

There are three insights of the last twenty years that are the cornerstones of our new way of working with infants and children with developmental problems. First, language, cognition, (including math and quantity concepts), as well as emotional and social skills are all learned through interactive relationships which involve affective exchanges. It was once thought that if you want a particular cognitive skill, you stimulate that cognitive skill. Now, we know that the mind and brain grow most rapidly in the early years as an outgrowth of interactions with caregivers. These inter actions must have a number of critical features including:

- Warmth and security
- Regulation so the child is not overwhelmed
- Relatedness and engagement
- Reciprocal emotional signaling and gesturing
- Problem Solving
- Using ideas in a meaningful and functional way
- Thinking and reasoning

Most essential are multiples of interactions with children that exchange emotions and that provide a fundamental sense of relatedness. When we deprive children of this relatedness, as we have seen in children in orphanages and other settings, they don't grow. Without fundamental relating, language and cognition do not develop well. We have seen in our observations and our studies that even the simplest task of learning how to say hello is dependent upon our emotions and our relationships.

Thus, emotions lead to the way all the way through. Language, cognition, math, and quantity concepts are all conveyed through interactive relationships through affect. We cannot teach children in the old fashioned ways anymore, particularly children with special needs who have processing problems. This means working on the relationship with the child and the whole family pattern because it is within the family context, as well as the cultural and community contacts, that these relationships, and emotional interactions occur. Intervention must mean a much broader relationship-based, cultural and community approach to children with special needs.

The second insight relates to variations which exist in underlying motor and sensory processing, i.e., regulatory capacities. In the last ten to twenty years we have also identified the important underlying processing capacities that are behind children's worrisome behavior. We understand how children are different, i.e., individually different in the way they process sounds (auditory processing and language), the way they process what they see (visual/spatial processes), and the way they plan and sequence actions (motor planning and sequencing). We find enormous variations in how well children can plan (and execute) actions to express their ideas. We find that many of the children with autistic spectrum disorders have severe problems with their motor planning and sequencing that underlies much of their repetitive behavior. If you cannot plan in sequence, you are going to repeat. Motor planning is very important in understanding these symptoms.

We have also observed that many of the children have differences in the way they modulate sensations. Some are very over reactive to things like sound and touch, other children crave sensory input and they

want more touch or they want more noise. And some children have both the craving, they want more (sensory input) but they get overloaded because they also have areas of sensitivity. For these children it is very hard to find the right sensory pattern to pull them in and engage them. We find that a lot of children who are self- absorbed are under-reactive to things like touch and sound. Other children who are very avoidant and keep running away from people, not because they do not love people, but because they are over reactive (hyperactive) to things like touch and sound. We need to look at the sensory modulation of the child to find the right pattern to pull that child into a relationship. If you work with the underlying processes, then you can influence many behaviors and help the child be adaptive, across a broad range of issues rather than just work on isolated cognitive skills or isolated cognitive behaviors.

The third area of insight, based on our new research, is to understand what the early Stages of development are. Historically, we thought of development in very isolated ways. Fro motor development we had a timetable for sitting up, for walking, etc. In language development we knew when the first sounds are made, when are the first words are made, etc. In different cognitive areas of development, we knew when a child searches in your have for an object, when a child can stack blocks in a certain way, and so forth and so on. In social and emotional development we knew when a child will greet, when a child will play will peers, when a child will do some pretending, etc. But each area has been separate, as though these areas are independent of one another. But in fact, for the child, all these lines of development are interrelated. The child doesn't separate out their language and their motor skills. We haven't had a developmental road map for the mental team: language, cognition, affect and emotions.

In the last ten to twenty years we've put together a functional developmental road map where we now understand the core levels that synthesize and integrate all the developmental capacities. We have identified six core levels (and then additional ones beyond that) that help us organize where we want to work with the child. The six levels, very briefly are:

- The first level is the ability for regulation and shared attention, which you need as a foundation for the next level.
- The second level is engagement with warmth, trust and intimacy.
- The third level is two-way purposeful communication-opening and closing circles of communication is a back and forth way with a lot of affective gesturing and micro affective gesturing smiles, smirks, head nods: the ability to take these gestures and organize them into problems solving patterns so we can actually take mommy by the hand, walk her to the refrigerator, bang on the door and point to the juice. That may be 10 or 20 interactive gestures all targeted towards solving a problem.
- The forth level is interactive problem-solving/ use of gestures in a continuous flow.
- The fifth level is the functional use of ideas. In language, for example, it would be, me hunger juice please or in pretend play, feeding the dollies, hugging the dollies.
- The sixth level is the ability to build bridges between ideas so you can use language logically and realistically and shift gears between reality and fantasy so when the child says I want to go out and you say Why? because I want to play, our the dolly is having a tea party well how come the dolly wants to have tea party? because the dolly is hunger the dolly is having a birthday and they like to have tea parties on their birthdays. So now we have logical use of ideas supporting imaginative play and negotiating and problem-solving with the world having debates, having problem solving discussions, at the symbolic level.

For each of the six levels we can look at the particular motor skills, language skills, visual/spatial processing skills that relate to that level that are needed to support that level. This gives us a much more integrated picture of development. When we now see a child we can figure out where they are in his or her functional level.

The Developmental, Individual-Difference, Relationship-based (DIRTM) Model summarizes an approach that builds these growing insights regarding functional developmental capacities, biologically-based processing differences, and emotionally meaningful learning interactions between families, caregivers, and children. D Functional Developmental Levels; we want to see where the child is in his/her development. I Individual Differences in Processing; the processing profile in terms of auditory processing, visual/spatial, sensory modulation, motor planning. And R, (stands for) what the relationships are like. What are the interactive relationships and use of affects like in the family now and what would be the ideal pattern to

support and enhance development. What is the pattern we what at the therapeutic program at home and at school to support enhanced developmental?

The DIRTM Model looks comprehensively at the child and is an advance over the older ways of thinking, because we are not just focused on isolated cognitive skills and we are not just focused on surface behaviors. We are focused on integrated understanding of human development. The integrated model of development includes interaction with caregivers and the environment, biologically mediated motor and sensory processing difference, and the child's functional developmental road map, i.e., determining where the child is in terms of the six functional developmental elements. This changes the way we do assessments and the way we plan interventions.

The DIRTM Model, therefore, serves as a framework to understand the development profile of an infant or child and his/her family. It enables caregivers, educators, and clinicians, to plan an assessment and intervention program that is tailored to the child's and family's profile. It is not intervention, but a method of analysis or understanding that helps to organize many intervention components into a comprehensive program. Sometimes, the DIR Model or method of analysis is confused with Floortime. Floortime is specific component of a comprehensive DIRTM based intervention program. It focuses on creating emotional meaningful learning interactions that facilitate the six functional developmental capacities outlined earlier (i.e., attention, engagement, purposeful emotional signaling and gesturing, pre-verbal and verbal problem solving and imaginative interaction, thinking, etc.). Other components a DIRTM based comprehensive program may include semi-structured problem-solving, learning interactions, speech therapy, occupational, therapy, peer play opportunities, educational programs, etc.

The DIRTM Model is the most comprehensive conceptual framework to understand and organize program of assessment and intervention for children with special needs. It has helped many children with special needs including Autistic Spectrum Disorders, learn to relate to adults and peers with warmth and intimacy, communicate meaningfully with emotional gestures and words, and think with a high level of abstract reasoning and empathy (Greenspan and Wieder, 1997), and also see Research Support for Comprehensive Developmental Approach to Autistic Spectrum Disorders and Other Developmental and Learning Disorders: The Developmental Individual-Difference, Relationship-based (DIRTM) Model at http://www.icdl.com.

Now we have much knowledge about the life long challenges in the variations in Underlying motor and sensory processing or regulatory capacities. We understand how children differently process sounds (auditory processing and language), the way they process what they see (visual/spatial processes), and the way they plan and sequence motor actions. Also, children have differences in the way they modulate sensation (over, under reactive or mixed to sound, touch and sight). Understanding a child's particular pattern of sensory modulation can help the child relate and learn better. Awareness of these individual neuro-physiological differences explains much about surface behaviors and can help the child become more comfortable and therefore, adaptive, related and learned.

We respectfully offer the Taskforce the DIRTM model which we believe provides this a Big Picture Framework; to address the needs of children with developmental challenges in the context of their families, community, and culture. Full adoption of this functional developmental approach will require changes at a number of levels, including clinical services, special education, prevention and screening, national and community policies, and research. Components of a Functional Developmental Approach

In using a functional developmental approach, providers should include the following areas in an evaluation and intervention program.

Functional emotional developmental capacities, which identify how the child integrates all her separate abilities (e.g., emotional, language, sensory modulation, spatial, and motor skills) to relate to the social and cognitive world in a meaningful manner. They include the capacity to attend and regulate; relate to others; initiate purposeful interactions with gestures and/or emotional cues; engage in long, social, problem-solving sequences; create ideas, words, and imagine; and think, abstract, and learn. Mastering these critical functional developmental capacities depends on the child learning to connect her emotional interests, intent, or goals with her emerging motor-planning, cognitive, language, and sensory skills.

These critical connections enable the child to create purpose and meaning in her world. Children with complex developmental and learning problems, including autistic

- spectrum disorders, often only learn skills in an isolated, unpurposeful, or
- nonmeaningful way (e.g., memorizing scripts). They tend to have a harder time
- integrating these different capacities meaningfully. An appropriate intervention
- program must, therefore, focus not on isolated skills but on the most essential
- functional developmental capacities.

Individual differences in the functioning of the central nervous system, with a special focus on how these differences are expressed in the way a child reacts to and processes experiences, as well as how she plans and organizes responses. This area typically includes sensory modulation (e.g., over- or underreactivity in each sensory modality, such as touch, sight, and sound); sensory processing (e.g., auditory [receptive language], visual-spatial, tactile, vestibular, and proprioceptive); motor planning and organizing actions, behaviors, and ideas); and other affective, cognitive, and learning processes (e.g., special talents and executive functions).

Child-caregiver interactions and family and service system patterns, particularly as they mobilize developmental progress by working with the child's individual differences at the child's functional developmental level. In working with developmental, emotional, and behavioral problems, there is a tendency to lose sight of the functioning of the whole child and her family. Instead, the tendency is to work with isolated behaviors or processes (e.g., compliance, aggression, or matching shapes or colors), with insufficient attention paid to the emotional relationship to her caregivers, her ability to engage in a continuous chain of back-and-forth affective and gestural interactions, or her capacity to generate creative ideas. For example, teaching a child to carry out a particular task in a rote manner may decrease her capacity for relating with joy and warmth, expressing a range of feelings, and communicating meaningfully.

A comprehensive program that deals with the whole child and his family (as well as his community and culture) provides a framework within which specific techniques may be quite effective as part of a comprehensive approach and ineffective, or even deleterious, as an isolated intervention. A team approach to an individualized, comprehensive functional program that works with each child's unique pattern of functional deficits and strengths and often includes, as needed, speech therapy, occupational and/or physical therapy, special education, biomedical interventions, and mental health or developmental work with the child, and child-caregiver interactions and/or family patterns-with all team members working together.

There are number of research and clinical practice observations that can contribute to conceptualizing a comprehensive developmental approach for autistic spectrum and other disorders of relating and communicating. One of these is the importance of working with the different processing areas compromised in these developmental disorders. These processing areas include work with (1) speech and language, which is well-documented in both research studies and clinical practice descriptions (Goldstein & Hockenberger, 1991; Law, 1997; McLean & Cripe, 1998; Wetherby & Prizant, 1993, 1995) and (2) the motor and sensory systems, including visual-spatial processing, which also is supported by research and clinical practice (Blackman & Goldstein, 1982; Case-Smith & Bryan, 1999; Chez, Gordon, Ghilardi & Sainburg, 1995; Lincoln, Courchesne, Harms & Allen, 1995; Williamson & Anzalone, 1997).

There is also considerable research and clinical support for working with important functional developmental capacities (Greenspan, 1992; Tanguay, Robertson, & Derrick, 1998), including attention and preverbal gestural interactive problem solving (e.g., joint attention [Mundy, Sigman, & Kasari, 1990]), reciprocal affective interactions (Dawson & Galpert, 1990; Lewy & Dawson, 1992;Tanguay, 1999), different levels of symbolic functioning in affective, interpersonal, cognitive, and language domains (e.g., theory of mind [Baron-Cohen, 1994] and the pragmatic [i.e., social functional] use of presymbolic and symbolic communication [Wetherby & Prizant, 1993]). These important areas of developmental functioning can be systematized clinically into six basic functional developmental capacities described above, which also have support from the normative child development literature (Greenspan, 1992; Greenspan & Lourie, 1981). These six functional developmental capacities are:

There also is considerable support for focusing on child-caregiver interactions and working with the family (McCollum & Hemmeter, 1998; Krauss, 1998; Turnbull & Turnbull, 1982). In addition, two other elements appear to have importance. One is employing a very intensive approach to working with children and their families. In an intensive program, the majority of the child's time is involved in various types of pleasurable, soothing, and learning interactions, leaving very little time available for self-absorption or preservative activities. In most studies, the intensity factor (30 to 40 hours a week) appears to discriminate between greater and lesser outcomes (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Scheinkopf & Siegal, 1998) at least in terms of IQ levels.

However, defining the active ingredients of a more intensive approach and the threshold levels of very intensive programs is not yet clear from available research (Rogers & DiLalla, 1991; Venn, Wolery, & Graco, 1996; Zelazo, 1997). Intensity is not defined just by the number of hours spent in one-on-one instruction, but also by the amount of time spent during a child's day in helping him generalize skills through the more spontaneous experiences and interactions of daily life and the classroom. It also appears that one-on-one child-caregiver interactions, especially for children who are not yet social and interactive, is essential for significant progress (Dawson & Osterling, 1997; Powers, 1992). Additionally, as children become available for social interaction, it appears that balancing adult-child one-on-one work with peer-topeer and small-group work is quite helpful (Hoyson, Jamison, & Strain, 1984; Strain & Cordico, 1994).

The Developmental, Individual Differences, Relationship-Based (DIR) Approach

The promising elements just identified can be conceptualized as part of a comprehensive developmental model (Greenspan, 1992; Greenspan & Wieder, 1998, 1999) by systemizing the elements into the three broad categories.

1. D Developmental capacities that integrate the most essential cognitive and affective processes. These are the six functional developmental capacities.
2. I Individual differences in motor, auditory, visual-spatial, and other sensory processing capacities.
3. R Relationships that are part of child-caregiver and family interaction patterns and which provide:
    - ongoing nurturing support
    - orchestration of the specific educational and therapeutic elements incorporated in 1 and 2 above
    - provision of ongoing interactive learning opportunities geared to the child's individual differences and current functional developmental capacities throughout most of the child's waking hours (at an appropriate intensity); and
    - a balance between one-on-one caregiver-to-child interactions and peer-to-peer interactions appropriate to the child's individual differences and functional developmental capacities

In the Developmental, Individual Differences, Relationship-based (DIR) approach, functional developmental capacities, individual differences in processing capacities, and relationships embedded in the child-caregiver and family patterns are utilized together in clinical decision making to create an individualized program for a given child and family.

In conclusion, there is a wide range of research and clinical experience not just from the field of autism but from the field of early intervention and child development at large, which, when taken as a whole, provides considerable empirical support for a comprehensive developmental model.

The Intervention Model: Recommendations

A Developmental, Individual Differences, Relationship-based (DIR) approach. The intervention program must work with all essential functional developmental capacities (regulation and attention, engagement, two-way purposeful interaction, problem-solving interactions, the creative use of ideas, and logical thinking), individual processing differences (auditory, language, visual-spatial, motor planning, and sensory modulation), and child-caregiver interactions and family functioning, as well as, additional cognitive and learning skills.

Three types of learning involved in a comprehensive functional developmental intervention program. The first type of learning involves following the child's lead and engaging in child-initiated interactions that are based on the child's natural emotional interests (Floor Time). The goal of these spontaneous interactions is to mobilize and improve attention, engagement, purposeful and problem-solving interactions, and, if the child is ready, the creative and logical use of ideas and words. The second type is semi-structured problem-solving interactions that meet specific language, cognitive, and social goals. An example of this is an adult enticing a child to try to open a door to get a favorite toy, and using the child's motivated state to teach her to say open. Semi-structured learning can also be relatively structured, if needed. A child with severe challenges in motor planning and sequencing that are interfering with his capacity to imitate and use words, for example, will often require, together with dynamic interactions, a very structured program for a period of time to strengthen motor planning and imitative capacities. Many other techniques such as Miller, Teacch, ABA, PECS, etc. can be utilized to enhance overall developmental relational progress. Each of these structured elements, however, needs to be embedded in a comprehensive, functional developmental program that works with all the child's important functional capacities and his family relationships. The third type of learning that characterizes a functional developmental intervention program is motor, sensory, and spatial learning activities oriented toward facilitating motor planning and sequencing, sensory modulation, and visual-spatial thinking.

All-day and evening programs. Children with severe developmental problems, including autistic spectrum disorders, often cannot, on their own, initiate or carry through developmentally appropriate interactions or learning practices as recommended by the National Association for the Education of Young Children (NAEYC). If left alone, children with developmental challenges may perseverate, become self-absorbed, or self-stimulate. Therefore, they often require one-on-one or small-group interactive and learning opportunities throughout their waking hours, either in the school or at home, geared to their unique developmental profiles. These should include relationship-based interactive, relaxing, and soothing times. Individual therapies, including speech and language and occupational and/or physical therapy at sufficient intensity (based on the child's developmental profile) to facilitate optimal progress.

Integrated education program as peer interaction and play opportunities. Once children with special needs can imitate gestures, sounds, and words, and interact with others, they often benefit from an integrated education program. If they are in a home-based educational program, they benefit from daily opportunities for substantial social interactions during which the other children can understand and respond to their communications. The education program at school or at home should also be based on the three types of learning described earlier in one-on-one and small-group contexts.

An appropriate education program. The child's Individual Education Program (IEP) should include the main functional developmental capacities of attention and regulation, engagement, purposeful two-way circles of communication, problem-solving interactions, the creative use of ideas, and the capacity to build logical bridges between ideas, as well as, work on each processing capacity (i.e., auditory, visual-spatial, motor planning, and sensory modulation) as the primary goals. Often, a child can master these developmental goals in conjunction with specific academic or pre-academic skills.

Biomedical approaches should be tailored to each child's individual difference and developmental capacities, including consideration of medication and/or nutritional approaches.

Technology-based learning opportunities should be geared to each child's individual profile.

Consultations by a developmental and/or mental health specialist to help construct and monitor the overall program including the three types of learning and child-caregiver and family interactions.

A full evaluation and, if required, an intervention program should be initiated immediately if functional developmental capacities, as outlined in the screening approach are not progressing.

An intervention program should offer the potential of continuity. The typical change from an infancy to a preschool program at age 3 is often disruptive for children who are working on learning to relate to others and trust relationships.

