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**NEW HAMPSHIRE
COMMISSION ON
AUTISM SPECTRUM DISORDERS**

Findings and Recommendations

2008



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**NEW HAMPSHIRE
COMMISSION ON
AUTISM SPECTRUM DISORDERS**

Findings and Recommendations

2008

EXECUTIVE SUMMARY

In June 2007, the New Hampshire Legislature passed and Governor John Lynch signed into law HB 396 establishing the New Hampshire Commission on Autism Spectrum Disorders. The Commission, formed in response to the rapidly growing prevalence of autism spectrum disorders (ASD) in New Hampshire and nationwide, was charged with examining and making recommendations regarding the care, treatment, and quality of life for children and adults with ASD and their families.

Autism spectrum disorders refers to a group of three neurologically-based developmental disabilities. These include autism—the condition that people are most familiar with—Asperger syndrome, and pervasive developmental disorders not otherwise specified.¹ While each has distinctive diagnostic criteria, all are characterized by marked difficulty in communication and social interaction, as well as unusual behaviors or thought patterns. ASD varies widely both in its presenting symptoms and in its severity. It may be accompanied by sensory integration difficulty, speech delay or absence, cognitive impairment, medical conditions, and motor involvement.

For reasons still unknown, the prevalence of ASD has been rapidly escalating. In 2001 when New Hampshire's Division of Developmental Services formed the state's first Task Force on Autism, the prevalence for ASD was one in 250. According to the most recent data released by the national Centers for Disease Control, ASD now affects one in every 150 children. More children will be diagnosed with ASD this year than with juvenile diabetes, cancer, and AIDS combined. At this rate, nearly all of us have, or will have, a personal connection with someone who is affected by this condition—perhaps a neighbor, the child of a friend, or a member of one's own family.

MISSION AND APPROACH

Composed of a broadly representative group of stakeholders, the New Hampshire Commission on Autism Spectrum Disorders began its deliberations in August 2007. Building upon the findings of the 2001-2002 Task Force on Autism, the Commission considered the impact that ASD currently is having on our state and developed recommendations for the future direction of ASD services. In its work, the Commission on ASD interviewed lead administrators from relevant departments within state government, researched the most current outcome data, and referred to nationally recognized assessment and treatment guidelines. The Commission invited and received public comment on its findings and recommendations through an online posting of its draft report.

The Commission was particularly struck by the tremendous financial impact that ASD has on affected individuals and families and on our society. In the 2007 study by the Harvard School of Public Health, researcher Michael Ganz, M.S., Ph.D. estimated for a single individual, the lifetime cost—both direct and indirect—associated with autism to be \$3.2 million. Prevalence data for ASD in New Hampshire has been difficult to obtain, especially for adults. The 2001-02 School Year Review by the New Hampshire Bureau of Special Education

¹ The three are sub-types of the broad category Pervasive Developmental Disorders (PDD). Two other neurologically based disabilities, Rett syndrome and childhood disintegrative disorder, also are included under PDD. Both are rare and not considered to be autism spectrum disorders, though they share some characteristics of ASD.

reported 932 students received special education services under the specific code for autism. It should be noted that this does not reflect the entire ASD school population, as many students with ASD receive special services that do not fall under the autism code. Using the model from the Harvard study, the impact over the average lifespan for the 932 autism coded students comes to a staggering \$2.9 billion in health care, services, and lost productivity. Given that the actual number of ASD students is larger and no adults are included in this count and the number of individuals diagnosed with ASD is steadily increasing, the true financial impact is significantly greater.



The Commission recognizes that focusing on financial costs is but one narrow measure of the overall impact of chronic health conditions such as ASD. It does not take into account lost opportunities, the emotional drain on families, or the effect on an individual's quality of life. However, the extreme financial burden imposed by ASD does provide an indication of the scope of the problem that New Hampshire is facing. If our state is to effectively address a public health crisis of this proportion, it must develop a comprehensive plan that emphasizes early identification and significant intervention. The Commission in its recommendations seeks to encourage the adoption of policies and practices that will reduce these costs and increase the long-term economic independence, health, and well-being of New Hampshire's citizens with ASD.

