

PENNSYLVANIA AUTISM TASK FORCE

EXECUTIVE SUMMARY

DECEMBER 2004

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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.

Solutions:

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.

Solutions:

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.