Conclusion Pennsylvania is moving in important and meaningful ways as it organizes to enhance services for autistic children and their families. The Developmental, Individual Difference, Relationship-based (DIRTM) Model offers the most comprehensive Big Picture Approach. Professional and parents work together to implement appropriate individualized comprehensive intervention program which supports each child's development in the context of his/her family, educational setting, community culture. Parents who understand their children's comprehensive needs can truly head their team and facilitate services in the worlds of early intervention, medical care, mental health, developmental services and education as needed. A critical result is the increase in the families capacities to cope and meet the ongoing needs of the child and family.

While the Developmental, Individual Differences, Relationship-based (DIRTM) Model is relies on implementation at home by parents, both parents and professionals/ paraprofessionals, once trained, work together to provide high quality, individually-prescribed care in all relevant settings in a cost effective manner. What will result for the children and their families is the increase in family capacity to manage life. Pennsylvania's citizens deserve the opportunity to easily choose dynamic developmental-relational services as offered by the Developmental, Individual Differences, Relationship-based (DIRTM) Model.

Respectfully Submitted,

UNDISCLOSED, L.C.S.W., B.C.D.
Salazar Associates
Senior Faculty/ DIR Trainer Level Certificate
Interdisciplinary Council on Developmental
and Learning Disorders (ICDL)

Information and Advocacy

Subject = Information and Advocacy
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Information and Advocacy
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10
Comments: I strongly agree that two waivers, one for adults and one for children, should be developed and implemented ASAP. Also, agree we need an Office of Developmental Disabilities as stated in this report.

Subject = Information and Advocacy
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Information and Advocacy
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8
Comments:

Subject = Information and Advocacy Name = State = PENNSYLVANIA County = ERIE Country = United States CountryOther = Email Address = How found out = From a meeting How found out Other Description = email Report being commented on = Information and Advocacy Interest category = Family, Provider, Advocate, Primary/Secondary Educator Interest category Other Description = Draft Report Rating = 10 Nature and Scope Rating = 10 Presentation Rating = 10 Overall Rating = 10 Comments:

Subject = Information and Advocacy Name = State = PENNSYLVANIA County = ERIE Country = United States CountryOther = Email Address = How found out = From a meeting How found out Other Description = email Report being commented on = Information and Advocacy Interest category = Family, Provider, Advocate, Primary/Secondary Educator Interest category Other Description = Draft Report Rating = 5 Nature and Scope Rating = 5 Presentation Rating = 5 Overall Rating = 5 Comments: Agree with recommendations in report.

Subject = Information and Advocacy Name = State = PENNSYLVANIA County = DELAWARE Country = United States CountryOther = Email Address = How found out = Other (please specify) How found out Other Description = I represent community MH/MR/D&A provider agencies to DPW Report being commented on = Information and Advocacy Interest category = Provider Interest category Other Description = Provider Policy Specialist Draft Report Rating = 8 Nature and Scope Rating = 8 Presentation

Rating = 5 Overall Rating = 8 Comments: I am submitting the comments and recommendations of the Pennsylvania Community Providers Association. A cover letter and hard copy of our recommendations has been sent to Secretary Richman, The Acting Secretary of Education and the Deputy Secreries for OMHSAS and OMR. Our comments and recommendations follow (formating may be lost in this cut/paste process). A MS Word copy of this document can be sent by contacting (UNDISCLOSED) PCPA, email address (UNDISCLOSED)

August 20, 2004

Estelle B. Richman, Secretary
Department of Public Welfare
333 Health & Welfare Building
Harrisburg, PA 17105

Dear Secretary Richman: It is with enthusiasm and appreciation that the Pennsylvania Community Providers Association (PCPA) offers our comments on the reports and recommendations of the Autism Task Force. PCPA extends thanks and compliments to all of the participants in the Autism Task Force – families, professionals, advocates, and other stakeholders who committed themselves, their expertise, and their time to completing this important task. The Association also compliments you and your staff for leading and facilitating this endeavor.

PCPA members and staff have participated in and reviewed the reports and recommendations from this comprehensive needs analysis and system improvement initiative. There is no doubt that the work of the Autism Task Force has provided an invaluable service to the Commonwealth and its most vulnerable citizens. The task force recommendations provide a blueprint for addressing the resource, training, consumer service, family and community support, and system integration challenges facing Pennsylvania.

PCPA looks forward to working with you and the stakeholder community at the state and local levels to implement these recommendations. We share the desire of the Commonwealth and the task force to move forward in improving and reforming the systems that manage, support, and serve our neighbors and families experiencing the challenges of Autism Spectrum Disorders. In that vein, attached please find a report of recommendations from PCPA in continuing to move the process forward. Sincerely,

UNDISCLOSED NAME
Executive Director

cc Deputy Secretary,
Office of Mental Health and Substance Abuse Services
Deputy Secretary,
Office of Mental Retardation

Comments/Recommendations

PCPA Guiding Principles for System Redesign In 2003 the PCPA Board of Directors established a "Systems Redesign Work Group." This action was in response to the call from federal and state leadership to improve the systems that serve the country's most vulnerable citizens in the publicly funded mental health, drug and alcohol, and mental retardation systems. One of the first tasks of the PCPA System Redesign Work Group was to identify a set of guiding principles to be applied to all initiatives, proposals, and recommendations affecting those service systems. The recommendations from the Autism Task Force have been reviewed in the light of the following PCPA Guiding Principles for System Redesign adopted by the Association. These principles call for recommendations supported by PCPA to reflect:

- Best Practice
- Economic Respons
- Community-Based
- Accountability
- Adequate Staffing

- Adequate Data Systems
- Effective Integration with Related Systems
- Adaptability and Growth Responsiveness, and
- Development with Appropriate Partners.

Overview of Task Force Recommendations In the Association's development of commentary on the Autism Task Force recommendations we sought the input of member agencies, managed care organizations, county MH/MR staff, and – through them – families and other service systems. Included here are the representative observations and reactions of PCPA. I

n reviewing the reports from the task force subcommittees there are many similarities in findings, comments, and recommendation across reports. Nearly all urge the creation of a single government department or office for the management, leadership, administration, regulation, and funding of autism services. A number of the subcommittees call for the development of Medical Assistance (MA) waivers and legislative action that will result in new and more fiscal resources for service delivery and for the education and training of staff. Many subcommittees also note the need for the Department of Public Welfare (DPW) and the Pennsylvania Department of Education (PDE) to establish models that will result in the coordination and integration of resources and regulation. Several subcommittees urge the creation of statewide and regional centers to support research, model program development, training, and the dissemination of uniform information on autism for families and professionals. PCPA finds these, and numerous other specific recommendations, to be important and valid areas for action and resource allocation with the objective of improving the depth, breadth, quality, flexibility, and outcomes of a system of integrated and coordinated autism services.

State Administration and Leadership Structures PCPA supports the subcommittee recommendations that call for sustaining the Department of Public Welfare as the administrative, regulatory, and fiscal "home" for autism services. Our Association urges that the governor and the Secretary of Public Welfare move forward in exploring the feasibility of establishing a single management structure to lead and implement an effective system of services for adults with autism. Several subcommittees have called for the creation of an Office of Developmental Disabilities. While this may be an effective leadership and management structure for services for adults experiencing pervasive developmental disorders, this approach should be carefully considered. The structure, cost, and collateral changes must all be identified and considered in such a change. In an administration committed to "tearing down silos" and enhancing integration, caution should be exercised in considering the establishment of potential barriers.

PCPA looks to the Governor's Cabinet on Children and Families to move rapidly to address the need for the Departments of Public Welfare and Education to work together to establish clear priorities and direct an effective process that will ensure the needs of children affected by autism and, indeed, all children with disabilities are met. Children must have their educational, treatment, and rehabilitation needs met in a much more efficient and effective manner. PCPA urges that a high level DPW/PDE task force be created to develop models for integrated services that reduce barriers to any needed service and increase access to services in school and community settings.

The reshaping of state government will not happen quickly or easily, nor will changes in funding streams or in federal and state regulations recommended by the subcommittees. These are important intermediate and long-term goals. The priority of autism system improvement initiatives, work group activity, progress, and products of this reform should be publicly reported on a regular and frequent basis.

Funding Initiatives and Coordination of Funding for Services and Supports Sustaining the Department of Public Welfare as the administrative, regulatory, and fiscal "home" for autism services will be vital to rapidly moving forward in pursuit of a Medicaid waiver and in weaving these services into existing fee-for-service and HealthChoices structures for adult clients. PCPA supports the recommendation that DPW move expeditiously to pursue Medical Assistance waivers designed to address the needs of children and adult clients with Pervasive Developmental Disorders

(PDD) and Autism Spectrum Disorder clients (ASD). Medicaid waivers for autism services – along with other recommendations – would increase the level of funding, resources, and services available to flexibly and more effectively address the need for discrete and focused autism services in Pennsylvania. Again,

PCPA urges that the waiver design support the vision of service integration and coordination wherever possible. We also urge that the array of services included in the waiver be flexible and guided by evolving evidence-based practice

As several subcommittees note, entitlement to services for children has been established in health care and education services and funding statutes and regulations. The coordination of regulations, service, and funding for children between DPW and PDE is a critical problem that cannot be fully addressed in a Medicaid waiver for children's autism services, due to other regulatory and fiscal operations already in place. This issue must be addressed at the highest levels of state government. PCPA recommends that the Office of Mental Health and Substance Abuse Services (OMHSAS) and its Children's Bureau retain the responsibility for managing behavioral healthcare autism services to children, adolescents, and transition-age older adolescents. PCPA further recommends that the Governor's Cabinet on Children and Families ensure the development of a cross system DPW/PDE task force under the leadership of department secretaries to manage the coordination of services, regulations, and funding between those departments.

Supports and Funding for Staff Training The provider community has long recognized that "strong treatment outcomes for children with disabilities depend heavily on highly trained professionals providing such treatment." The Association supports the recommendation of the several subcommittees urging the development of loan forgiveness legislation and dedicated funding for the ongoing best practice-based training of professionals and paraprofessionals engaged in serving individuals with ASD/PDD. PCPA is also very supportive of the recommendation that the state, providers, and other stakeholders work with institutions that provide training to those working in the fields of education, rehabilitation, behavioral health, and physical health care. A link between the service systems, universities, and community colleges would be a major contribution to service quality, continuity of care, and staff recruitment and retention. PCPA looks forward to supporting and participating in the strategies for providing the resources and structures for improving the training of staff working with children in all contexts across all communities.

While the creation of training requirements and standards are vital, PCPA has significant concerns that the state not create unfunded and unsupported training and certification mandates. While virtually all Local Education Agencies are able to generate funds to require and support continuing education of school personnel, few behavioral health and mental retardation service providers are able to afford similar employee training subsidies. PCPA supports the recommendations from those subcommittees that call for new funding, loan forgiveness, and other mechanisms that support the systems' ability to provide essential training to the staff working with individuals with disabilities.

PCPA endorses the recommendation that efforts must be made to include the Autism Spectrum Disorder diagnosis and related assessment, treatment, and support services in private insurance coverage. Further, the Association recommends that the Commonwealth act to add this expanded coverage to both the state supported programs: the Children's Health Insurance Program (CHIP) and the "adultBasic" health insurance plan.

Improving Efficiency in the Service Systems PCPA supports the subcommittee recommendations that call for the reduction of inefficient, redundant, and seemingly arbitrary requirements related to client transitions, paper work, staffing requirements, and service activity timeframes. PCPA is prepared to work with the Department of Public Welfare, the Department of Education, and other stakeholders in reforming these barriers to effective and efficient service delivery.

Measuring Client Impact and Service Effectiveness and Satisfaction Many of the disorders and disabilities in the autism spectrum are chronic or long lasting. PCPA questions the validity of applying a acute medical "outcome based" approach to measuring service, service quality, and impact. It may be prudent and more appropriate to consider quality of care measurement models used in the context of mental retardation, rehabilitation, or even chronic disease management services. One significant advantage of PDD/ASD-specific MA waivers and services would be that the service array, along with their cost/rate structure and quality measurement models could be developed "outside the box" of current behavioral health services and rate structures.

Should the Commonwealth elect to pursue an "Outcome-Based Payment Structure" for these services, PCPA urges that it be linked and timed carefully and reasonably and designed in collaboration with

providers, public managed care organizations, and other key stakeholders. The implementation of outcome based models must occur in a manner that allows for the development of "reliable and valid quality of care indicators." The Association also supports the subcommittee recommendation that any outcome based expectations must be linked to the training of an adequate pool of professionals and paraprofessional to provide high quality, evidence-based care in every community – urban, suburban and rural.

Reducing System Fragmentation, Silos and Duplication In reviewing subcommittee comments related to "State of Current Practice" and "Problems with Existing Practice," PCPA found a many concerns and perspectives presented to be valid. Issues of service fragmentation across state agencies, counties, and school districts are issue reflected in nearly all the reports. This is a strong indicator that a more unified approach to the interpretation of service needs, related regulations and standards, service availability, and cross-system coordination must be among the most immediate problems addressed.

Supporting Quality through Centers of Excellence PCPA recognizes the value of the creation of regional centers of excellence recommended by the subcommittees. The Association believes that this recommendation requires more analysis to consider the number, cost, structure, and function of regional entities. This analysis and planning should take into consideration the recommendations of all of the subcommittees that urged the development of similar local and regional centers of excellence for autism assessment, treatment, rehabilitation, training, and research services. Existing state models such as the Bureau of Drug and Alcohol Programs supported Institute for Research, Education and Technical Assistance in Addictions (IRETA) and the Department of Education's Pennsylvania Training and Technical Assistance Network (PaTTAN) should be considered.

PCPA supports the recommendation for the creation of a centralized and unified source of current and comprehensive information and advocacy for autism and autism supports and services. PCPA recommends that consideration and planning for this statewide resource be undertaken in concert with other similar state and regional resource recommendations. The Association further suggests that this family support resource also provide information and advocacy to families relative to their private insurance benefits and conflict resolution, in addition to supports related to Medical Assistance, the Individuals with Disabilities Education Act (IDEA), Act 504, and other service policies and entitlements. A careful cost analysis is essential as is the use of existing resources such as those identified for consideration for regional centers of excellence.

Services to Clients in the Community In reviewing the recommendations on Early Intervention, Children, and Adolescents, PCPA found many of the same experiences and recommendations previously noted. Repeatedly, subcommittees found the need for expanded resources in all communities – urban, suburban, and rural.

PCPA is particularly interested in the recommendation of the Rural Services Subcommittee related to the use of teleconferencing. The use of this technology for parent support, clinical consultation, training, and other important tasks could help to close the travel and resource gap experienced by families and professionals in rural communities. Again, the will and the resources to develop and implement a unified technology network will be challenging.

In reviewing the comments of the Subcommittee on Transition Age Clients, PCPA shares the view that there is a critical need for a more unified approach for planning for this population. A good model for meeting this need is the multi-system "Community of Practice" model used by the state's Transition Coordinating Councils already operating in many communities under the guidance of the Pennsylvania Department of Education. PCPA concurs that there is a great need for the development of cross system, cross departmental client supports, client services, and community supports including housing, vocational supports, and transportation services for this population as they move from school and family toward work and relative independence. The development of either specific Behavioral Health Rehabilitation Services or a new MA waiver with flexible components, funding, and services for this subgroup would be an important step in addressing existing and growing needs.

Finally, PCPA shares the perspective of the Adult Subcommittee that there is virtually no real system of services for adults with autism. While some adults with autism are able to access limited resources from

various public and private sources, there is no unified, statewide leadership, management, or model for the few resources for these individuals and their families. Again, PCPA supports those recommendations calling for the development of a specific MA waiver for the funding of an ASD/PDD service system that would effectively supplement and complement existing services. In addition to efforts to secure funding for appropriate and flexible resources for services and supports for this population, it will be essential for the Department of Public Welfare to providing the leadership, management, and implementation of the adult services recommendations of the task force.

Final Comments PCPA's goal in offering these comments, recommendations, and views is to acknowledge the work of the task force and to contribute to the process of informing and advising Commonwealth leadership. It is now essential that the leadership begin immediately to prioritize these recommendations. In this culture of "deliverables" and "performance-based outcomes," a level of high expectation has now been created through the task force process and product. The Pennsylvania Community Providers Association looks forward to working with state leaders and all stakeholders in moving these recommendations into action and outcomes.

Subject = Information and Advocacy
Name = Employee, Family-Child Resources
State = PENNSYLVANIA
County = YORK
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Information and Advocacy
Interest category = , Family, Advocate,
Other (Please specify) Interest category Other Description = Former Director of Asperger Syndrome Coalition, Current Development Director Family-Child Resources
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating =
Comments: Family-Child Resources (FCR) supports and applauds the comprehensive nature of this subcommittee report. In particular, we believe the task force did an exceptional job of capturing the scope of barriers associated with finding accurate, thorough information for parents or providers in PA. It is of interest that the report does refer to ASD's inferring the range of disorders and we would encourage the Task Force to be as inclusive of issues for PDD and Asperger Syndrome wherever possible. As an agency focusing on program development for the higher functioning individuals, we are in regular contact with individuals in the region who express that there are even fewer resources for the PDD and AS diagnoses. Many of the print materials suggessted as improvements exist in other states so perhaps there could be opportunities for collaboration or partnerships as opposed to "reinventing the wheel." Family-Child Resources would be happy to cooperate with or participate in any planning or implementation efforts in the future.

Rural Issues

Subject = Rural Issues
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Rural Issues
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 5
Nature and Scope Rating = 5
Presentation Rating = 5
Overall Rating = 5 Comments:

Research

No comments received during the Public Comment Period.

Funding Streams

Subject = Funding Streams
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Funding Streams
Interest category =
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8 Comments:

Subject = Funding Streams
Name = Employee, Family-Child Resources
State = PENNSYLVANIA
County = YORK
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Funding Streams
Interest category = Family, Advocate, Other (Please specify)
Interest category Other Description = Former Director of Asperger Syndrome Coalition, Current Development Director Family-Child Resources
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8 Comments: Family-Child Resources (FCR) supports the material in the report and would suggest that subcommittee members stay in contact with the Interagency Autism Coordinating Committee at the National Institute of Mental Health. This interdisciplinary committee can be lobbied for future funding directions in Autism programming and research. As always, we would encourage strongly the inclusion of funding for services that include individuals with the PDD and AS diagnoses by name. Family-Child Resources would happily support and participate any efforts toward this cause.

Subject = Funding Streams
Name =
State = PENNSYLVANIA
County = BUCKS
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Funding Streams
Interest category = Advocate
Interest category Other Description =
Draft Report Rating = 5
Nature and Scope Rating = 1
Presentation Rating = 8

Overall Rating = 4 Comments: 1,130,516 People with severe disabilities are "not" served by MH/MR or other waivers in Pennsylvania. That's greater then the total of people with autism in the nation.

This number was calculated by taking the US census total number of people with severe disabilities, less people served by MH/MR and the 3 waivers with that, and then less people served by the 7 other waivers.