RECOMMENDATIONS

The New Hampshire Commission on ASD developed recommendations to affect six broad goals. Four goals supported by the Commission look to increasing New Hampshire's capacity to serve individuals with ASD and their families through investment in both infrastructure and social capital. Two additional goals reflect the conviction that intervention and supports during certain pivotal developmental periods—early childhood and the transition to adulthood—are crucial to improving real life outcomes. Timely and effective intervention will increase the likelihood that individuals with ASD will continue their education beyond high school, be gainfully employed, and live independently.

The Commission's recommendations include expanding ongoing training for those professionals and paraprofessionals who work with individuals with ASD, clarifying Medicaid eligibility, and providing insurance coverage for evidence-based treatments. The following recommendations are important first steps to begin addressing the challenges that ASD poses to our state:

- The New Hampshire Legislature will establish a Council on Autism Spectrum Disorders to provide leadership in promoting comprehensive and quality education, health care, and services for individuals with autism spectrum disorders and their families. Among its duties, the Council will encourage the establishment of regional collaboratives with representation from educational, health care, and community service providers to ensure that individuals with ASD and their families receive necessary services. The Council also will advise participating state agencies in the implementation of the Commission recommendations set out in this report (Passage of HB 1634 by the New Hampshire legislature would establish this Council).

- ▶ The Department of Health and Human Services and Department of Education, through an interagency agreement, will endorse and facilitate the implementation of the most recent national health care guidelines on ASD. These guidelines call for the universal screening of all children for ASD through continuous surveillance, the use of autism-specific screening tools, and valuing parental concerns. The guidelines recommend prompt referral for both early intervention and timely diagnosis and endorse a minimum of 25 hours per week/12 months a year of structured programming.
- ▶ The Department of Health and Human Services, through the Bureau of Developmental Services and in collaboration with the Department of Education, will identify and support leadership for a regionalized system of autism diagnostic clinics using or expanding upon available resources to increase access to timely diagnostic evaluations by improving geographic access and reducing wait times for clinical appointments.
- ▶ The Autism Society of New Hampshire, in partnership with the state's Division of Public Health Services, will launch the New Hampshire Autism Awareness Campaign to inform the general public, all families of young children, medical professionals, child care providers, early childhood educators, and therapists about the prevalence of ASD, the earliest signs and symptoms, available sources of information and support, diagnostic services, and evidence-based approaches to treatment and intervention.
- ▶ The New Hampshire Department of Health and Human Services and the Department of Education will work collaboratively to ensure that, beginning in the early teenage years, individuals with ASD are offered opportunities for a variety of work experiences during typical life and school routines. These will include providing vocational assessment, job development, job training, and employment supports on a time-limited and long-term basis, depending upon the strengths, talents, needs, and choices of the individual.

CONCLUSION

The New Hampshire Commission on Autism Spectrum Disorders fully recognizes that to successfully meet the challenges posed by ASD will require significant effort. As members of the Commission, we are committed both individually and collectively to furthering this process, and are grateful for the opportunity to present these recommendations to the Governor and legislators of our state.

INTRODUCTION

In 2001, the New Hampshire Department of Health and Human Services convened the first statewide Task Force on Autism to consider how the state should respond to the increasing prevalence—at the time one in 250—of autism spectrum disorder (ASD). In the years that have followed, the prevalence of ASD has continued to rise dramatically; in 2008 the prevalence is one in 150. However, there has been progress on a number of fronts. Research has brought advances in our understanding of the physiological and biological differences underlying ASD. Esteemed professional associations, including the American Academy of Pediatrics, have developed guidelines for the identification, evaluation, and treatment of individuals with ASD. There has been increasing pressure to broaden the national research agenda to encompass the search, not only for the causes of ASD, but also for a wider range of evidence-based treatments and support. Thanks to widespread media focus on this issue, the general public is far more familiar now with autism and the challenges it presents to affected individuals and their families.

In 2006, under pressure from parents and organizations like the Autism Society of America and Autism Speaks, Congress passed the first piece of legislation specific to autism spectrum disorders. The Combating Autism Act (CAA) authorizes \$920 million in federal funding over the next five years for basic research, surveillance, public awareness, and early identification initiatives. While the majority of the funds are targeted for research, CAA has earmarked a significant amount—\$36 million in 2008—for treatment and support services through the Health Resources and Services Administration. A second bill, Expanding the Promise for Individuals with Autism Act (EPIAA), now making its way through Congressional committee review, would provide an additional \$350 million in new federal money for initiatives related to treatments, interventions, and services for both children and adults with ASD.