People should recieve what they need based on their individual needs, not eligibilty according to a label. Focusing on labels uses up limited funding on sorting and categorizing and looking at eligibility rather then providing individual services and supports. The same issues apply to the other over a million people with "severe" disabilities in Pennsylvania that do not fit into the MH/MR system or other agencies as they do to the sub-group labeled as having autism. They also have significant needs to daily living, physical, cognitive, behavioral and sensory issues that should not be ignored because they don't have the "label".

The same reasons it is important to address the needs of people with autism are the same reasons it is important to address others that have similar needs and face the very same issues.

70% of children with learning difficulties have sensory integrative problems, according to book: What Exactly Is Sensory Integration Dysfunction?, Author: Olga Bogdashina,: March 1, 2003.

Children and adults with various disabilities/ developmental delays or multiple disabilities, that do not have a label of autism deal with the same hardships of not fitting into existing systems. The numbers speak for themselves. Not having sufficiant supports and services and appropriate trained professionals in education or the medical fields, and issues with fundings and respite etc. etc. are all the same things that the majority of people face.

To focus only on autism perpetuates what already doesn't work. There will continue to be people with significant needs that don't fit into a system, because even though they have the similar or greater needs (or have autism and are not diagnosed), if they don't have the right label, they loose. If this is not acceptable for those who support individuals with autism, how can you justify doing the same thing again to other groups outside of yet another category of labels?

In each report you can replace the "autism" with the words "various disabilities" and the statements remain correct. For example, People with various disabilities that have an IQ number over 70, but have significant functioning needs do not fit into the current service structure, if they are to qualify under MH, it isn't designed to meet the needs of those who have neurological and developmental disabilities.

We need a developmental disability state to support all those people who must fight for services, education, supports, resources, those with autism and the million others who currently are not served. We don't need more fragmentation, eligibility rules, more separate funding streams and divisions of supports and services. Another disability label specific waiver is a step in the wrong direction.

Medicaid Waiver

Subject = Medicaid Waiver
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Medicaid Waiver
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: I strongly agree that two waivers, one for adults and one for children, should be developed and implemented ASAP. Also, agree we need an Office of Developmental Disabilities as stated in this report.

Subject = Medicaid Waiver
Name = Delaware County Department of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Medicaid Waiver
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 7
Presentation Rating = 7
Overall Rating = 7 Comments: The Delaware County Department of Human Services gave this Subcommittee on Developing a Medicaid Autism Waiver as it does an excellent job of making a case for a separate administrative approach to providing program design and funding. We agree with the examples given to show that the current systems for mental retardation and behavioral health cannot fully meet the needs of persons affected by autism. It would be better to design a different system than to try to squeeze persons into inappropriate services .It should also be pointed out that there are long waiting lists for services for persons who do meet the criteria for mental retardation services.

We did not assign a higher rating due to some inaccuracies in the report:

On page 7, the report states: "Currently, in the Southeast region, counties and MCO's such as Magellan are insisting nonverbal children have mobile or "talk" therapy in lieu of therapeutic staff and behavior specialist consultant services." In our experience, mobile therapy is a valuable resource for working with parents and siblings of children with ASD to help them cope with the ongoing ramifications that this diagnosis can have on the family, as well as to develop clear and realistic expectations for the child and family. Mobile therapy provides the parents/siblings with an opportunity to work with a therapist regarding their feelings regarding the diagnosis and the child, as well as some time for problem solving and developing strategies for coping with difficult behaviors. It is not expected that a nonverbal child will utilize "talk therapy". Since this is a voluntary service, as are all mental health services, a parent can choose to decline a recommendation for this service. Mobile Therapy is not used in lieu of therapeutic staff and behavior specialist consultant services if the latter are medically necessary. A recommendation for either of these two other services would be made by the evaluator. The MCO's authorization or denial

would be based on documentation of medical necessity in the referral packet. If either of these services was recommended and denied, the parent could file a grievance.

On page 9, fifth paragraph discusses a perceived limitation of accessibility of services through the use of an extended evaluation. This is not an accurate generalization. The intent of such an evaluation is not to limit the accessibility of service. In fact, in the counties in the Southeast Region that offer this type evaluation, the MH/MR Administrators have not found it to be a barrier to service. Feedback that has been received from a high percentage of families who have actually used this service has shown a high level of satisfaction.

On page 18, third bullet – refers to the desire of the Subcommittee to perpetuate the model of the pilot program which seems to working well. It is not the desire of this Department to pass judgment on the specific organizational structure that will best meet the needs of the autistic community. However, in contrasting your projected service model to the current one in place, MH/MR is referred to as a "county-based political patronage system". This is not accurate. A State requirement from the inception of the County system is that the employees be hired through a merit, not politically based, system. In most counties (except first class cities which may use their own approved system) the State Civil Service Commission procedures prevail. The County system was put in place to allow for differing circumstances and needs of local areas in the State at the time the MH/MR Act was written. In recent years, with the advent of Federal funding, there has been much more uniformity across counties. In designing a new system, The autism Task Force does have a duty to examine which aspects of existing systems make sense at this time.

On Page 18, the last bullet makes a generalization about the policies of MH/MR toward inpatient institutionalization. For many years, the stance of the State and local mental retardation program has been that with rare exceptions, persons belong in and are served in the community. Even though there are long waiting lists for residential placements, this county does not see institutional placement as the typical option. It is true that the residential services available in the community often have difficulty dealing with major behavioral issues; this may be the reason for the perception expressed.

Subject = Medicaid Waiver
Name =
State = PENNSYLVANIA
County = BUCKS
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Medicaid Waiver
Interest category = Advocate
Interest category Other Description = Comments:

I strongly oppose a disability specific waiver and encourage consideration of meeting the needs of all those who have the same issues. Various individuals with disabilities don't fit into the existing systems, deal with the exact same issues described in this report and are in need of the same solutions.

I you go through the report and replace the word "autism" with a "variety of disabilities" and looking at individuals' needs, it becomes reflective of the bigger picture. (I added parts below and it clearly does not change the intent, nor the focus on needs, but simply shifts from a label to the individual's needs)

If shouldn't matter if the reason that you don't fit into the MH/MR systems is autism or any other disability, those with significant needs that don't fit the current systems all face the same challenges. A waiver should be for developmental disabilities in general. A disability specific waiver will cause more focus on eligibility, more fragmentation and bureaucracy for anyone with a need to get supports, it will create yet another category where others won't fit.

Adapted.....

The waiver(s) should be specially designed to provide continuum of service options unique to the individual's needs, providing them lifelong supports and services to lead successful, healthy and safe lives integrated in their communities. It should not be unique to a disability label. If a person has sensory/behavioral issues, developmental delays, but doesn't fit into the MH/MR category, they should all qualify for a waiver whether the needs are diagnosed autism, other, or not diagnosed.

Report Summary

Individuals with disabilities and their families face pervasive and complex challenges in finding services to meet their needs in Pennsylvania. This is due not only to the spectrum nature of any disorder and its complexities, but because of the less than optimal fit of Pennsylvania's existing mental health and mental retardation systems for any person who doesn't fit those two categories. Parents and individuals who have accessed these systems have described barriers such as IQ, treatment modalities for mental retardation or mental illness and the gate keeping and rigid medical necessity standards of managed care organizations. This report will examine the current state of barriers and recommend the following solutions in detail:

A developmental disability department within the Department of Public Welfare to house an waiver; (Should be a waiver for anyone who doesn't fit into the MH/MR service system)

Two aggregate waivers, one designed for children and one designed for adults, with a transitional period from 14-21 in which children could apply for the adult waiver under certain circumstances; Elimination of eligibility barriers which are based on mental health or mental retardation criteria, particularly IQ, and replacement of eligibility criteria based on functional assessment of individuals;

Regional, rather than county, administration of waivers; An education component developed by DPW and reviewed by stakeholders, for parents and individuals applying for an autism waiver;

A housing component for adults, established with non-waiver monies;

Establishment of an waiver workgroup at the time DPW begins the CMS application process, including members from the waiver subcommittee;

Inclusion of the waiver services and definitions crafted herein within the CMS waiver applications;

Consideration of the expansion of non-waiver services (such as the Medicaid State Plan or other services) for individuals who will not meet the eligibility criteria for a waiver.

Through these recommendations and the discussion which follows, we hope to fulfill our mission and begin the steps necessary to improve the lives of Pennsylvanians with autism.

Family Perspective

Education Services - Group consensus was that education services alone are insufficient to meet the pervasive needs of children with a variety of disabilities, and many children will need additional services through Medicaid, whether it is through EPSDT 1 (the existing Medicaid state plan) or through a waiver. Problems with the education system mirror problems identified in other states. Education in Pennsylvania for persons with a variety ofr disabilities has been accustomed to viewing many of them as either serving persons with mental retardation (e.g., with life skills classes) and mental health issues (e.g., with classes for those with social and emotional disturbances). Teacher training in colleges has not focused on many specifc disabilty types and most teachers know little to nothing about specific disabilities. State initiatives have not reached down to individual staff persons (regular educators, bus drivers, cafeteria workers) who encounter children with specific disabilities daily. Since schools perceive they lack the resources, expertise and ability to serve students with disabilities, students are frequently placed in self-contained or ut-of-district placements unless parents become the sustaining force for inclusion (if, in fact, inclusion is appropriate for a particular child). In addition, slots in approved private school placements are few and children sometimes end up in inappropriate placements because appropriate placements are limited.

Mental Health/Mental Retardation Systems - There was general agreement that Pennsylvania's existing Medicaid waivers in the mental- retardation system were nearly impossible for children or adults to participate in for a variety of disability types. The Subcommittee noted some of the deficiencies of employing the existing mental-retardation system to provide services to persons with various disabilities:

Persons whose IQ is below 70 are considered to have mental retardation and referred to the Mental Retardation System where services are not appropriate and where decades-long waiting lists may make access to waiver services impossible while parents or other caretakers are still living;

Persons whose IQ is above 70, but who are nevertheless limited in living independently, are considered to have mental illness and end up in the Mental Health system 3 ;

No other disability labels are relevant to qualify services as systems are currently configured, so persons with disabilities must seek to qualify as having either mental retardation or mental illness to receive services in Pennsylvania. 4

The cultures of the Pennsylvania Office of Mental Retardation ("OMR") and the Pennsylvania Office of Mental Health and Substance Abuse Services ("OMHSAS") are not conducive to the needs of individuals with a variety of disabilities. Adults in the MR system are considered to have the intellectual age of children and placed in group homes, or they might not receive services at all. Staff act as surrogate parents and provide care giving in homes owned by providers. Adults and children who gain access to services through the mental- health system are given medical treatment.

Adults and children served by MH are considered to have mental illness and are sometimes presumed to be in need of drug and psychotherapy treatments. Some managed care organizations ("MCOs") have recommended or, in some cases, demanded that elementary school children be placed on psychotropic medications such as Lithium, rather than to provide appropriate interventions and therapies. Currently, in the Southeast region, counties and MCOs such as Magellan are insisting nonverbal children have mobile or "talk" therapy in lieu of therapeutic staff and behavior specialist consultant services. Adults with autism in crisis are often placed into mental hospitals, some of which may not have staff equipped to treat developmental disabilities and, thus, mental illness medical treatment is applied. These services are costly, ineffective and waste resources that could be applied elsewhere to appropriate services.

Office of Social Programs - Pennsylvania's Office of Social Programs ("OSP") has traditionally been a small agency to serve persons with disabilities not served by OMHSAS or OMR. The majority of those served have been persons with physical disabilities, although OSP has served as a "default" agency in state government for those who do not fit into existing systems. There is currently an autism pilot program (addressed in greater detail below), which is housed in OSP.

Application of categorical treatment modalities will not work for individuals with variety of disabilities. A Variety of disabilities must be considered as their own category and individuals within those categories treated according to their individual needs.

Although individualized applications of treatments within acronym>MH or MR categories may be helpful in some cases (e.g., teaching of life skills, individualized use of medication as an adjunct to other treatments), it is critical to regard many disabilities as a distinct so that treatments can be appropriately tailored to individuals. Not only can inappropriate treatments designed for MH or MR be ineffective if not tailored to the individual, but in some instances they could be counter-productive or harmful. (e.g. individuals with various disabilities are extremely sensitive to medications and do not always respond as would be expected.) The needs of individuals with various disabilties cross various systems domains and require additional services which are currently not anticipated or provided within existing systems. Therefore, many disabilities need a system for those who do not fit into existing systems. Although OSP does not require that services be based on a particular IQ level, Pennsylvania's IQ-driven culture has affected the pilot program in that persons participating with low IQ have been rejected during the second round of selecting participants for the autism pilot, contrary to earlier agreement in the autism pilot work group. In contrast to the caretaking culture of OMR and the medical- treatment culture of OMHSAS, OSP has primarily served persons with physical disabilities who were able to advocate for themselves. Therefore, OSP has fostered a culture of "independent living." Families of those served by OSP are not

usually deemed to be stakeholders. Independent living agencies, which are governed by - and employ - a majority of consumers, direct some of the case management and service provision in this system.

Office of Vocational Rehabilitation - Parents have reported expressed that the Office of Vocational Rehabilitation ("OVR") generally provides short-term services (contrary to what most adults with autism require for success), and that the job coaches may not be well educated or trained in how to coach persons with autism. The service OVR provides has a long wait-time and is not well suited to the long-term kinds of job support persons with autism, pervasive developmental disorder ("PDD") or Asperger's Syndrome may require.

parents, providers and systems administrators that Pennsylvania's delivery of services to person with disabilities is:

Decentralized, fragmented, complicated, and difficult for parents to navigate…[with]…only the most skilled and aggressive parents…able to obtain proper service for their children. 5

Family Perspective

Barriers - As noted in Section 2, the configuration of Pennsylvania's systems presents the most barriers for both children and adults with disabilities.. Policy and funding at the Commonwealth level drive services and expertise at lower levels. Therefore, the configuration of a state that still considers itself basically serving those with mental illness or mental retardation alone presents the following barriers:

For persons with various disabilities, only mental retardation and mental health services are available via the 67 Pennsylvania counties. This adds to the de-centralized and fragmented nature of services for persons with various disabilities. Although some counties have cooperative arrangements, this still creates dozens of different levels and qualities of service that vary according to a person's home county. As noted in DPW's EIBI Public Meetings Report, although there was general agreement about the systemic problems and need for solutions, the Southeast region participants had harsh criticism of the quality of and access to services due to the low quality of services in their region in contrast to Western Pennsylvanians, who had some complimentary things to say about services in their region 7. Application is simply not consistent.

The education system in Pennsylvania has 501 different models since school boards and districts create special education models and programs independently, with only cursory approval and oversight by the Pennsylvania Department of Education. Twenty-nine intermediate units ("IUs") also exist to assist school districts. However, school districts have the option of funding or utilizing IU programs. This makes for inconsistent regional availability of appropriate education programs for children with various disabilities. For example, the Bucks County Intermediate Unit has many support classrooms in schools. In contrast, the Delaware County Intermediate Unit has developed only a handful of classrooms. T

he MR Person and Family Directed Services Waiver provides services for those who do not require a licensed residential program. It is capped at $21,225 per person per year. Generally this is used to gain Federal Financial Participation ("FFP") for services of sheltered workshops and day programs for individuals cared for by their parents. Persons with various disabilties receiving services from this waiver must have mental retardation as a primary disability. Even if a person has significant functional limitations, if IQ is above 70, they are ineligible.

The MR Consolidated Waiver provides services including residential services. This is an aggregate waiver. The aggregate cost of the waiver cannot exceed the cost of an Intermediate Care Facility for Mental Retardation ("ICF-MR"). A very small number of persons with disabilties are using this waiver and only if they have a primary diagnosis of mental retardation. Most people utilizing this waiver have no living parents or caregivers. Services in both MR waivers are generic to mental retardation. Clients who exhibit problem behaviors (common for persons with a diagnosis of autism) are outplaced in MH crisis services. 8

The OBRA Waiver is currently being used by persons in the 20-person Autism Pilot Program. Cost cap is an aggregate cap based on costs of an Intermediate Care Facility/Other Related Condition ("ICF-ORC"). This

waiver is funding a range of services and hours of services for adults in the Autism Pilot Program, initiated by a joint OSP and Autism Living and Working, Inc. ("ALAW") working group.

- In order to obtain either the MR Person and Family Directed Waiver or the MR Consolidated Waiver, individuals must have: an IQ under 70 9 Prioritization of Urgency of Need for Services ("PUNS") 10 classification of "Emergency" - no caregiver available; Apply at County OMR office, document eligibility, and be placed on a waiting list; and sometimes political "pull" is needed in some counties.
- In order to obtain the OBRA Waiver, an individual must: be selected by OSP from information finders filled out and submitted to ALAW and forwarded to OSP; demonstrate "three-functional limitations" federal eligibility standard; have eligibility determined by OSP administrative entity (UDS of Lancaster); and Develop individual service plans and budgets via UDS case management; the pilot program is capped at 20 people.

Services Needed, But Not Currently Available - The attached survey and chart of results shows the subcommittee's development of service categories considered to be critical for inclusion in any Medicaid waivers for children and adults. The subcommittee met on November 23, 2003 to finalize the following categories of recommendations for Solutions (Part 4)

Administrative entity to house Developmental Disability Waiver and Medicaid Services; Advantages to administration of one waiver (Child/Adult) versus two Waivers (Children's Waiver and Adult Waiver); Funding recommendations regarding waivers; Service descriptions to be included in waivers; Services suited to limitations under waivers and those which should be considered for "unlimited" status; Continuum of housing and other community service recommendations; Recommendations for Medicaid services outside the scope of waivers. Access Challenges and & Differences

Under the best of circumstances, it is difficult for families to help their family member obtain services. There are cultural differences such as income, family configuration, regional and particularly families of children with multiple disabilities which make the challenges even more formidable.

The group had 100 per cent consensus that, although Pennsylvania systems are difficult to navigate,navigate; families with more education and income were more easily able to gain access to them because of the ability to sift through complex grievance and legal processes. We identified the following cultural factors that could affect a family's access to any potential autism waiver services:

Low Income: Many parents find the need at some point to seek legal counsel or advocates in order to deal with systems which are either non-responsive or lack compliance in order to obtain the appropriate services. If parents cannot afford to seek legal advice or counsel, they may obtain less appropriate services than parents who can afford these options.

Single Parents: It is recommended that single parents be considered for any additional task forces relating to autism. Family life for those with children with autism is difficult, even with two parents contributing to a child's well being. Single parents will have a unique perspective on how much more difficult raising a child with autism is in a single-parent family.

Rural Families: We echo the recommendations of the rural subcommittee report with respect to the challenges of obtaining services in a rural region and look forward to their comments for the Waiver Report.

Families in Major Cities: We recommend representation from Pennsylvania's major cities be sought in the future. Parents have unique challenges with schools and services in cities.

Families of Children with Multiple Disabilities: Some children with specific disabilities have additional co-occurring conditions such as blindness, deafness, physical disability, etc. The problems of access, training and appropriate services, in relation to children and adults in Pennsylvania with various disabilties, are exacerbated when an individual also has another disability. One example of this is a child who has autism and is deaf. It is imperative that this unique subset of individuals be provided with professionals that are

fluent in American Sign Language. This includes those that give assessments and provide direction interventions/support. Many disabilities can include impairments in language and communication. These difficulties often compound behaviors that result from frustration. These behaviors are accentuated when the individual cannot communicate because therapists/providers are not fluent in their native language.

Special consideration should be given to this and similar problems. For any person with a disability, that difficulty will be compounded if the staff must also be fluent in American Sign Language. Perhaps, this skill could qualify for a higher rate differential. This may also be necessary for other subsets of children who have another severe co-occurring disability such as blindness, physical disability, etc.

Services Needed By Persons With various disabilties , but Not Currently Available - Services include, but are not limited to the following:

Respite services

Case management/Case coordination, including independent case management or brokerage Life Skills Social Skills/Social Competency Groups (both for children and for adults and High Functioning) Housing 12 Communication Skills.

Family Perspective

The members of the Waiver Subcommittee were in agreement that, while new systems are desperately needed, existing systems must remain available to persons with disabilities while waivers and other systems changes are under development. We recommend that DPW sustain oversight in this regard during what may be a lengthy transition to development of new systems for persons with various disabilties.

Elimination of Barriers - There is consensus that the following needs to be done in Pennsylvania in order to eliminate barriers to services for persons with disabilties:

DPW should make plans to develop an developmental waiver for adults and an developmental waiver for children as soon as possible;

DPW should establish an developmental waiver workgroup with representatives from the Medicaid Waiver Subcommittee for stakeholder input;

DPW should, with help from the work group recommended above, and utilizing the service descriptions within this report, submit an application for an dvelopmental waiver with the Center for Medicaid Services (CMS);

DPW should include a housing component for adults utilizing non-waiver monies;

DPW should establish a bureau within an Office of Developmental Disabilities dedicated to the administration of a waiver or waivers with regional parent boards consisting of 51 per cent individuals or families of individuals with developmental delays

DPW should give special consideration to ensure waiver services are as accessible to families with specific cultural issues such as low income, single parents, inner city families, rural families, families whose children have multiple disabilities, etc.

DPW should strongly develop and define eligibility requirements for individuals with autism which are not tied to IQ.

DPW should consider expanding the Medicaid State Plan to add services which could help maintain persons with developmental disabilities who do not fit into MH/MR and other groups in the community. :

MR eligibility is based on low IQ. Eligibility for services for any person must be based on functional limitations; IQ is irrelevant.

MR system lacks the capacity to accommodate any new group of individuals; many people are on the PUNS waiting list.

The MR system's reliance on "natural supports" (person lives with unpaid family caregivers as long as possible) and on "family living" (services provided by a new family caregiver when parents die) does not provide adequate or appropriate supports for persons with various disabilties and places them at risk of inappropriate crisis placements (i.e., mental hospitals).

MR county-based service delivery system lacks understanding of specific disabilities and the needs of individuals with each type of disorder. Scarce resources are already stretched too thin and cannot accommodate new clients.

Providers of basic MR services such as group homes, day programs, and sheltered workshops cannot accommodate most persons with various disabilities since not all persons with disabilities handle group situations well; people with various disabilities often get ejected or sent to psychiatric treatment programs.

Various disabilties are not a mental illness. Interpreting certain behaviors as symptoms of mental illness leads to inappropriate medical interventions.

MH treatment models, involving inpatient stays alternating with periods of relative normal functioning, do not fit the chronic needs of persons with various disabilities.

MH community services tend to be larger residential treatment programs rather than self-determined living and working with supports; day treatment centers or clubhouses are too group oriented and unstructured to work for people with various disabilties.

MH county offices lack understanding of specific disabilities, lack resources to assist people with various disorders and lack programs that are helpful.

MH models deny vital services related to treatment of specific disabilities core deficits and restrict the very services which help ameliorate the behavioral difficulties (i.e., communication and social skill help, life skills training, sensory integration, etc.)

MH providers offer therapies and other services that are governed by managed care models that restrict or terminate services unless improvement is occurring.

OSP sees its constituency as physically disabled only. People with various other disabilities, who are seen as cognitively impaired, are outside its scope.

The OSP service model, self-determination, is excellent, but the exclusion of families as stakeholders is not workable for the many differebt constituencies at present.

Some regional administrative entities are Independent Living agencies who believe their funds are for physically disabled only.

OSP administrative entities lack understanding of various disabilties and lack familiarity with service delivery for those needing around-the-clock services.

OSP providers lack understanding of various disabilities and are used to provide mostly ADL services. Billing system is cumbersome for clients needing around-the-clock services.

Rationale For a Developmental Disabilitites Office to Address Needs

Neurological differences in a person's communicative, sensory, motor and social systems, which affect social interactions, communication, self-direction and executive function, interpretation of sensory input and capacity for living independently. Persons with neurolocial differences can range widely in tested IQ, so low or high IQ is not a relevant measure in determining a need for supports and services. Even persons of sufficient intelligence to attain college degrees can be severely challenged by everyday situations such as a sudden change in schedule or another person's offhand remark, requiring skilled assistance to successfully cope. Persons of high IQ may also have the intellectual knowledge of a subject, but not the executive function to manage their own life and social skills in order to maintain employment within their field of expertise.

Since various disabilties includes persons along the entire IQ spectrum, a place in state government is needed where eligibility is not based on IQ, but on functional need. The federal category of Developmental Disability provides such a framework. Moreover, other persons with developmental disabilities such as cerebral palsy or spina bifida, whose families also have trouble accessing appropriate services in the current MH/MR system, could be accommodated in the DD office as well (if stakeholder concurrence from those disability groups is obtained from DPW).

The need for a cross-disability system in PA has been a topic of discussion for some 20 years, but these discussions have generally not included the many disabilities in the community. Efforts at systems change have not succeeded due to resistance of some existing agencies and constituencies to adopting a new framework. Therefore, weOur proposal does not involve changes to existing systems. Rather we suggest creating a new DD eligibility and service model alongside OMHSAS, OMR, and OSP and letting consumers sort themselves out, over time, among the various agencies.

In PA's MH/MR system, developed before the federal developmental disabilities language, eligibility is based on IQ: a disabled person with an IQ below 70 qualifies as MR. If the person has a higher IQ and has a disability, they must try to qualify for MH. Over many years, persons with various disabilties have navigated this landscape by seeking to test low enough to qualify as MR or, failing that, trying to persuade the MH system to serve them. In recent years, the MH behavioral health system has provided some "wraparound" services and therapies to persons under age 21, though lately eligibility restrictions have limited access.

Consumers and families also attest to the fact that these services are not tailored to persons with spevfic disabilties , which contribute to inefficient use of funds, difficult systems, frustration among consumers due to inappropriate services and a risk for a higher and more costly level of care in institutions and hospitals.

As the default agency in PA, OSP 1's eligibility system screens out everyone who could qualify for MR or MH.

Not only do PA's current systems present eligibility problems for persons with various disabilities, the existing service paradigms do not fit many disorders either.

The mental retardation system assumes a close correlation between IQ and functional deficits, so that anyone with an IQ much over 70 is deemed not disabled enough to need services. An adult with an IQ below 70 has the mental age of a child or adolescent, so MR services have a caregiving/custodial framework. However, a person with a disabity may have an IQ well over 70 and might need supports in order to function successfully, but these supports need to be accommodations and support independence skill building rather than caregiving.

The mental health (now behavioral health) system regards the behaviors of a person with disabilities as symptoms of mental illness for which therapies and medications are prescribed--but with the managed care requirement that improvement must take place. A person with various disabilities may benefit from therapies or medication, but these will not cure the disability or lead to a period of recovery. Indeed, reactions of individuals with various disabilties to some medications can result in a worsening of symptoms.

The Office of Social Programs serves those who cannot be classified as MR or MH. Its main constituency is adults with physical disabilities who are mentally alert---people who can manage their lives and direct their staff, who mainly provide physical assistance with activities of daily living. A person with various other disabilities, in our view, does have a physical disability, but needs assistance with more than the basics of Activities of Daily Living.

Even the most challenged adults with disabilities see themselves as adults and want to be treated and respected as adults. All persons with disabilities deserve respect, particularly adults with disabilities. While adults with various disabilties need assistance, some a great deal of assistance, that assistance needs to take the form of creating a prosthetic environment. The staff members are the wheelchairs, the sign language interpreters, the facilitators. They must maintain the agreed-upon schedule of activities through cues and prompts that are as unobtrusive as possible, so that the adult feels confident--and in charge.

What is a Waiver?

Medicaid Home and Community Based Waivers are an important but limited part of a state's whole planned approach to helping citizens with various sorts of special needs. Waivers are state-federal contracts that "waive" certain requirements of federal Medicaid long- term care funding to provide community-based services as an alternative to institutional care. Many people seem confused about where waivers fit in relation to other services for children and adults, leading to the mistaken expectation that an autism waiver (or waivers) will be a far-reaching solution to getting necessary services for most people with autism. First, unlike EPSDT and IDEA services, waivers are not an entitlement. Second, waiver contracts are always for a specified (limited) number of persons who meet targeting criteria (e.g. mentally retarded). Third, only people who require the level of care provided by an ICF (an institution) can receive waiver services, which is a much stricter eligibility standard than for the IDEA or EPSDT services to which children up to age 21 are entitled.

The distinction between "eligibility" and "entitlement" is extremely important, particularly because that distinction is the reason some subcommittee members believe there should be wholly separate waivers for children and for adults. "Eligibility" means meeting the criteria to receive services. "Mental retardation" is an example of an eligibility requirement. However, being MR is not an entitlement in the MR system. One could be eligible and still be on a waiting list indefinitely if funding is not available for everyone who is eligible, and others have more urgent needs. "Entitlement" means that if you meet the eligibility requirements you must be served promptly and not put on a waiting list. Being a child with a disability is an example of an eligibility criterion that is an entitlement to special education and related services, and to EPSDT.

Subject = Autism Taskforce Subcommittee Report Review - Medicaid Waiver
Name =
State = Pennsylvania
County = CLARION
Country = United States
CountryOther =
Email Address =
How found out = Surfing the Internet
How found out Other Description =
Report being commented on = Medicaid Waiver
Interest category = Family,Provider,Advocate
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 5
Presentation Rating = 8
Overall Rating = 6 Comments: I am a step-parent of a 14 year old boy with Aspergers Syndrome. I am also a Supports Coordinator for my county's MR services. My step-son is high functioning (IQ above 70) and also has mental health issues (depression, ADHD, possible bi-polar, we are still investigating his issues). He has had many MH diagnosis and been on several different psychotropic meds. He has been hospitalized in the local Psychiatric Center 5 times in the past 2 years. He is currently in an Emotional Support classroom with full time TSS support. Although he is receiving probably the best services

available to us, they are not the most appropriate. TSS has a huge turn-over, TSS and BSC are undereducated in this area, local psychiatrists just want him to 'stop it' (behaviors). It took us three years after we got custody to get a diagnosis that describes his problems. There is such a lack of options that we choose the best of the worst. I have been aware of the Autism waiver for quite some time and agree with the medicaid waiver report on Autism services. However, I also found some of the information included in this report about MR services to be inaccurate. MR services are driven by IQ (below 70 before 21st birthday). I do have some young children (4 years, 6 years) on my caseload that have dx of autism but do not have an IQ at this point, they are considered developmentally delayed since they cannot be tested. I know that if they were tested, they would likely test off, but I want to keep their waiver services (PFDS) available to them as long as possible, especially home safety adaptations and respite. (We are lucky in our county to not have a long waiting list). They both have a PUNS of planning for services and neither were ever placed on the waiting list. I am as frustrated as these parents about the services available to our children. It is clear to me that Autism/Aspergers dx are not MR diagnosis, but also not MH diagnosis, either. I am doing my best to provide services to these children until I no longer have a choice. I would be so happy for my husband and I to have some respite time for my step-son. This has really put a strain on our marriage, not to mention being stressful on our other three children (2 are mine, 2 are his from other marriages). From an MR perspective, my point would be that on page 7 of the medicaid waiver report, there are 4 requirements for PFDS/consolidated waiver funding. I would like to address those with how I perform my job: 1. Yes there is an IQ requirement (under 70 before the age of 21). Children who leave EI at three are many times put on MR caseload with developmental delay because they cannot perform an IQ test. 2. Individuals do not need an emergency PUNS to receive services, however, if you live in a county with a large waiting list, emergency PUNS takes precedence over critical and planning. I have put plenty of people in planning on waiver immediatley if I had the slots. 3. In many counties, individuals will be placed on a waiting list, but not every county or every individual. Alot of consideration goes into who to put on waiver funded services. 4. I am sure that political pull is needed at times in some counties. I have absolutely no political pull in my county, but I do what is best for my consumers. This may not be the case in all counties. The requirements you listed were very cut and dry and may be perceived as being this way in every county in PA. Although I will not speak for other counties, I do know that these are often not the case in my county. There are also some other misunderstanding about the services provided by PFDS and consolidated waiver, but I don't have time to address them right now. I will be glad to give any input at a future time. I hope I have made myself clear in stating that we desperately need services for individuals that do not fit into MR or MH services. I am very worried about the future of my step-son. I also am concerned about all of the individuals that I provide services to on my caseload. I wish I had better advice for them when they ask me what to do or where to go.

Subject = Medicaid Waiver Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = I consult for OMHSAS
Report being commented on = Medicaid Waiver
Interest category = Provider
Interest category Other Description = Policy consultant
Draft Report Rating = 7
Nature and Scope Rating = 7
Presentation Rating = 8
Overall Rating = 7 Comments: Please note: Comments that follow pertain to the Autism Report as a whole, since I have reviewed the entire document. The first response offers comments about the Report. The second response, below the first, is a document that I wrote in 2001 at the request of OMHSAS, which pertains to the DIR approach to children with Autism Spectrum Disorders. (UNDISCLOSED)

8/14/04 COMMENTS ON PENNSYLVANIA AUTISM TASK FORCE REPORT

I commend the Task Force on the enormity of effort, as well as the scope, of the Report. I am in agreement that Autism Spectrum Disorders (ASD) requires specialized knowledge and expertise, planning,

research, funding, and oversight. For these reasons, I believe creation of a Bureau of Developmental Disabilities is indicated. I agree that ASD is a lifetime disorder, and that there is need to provide appropriate services and support to individuals with ASD across the life span. The nature of the needs will vary according to many factors, including the age of the individual, the level of functioning and disability, the nature of pre-existing family and community supports, the individual's physical health, and many other individualized factors. Therefore, it is important that potential ASD interventions remain flexible and be based on assessment of each individual's strengths and needs and supported by ongoing monitoring of progress. I believe, along with members of many subcommittees, that efforts to configure BHRS services to meet the needs of children and adolescents (children) with ASD have proved challenging in the past, and that efforts to reconfigure BHRS in the future for this population would likely continue to be problematic. For this reason, I endorse the Report's proposal to create and define new positions for professionals to work with children with ASD, such as the proposed "Autism Specialist" and "Autism Therapist" (Education/Certification Programs Subcommittee" Certification Focus Group," pp. 6-10). There is, however, great need to carefully determine the appropriate qualifications for such individuals. I also strongly endorse efforts to identify infants with ASD early in their first year of life, so that they can benefit from early intervention and their families from education and support.

It is in reference to the appropriate qualifications of ASD Specialists and also ASD Therapists that I propose a broadening of the perspective within the Report. For example, the Report presupposes that the necessary qualifications of an ASD Specialist (or a BSC serving this function) involve training and certification in Applied Behavioral Analysis (ABA). While I appreciate the benefits that may accrue for many children with ASD through use of ABA, there is currently limited acknowledgement of the critical contribution of relational approaches to ASD in the Report. At the most basic level, Autism is a relational disorder. From the child's inability to relate to others in a reciprocal manner and to develop broadly based affective connections, many other consequences follow, including often global difficulty in acquiring a broad range of skills and abilities. The child's developmental process is disrupted by his/her inability to form relationships and by the absence of affective readiness for learning. Without careful assessment of the relational capacity of the child and direct efforts to cultivate that capacity – which includes intensive work with parents and other primary caregivers – children with ASD are at risk of developing isolated, splinter skills without the ability to relate effectively to others, experience a broad range of affect and develop self-regulation, a sense of self, and active problem solving. ABA is often an essential component to a comprehensive intervention program for a child with ASD, as may be Occupational Therapy, Speech and Language Therapy, etc. However, these components work most effectively when subsumed under a broadly based, conceptual and pragmatic framework. I believe that the most appropriate framework involves relational approaches to children with ASD.

Among the various relational approaches, the DIR Approach developed by Stanley Greenspan and Serena Wieder seems especially relevant. I am attaching, with this current document, a summary that I wrote for OMHSAS in 2001, regarding the relevance of DIR to children in Pennsylvania with ASD. From my current perspective, the following are of particular importance:

1. DIR helps organize comprehensive interventions for the child with ASD with a primary focus on the child's relational and affective capacities, which in no way precludes the use of adjunctive approaches in response to other identified needs. ABA, for example, is not uncommonly combined with DIR. In some instances involving children with improving relational abilities, ABA may even be the primary intervention.

2. DIR directly promotes the child's overall capacity to learn – including recognizing and responding to social cues and developing empathy, self-regulation, and problem solving, so that gains in skills are fluid, linked to the child's overall social-emotional development, and likely to generalize and become self-sustaining.

3. DIR involves working directly with parents/family in the home and with caregivers in the child's other settings. Thus, it is caregivers and not just the child who benefit from the interventions. This serves not only to promote the relationships crucial for the child's development, but also increase the sense of mastery and empowerment of the family.

4. It is important to increase choice for parents in Pennsylvania who have children with ASD, and to broaden the array of potential services, so that those interested in learning more about relational

approaches including DIR can do so and gain access to them. Requiring that the ASD Specialist (or BSC) necessarily to have earned "advanced certification in ABA as specified by the Behavior Analyst Certification Board" ("Recommendations of the Education and Certification Subcommittee: Broad Focus," p. 17) would unnecessarily narrow the range of acceptable service options.

It is quite important that staff work directly with family and caregivers and not just with the child. The purpose of services for children with ASD, as with all services for children, should be kept in mind. There is a line of thinking within several Subcommittees of the Report that ASD services should be offered more often by professionals in the absence of family caregivers, and that the current expectation of family participation constitutes a burden for families. While I agree that parents should not be placed in jeopardy of losing their jobs in order for their child to receive services, this latter issue can be addressed without compromising the basic principle that children belong to their families and that services for a child always should promote the caregiving capacity of parents and legal guardians. This idea is embedded in CASSP Principles and is also found in most conceptualizations of effective help giving for children.