Recognizing the need for a coordinated response to ASD—and the advantage this would have in competing for federal funds—a number of states have convened commissions to consider this issue. New Hampshire is among this group; in 2007 the state legislature passed and the Governor signed into law HB 396 establishing the New Hampshire Commission on Autism Spectrum Disorders. The Commission includes family members, an individual with ASD, state legislators, and representatives from public and private agencies providing health care, educational, and other community services. Charged with making recommendations regarding the care, treatment, and quality of life for individuals with ASD and their families, the Commission created four work groups: early identification and intervention, best practices and training, services, and funding. Beginning in August 2007, the full Commission met at least bimonthly with the work groups meeting more frequently.



The findings of New Hampshire's Commission on ASD are comparable to those in other states. Virtually all state plans released to date call for increased services through a coordinated approach that brings together multiple governmental agencies and private organizations and caution against developing a separate system specific to ASD. Early identification and treatment, expanded adult services, and the creation of regional autism training and resource centers are all common themes.

CHALLENGES FOR PUBLIC POLICY

As our understanding of autism spectrum disorders has advanced, so has our appreciation of the challenges that it poses for those working to craft effective public policy.

BUILDING CAPACITY

First and foremost is the problem of scale. The sheer number of individuals affected—especially children—has already stretched many public resources, particularly in our schools, to a near breaking point. In spring 2007, the Centers for Disease Control (CDC) revised upward its estimate of the ASD prevalence to one in 150. Considered a “rare” disability as recently as the 1980’s, the prevalence of ASD has been rising 10-17% annually for the past decade. While shifting diagnostic criteria and an increased awareness of the clinical presentation of ASD account for some of the increase, it is widely accepted that these factors alone do not explain the rising prevalence.



Still more concerning is the age distribution of affected individuals. In California, which has kept some of the most detailed data, 85% of those with “full spectrum autism” are under the age of 21, 78% are under the age of 18, and more than a quarter of children with ASD served by their state’s developmental services system are between the ages of 6 and 9.² CDC has found incidence rates, and therefore age distribution, to be relatively uniform across the country. New Hampshire, along with the rest of the nation, can expect a surge in demand for services as each successive wave of children with ASD ages into adulthood.

New Hampshire must begin now to expand its capacity to address the challenges presented by a rapidly growing ASD population. This does not mean the creation of a separate system of care specific to ASD, but rather increasing the workforce and the knowledge base within our existing systems. Children, youth, and adults with ASD rely on many different public systems. To meet their needs, New Hampshire will require—in fact, already requires—more professionals such as special educators, occupational therapists, speech and language pathologists, behavioral specialists, and child psychologists and psychiatrists. Moreover, practitioners of many kinds—general education teachers, nurses, police officers, and health care providers—regularly encounter individuals with ASD in their work. An important, but often overlooked component in capacity building is the need to increase public awareness and general knowledge about autism spectrum disorders. As members of the public come to understand ASD better, the myths and stereotypes that contribute to the isolation of affected individuals and their families hopefully will begin to fade.

SYSTEMIC CONSIDERATIONS

While awareness of the demographic trends can be helpful, it cannot capture the full picture. ASD is a spectrum disorder, and as such there is tremendous variability within the population. How ASD is manifested

² California’s Department of Developmental Services. (2008).

and how severely it affects one's life is unique for each individual. Additionally, those with ASD frequently experience other chronic conditions, including immune system and gastrointestinal disorders, seizures, and psychiatric conditions such as anxiety and depression. Any single individual with ASD will have a unique mix of symptoms within a complex array of ASD and coexisting conditions, and this personal profile will change over time.

The variability and fluidity associated with ASD pose a second challenge to public policy. Eligibility requirements for the state's developmental disabilities system, for example, are not sensitive to degrees of variation—one either qualifies or doesn't qualify for Medicaid funded supports. While there is some ability to individualize the level of service for those who qualify for developmental services, there is not a tiered system of services available to those who do not meet Medicaid criteria, but who would still benefit significantly from a relatively modest investment in ongoing support. Taking another example, the behavioral health system is able to accommodate episodes of acute need, but is not designed to provide a consistent presence in the lives of individual patients.