Families can be directly involved in learning about and performing interventions with their child without feeling overly stressed by strengthening the child and family team. Through use of the child and family team, parents/guardians can identify a range of individuals – extended family, neighbors, community resource persons, and others – who can become part of the child's team and participate in the child's treatment. In many instances of DIR, parents have recruited volunteers from within the community and a nearby university. By setting up a schedule, the parents can participate intensively in their child's services while at the same time relying on others who are also committed to the child and the family. Older siblings have also taken on this role. As a result, rather than feeling neglected and under-valued, siblings can feel proud of their efforts and value their contribution to their sib\ling and family. Parents who participate in DIR describe satisfaction with how much they are learning about their child and the changes they are seeing.

With regard to BHRS, I believe that there might, in some cases, still be a role for BHRS service providers, although it is possible that these functions could also be subsumed under the role of the new ASP Specialist. For example, those parents in need of support in coping with family or marital stress, or concerned about another child in the family, might benefit from MT. Some children with ASD might benefit from use of psychotropic medication, assuming concurrence of child and family and the absence of coercion. Psychotropic medication may be indicated in the presence of a secondary disorder (e.g. depression, obsessive-compulsive disorder, other anxiety disorder, etc.) known to be medication responsive. Other examples include behaviors that represent a threat to the safety of the child or others. While no medication at present addresses the core deficits of ASD per se, medication can nevertheless be helpful in promoting the child's safety, functioning, and quality of life under carefully identified circumstances.

Finally, there may be special considerations to take into account for some individuals with Asperger's Disorder. Some relatively high functioning children with Asperger's Disorder appear to fare better with traditional services used for children with SED than with primarily behaviorally based interventions for ASD. For these children, relationally based ASD approaches would be helpful, as might traditional psychotherapy and family therapy approaches that maintain a primary focus on relationships and social interaction. This type of potential overlap further supports the need for individualized assessment and treatment planning, as identified in the Task Force Report.

I hope that the foregoing comments are helpful.

UNDISCLOSED, MD

Child and Adolescent Statewide Consultant, OMHSAS

What follows are comments about the DIR approach to Autistic Spectrum Disorders, which I wrote for DPW in 2001. These comments remain relevant today:

UNDISCLOSED,MD

THE DIR APPROACH TO AUTISM SPECTRUM DISORDERS

INTRODUCTION:

The DIR (Developmental, Individual-Difference, Relationship-Based) approach to Autism Spectrum Disorders (ASD) is a functional, developmentally based model developed by Stanley Greenspan and Serena

Wieder that guides both assessment and intervention. Due to its underlying assumptions and the scope of its assessment and interventive efforts, DIR represents a broadly based philosophy for understanding and working with children and their families, the applicability and relevance of which extend beyond just this specific disorder. In what follows, the key components of DIR, which works with infants, toddlers, and preschoolers primarily, are summarized.

DIR is predicated on the assumption that affect and the capacity for positive affective experiences and interactions constitute the primary driver of a child's development, beginning with the development of an ability to attend to others and gradually develop a sense of self, and eventually encompassing the full range of intellectual development. It is through affect that the child is able to engage the world and develop the capacity to interact meaningfully with others. Affective engagement and reciprocal interactions, in turn, serve as the basis for all learning, including intellectual and cognitive learning. While it may be possible for a child with restricted affective and interactive capacity to learn specific splinter skills, these gains are typically limited, since the acquired skills are unlikely to be connected to other acquired learning and be generalized, and the child is not likely to develop the capacity for abstract thinking. In addition, the child with isolated skills will likely remain significantly disconnected from the world, unable to engage in and enjoy reciprocal relationships.

DIR has three component parts in its title. The child, whatever abilities or limitations may be present, is always viewed as a developing person and there is interest a broad range of functions referred to as the child's "core functional developmental capacities." DIR is also focused on individual differences, recognizing that each child is uniquely different in important ways, and these variables need to be identified and understood, for the child's development to be adequately promoted. Finally, DIR is interested in the nature of the child's relationships and interactions with important others, and the reciprocal interactions of these others (primarily adults, and especially parents) with the child, since "interaction patterns between the child and caregivers and family members bring the child's biology into the larger developmental progression and can contribute to the negotiation of the child's functional developmental capacities" (5th Annual International Conference, Interdisciplinary Council on Developmental and Learning Disorders [ICDL], 11/01, conference handout, p. 106).

Recognition of the importance of a child's affective experience and his/her need to develop the capacity for meaningful interaction has broad implications for child development and potential interventive strategies. The applicability of these ideas to ASD becomes apparent when it is appreciated that a core deficit in children with ASD involves the inability to engage in reciprocal interactions with others, presumed to be due to an inability to connect affect or intentionality to motor planning and symbol formation (ICDL, p. 108). If, in fact, the development of affective capacity is a precursor to the gradual development of reciprocal interactive capacity, intentionality, and the early abstraction of a sense of self, with these elements the basis for all learning (emotional and cognitive, among others), then DIR becomes an important mechanism for promoting development in children with ASD.

PARAMETERS OF ASSESSMENT:

Drawing from a broad range of information -- including developmental history and review of the child's current functioning, biomedical assessment, review of family and caregiver functioning, information about the child in current programs and with peers, and consultation with other involved professionals -- DIR directly assesses children to gain information about the child's functional developmental capacities, along three dimensions (ICDL, p. 99-100):

(1) the child's functional emotional developmental level;

(2) the child's individual differences in sensory modulation and processing, and motor planning; and

(3) the child's relationships and interactions.

Assessing the child in this manner is a functionally based process highly dependent on close observation, which "uses the complex interactions between biology and experience to understand behavior" (ICDL, p. 107). Regardless of the presentation or identified concerns involving the child, the authors emphasize the importance of obtaining a full profile of the child, based on an understanding of the specifics of these important dimensions for the child. Each dimension is now considered in greater detail:

(1) Functional emotional developmental level:

The assessment of the child's functional emotional developmental level is based on a normative understanding of a young child's unfolding abilities to develop emotionally. The child is observed, based on chronological age, against this normative standard. The developmental schema begins at age 3 months (Stage 1), and extends to ages 36-48 months (stage 6). These skills are known as the 6 functional developmental capacities. The basic theme of each stage is identified below, along with the expected age of attainment of each emotional developmental capacity (ICDL, pp. 230-232):

- Stage 1 (3 months): Regulation and attention.
- Stage 2 (5 months): Engaging in relationships.
- Stage 3 (9 months): Interacting in a purposeful manner.
- Stage 4 (14-18 months): Organizing chains of interactions, and problem solving.
- Stage 5 (24-30 months): Using ideas -- words or symbols -- to convey intentions and feelings.
- Stage 6 (36-48 months): Creating logical bridges between ideas.

(2) Individual differences in sensory modulation and processing, and motor planning:

Differences in these areas are seen as biologically based, the result a range of possible factors: genetic, prenatal, perinatal, and maturational. The individual differences can be characterized in 4 ways (ICDL, p. 106):

- Sensory modulation, involving possible hypo- and hyper-reactivity in each sensory modality -- touch, sound, smell, vision, and movement in space.
- Sensory processing in each sensory modality, including auditory processing and language and visual-spatial processing. Specific processes include the capacity to register, decode, and comprehend sequences and abstract patterns.
- Sensory-affective processing in each modality -- the ability to process and react to affect, including the capacity to connect "intent" or affect to motor planning and sequencing, language, and symbols.
- Motor planning and sequencing, which includes the capacity to sequence actions, behaviors, and symbols, including symbols in the form of thoughts, words, visual images, and spatial concepts.

(3) Relationships and interactions:

It is through relationships that the child develops a range of capacities, including the ability to achieve developmental levels that have not yet been reached:

- The patterns of interaction of child with caregivers, especially the mother, are carefully observed.
- The underlying assumption is that "developmentally appropriate interactions mobilize the child's intentions and affects and enable the child to broaden his/her range of experience at each level of development and to move from one functional developmental level to the next one" (ICDL, pp. 107-108). Stated differently, the authors contend that children "can only learn to abstract and generalize through active, emotionally meaningful experiences (ICDL, p. 111).

CLASSIFICATION OF SPECIFIC SUBTYPES OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS OF RELATING AND COMMUNICATING:

As a result of the comprehensive assessment of the child (the child's functional developmental evaluation), it becomes possible to formulate a developmental profile for the child, and to place the child within a broad classification scheme. Given the number of independent variables evaluated, it is fortunate that a small group of profiles have emerged, within which a child can be usefully classified. In fact, 4 different types of individuals with ASD, referred to as subtypes of children with "neurodevelopmental disorders of relating and communicating" have been identified (ICDL, p. 113). Some of these types have variations, or subtypes, within them. The classification of children within this typology, interestingly, is not based on the children's level of impairment as based on use of standard diagnostic instruments. Instead, the classification is based on the functional emotional profile of the child, based on the child's degree of progression through the 6 developmental stages, the nature of the child's individual sensory-affective processing, the child's motor planning and sequencing, and the level of response by the child to DIR interventions.

The typology is further described as follows: Children in Type I have the best prognosis, while children in Type 4 have the least degree of progress with intensive intervention, and children in Types II and III show intermediate levels of need and response to intervention. Children in Type 1 and II are able to develop language and use it for communication, although in Type II there is often reliance on familiar phrases rather than fully spontaneous speech. There is very little communicative use of language in Type III, although the child may acquire the use of some phrases. In Type IV, the child develops little or no use of words and symbolic communication (ICDL, pp. 113-118).

THE DIR COMPREHENSIVE FUNCTIONAL INTERVENTION PROGRAM FOR ASD:

The DIR intervention program is individualized to the needs and developmental level of each child, based on the results of the assessment. Underlying intervention is the assumption that, for the child to progress meaningfully in learning and development, he/she needs to be affectively engaged. Therefore, intervention begins at the specific point of functional emotional development that the child has thus far reached. All learning, including cognitive learning and skill development, needs to proceed within the context of affective connections between the child and significant others.

The scope of the comprehensive DIR program:

The DIR intervention program, especially significant for its home program component, is comprehensive in nature and can also be implemented in the school setting. From the broadest perspective, the DIR intervention model includes the following components, individually crafted based on the functional developmental evaluation and the emerging developmental profile of the child (ICDL, pp. 101-104):

- An intensive home program.
- A school program.
- Biomedical interventions, as indicated.
- Specific therapies, as indicated (speech and language therapy, occupational therapy, physical therapy, perceptual motor interventions, and visual spatial interventions).
- Family support, as indicated.

It can be seen that DIR interventions are developed to be used in multiple settings, and that the program draws upon a range of external expertise as needed to fully address the child's developmental needs (e.g. use of biomedical interventions and specific therapies). This is reflective of the comprehensiveness of the DIR approach. This is further reflected in the fact that interventions within the home and school involve not just spontaneous floor time, but also semi-structured learning and activities that promote specific skill development (see below). Thus, characterizations of DIR by those unfamiliar with the model -- as being narrow in scope, involving "just play" without attention to the child's developing a range of skills, and as being unconcerned with promoting academic readiness and academic learning -- are inaccurate. The common link within the DIR umbrella is that all interventions are pursued within the context of affectively based relationships, with the goal of promoting the child's ability to interact in increasingly age appropriate ways with others and being able to learn a range of additional skills through this affectively based process.

Although implemented in different settings, both the home and school program contain 3 common, key elements. Given its importance, the home program is described further below.

The typical home program:

There are 3 components to the home program for ASD (ICDL, pp. 101-102):

- Semi-structured problem solving interactions, which include cognitive, language, social, and emotional skills.
- Motor, sensory, and visual/spatial activities, which include the following elements: sensory integration occupational therapy exercises (such as running, jumping, spinning, and firm tactile pressure); perceptual motor exercises (such as throwing, catching, kicking, and tracking); visual/spatial problem solving (such as hide-and-seek, treasure hunt, and flashlight games); visual/spatial thinking activities; and, when the child is ready, the addition of pre-academic, conceptual, reasoning, and math exercises.
- Floor time -- spontaneous, developmentally appropriate interactions mobilizing the 6 functional developmental capacities.

These 3 components can be addressed separately in the home and, once a child's individualized program is fully developed, often can be addressed simultaneously.

Since it is through floor time that caregivers are best able to promote the child's emotional development and his/her capacity to interact in a reciprocal, affectively based manner, this approach will be further described.

The use of floor time:

Floor time is actually both a philosophy toward promoting a child's development and a practical approach to achieve it. In his book, The Challenging Child, which discusses five "difficult" types of children and not children with ASD, Greenspan operationalizes floor time by stating that the parent "simply joins the child at her level, playing or engaging in the child's chosen activity for about twenty minutes" (p. 66). Although elaborating elsewhere in greater detail, in this book Greenspan indicates that the goal of floor time is "to establish some sense of warmth, and some sense that you're responding with rapport to your child's interests" (p. 69). What is notable is that, in discussing the approach to each type of difficult child (the highly sensitive child, the self-absorbed child, the defiant child, the inattentive child, and the active/aggressive child), Greenspan in each instance advocates the inclusion of floor time. Thus, the use of floor time is not restricted to interventions with children with ASD, but rather is an approach that can be used with a broad range of children, to promote their development.

Floor time in the home is primarily a one-on-one activity between a caregiver and a child, but it can also become a family activity, and siblings can become involved as well. Because floor time is most effective when pursued frequently, the family can develop a network of individuals who engage in floor time with the child, including friends, volunteers, and students. Floor time can also be used in educational settings and as part of other specific therapies, such as occupational therapy and speech therapy.

In The Child With Special Needs, co-authored by Greenspan and Wieder, the authors characterize floor time as "the heart of what we call the developmental approach to therapy," because floor time can enable the child to "climb the ladder of milestones, one rung at a time, to begin to acquire the skills that he is missing" (p. 121). Four goals for floor time are identified, to be approached sequentially in the beginning:

- Encouraging attention and intimacy. This includes helping the child settle and become calm, when needed, and "helping the child tune in to you and enjoy your presence" (as above, p. 125).
- Establishing two-way communication. This involves entering the child's world through play and interaction and creating "a gestural dialogue," in which the child uses affects and emotions, hands, face, and body "to communicate wishes, needs, and intentions" (as above, p. 125). The adult creates a gestural dialogue by purposefully but gently entering the child's activity, as a way to promote interaction.

- Encouraging the expression and use of feelings and ideas. This involves the extension of expression of feelings and intentions through pretend play and dramas.
- Promoting logical thinking for the child. Eventually, the child becomes able to connect thoughts in a logical way, to develop "a logical understanding of the world" (as above, p. 125).

The key to effective floor time in practice lies with the adult, who is expected to set aside an uninterrupted period of 20-30 minutes to fully be with the child -- attentive, supportive, creative, and patient. The technique involves more than merely getting on the floor with the child, and in fact at times parent and child may not be on the floor. The parent needs to follow the child's lead, building on the child's interests and immediate involvement, with the goal of transforming the child's individual actions into reciprocal interactions between parent and child. To achieve this, the parent must be very attentive to what the child is doing and what the child may be communicating non-verbally. Since the goal is to promote interactions and not just passively support the child's solitary activity, the parent at times needs to act as a gentle "provocateur," by doing "whatever it takes to turn (the child's) activity into a two-person interaction" (as above, p. 124). Thus, the parent needs to follow the child's lead in "an active and challenging way" (as above, p. 124). Among the positive effects of floor time are the creation of an interaction between the child, previously withdrawn and self-absorbed, and the parent, and the mobilization of affect as a means to motivate the child to actively enter the larger world.

The authors acknowledge how tempting it is, especially with an older child who is behind in terms of substantive skills and learning, to want to move immediately to cognitive learning rather than relational approaches. They caution, however, that floor time is needed here also, in order to help the child link emotions to behaviors and words "in a purposeful way, instead of learning by rote" (as above, p. 123). Use of floor time over time is seen as helping the child learn to relate to others and the world "more meaningfully, spontaneously, flexibly, and warmly" (as above, p. 123). In so doing, the child gains "a firmer foundation for advanced cognitive skills" (as above, p. 123), which can then be acquired more easily and integrated into a more coherent whole by the child.

Similar temptations may occur for a parent whose child with ASD has serious behavior problems -- the parent may desire to immediately address the behaviors, rather than engage in floor time. However, while acknowledging the need to deal with such behavior in order to keep the child safe, the authors caution to "keep the primary goal in mind" (as above, p. 126) -- the need to mobilize affect, promote the child's capacity for relating, and support the overall developmental process. The rationale for this focus is clearly stated to the parent: "Once the basic skills are in place, you will find it easier to work with problem behavior because you will be dealing with an interactive, communicating child" (as above, p. 126).

For children with ASD, the amount of floor time recommended is quite extensive -- the authors recommend six to ten 20-30 minute floor time sessions per day as "optimal" (as above, p. 129). This is in contrast to the use of floor time with "difficult types of children," whose needs are less extreme than children with ASD. While the recommended investment in floor time is substantial, caregivers are also encouraged to be attentive to the needs of the child at all times. In addition, the interactive activities that constitute floor time are seen as "part of playful interactions where (the child's) interests and initiative are followed and opportunities are created for joyful, soothing, and pleasurable interactions" (ICDL handout, p. 109).

Because it builds on the interests and strengths of the child, promotes positive, rewarding interactions between parents and child, and views development as an ongoing process, DIR is typically experienced by families very positively. Families previously experiencing themselves as out of control gain a framework and set of procedures to guide their efforts. They become hopeful and in fact often celebrate their child's abilities and gains, rather than succumb to the pessimism of a label or a preconceived, inevitable outcome.

OUTCOMES:

Greenspan and Wieder have not yet conducted prospective, controlled studies of DIR in the treatment of ASD. However, information from their chart review of 200 children treated with DIR provides relevant perspectives, even though they acknowledge that their population did not constitute a representative sample of children with ASD (The Child With Special Needs, pp. 449-483). The authors found that

treatment outcomes did not necessarily mirror the severity of children's presentation on entry, as measured by a traditional rating instrument (the Childhood Autism Rating Scale, CARS). Using the development of functional emotional skills and relational capacity as primary criteria of outcome, the authors found that 58% of the 200 treated children achieved "good to outstanding" outcomes. Twenty four percent had "medium" outcomes, while 17% had "ongoing difficulties" with limited outcomes (as above, p. 464). Individuals in the "good to outstanding" group included children who no longer evidenced self-absorption, avoidance, self-stimulation, or perseveration. Also present were the following additional characteristics: "joyful relating"; simple preverbal gestures with a variety of affect cues; purposeful, organized, long problem-solving interactive sequences; and, "most important, in this group, the children's symbolic activity was related to underlying intent and affect, rather than memorized or rote sequences" (p. 463).

When the outcomes of the treated children were compared to the severity of their initial presentation, the findings were quite interesting (as above, pp. 464-465). For example, of the children in the "good to outstanding" outcome group, 20% had presented initially with a significant degree of autistic difficulty, while another 43% had presented with a moderate degree of impairment (e.g. 63% of the children in the best outcome group had initially presented with moderate to severe impairment, on initial evaluation). Within the group with the poorest outcomes, 10% had presented with only mild impairment, while another 20% had presented in the moderate range of impairment (e.g. 30% of the children in the worst outcome group had initially presented with mild to moderate impairment, on initial evaluation). The authors conclude that "the degree of impairment in itself, therefore, is not an overriding factor, although likely an important one" (as above, p. 465).