A third challenge is posed by the degree to which treatment and support of those with ASD cuts across numerous service delivery systems, including medicine, education, behavioral health, vocational rehabilitation, and developmental services. Each system maintains independent, and often different, eligibility criteria, protocols for service planning, limits to service delivery, and guidelines for quality assurance and consumer protection. Families are left on their own to piece together resources from multiple sources. In addition, there is no easily accessed mechanism by which providers from different systems can come together to create a coordinated plan of care. Not surprisingly, there is sometimes tremendous controversy over which system will cover the expense associated with a specific service.

In developing appropriate models for intervention, policy makers must consider both the level of service needed and the cross-disciplinary nature of an overall plan of care. Eligibility criteria requiring that individuals or families reach a certain critical level of need before receiving necessary supports can cause problems down the line. New Hampshire should look to primary prevention models that focus on early supports and ongoing monitoring as a means of avoiding costly, crisis-driven interventions. Additionally, the state must consider a cost effective means of bringing interdisciplinary teams together both at the local level, to review an individual's program, and at regional and state levels to consider appropriate systems change.

IMPROVING OUTCOMES

As parents are all too aware, for a child diagnosed with ASD, the clock is ticking. Unlike a number of other disabling conditions, ASD is treatable—though not curable—with medically necessary interventions. As information about both child development and the plasticity of human neurology has become more available, there is a heightened sense of urgency to obtain, as early as possible, an individualized program that meets the standard set out by the National Research Council in 2001. As recommended by the Council, *“Educational services should include a minimum of 25 hours a week, 12 months a year in which the child is engaged in systematically planned, developmentally appropriate educational activity aimed toward identified objectives.”*³ Programs that

3 National Research Council. “Educating Children with Autism.” (2001).

meet these criteria have been consistently shown to improve the long-term outcomes for children with autism spectrum disorders.

Researchers have posed a fourth challenge to public policy by clarifying that ASD is a neurobiological medical condition associated with unique abnormalities in brain development. This, in turn, raises the question of who will pay for treatment. Private health care insurance either does not cover—or covers only a portion of—standard treatment modalities such as speech and language therapy, applied behavior analysis (ABA), and occupational therapy. Schools, which in many cases carry the majority of cost, are quick to point out that special education was never intended to be the provider or the primary payer for what is essentially medical care. State governments across the country have begun to pressure the insurance industry to come to the table as an equal partner with public entities to negotiate a fair and balanced approach for covering the costs of treatment associated with ASD.

A fifth and final challenge makes this debate all the more urgent. There is increasing evidence that the societal costs of ASD are considerable. An influential study released in 2007 by Harvard School of Public Health researcher Michael Ganz, M.S., Ph.D. is the first to look at the age-specific and lifetime incremental costs of autism in the United States. Ganz estimates that, for a single individual, the lifetime cost associated with autism to be \$3.2 million. His model includes both direct costs, such as special education and medical care, and indirect costs, such as the productivity losses of both the individual affected and family caregivers.⁴

Additional research finds that using real life measures—such as employment, independent living, and meaningful relationships—the long-term outcome for individuals with ASD is quite poor. A 2002 study by Seltzer and Kraus is representative; they found that 73% of adults surveyed lived with their parents, 13% lived semi-independently, and only 4% lived entirely on their own. Ninety percent of those enrolled in the study could not gain and maintain competitive employment. Fully 95% reported difficulty making and keeping friends. Such outcomes suggest that direct and indirect costs—especially loss of productivity—are substantial across the entire ASD population.

Research also confirms what virtually any parent reports in vivid and even tragic detail—that ASD has a significant impact upon parents, siblings, and family systems as a whole. In contrast to other types of disabilities, parents of children with ASD appear to be at greater risk for depression, anxiety, social isolation, fatigue, and frustration. Parents report many causes, including difficulty in obtaining accurate diagnoses and services, misunderstanding by friends and peers, and a negative impact on the career or vocation of at least one parent.⁵ There are also indicators that the presence of ASD places the family at risk of divorce, which is in turn associated with a decline in the standard of living for one or both households. Other secondary effects may include mental health issues for siblings and/or parents, loss of productivity for family members other than parents, and stress-related illness.⁶

4 Ganz, Michael L. “The Lifetime Distribution of the Incremental Societal Costs of Autism.” *Archives of Pediatrics & Adolescent Medicine* 161.1 (2007): 343-349.

5 Bromley, et al. “Mothers Supporting Children with Autistic Spectrum Disorders.” *Autism* 8.4 (2004).

6 Sharpley, Bitsika, and Efremidis. “Influence of Gender, Parental Health, and Perceived Expertise of Assistance upon Stress, Anxiety, and Depression among Parents of Children with Autism.” *Journal of Intellectual and Developmental Disabilities*. 22.1 (1997).

As alarming as these findings are, it is important to remember that it is within our power to turn things around. There are a number of steps that public policy makers can take that will both improve life outcomes and lower societal cost. Ganz's research corroborates earlier findings that 90% of the lifetime cost of an individual with ASD is incurred after the age of 21. We need to shift our policy for treatment of ASD to make intensive intervention in early childhood a priority. Not only is this in keeping with what we know to be best practice, there is considerable evidence that early intervention and treatment sharply reduce both the direct and indirect costs of ASD. A 1998 study by Jacobson, Erlick, and Green estimated that a three-year investment in Early Intensive Behavioral Intervention would produce considerable savings by lowering support costs during adulthood. Their concluding comments call for recognizing interventions for children with ASD as medically necessary treatment.

*"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/PDD. We should all recognize that the most expensive interventions are those that fail to produce meaningful, measurable, lasting benefits, regardless of cost."*⁷

One final caveat—perhaps the single largest challenge presented by ASD is finding a way to advocate for needed treatment, while at the same time respecting the perceptual differences experienced by individuals on the autism spectrum. We are fortunate to have more and more individuals with ASD who can articulate these differences and share with us what they value in their unique understanding of the world around them. It is important to guard against the tendency to view all aspects of ASD as pathologies, forgetting that individuals with this condition bring valuable diversity to the human family.

GUIDING PRINCIPLES



While there have been exciting advances in the understanding of ASD and its treatment, the Commission also respects the established values and integrity of New Hampshire's existing developmental services system.

New Hampshire holds a proud place in the history of disability rights. As the first state in the nation to close its institution for those with developmental disabilities, New Hampshire has maintained a strong commitment to community inclusion, independent living, and consumer choice. Consistent with best practices and the values of our state's developmental services system, the New Hampshire Commission on ASD adopted the following set of guiding principles.

⁷ Jacobson, Mulick, and Green. "Cost-benefit estimates for early behavioral intervention for young children with autism – general model and single state case." *Behavioral Interventions*. 13.4 (1998).

GUIDING PRINCIPLES FOR EDUCATIONAL AND COMMUNITY SUPPORTS AND SERVICES FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

- ▶ Do no harm.
- ▶ Listen to individuals with ASD and their families. Provide support, including assistive technology, to enable individuals with ASD to communicate their needs and preferences.
- ▶ Support individuals and families to participate in decisions concerning educational and community supports and services.
- ▶ Provide identification and intervention as early as possible for children with ASD. Investment in early intensive treatment results in the best clinical outcomes and significantly reduces the lifetime cost of care associated with ASD.
- ▶ Recognize the dynamic and changing needs of individuals and families and assure that a seamless coordination of services and resources occurs across the lifespan.
- ▶ Assure that comprehensive and coordinated services are available to individuals and their families throughout the state.
- ▶ Assure that all individuals and families, including those with diverse cultural backgrounds, receive information and supports in accessible formats.
- ▶ Provide support to families in order for their children to live safely at home and in their communities.
- ▶ Provide resources to schools, communities, and families to ensure inclusive and meaningful participation in all environments.
- ▶ Adapt physical and social environments in school, service, and community settings to meet the needs of individuals with ASD and their families.
- ▶ Assure that all providers - medical, education, and human services - systematically assess progress and modify services and supports as needed to achieve individual and family goals.
- ▶ Provide quality pre-service and in-service professional development, mentorship, and ongoing consultation on the best practices for treating, educating, and supporting individuals with ASD.
- ▶ Support a workforce capable of meeting the needs of individuals with ASD and their families.
- ▶ Maintain high expectations for individuals with ASD and provide the education, supports, services, and opportunities necessary to achieve a meaningful life, including employment.