While a controlled, prospective study with a representative sample is still needed, the authors' retrospectively based data on previously treated children suggests that DIR represents a meaningful intervention approach for children with ASD.

IMPLICATIONS AND CONCLUSIONS:

DIR is a developmentally based philosophy, model, and approach to children with developmental problems or challenging modes of functioning, especially but not limited to children with ASD. DIR appears to be of considerable relevance to children with ASD in the public sector in Pennsylvania, since it is compatible with CASSP Principles in important ways:

- DIR is developmentally based, consistent with the child centered principle.
- DIR is highly individualized and strengths based, also consistent with the child centered principle.
- DIR is based on family participation and empowerment -- in fact, the most critical interventions occur directly between the parents and the child -- consistent with the family focused principle. In addition, parents help organize and direct the implementation of DIR in other settings and help ensure that there is integration across settings.
- DIR is multi-system, in that, when implemented comprehensively, there is linkage to multiple settings of the child and applicability to adjunctive therapeutic approaches used.
- By drawing on the capacity of parents to implement floor time and other program components as described, DIR is intrusive to only a limited degree, in terms of the overall intensity of service providers and professionals.

By virtue of its overarching philosophy, approach to assessment, and model of implementation, DIR appears to be an important method of intervention for children with ASD. It is concluded that DIR is deserving of greater familiarity and understanding, on the part of parents, providers, and behavioral health managed care organizations within the Commonwealth.

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Greenspan, S. and Wieder, S.: The Child with Special Needs: Encouraging Intellectual and Emotional Growth, Reading, Massachusetts: Perseus Books, 1998.

Greenspan, S.: The Challenging Child: Understanding, Raising, and Enjoying the Five "Difficult" Types of Children, Reading, Massachusetts, Addison-Wesley, 1995.

Greenspan, S. and Wieder, S.: The 5th Annual International Conference of the Interdisciplinary Council on Developmental and Learning Disorders: Autism and Disorder of Relating and Communicating, handout booklet, November 2001.

Pa/Policy/DIR-ASD
11/24/01

Early Intervention

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
Country Other =
Email Address =
How found out = Surfing the net
How found out
Other Description =
Report being commented on = Early Intervention
Interest category = Family, Provider, Advocate
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 10
Overall Rating = 10
Comments:

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = LEBANON
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = I am a child psychiatry consultant to OMHSAS
Report being commented on = Early Intervention
Interest category = Medical Professional
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating = 9
Comments:

This and the other draft reports clearly reflect admirable and productive effort by many caring and knowledgable contributors, and should become the basis and impetus for meaningful changes and innovations.

My chief concern is the absence throughout the reports of a consensus definition of autism. Perhaps this emanates from the reality that we do not know the etiology of autism, and the Research report thoroughly presents the state of the art in autism research. Nevertheless, the general lack of consensus regarding the fundamental nature of autism is reflected especially in those portions of reports referring to "treatment" approaches. For example, is autism a medical condition? A complex learning disorder falling under the domain of educational approaches? A behavioral problem amenable to ABA? A mental health diagnosis? In the 5-12 report autism is referred to as "a life-long, incurable biological disorder." This feels like the biological reductionism from which we are struggling to emerge. In fact, not infrequently children with autism, especially when treated early, intensely and appropriately, later no longer meet the diagnostic criteria for autism.

Another troubling attitude expressed obliquely in many reports but overtly in the report on Adolescence, is that autism "is not a mental health disorder." This categorical statement is unfortunately congruent with a bias against psychotherapeutic interventions reflected in the Research report, which urges further

research in the areas of "behavioral, educational, pharmacological and biomedical" treatments. Further, "In the longer term the goal is to achieve biological treatments."

Regarding treatments, the reports urge that "all research-proven methods should be available [to children with autism.]" This would seem to exclude treatments such as Greenspan's floortime, demonstrably of great value when applied by skilled clinicians, but not yet canonized with the imprimatur of "evidence-based medicine." We are far too early in our understanding of the nature and treatment of autism to be confining the size of our "toolbox" for treating it.

Children, adolescents and adults with autism are persons first and always; not ultimately behaviors, social skills, neural circuits, or verbal skills, but persons. And they have minds, however inchoate or disorganized. And our ultimate focus must be on their mental development. I believe these realities must somehow be more amply reflected in these reports.

But in closing let me once again thank and praise all of those who organized and executed this daunting challenge. It constitutes a great start on what must prove to be a successful effort!

Subject = Early Intervention
Name = Delaware County Dept of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Early Intervention
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 5
Presentation Rating = 5
Overall Rating = 5
Comments:

The Delaware County Department of Human Services gives this report a 5 for an average rating because it obviously reflects the frustration felt by the participants at trying to have their specific needs met by existing service systems which were not designed to deal with many children with autism. It is not possible for us to give it a higher rating due to some serious inaccuracies in the report which seem to reflect a lack of understanding of the systems that do exist.

Throughout the report, comments are made that seem to lump the" birth to three" and "three to five" systems together even though it is acknowledged that the" birth to three"falls under the jurisdiction of County Offices of Mental Retardation. Our responses are based on the reality of the birth to three program. It is hoped that the Education Profession is also studying these reports and making responses.

The most glaring inaccuracy is on page one of the report where it discusses the Federal mandate for Early Intervention and misrepresents the pertinent sections. In actuality, Part C covers birth to three and Part B covers age three to school beginner.

Early Intervention is referred to as a medical model pm Pages 1 and 3. This is not true even though the pediatrician is often involved in diagnosis and, at times, treatment recommendations. The "birth to three" is a family centered, behaviorally based, developmental model based upon Federal requirements.

The report refers repeatedly to lack of consistency among the various counties and jurisdictions in the State. (pages 3,5,6,78,&10) The Office of Mental Retardation E.I. program has statewide regulations to assure consistency of application with Federal intent. The County programs are monitored by the Regional

Offices of Mental retardation to maintain compliance. Children are able to transfer from one county to another and maintain their service plan. It will always be true that providers of service will vary from one part of the State to another.

Even though County programs are still commonly referred to MH/MR, Office of Behavioral Health and Mental Retardation operate under very different State and Federal policies and procedures. It is understandable that these distinctions would not be clear to the task force. An example is on page 5, referring to "FSS funds through Mental Health". In fact, FSS (Family Support Services) are funded through the Offices of Mental Retardation for persons who do not receive waiver funding. These are very valuable, but non-mandated, services with long waiting lists and decreasing funding. Each county does have the right to establish somewhat different procedures for implementation in compliance with State guidelines.

Throughout this subcommittee report are comments that reflect the desire of families of children with autism to have their own service system that cuts across existing service boundaries. It is true that existing programs cannot fully meet the needs of young children who appear to have autism. The Federal IDEA of 1997 is geared to children with a variety of disabilities. While the "birth to three" services are not limited to children with retardation; it is true that it is limited to developmental delay. For some children with autism with average or above cognitive ability, there might not be a significant enough delay during the early years to give them eligibility. There is currently no existing, mandated, funded service for young children except IDEA and the subcommittee is accurate in pointing out that this creates gaps at a crucial stage of development.

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Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Early Intervention
Interest category = , Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 7
Presentation Rating = 7
Overall Rating = 7
Comments :

One additional comment: I am concerned how county clinics will be funded and staffed.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Early Intervention
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10
Comments: This is for the Screening, Diagnosis, Referral and intervention report.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email

Report being commented on = Early Intervention
Interest category =
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 7
Presentation Rating = 7
Overall Rating = 7
Comments:

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = CAMBRIA
Country = United States
CountryOther =
Email Address =
How found out = Surfing the net
How found out Other Description =
Report being commented on = Early Intervention
Interest category = Family
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 7
Presentation Rating = 8
Overall Rating = 7
Comments:

I am frustrated by the lack info out there. It took us forever to find a support group in our area and when we finally did we were amazed to find out how small the turn out. We were also amazed to find out that out of the 9 families present 5 represented a 5 block radius around our home (past or current residence)

We feel that we are currently at the whim of the providers of wrap around. TSS changes can be made without consulting us by people who claim to have the best interest of our child. Often the changes seem to come from staffing or provider need rather than the need of the affect on the child.

I was disheartend to see the lack of representation on your commitees of small city parents or providers. Places like Johnstown who are just on the outskirts of major cities, i.e. Pgh or Phila seem to get the leftover services unless we want to travel the 80-100 miles to get help.

I was happy to see that you are considering the needs of the families particularly with respit and childcare services. I am the grandmother of a very special boy, but my heart breaks for my daughter when I see her trying to find a few stolen moments to nuture a new marriage and also provide her son with his needs. As a hair dresser my daughter receives $6.15 an hour + tips and commisions she pays $5 per hour for after school childcare for the days she works. Both her and her new husband are trying make up for the SSI lost because of their marriage while they eek out a living, provide her son with his needs and build their family. They are especially learning to dread those 3 pay months, because it can mean there will be no SSI at all, even though the weekly bills remain the same. She is lucky she has a very supportive extended family, but there is only so much working grandparents or a 75 year great grandmother can do to help. We need tax credits for childcare, a homeowners insurance legislation that won't drop you because you have a trampoline or a pool in your back yard as a theraputic means to let out all that extra energy and maybe just maybe help to get a good night's sleep. What does the person do who rents? (saving for a down payment for your own house seems to be the last place money can go) Private landlords frown on alarms or special locks on doors and windows. It's also a shame that you have to determine your place of residency by the school district who will be the most cooperative in meeting the needs of your autistic child. We applaud the current efforts, but when you need services now, it's so hard to wait for the wheels of democracy to turn. We continue to support your efforts and look forward to your progression.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = I was a member of the task force
Report being commented on = Early Intervention
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 4
Nature and Scope Rating = 4
Presentation Rating = 4
Overall Rating = 4
Comments:

I have two main points that could be part of all the reports. 1. Support services to families dealing with autism should be services available to all families. Funding should be included for this, support is as critical as education and other interventions. Without these services, the entire family is at risk. Out of home placements would be much less likely.

2. The system must see individuals with autism and their unique needs as a separate group and not make the services fit into the catagory of mental health services. The criteria and types of services are quite different.

Subject = Early Intervention
Name =
State = PENNSYLVANIA County = WARREN
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = I am on the Rural committee
Report being commented on = Early Intervention
Interest category = Primary/Secondary Educator
Interest category Other Description = Currently taking Applied Behavior Analysis
Draft Report Rating = 8
Nature and Scope Rating = 9
Presentation Rating = 6
Overall Rating =
Comments:

The report is very comprehensive. I only want to mention that we should not be looking for a specific cookie cutter approach. We must consider sound and valid approaches that are available, and then tailor our approach to the child. Applied Behavior Analysis is not a specific approach that can be used equally on any one person, rather it is the approach that focuses on the individual while considering all aspects of the environment. ABA also leaves the door open to try any intervention that may affect antecedants or consequences in the manner that would best allow the person to have better qualify in their life.

Subject = Early Intervention
Name =
State = SOUTH DAKOTA
County = CLARION
Country = United States

CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = at The Penn State Autism Conference
Report being commented on = Early Intervention
Interest category = Family
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 7
Overall Rating = 8
Comments:

As a parent of a child with Autism, I look back and see how much time was lost in my son's early years. I agree with the report that many of the early intervention agencies like Infant Stim and even physician's offices do not have the knowledge to recognize the early signs of Autism. With this disorder, it would be better to error in a diagnosis and treat a child with intensive intervention than to "wait and see". Many of the interventions that are successful for children with autism are successful with all children. Additionally, Intervention should be as early and as intensive as possible but there are few programs available during the summer in our rural area. How can that be intensive?

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = e-mail
Report being commented on = Early Intervention
Interest category = Family
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 10
Overall Rating = 9 Comments :

I would like to see Assistive Technology (AT) mentioned. AT should be considered as early as possible as an intervention, including communication devices and systems, adapted toys, etc.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = LUZERNE
Country = United States
CountryOther =
Email Address =
How found out = Provider
How found out Other Description =
Report being commented on = Early Intervention
Interest category =
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10

Overall Rating = 10
Comments:

State of the Art Blueprint. Very well done Read all the reports and feel the same about all of them

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = LAWRENCE
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = work at MH/MR office
Report being commented on = Early Intervention
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10
Comments:

I feel the identified barriers and concerns listed in the report are accurate and the identified problems between the two systems in E.I. has long been a problem. Even with good transition planning the focus of each program is different making the transition for the child and the family difficult and even more so with a child with autism. The 2 system E.I. program needs to become 1 in order to provide the seamless system all families should have access to. The report deals with this issue in detail and I feel this is a positive direction the sudcommittee is heading towards.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Early Intervention
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating = 8
Comments:

Provider Perspective Perhaps there should be wraparound agencies that specialize in serving the young child. There would need to be different training requirements including a heavy emphasis on typical development, the development of communication and basic motor development. Although issues concerning behavior management should still be a significant part of the training, the developmental training would take front row. The problem with many wraparound agencies taking the occasional 18 month old or 2 year old is that the intervention must be designed with the developmental needs of the very young child in mind. Those issues are not the ones normally required as background or training for wraparound staff. It may be unrealistic to assume that wraparound providers are trained to serve all

children with ASD at any age. Maybe specialized programs, some serving the young child, some serving school aged children and some serving teens would be more appropriate. Then the agencies can really become proficient in their targeted population.
Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = BERKS
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = ASA Berks County
Report being commented on = Early Intervention
Interest category = Family
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 10
Comments:

The IU must go above and beyond to provide parents with a comprehensive list of services available to kids on the autistic spectrum--brochure, pamphlet, etc.

A list of all available tests available through the IU for kids on the spectrum should also be provided. It's imperative that the First Signs Program be implemented asap.

The IU should provide PROPER training AND certification for those on their staff to administer certain testing--OT, ST, ADOS, etc.

The IU/state needs to look into providing MORE services to those children who are high-functioning, Asperger's, Residual Autism, etc.

The IU needs to provide training at the most basic level--training for Service Consultants. These employees are the intermediaries and need to know how to be able to communicate effectively between parent and IU.

Great job to all those involved in these reports! Thanks!

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = DAUPHIN
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = PDE/BSE staff
Report being commented on = Early Intervention
Interest category = Government Agency Official/Staffer
Interest category Other Description = Government Agency Staffer
Draft Report Rating = 4
Nature and Scope Rating = 3
Presentation Rating = 5
Overall Rating = 4
Comments:

There are several glaring errors in this draft report as follows:

I. B second paragraph, you have confused Part B and C. Children identified birth to 3 are under Part C not Part B as stated in this report. It is consistently incorrect in this paragraph

II. Referral second paragraph, there is a category for Autism in the Part B preschool Penn Data. The statement that "unfortunately, transitions are not coordinated", is not correct. There is a well spelled out system of transition from Part C to Part B preschool. Both County MH/MR and the education agencies are required by law to conduct joint meetings to prepare parents and children for the transition. In addition, there are Local Interagency Agreements in place to ensure that transition is effective and smooth.

In the same paragraph the wording implies that because the 3-5 system uses education driven interventions that is somehow not good. In fact, IDEA Part B requires that education agencies address educational needs specifically. According to the law, the duty is owed to the child and not the parent beginning at age 3.

A. Family

1. General group consensus

2nd paragraph again states incorrectly that services available to families 0-3 are based on FAPE. Only children ages 3-21 are required to have FAPE. There are no variations to FAPE no matter where the child is served in an education agency 3-21. In the same paragraph, the last couple of lines state that no matter what the IEP says, a school district will place a child in an Autism classroom if they have one and that a cookie cutter approach is used for the diagnosis. Nothing is further from the truth, especially in the 3-5 programs. Children have IEPs that are based on their specfic needs and there are many options within each MAWA agency to serve children with Autism ranging from inclusive placements with supports to intensive ABA programs which include both classroom and homebased services in addition to related services such as speech, OT and PT. The statement as written is misleading and inflammatory and does not foster cooperation and coordination.

III.What are the problems with existing practices

A. Family perspec....

1. Intervention 2nd paragraph, states incorrectly that age of beginners is 7. Age of beginners is 6 or age when a child can be admitted to the school district kindergarten.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Early Intervention
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating =
Nature and Scope Rating =
Presentation Rating =

Overall Rating =
Comments:

I didn't get past the first paragraph. Due to the errors found there, I lost faith in the rest of the report. Part C is the birth to 3 portion of IDEA and Part B is 3 to age of beginner. You have it the other way around. Part C(you incorrectly note Part B) is not a medical model, it is a parent teaching model that provides supports/services in settings where children typically play and learn. The goal is to help families incorporate stategies into their daily routines that encourage and promote their child's development.

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = BUCKS
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Early Intervention
Interest category = Advocate
Interest category Other Description =
Comments:

I do not see issues in Early Intervention that are unique to Autism and not developmental delay/disability in general, regardless of the eventual label or lack there of. Children who have behavioral needs, developmental delays, sensory issues and are in need of supports to meet those needs face the same challenges whether they have a diagnosis of autism, are undiagnosed, or have a variety of other causes that create their needs.

Screening (Not unique to autism)

- The "wait and see" is common practice for any child, and the "red flags" are not seen for a variety of disabilities and needs.
- Waiting lists for evaluations are long regardless of the cause for a child's delays.
- There is a shortage of trained to professionals to disagnose many types of disabilities.
- Intervention is generally not specific to many disability types.
- All children with various disabilities do not qualify for services when they have better academics and functioning.

Diagnosis (Not unique to Autism)

For many families with children with a variety of diagnosises or who are undiagnosed there are no supports, or no no supports for a at the time of diagnosis, which many consider to be the most crucial time when support is needed. Parents may feel guilty and may be grieving or in mourning regarding what they expected their child's life to be like. They may be in denial and may not know how to effectively deal with their child because of their own lack of knowledge about thier child's disability, needs and abilities

- The person who evaluates and makes a diagnosis for a variety of types of disabilities may not be verse in information and resources available to parents.
- Diagnosticians may be lacking current information for recommendatin of intervenation and plan of care for a variety of disabilty types and needs.
- It is important for pediatricians to refer parents rather then prescribe a particluar service or stratefy based ona label for any child
- Professionals may reccomend services hard to obtain, unavilable or inappropriate to meet the needs of the child or family fro any child with any disability.

Referal (Not unique to Autism)

- There is no information system, or database method for tracking referrals. Currently, there is no system to coordinate screening, diagnosis and treatment, with no tracking system to monitor progress for a variety of disabilities.
- There is a lack of consistency in a system that should be statewide and a shared responsibility. There is no uniformity for referral or the services recommended. Rules are different for different services and vary by region and county, for all disabilties.
- Services that family may be referred to as appropriate may not meet the needs of the family. The family may not be able to accept the services because of required intensity in certain settings that could cause hardship by forcing a family member to quit a job or hire in-home help in order to access services.