INFRASTRUCTURE

GOAL:

The State of New Hampshire will provide leadership to ensure that at all levels—local, regional, and state—services for individuals with ASD are provided in the most timely, collaborative, and effective manner possible. This includes developing and supporting a service infrastructure that is multi-disciplinary, person-centered, and easily accessed by children and adults with ASD and their families.

A STRONG INFRASTRUCTURE IS ESSENTIAL



Over the past five years, New Hampshire has seen several initiatives to improve collaboration among organizations serving individuals with ASD and their families. The Parent Information Center, through a Department of Education grant, has promoted a regional approach to address issues affecting students with ASD, including working to meet the need for quality summer programming. Easter Seals has brought together New Hampshire's leaders in ASD services to inform its expansion of support to affected families who live in the Manchester Area and the North Country. Both of these projects have drawn upon the expertise and good will of existing organizations to improve services; they have not, however, tackled the larger and more fundamental problems with the underlying infrastructure that must be addressed if we are to provide quality supports to our citizens with ASD.

This “infrastructure” encompasses the complex support system that stands behind the delivery of front-line services. It includes: 1) personnel preparation, 2) technical assistance, 3) applied research and program evaluation, 4) communication, 5) demonstration programs, 6) data systems, 7) comprehensive planning, and 8) coordination of support.⁸ Gallagher has likened these elements to the societal structures behind a medical practitioner. While the patient may be unaware of it, the treating physician relies upon numerous other systems, including medical education, pharmaceutical research, and laboratory protocols, to ensure the provision of quality health care. What the patient sees as a “good doctor” is in reality a good medical system.

In its landmark study, Educating Children with Autism, The National Research Council underlined the societal change that will be necessary in order to build a successful system of care for individuals with ASD. “Effective programming for children with autism and their families requires that the direct service provider (e.g., special education teacher, regular education teacher, early childhood teacher, speech and language pathologist) be a part of a support system team, not an isolated individual that is struggling with complex neurological, sociological, educational, and behavioral problems.”⁹

8 Gallagher, J. and Clifford, R. “The Missing Support Infrastructure in Early Childhood.” (2000).

9 National Research Council. “Educating Children with Autism.” (2001).

ELEMENTS OF A SUPPORT INFRASTRUCTURE

Personnel Preparation

There is need for a continuous flow of qualified personnel. To that end, there needs to be a series of training programs and experiences directed at pre-service and in-service needs.

Technical Assistance

Many professionals and programs run into situations related to autism that cause them to seek additional professional help. Programs of technical assistance are designed to provide consultation and short-term training to meet the needs of the requester.

Applied Research and Program Evaluation

There is a strong need to be reflective about our own performance as part of a strategy of continuous improvement. Public calls for accountability stress the importance of developing the proper tools and measuring instruments and personnel to conduct effective program evaluation.

Communication

It is important to establish a communications network so that there is continuous contact with other professionals who are working on the same or similar problems. It is a way of keeping up with the latest knowledge and practices.

Demonstration

One of the strategies that has been often used to improve program quality is to identify outstanding programs,

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If New Hampshire is to successfully address the challenges of ASD, it is clear that we must do far more than promote exemplary projects. A systematic review and redirection of the existing infrastructure will be necessary if we are to deliver effective treatment and supports throughout our community clinics, schools, area agencies, vocational centers, and other front-line services. The New Hampshire Commission on ASD envisions a model that reflects both the need for strong central leadership and the need to engage providers at the regional level and within their own communities. At all levels, this model must be multi-disciplinary and inclusive of consumers and family members. While other aspects of state infrastructure will be treated later in this report (for example, personnel preparation), we believe that ensuring an ongoing means for coordinated planning at all levels is a critical first step toward improving supports and services.

ESTABLISHING A STATEWIDE COUNCIL

Critical to developing a sound infrastructure is the ability to undertake comprehensive and ongoing statewide planning and to manage resources in a systematic manner to reach broadly supported goals. In carrying out its work, the Commission has engaged experts—professionals, policy makers, and consumers of service—from all across New Hampshire who generously have given of their time and talent. We believe that there is an important leadership role for a broadly representative group of this type to oversee the ongoing work of expanding the capacity of New Hampshire's infrastructure. We propose establishing the New Hampshire Council on Autism Spectrum Disorders to establish priorities, set direction for services, and ensure support for those who deliver the services. The recommendations of this report will serve as the Council's agenda. Additionally, we believe that this central body, which will include a number of volunteers willing to share their expertise for the public good, should have a full-time Executive Director to support its work.

KEY FINDINGS

- There is no single entity responsible for insuring that high quality care is provided in an efficient, individualized, and consumer-directed manner to individuals with ASD across all participating systems.

- While there has been a great deal of interest in building a statewide network of ASD related providers, there has yet to be an initiative with the authority to address the systemic challenges presented by the dramatic increase in the incidence of ASD.
- Under the Combating Autism Act and other federal initiatives, funds will be made available to states for demonstration projects and other initiatives. In competing for grants, it will be to New Hampshire's advantage to have put in place both a well thought out plan and a mechanism to oversee its implementation.

RECOMMENDATIONS

- The legislature will establish the New Hampshire Council on Autism Spectrum Disorders to provide ongoing leadership in all statewide efforts to address the needs of individuals with ASD and their families, as per HB 1634. As a broadly representative group of stakeholders, the Council will foster a spirit of interagency collaboration and innovation.
- In collaboration with the New Hampshire Department of Health and Human Services (DHHS) and other stakeholders, the Council will identify and secure funding for an Executive Director; this will be a full-time position within the Bureau of Developmental Services in DHHS. Under the joint direction of the Bureau of Developmental Services and the Council on ASD, the Executive Director will provide leadership in pursuing the Commission recommendations set out in this report.
- The New Hampshire Council on ASD will ensure that both the state Senate and the House of Representatives are well informed about the public health issues surrounding ASD and the initiatives of the Council, as per HB 1634.

CREATING AN EFFECTIVE FRAMEWORK FOR CARE

As already noted, the treatment of ASD involves many disciplines and service systems; typically individuals with ASD and their families rely on several different providers to address their needs. Without an easily accessible means of bringing these providers

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establish them as demonstration centers, and then urge other professionals to observe and emulate what is happening in those centers or programs that could be transferred to their own program.

Data Systems

There are many important policy questions that cannot be answered without an organized data system. Questions such as, "How many children with autism are there?" or "How many teachers are needed?" can only be addressed if one has a data system to compile the demographics of the individuals or programs.

Comprehensive Planning

One of the key aspects of an infrastructure is the ability to do comprehensive statewide planning and to be able to allocate resources over time and in a systematic manner to more easily reach the goals of the program.

Coordination of Support

It is not enough to have all of these components present in a particular state; they must be linked together for maximum payoff. Interagency cooperation relies upon the perceived legitimacy of the project involved and the ability to include all key stakeholders, especially in a domain where resources are scarce.

SOURCE: Gallagher and Clifford (2000) as presented in "Educating Children with Autism," National Research Council (2001). The final entry is taken directly from Gallagher and Clifford (2000).

CHARGE TO THE NEW HAMPSHIRE COUNCIL ON AUTISM SPECTRUM DISORDERS

- ▶ Provide leadership in developing training opportunities, policy analysis, research initiatives, and the means by which to ensure the coordination of supports and services for individuals and their families.
- ▶ Ensure that families and individuals with autism spectrum disorders receive information about evidence-based and promising practices for community-based education, support, and treatment. This would include organizing and supporting a system of electronic communication, such as a web page.
- ▶ Work with the educational, area agency, community mental health, and vocational rehabilitation service systems to identify exemplary supports and services and replicate successful practices throughout New Hampshire.
- ▶ Develop competency criteria for professionals and paraprofessionals who work with individuals with ASD.

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together, there will continue to be confusion about who is responsible for delivering, coordinating, and paying for services. Sadly, when communication breaks down between the family and providers, valuable time and energy are lost. Transitions between service delivery agencies are especially problematic.