Intervention: (Not unique to Autism)

- Any child, birth to three years, or three to the age of beginners can participate in Early Intervention if they have met the criteria for a delay or have a diagnosis (autism or other). The child then transitions to the school district at kindergarten or at the age of beginners until the age of 21 (IDEA). Higher functioning children with autism or Aspergers Syndrome (And a variety of other disabilities) may not be identified as having a delay or disability, and may not qualify for services. These children with high-functioning still have the need for intervention for their disability, many specifically in the area of social skill and pragmatic language development. These services are currently available mostly at the private pay level. Many in the educational establishment will argue that social skill development is not required under IDEA. Even if they agree that these services should be covered, there is a lack of professionals capable of carrying out this intervention.
- There is no one method of intervention used or recommended across the state of Pennsylvania. The various systems often may not communicate with each other and due to differing Rules and Regulations may often work against each other. Funding systems and regulations differ across early intervention, school age and mental health systems. Mental Health service providers often do not know early childhood development and this lack of knowledge impedes providing adequate services to children with various disabilities and their families. At times in an disability specific support classes there may be more adults than children competing for space and providing treatment that is not coordinated.
- The birth to 3 years Infant/Toddler Early Intervention is funded by The Department of Public Welfare through each county Mental Retardation System. The Infant/Toddler EI focus is family driven with a lack of intensity for the child and becomes more educational causing the focus to change from family to child. This causes difficulty in transitioning from one system to the next. As the child transitions to Kindergarten/age of beginners, more difficulty can develop as each school district, county and region differs as to the types of interventions used for children with a variety of disabilities. Similarly, Mental Health services "Wraparound" provided across the state varies from provider to provider with various methods of intervention.
- Accessing educational services is equally difficult for all families of children with disabilities. and varies considerally accross considerably across counties, IUs, school districts and private schools. The programs that are available in each district vary in the level and quality of support as well as the staff's knowledge of a variety of disabilities. While these 'services' are an entitlement and are mandated by law, often times it is difficult to find and receive an appropriate education for children with disabilities in general.
- Children are placed in programming but it is usually the parents involvement that helps the development of a program and placement that will allow for meaningful progress to take place. The IEP establishes the goals and objectives and should drive an appropriate program and placement for the child. In some cases, the School District does have an autism support classroom in place. So, no matter what the functioning of the child or what the IEP supports, the placement for every child with a similar disability or category of disability in that District calls for the same placement. This cookie cutter approach is problematic for kids who, despite having the same diagnosis, have very different strengths, needs, and abilities.
- A child is eligible to receive Medical Assistance with a diagnosis of autism/developmental delay. Medical Assistance provides services through wraparound and will pay for other related services through outside facilities, such as Easter Seals or a Rehabilitation Hospital. Again, just as

education, the Medical Assistance and Behavioral/Mental Health Services are entitlements to a child with autism. Parents can experience great difficulty in applying for and accessing these services.

- Steps must parents take to get Medical Assistance for their child with a disability? They must file for the ACCESS Card through the County Assistance office. A form is to be filled out and a process must be followed in order to be approved for the ACCESS Card. This process varies not only across the state, and across counties, but also from one individual to the next when calling for information. Once the Card has been obtained, the parent may go through a BASE SERVICE UNIT that will coordinate an assessment for the diagnosis and determination of hours, or the parent may be able to go directly to the provider. This also varies from county to county.
- There are other available funds such as FFS funds through Mental Health, and funds for Mental Retardation (MR) diagnosis. A child with a dual diagnosis of any disability and MR is entitled to greater funds for materials, respite care and other support. ALthough it tends to only be a few hundred dollars and are difficult to obtain. FFS funds are supportive funds to augment services that are in place. Both of these funding streams are not really well known and understood. There are no publications readily available to explain these funds or describe methods to access them. We were unable to obtain written criteria that explain how the money is determined or how it is distributed to families.

Other views expressed (Not unique to autism)

Wraparound looks different depending on where you are in the state (in some areas of the state Wraparound Services include in home ABA services, yet in some areas of the state Wraparound services includes a TSS as a shadow for the child in a specialized program, etc. to address the behavioral health plan. Inadequate/appropriate training for staff that interact with children with disabilities including training on early childhood development. Lack of options of interventions- at the mercy of what provider wants to utilize; no clarity or regs/recommendations from DPW or PDE Multiplicity of where services take place EI, IU and Wraparound systems do not communicate with each other or work together. MH/MR not qualified to deal with a variety of disabilities Some services cannot be given at required intensity in certain settings Limited communication between the clinical and educational systems Rules are different for different services and vary by region and county Lack of current and comprehensive information for parents Need to define types of interventions, who provide and who pays Often an exclusion or not comprehensively covered under private/third party insurers Often considered mental health issue 'Hot Potato' between the education system and behavioral health system.

Other views expressed (not unique to Autism)

Parents should have the option to hire their wraparound staff aids directly Not enough attention given to parents' need for respite Quarterly re-evaluations for services are an unnecessary burden for families, many disabilites doesn't go away Looking at alternative treatments such as a biomedical approach as a part of the equation for a child with various disabilities Treatments usually are not intensive or data driven to guide programming and report progress

What are potential solutions to improve existing practices? Family perspective (How could barriers to existing services be eliminated? What additional services should be provided?)

General group consensus (not unique to autism)

Single point of entry into system

Need for 'newly diagnosed' packet (STATEWIDE) Caseworker to help navigate systems with bilingual ability One form to access system Combining welfare, education, behavioral health, school systems Need for plan of care vs. IEP or treatment plan? Continuous progress monitoring Tailored to family needs Comprehensive, intensive, flexible Data driven, research based Parent support/grief counseling Options to choose between home/center-based settings

Other views expressed - none

Provider perspective (What changes would improve the ability to provide high-quality services in a timely manner?)

General group consensus

Widespread training/technical assistance across all entities County team for case management from diagnosis Collaboration between welfare, education, behavioral health, school systems Statewide physician training Single point of entry Agencies to network Continuous progress monitoring Data driven, research/evidence based such as with ABA Not one size fits all approach; Individualized Research needed on best practices

Other views expressed - none

Administrative perspective (How could the organization of and payment for services be improved? How could coordination among different systems be improved?) General group consensus

Statewide physician training such as First Signs through the medical home project Alliances with American Academy of Pediatrics and County medical societies Combine birth to school age children systems (seamless system from diagnosis to age of beginners) Single point of entry into system Caseworker to help support program Combine welfare, education, behavioral health, and school systems Autism Caucus to educate policy makers House funding and information in one area such as PA Dept of Disabilities.

Other views expressed - none

Subject = Early Intervention
Name =
State = PENNSYLVANIA
County = CUMBERLAND
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = Autism Society of HGB
Report being commented on = Early Intervention
Interest category = Family
Interest category Other Description =
Comments:

Listening therapy should be part of all programs. We saw the greatest improvement since the IU started the listening program.

Needs of Children

Subject = Needs of Children, Ages 5-12
Name = Delaware County Department of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 9
Presentation Rating = 9
Overall Rating = 9
Comments:

The Delaware County Department of Human Services gave this subcommittee a 9 because it does seem to accurately reflect the current status of service needs for this age group. Most concerns expressed deal with the education system which is appropriate, given that this is the major program involved in any child's life.

The task force does exhibit a grasp of the FSS program as it applies to those families with children who meet criteria for registration in the Mental Retardation system. The Family Support Services do vary among counties depending on overall priorities for funds and the particular County standards for eligibility for FSS. This task force is commended for their understanding that rather than trying to change the criteria for using the Mental Retardation system, the Autism community needs to have some services for their constituents who are not retarded.

On page 11- 4th paragraph asks that there be a provision that a wraparound provider cannot retaliate against a complainant by dropping service. This concern might best be handled with each county's Managed Care Organization. In the handbook of the Delaware County/Magellan Health Choices program, one of the rights of the member is to "Make a complaint or file a grievance without getting a penalty." If this provision is violated, we would deal with it as a serious problem.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = BUTLER
Country = United States
CountryOther =
Email Address = Not Available
How found out = Surfing the net
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family
Interest category Other Description =
Draft Report Rating = 5
Nature and Scope Rating = 3
Presentation Rating = 3
Overall Rating = 3 Comments: As a member of the committee, much important information was deleted from the final draft of the report. My main concern regards the needs of homeschoolers. We have children who fit a very common profile. Their skills are very scattered and their abilities range from very high to very low in various areas. We feel that school districts cannot appropriately meet our childrens' needs in a traditional classroom setting without extreme individualization.

We have also pulled our children out after they have been targets of serious bullying. Our children are natural targets due to their disabilities. Bullying over a long period of time has been connected to post traumatic stress syndrome and we have seen symptoms of stress in our children. School districts often either have no anti-bullying curricula, inadequate curricula, poorly enforced policies, or a combination of the above. We pull our children out for their physical and emotional safety needs.

There is a great lack of support from school districts. We homeschooling parents have to set up our childrens' curriculum, assess their skill levels, determine how to motivate them, figure out how to deal with difficult behaviors, attempt to create appropriate social opportunities for them, try to plan their futures for them, plus many more roles. We are basically performing the function of an entire support staff for our children. Often, we do not have degrees in education and we are hard pressed to create an appropriate curriculum and therapeutic interventions based on best practices. We cannot seek employment outside the home because we are preoccupied with these multiple full-time tasks. However, we expend a lot of money for school supplies, books, field trips, transportation, etc.

Additionally, it is a fight to receive related services such as speech therapy and occupational therapy from the school districts, although the regulations say that we parents need to have a meeting with the school, determine the child's needs, and when agreed upon, set up the requisite therapies. It is very difficult to get the school district to do this.

State homeschooling regulations were not set up with the needs of students and families with Autism Spectrum Disorders. We spend a great deal of time in meetings, taking our children to various appointments and trying to research the best therapies and social opportunities for our children. Sometimes we are hard pressed to fit in 180 days or 900 hours of schooling for our children. Our children are dealing with so much turmoil from their ASD's that sometimes they tire quickly and cannot complete a lesson. We need the timing requirement changed to include more flexibility for our children.

This is just a sampling of problems for those who homeschool their autistic children. Please consider these points in your determination of what to do with the needs of autistic children.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 8 Comments: Strongly agree with recommendation that regular education teachers and admin need training.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = e-mail
Report being commented on = Needs of Children, Ages 5-12

Interest category = Family
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 8
Presentation Rating = 9
Overall Rating = 9 Comments: I would like to see Assistive Technology (AT) devices and services considered for this age group. Many individuals on the autism spectrum have difficulty with reading and writing and keeping schedules. AT, whether low-tech or high-tech, should be considered whenever possible.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = MONTGOMERY
Country = United States
CountryOther =
Email Address =
How found out = Friend
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family, Advocate
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 9
Presentation Rating = 10
Overall Rating = 10 Comments: I am very happy to see that the needs of children with ASD and their families is being addressed. My family has been traumatized by my six year old ASD child. We have had to fight every step of the way to find out what services are available and how to get them. We have had an extremely difficult time retaining good people to help us. My non ASD children have had to seek psychological help as did my wife and myself. This has cost a fortune and taken an enormous emotional toll. We struggle every day to maintain as normal an existence as we can. Hopefully someone will listen to these recommendations and help families like mine to ease the pain and struggle. families dealing with ASD need help. This report correctly identifies many of the problems we face. I only hope and pray that someone cares.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 10
Overall Rating = 9 Comments: Regarding discharge criteria from Wraparound services… The phases of treatment (see below for Pressley Ridge / Center for Autism’s general phases of treatment) were mentioned later in the report, but they are helpful to use as a way of establishing discharge criteria. Discharge criteria can be met when the child/family/provider have completed phase three. There is nothing about "cure" imbedded in the discharge criteria, or "age-appropriate". It simply looks for the child’s skills and the community’s/family’s skills to be in sync. A child can be discharged when they are adequately/skillfully supported by school, home and community.

Phase 1 Intensive 1:1 services

Focus: Promoting early socialization and developmental growth

Targets:

- Self-regulation
- Social relatedness
- Social referencing with adults
- Ability to learn from environment
- Functional communication
- Repertoire of interests
- Idiosyncratic/stereotypical behavior

Phase 2 Working with child in social settings

Focus: Promoting generalization of skills in multiple environments with a variety of social partners

Targets:

- Repertoire of appropriate play skills
- Social referencing with peers
- Flexibility
- Recognizing/respecting social norms
- Friendship skills
- Compliance with social expectations in multiple environments

Phase 3 Getting ready for discharge

Focus: Helping the family and community support the child's needs without outside assistance

Targets:

- Making sure the family feels accomplished in supporting the child in multiple environments
- Making sure the child is supported in school through natural supports
- Making sure the child is supported in the community through natural supports
- Assisting the family in long term management of the child's needs

There are some children (according to the literature this is between17-20%) who respond only partly to intensive services (Phases 1 and 2). They continue to have very significant challenges in all areas of life. These children may be ready for discharge from the provider that did intensive early intervention in the home but not altogether from wraparound. They may need ongoing intervention just to maintain functioning. Phase 3, for these children, is not realistic and therefore the discharge guidelines are void. Yet for the majority of children, the goal of wraparound should be to help the community, school and family get ready to support this child. This may take intensive teaching of the child as well as good modeling and training of other caregivers.

Need for Specialized Services… To address many of the concerns highlighted in this report, it might be advisable to divide wraparound agencies up into specialized units, or specialized programs within each agency. These specialized programs could work with the young child (birth to 6, perhaps), the school-aged child (5-12, perhaps), and the teenagers. There might also be a program that specializes in the treatment of Aspergers individuals, or only those with Autistic Disorder. The staff of these programs could, then, be trained in issues particularly relevant to the age or diagnosis of the child and family they serve. By limiting the scope of what services an agency provides, you can more realistically expect real expertise.

Subject = Needs of Children, Ages 5-12
Name =

State = PENNSYLVANIA
County = BERKS
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = ASA Berks County
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family
Interest category Other Description =
Draft Report Rating = 7
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 10 Comments: More services and programs need to be set in place for higher-functioning kids on the spectrum.

All services provided to children on the spectrum can't solely rely on teacher/IU/government input--parent input is just as important.

Great job to all those involved in these reports! Thanks!

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = TIOGA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = Parent of my client
Report being commented on = Needs of Children, Ages 5-12
Interest category = Provider, Advocate
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 9 Comments: I work in an educational setting with an Autistic child as a T.S.S.S. Current issues we are facing include maintaining funding to continue long-term intensive intervention. The state has repeatedly denied funding to continue these services.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = MONTGOMERY
Country = United States
CountryOther =
Email Address =
How found out = Surfing the net
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: This draft includes pressing needs regarding children 5-12. I have a son with HFA and almost everything in the report pertains to us. Thank you!

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = TIOGA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = State Representative
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: My autistic son, M., who is 9, has received excellent wraparound services, plus speech and OT, for 5 years. We are in legal proceedings with medical assistance that say our request for 40 hours of TSS is no longer medically necessary, especially since he is 9 years old. One of their comments to us is to "harvest our local resources." Our school districts are moving forward, but have limited funds and personnel, and incentives, to develop programs to meet the unique and varied needs of these children. The amount of time and emotional energy required to be a sqeaky-wheel, but pro-active parent, is immense. There is so much to do, and often we feel as if there are few willing or able to help us make school and community programs successful, and help the community realize they have to do things differently in caring and raising autistic kids. Battling the system makes a tough job that much harder. My son M. is worth it, as is every other child living in our community, but we can't do this alone.

Could this report include any research and comments on the lives of families of these kids? We have 3 children in our family. The quality of these services affects not only my autistic son, but his 2 typical siblings as well. The system must recognize the human side of this--that this is not just a disorder, but a person with a disorder, a person with unique needs that should be treated with understanding, dignity and respect. An autistic person usually has a family that must cope with a puzzling set of behaviors and needs. If we meet those needs appropriately, we help the typical kids in a family be in a better position to have their own needs met, creating a stronger family unit, and more empathy for anyone with a disability.

Thank you for all your hard work. Please let me know if there is any help I can offer.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = INDIANA
Country = United States
CountryOther =
Email Address =
How found out = Co-worker
How found out Other Description =
Report being commented on = Needs of Children, Ages 5-12
Interest category = Other (Please specify)
Interest category Other Description = CSPD/ Assistive tech/Autism
Draft Report Rating = 2
Nature and Scope Rating = 2
Presentation Rating = 7
Overall Rating = 3 Comments: I have several concerns, the most significant one would be mental health evaluating educational programs. One has to know what questions to ask in order to obtain good data. One of the most interesting aspects of this being that there are no comments from educational providers in the last section.

Subject = Needs of Children, Ages 5-12
Name =

State = PENNSYLVANIA
County = MONTGOMERY
Country = Other (Please specify)
CountryOther = U.K.
Email Address =
How found out = Other (please specify)
How found out Other Description = e-mail message from a member of the task force
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family
Interest category Other Description = Conference attendee to several conferences related to Asperger's Syndrome/ASD
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments = The remarks regarding the barriers to getting existing services are particularly relevent, since we spent 6 months, and 4 IEP meetings in that time period, bringing our school district to the reluctant conclusion that it had to provide a proper, inclusive education, with all the necessary supports for our Asperger's syndrome 10 year old, who had been wrongfully placed in Emotional Support. We have also just won the ESY battle. We still have difficulty with the NOREP because our school district claims our son has to have a placement eligibility of itinerent emotional support, despite the Education Law Center saying otherwise. WE cannot agree on this. WE think the NOREP should state regular education and then list his services. They claim that he cannot receive services if the NOREP reads regular educxation. It has to state a special education which they, as a school district, provide. It's confusing as they seem certain about this.

On the issue of services I woould like to see a minimum level of relevent competence in aides employed by school districts as 1:1 aides for ASD children. Too often these aides are paid a small scale salary and have no prior knowledge, or background in the field of Autism. This results in a lack of empathy and ability to handle any problems, a lack of recognition of triggers causing behaviors, and a misperception of said behaviors with perhaps the wrong responsereaction to the behavior. There ought to be a requirement that any aide working with ASD children have a degree in mental health, or intensive training with subsequent trainings, be paid sufficient to ensure there is an interest in remaining in the 1:1 position.

I like the idea of unannounced visits to monitor services and progress of agencies and that insurance companies extend the time period for review as the child becomes older.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = CUMBERLAND
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = Autism Society of HGB
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family
Interest category Other Description = Comments: The transition from preschool to kindergarden should be handled better by the school districts. As an attorney with an autistic son, the more parents that I meet, the more complaints I receive about school districts unwilling to follow IEP's, refusing to provide services, perhaps more money to school districts would help and some type of "quality" control to ensure that the schools are following through. The number one complaint I hear is that school districts are difficult to deal with and refusing to provide services.

Subject = Needs of Children, Ages 5-12
Name =
State = PENNSYLVANIA
County = PHILADELPHIA

Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = Autism BOard
Report being commented on = Needs of Children, Ages 5-12
Interest category = Family, Advocate
Interest category Other Description = Comments: First of all, I wish I had been able to attend. I just wanted to say that in Philadelphia there are two classrooms for High Functioning Autistics. They are both in the Northeast (and ironically, there are NO HEADSTART programs in the Northeast). This school classroom setting has been wonderful for my son who Has aspergers. He was abused by a teacher in Kindergarden who told the other kids he was the "bad One". Now he has a teacher who is trained in this field and he is thriving. If there were more programs like this one across the city, in ALL neighborhoods, some issues in public schools would be solved. Also, there should be pamphlets available at the local welfare office for parents of disabled children. Pamphlets that give resource information. And when you have a child with a disability such as autism, you should not be determined ineligible for food stamps because you get SSI, it should not be included in the calculation. That SSI money is supposed to help us with our everyday expenses. ALl it did for me was take the place of food stamps. In the medical field, all general practicioners should be made to be more aware of Autistic traits so that diagnosis can be made earlier. My son wasn't diagnosed until the age of 6. That is all for now. Thank you for your time. Again, thank you. Sincerely, UNDISCLOSED Mother of G., Aspergers Syndrome

Needs of Adolescents

Subject = Needs of Adolescents, Ages 13-18
Name =
State = PENNSYLVANIA
County = ELK
Country = United States
CountryOther =
Email Address =
How found out = Provider
How found out Other Description =
Report being commented on = Needs of Adolescents, Ages 13-18
Interest category =
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 8
Overall Rating = 9 Comments: I have a son with autism/MR diagnosis who is 15. We recently moved to this small town in mountainous (remote) part of PA. Outside of school, there are FEW services available for Christopher. We would like additional information on leisure activities (sports, camps, etc.) that he would be eligible to participate in.

Subject = Needs of Adolescents, Ages 13-18
Name = Delaware County Department of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Needs of Adolescents, Ages 13-18
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 6
Presentation Rating = 7
Overall Rating = 8 Comments: The Delaware County Department of Human Services gave this subcommittee report a rating of 8 out of ten because the report accurately reflected the inability of the intersecting service systems to meet the needs of adolescents with autism. The report was correct in stating that the major service system for this age group is Education, a system that is not under the jurisdiction of the Department of Public Welfare.

We would endorse the call for separate labeling and funding for persons with autism since there will be inevitable frustration at trying to make either the mental health or mental retardation system fit their needs. Some of the understandable complaints in the report had to do with the harm that can come with trying to fit the needs into services that were designed to serve different disabilities. It is true that some persons with autism will fit within the definition of mental retardation and can be registered and perhaps receive some helpful services, but will not find services tailor made to their needs. On page 5 and 6, there is reference to the requirement that a person must have an IQ of under 70 to be registered in the Mental Retardation system and that creates problems for persons who need supports but who have IQ scores within the normal range. This is true; the solution is not to change the national definition of Mental Retardation, but to design a separate, appropriate service system. Autism and mental health concerns are not mutually exclusive, but many of the behavioral manifestations of autism are caused by the organic condition and are not mental illness. The managed care model based on illness is often ill suited to serving persons with a pervasive, chronic, developmental condition.

We did not give the subcommittee report a 10 rating because there are some inaccuracies that should be noted. On page 3, it states that "One must still apply and be rejected by Social Security (SSI) as one the contingencies of eligibility for MA" This statement is not accurate. One can go to the County Assistance Office and apply first for MA for a child with a disability without also applying for SSI. In fact, this is the quickest way to get approved for MA. If a person applies for SSI and is approved, they are automatically eligible for MA, however, the two processes are not necessarily related. On page 7, C.1.4 refers to the effects of the lack of local psychiatric units. This statement does not reflect the circumstances in Delaware County and certainly not all counties across the State. It is worded as if it is true across the board.

Subject = Needs of Adolescents, Ages 13-18
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Needs of Adolescents, Ages 13-18
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 5
Nature and Scope Rating = 5
Presentation Rating = 5
Overall Rating = 5 Comments: Strongly agree with recommendation that regular education teachers and admin need training.

Subject = Needs of Adolescents, Ages 13-18
Name =
State = PENNSYLVANIA
County = MONTOUR
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = ASA
Report being commented on = Needs of Adolescents, Ages 13-18
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 8
Presentation Rating = 10
Overall Rating = 9 Comments: I have read all the draft reports; I am the mother of a 12 year old with PDD-NOS. The reports are truly impressive and comprehensive. Particularly apt is the report on ages 5-12 and the resistance to inclusion in schools. I fought for inclusion, and won it, at due process. The school's position was that my son was too low-functioning. They were wrong and he is progressing beyond our hopes. My current concern is lack of childcare after age 12 - the age when centers for typical children close their doors, even when an aide is available. Thanks for a great job.

Subject = Needs of Adolescents, Ages 13-18 Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Friend
How found out Other Description =
Report being commented on = Needs of Adolescents, Ages 13-18

Interest category = Family
Interest category Other Description = Comments: As a parent of a teenager with ASD, I'm concerned with the adolescent report and as it impacts it, the transition report. My son is ok socially in school, but has no social life outside the classroom. He's content to spend his days watching tv and playing x-box. We can't interest him in any outside activities. Since he's minimally participating in school, his IEP has no social skills goals. Even though, as you point out, it's covered in IDEA, the school doesn't feel it is obliged to "make" him join an extra-cirricular activity. It would be different if he wanted to join and needed assistance. We've also tried wraparound and found that to be a dismal failure. The TSS's would sit and watch tv with him! They said they weren't allowed to take him out of the house. For a few months we had family-based therapy, and they would ask him too go out, but he refused. They dropped us after a few months, because they said they focus on parenting skills, at which we were efficient. The schools won't help us to get our son socially functioning,and wraparound was not a help either. I even tried calling OVR but the counselor said if he wasn't willing to do anything outside the house, OVR couldn't provide any training. I think your Deveopmental Disabilities department to integrate the educational and social aspects of PDD is an excellent idea. As a high-functioning ASD, my son is falling between the cracks - not disfuntioning enough to fit into a life-skills class, but spends the day by himself and electroniuc media. I'm afraid the only future he'll have is getting a college degree on the internet. I agree also with your concerns ab out due process. Our support group (Parent Learning Support Network) has come to learn that it is far better to take the money you would have spent on a laywer and spend it on the services your child needs outside the system. In Allegheny county, we've had no problem getting MA for our Aspberger kids. The clerk said there are no specific diagnoses for qualifying - only a voluminous case file indicates that help is needed. High -functioning autism cases need to be looked at differently than low-functioning: it is another "invisible" disability.

Thank you.
UNDISCLOSED

Transition to Adulthood

Subject = Transition to Adulthood
Name =
State = PENNSYLVANIA
County = LEHIGH
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = email from associate
Report being commented on = Transition to Adulthood
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: I was unable to get to this page from the Transition to Adulthood draft. Instead, I linked here from the Needs of Adults draft. I would give the same rating to that draft (Needs Of Adults) that I gave to this one. I will be forever grateful to those dedicated and committed individuals who spent countless hours preparing these incredibly powerful drafts. The content and proposals contained in the drafts are truly a dream for families facing ASD challenges.

Subject = Transition to Adulthood
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Provider
How found out Other Description =
Report being commented on = Transition to Adulthood
Interest category = Family
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 10
Presentation Rating = 8
Overall Rating = 9 Comments: It shows that we have a long way to go in order to provide what is necessary for our young adults to succeed. IT also shows that we are on our way with the input from the hard working people on the committee.

Needs of Adults

Subject = Needs of Adults
Name = Lonesome Doves
State = Pennsylvania
County = LANCASTER
Country = United States
CountryOther =
Email Address =
How found out = From a meeting announcement
How found out Other Description =
Report being commented on = Needs of Adults
Interest category = Advocate
Interest category Other Description =
Draft Report Rating =
Nature and Scope Rating =
Presentation Rating =
Overall Rating = Comments: The Lonesome Doves wish to thank the members of the Autism Task Force for their work on our behalf. We support the recommendations of the Adult Needs Subcommittee. We agree that none of the services currently being offered are totally suited for people disabled by autism. We would like to highlight a few points that elicited strong responses from our members.

Environmental adaptations

Existing services do not take into consideration the sensory sensitivity of autistic people. This seems to be the case in day programs and also in most group homes. We recommend that each individual's sensitivities be determined as part of his or her life plan so as to minimize distress.

Legislative support of a new autism waiver

It should be emphasized that the majority of funds for autism services will be used to create jobs for staff people. This is good for Pennsylvania's economy, in that most of the money spent to help us will also benefit the people who we employ. In addition, a number of people disabled by autism will be enabled to become employed, and all of us will be able to contribute more to society.

IQ

Most members of the Lonesome Doves have been mistakenly mislabeled as mentally retarded in the past. A number of us are outstanding college students, and all of us have proven our intelligence once we were introduced to a method of communication. Many of us question the validity of IQ tests, which we know to inaccurate. Even if there is such a thing as mental retardation (rather than neurological dysfunctions and communication disorders) , we believe that an individual with autism should receive appropriate autism services (instead of MR services), regardless of IQ score, because our needs for behavior supports and socializing aid differ significantly from those of people with other disabilities.

Training direct support staff

This will make or break our state's autism program. Without proper training about our quirks, reactive and stabilizing behaviors, methods of communication, sensory sensitivities, and socializing difficulties, staff cannot succeed in supporting us and enabling us to cope with and transcend our autism. Far too many of us currently live lives that are circumscribed by the limited skills and low expectations of staff members. We know that they do not want to disable us further with their own inabilities that result form lack of training. They, and we, desire the integrity and quality of service that comes from a professional understanding of our disabilities. Our quality of life depends on their training. We want meaningful lives. Our staffs want truly to help us. No one wants glorified babysitting.

We find it unfair that staff members are not paid for training. This communicates a message that training is not important, and it creates an assumption that training is not a continuing process for staff. We, ourselves, are constantly learning new methods of coping with our autism; our staffs should be able to be trained (for pay) to learn new techniques that can help us.

Staff pay

We are all too conscious that the people who work with us are not in the business for money, but they truly deserve to be paid better than they are. Pay rates for our support staffs should be improved. There should be a pay scale, rather than a flat rate. Job retention needs to be encouraged, incentives must be put in place for staff members to improve their abilities, and experience should be rewarded.

All autistic people experience a great deal of stress around change, so staff retention is a goal we all support. For users of facilitated communication, the fluency or our speech often depends on the experience of our facilitators. Their support and resistance to our awkward movements are built on trust that takes time to establish. If staff members change frequently, we don't have the chance to teach them the support-skills that enable us to communicate well, and our quality of life suffers considerably.

Expand range of employment we can accomplish with job support staff

The Lonesome Doves is a group of people (most of whom have autism) who communicate via facilitated communication (FC). Physically, most of us would be classified as "low functioning". However, our brains are average to high functioning. We want meaningful employment that depends on the strengths of our intellects, not the weaknesses of our bodies. We expect FC users to have a future place in society as writers, researchers, workshop directors, teachers, artists, and in other professions where our minds and talents can soar. This will mean that we will need to have staff members who can help us adapt and communicate as we seek higher education and work that is satisfying.

We think that work services, including OVR, should be need-based and individual-based with parameters that respect autism.

Communication

Communication is a right. People must be allowed to use the method(s) of communication that they choose. It must be available at all times. Not only do we have much to express, we can help our staffs by explaining or helping to figure out our baffling behavior.

Regarding the language of the Task Force document, we recommend that every time the refers to communication, it should read "communication of choice".

Keep services separate from housing

A person's life is not a "program" of a service agency. We want to control our own lives. We want to choose where we live and with whom. We understand that the economics of our support is a major factor in the funding equation, but we believe there are alternatives to agency-owned housing. We must become homeowners or renters and apartment dwellers in our communities. We must live as adults, not patients, clients, or grown-up children.

Offer services where people want to receive them

Often the stress of going to day programs is enough to cause emotional disturbances and can lead to unwanted behaviors. Services should be designed around the things we wish to accomplish in our homes, communities, colleges or universities, jobs, and with our friends and families.

Person-centered planning

Since the state supports self-determination, all plans for individuals should be driven by centered planning and (we suggest) individual support circles. This must included our behavior management plans. Person-centered planning will assure advocacy for the individual. Planning must be growth-oriented rather than maintenance-oriented. Person-centered planning should occur for everyone as a requirement of the waiver.

In conclusion, we suggest that the people involved with policy decisions in the state (and federal) government need to meet with the people who will receive services. It is especially important that they experience conversations with people who use alternative and augmentative means of communication, such as facilitated communication. Once they see us firsthand, experiencing our worth and witnessing our abilities, they will be better able to make the decisions that affect our lives.

Subject = Needs of Adults
Name =
State = PENNSYLVANIA
County = ALLEGHENY
Country = United States
CountryOther =
Email Address =
How found out = Friend
How found out Other Description = ABOARD-ALAW
Report being commented on = Needs of Adults
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: WE have a 26 YR> old adult HFA/Seizure disorder who has been thru the works. find inf.on him atpost-gazette.comheadlines/20010716juvdaytwomainnat2p2.asp/MARIOS Story. Somes true somes not. Changed diagnois to bipolar/IED/ Dual diagnois/Changed IQ. Gave parents no PUNS/OR included us in anything. Stated he did not Qualify forNew Transformation. Receives title 19. Provider from other county. ALls we need is a trusting provider @ supports who is capable of working with autistic needs. Stated MR DDD/ does not have anything for him in PA.

Subject = Needs of Adults
Name = Delaware County Department of Human Services
State = PENNSYLVANIA
County = DELAWARE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description =
Report being commented on = Needs of Adults
Interest category = Government Agency Official/Staffer
Interest category Other Description =
Draft Report Rating = 6
Nature and Scope Rating = 6
Presentation Rating = 6
Overall Rating = 6 Comments: The Delaware County Department of Human Services gives this subcommittee report an overall rating of 6. We recognize that the wording of this report arises out of the intense frustration of caring persons who have spent years attempting to use the current service system to serve individuals whose needs have not been met. We wholeheartedly agree that many persons with autism neither fit the criteria of mental retardation nor easily fit into the usual service patterns designed for person with mental health issues. The 1966

The Delaware County Department of Human Services gave this subcommittee report a 7 Act did set up a categorical system, which was based upon the knowledge as well as the Federal guidelines and funding at

that time. It is true that much has changed in the understanding, funding and service design of mental retardation and behavioral health services since the 1960 ’s. The changes in the overall understanding about autism are even more dramatic and are evolving at a rapid rate. In 1966, there was an insufficient common knowledge base to even design a service system for persons with autism.

Given the facts stated above, we endorse the taskforce’s efforts to secure recognition of the unique needs of persons with autism including the lifelong need for supports. It is not the function of our Department to recommend a specific organizational structure at the State level that would best serve the needs of autism. We do agree with the need for at least a unit,devoted to program design and funding for persons with autism.

The fact that the current systems do not meet the needs of persons with autism should not be attributed to insensitivity (even though it is always possible that can occur), but to the fact that in many ways the needs of persons who are appropriately served by the existing systems are not compatible with the needs of persons with autism. It appears that the disillusionment of the task force members has caused them to make broad statements about the existing County systems that are prejudicial and inaccurate. Examples of this tendency are on page 5 and page 10. What appears to be bloated bureaucracy to the task force members are in actuality attempts to staff up to meet the requirements, particularly of the very waiver funding stream that they wish to access, for monitoring and oversight. The community which is appropriately seeking funding for autism services will need to recognize that government funding always comes with administrative and services standards (appropriate when using taxpayer dollars) It does not seem possible to achieve necessary oversight without some bureaucracy and diversion of funds to administration. This fact is always frustrating when confronted with an inexhaustible need for funds to go to direct service. It may well be that the current waiver requirements contain some excessive monitoring requirements and those need to be addressed to free up some funds that are, in fact, needed to provide additional services for the service groups being served by those waivers. This Department is sincere in hoping that the State DPW can find ways to address the needs of persons with autism which do not take away from groups currently eligible and on waiting lists for services for persons with mental retardation.

Subject = Needs of Adults
Name =
State = PENNSYLVANIA
County = ERIE
Country = United States
CountryOther =
Email Address =
How found out = From a meeting
How found out Other Description = email
Report being commented on = Needs of Adults
Interest category = Family, Provider, Advocate, Primary/Secondary Educator
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8 Comments:

Subject = Needs of Adults
Name =
State = OHIO
County =
Country = United States
CountryOther =
Email Address =
How found out = Surfing the net
How found out Other Description =
Report being commented on = Needs of Adults
Interest category = Provider
Interest category Other Description =

Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8 Comments: I found this article very informative and interesting. I am wondering if there is funding, or grants to assist in providing transitional or group home to support to Autistic adults? I am interested in opening a group home in Mercer County that targets Autistic Adults that no longer live with parents, offering trainings, educational, vocational, and support systems as part of our program. Do you have statistic for Autistic Adults currently living in Mercer County? Or can you advise me how to find this information, as well as seeking State funding? Thank you very much!

Subject = Needs of Adults
Name =
State = PENNSYLVANIA
County = LEBANON
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = PSU Autism conference
Report being commented on = Needs of Adults
Interest category = Family
Interest category Other Description =
Draft Report Rating = 10
Nature and Scope Rating = 10
Presentation Rating = 10
Overall Rating = 10 Comments: I have just finished reading the Adult portion and I agree with everything that was mentioned. I am a mother of a 14 year old son with "low level" autism, severe mental retardation and severe ADHD. I am also an occupational therapist who has had the opportunity to visit a few group homes over the years. I am concerned that my son may not have any placement when he is an adult. We are told as parents to start thinking transition at age 14 but when we try to start planning we are told that planning is difficult due to lack of funding. At this point, I don't believe I will know where he is going until the day the school system stops paying for his residential school. I feel the need to be able to plan ahead due to his safety concerns. Autism group homes based on the individual's abilities would be wonderful & make it easier to train staff & develop programming.

Subject = Needs of Adults
Name =
State = PENNSYLVANIA
County = PHILADELPHIA
Country = United States
CountryOther =
Email Address =
How found out = Other (please specify)
How found out Other Description = e-mail
Report being commented on = Needs of Adults
Interest category = Family
Interest category Other Description =
Draft Report Rating = 9
Nature and Scope Rating = 9
Presentation Rating = 9
Overall Rating = 9 Comments: This report states "Assistive Technology-meaning devices and methods that enable adults with autism to communicate, manage sensory and motor challenges and control the environment in which they live." I would also like to see AT for activities of daily living, such as cooking, keeping a schedule, remembering procedures, taking medication on time, etc.

Subject = Needs of Adults
Name =
State = OHIO

County =
Country = United States
CountryOther =
Email Address =
How found out = Surfing the net
How found out Other Description =
Report being commented on = Needs of Adults
Interest category = Provider
Interest category Other Description =
Draft Report Rating = 8
Nature and Scope Rating = 8
Presentation Rating = 8
Overall Rating = 8 Comments: P.S. I currently work in Mercer County as a Behavior Specialist, and was also wondering how you can apply to be on this Task Force? Thank you for your time.