The Commission believes that regional and local leadership must mirror the multi-disciplinary model recommended at the state level. Efforts to improve the infrastructure that surrounds front-line providers will only be effective if there are clear and open lines of communication between state-level planning groups, most especially the New Hampshire Council on ASD, and regional leadership. A healthy dialogue will ensure that the statewide Council has adequate information about the needs of individuals, families, and providers. Conversely, it ensures that local public and private providers including schools, area agencies, mental health centers, vocational and other community services are able to take advantage of training opportunities and technical assistance and have a vehicle to share information about exemplary programs and effective practices.

Similarly, there must be a mechanism whereby individual teams, including all relevant services providers, the individual, and his or her family can come together to plan for services. This is especially critical during transitions in educational and service programs and in times of personal and family crisis. In these instances, teams will utilize a collaborative process, often referred to as a wraparound model, to develop a plan for treatment and support that carries over into all environments in which the child, teen, or adult participates. Plans developed through a wraparound model take full advantage of natural supports and community-based opportunities. Based on a family-centered, strength-based philosophy, wraparound is a well-established best practice for supporting those with complex behavioral and medical needs.

KEY FINDINGS

- ▶ At the regional level, New Hampshire does not have an entity with the authority to provide a multi-disciplinary and coordinated response to the challenges posed by the rapidly growing prevalence of ASD.
- ▶ While case management is provided within certain segments of a child or individual's program (for example,

special education), there is no mechanism to develop a coordinated plan of care that addresses needs and takes advantage of strengths across all environments.

- ▶ Despite the opportunities for training and information afforded by the Institute on Disability and others, New Hampshire families whose children have ASD continue to report tremendous difficulty in acquiring a knowledge base sufficient for them to participate most effectively in their child's development.
- ▶ School districts vary widely in the level of intervention that they provide for children with similar needs and in their willingness to seek technical assistance and additional training for their staff members.

RECOMMENDATIONS

1. The Department of Health and Human Services and Department of Education will review and revise their current policies, rules, protocols, contracts, budgets, and activities or embark upon new initiatives in order to provide the most effective and coordinated supports and services for children and adults with ASD.
2. The New Hampshire Council on Autism Spectrum Disorders will identify and engage local leaders in a collaborative effort to create a statewide network of regional autism collaboratives. The regional collaboratives will include representation from schools, area agencies, community mental health centers, early supports and services, vocational rehabilitation services, health care providers, and other relevant public and private agencies. Regional collaboratives will serve as planning groups for services within their catchment areas and as points of contact between the Council and front-line service providers. As part of a statewide network, these collaboratives will be able to share information, maximize training and professional development opportunities, and coordinate efforts across regions.
3. The Department of Education, the Department of Health and Human Services, and the New Hampshire Council on Autism Spectrum Disorders will create regional multi-

(from previous page)

- ▶ Increase resources for individuals with ASD and their families by accessing federal and state grants and pursuing development opportunities through foundations, corporations, and planned giving.
- ▶ Develop a clearinghouse for individuals, families, and providers who are seeking diagnosticians, behavioral specialists, speech pathologists, occupational therapists, psychologists, and others who have expertise in working with individuals with autism spectrum disorders.
- ▶ Facilitate the creation of regional autism collaboratives with representation from local educational, health care, and community service providers and from consumer groups. Regional collaboratives will be charged with promoting a coordinated approach to service delivery, sharing information about successful practices, and working to address gaps in the service system. Effective regional collaboratives will help to ensure that all individuals with ASD and their families are able to access resources and supports in an efficient and timely manner.

disciplinary teams to ensure that individuals with ASD and their families receive needed treatment and supports through a regional wraparound initiative.

4. The Department of Education, the Department of Health and Human Services, and the New Hampshire Council on Autism Spectrum Disorders will work collaboratively to ensure that comprehensive care coordination, family support services, information, and parent training are easily available to parents and other caregivers who support a child, teen, or adult with ASD.
5. The Department of Health and Human Services and Department of Education will support a person-centered approach for planning for individuals with ASD and their families and will promote purposeful and timely planning for program changes. This will include planning for a change in building, a significant change in staff, a major change in program structure, or extended school year programming (ESY). This planning is recommended to occur at least 90 days prior to the program change through a process involving families, the “sending” team, and the “receiving” team.

EARLY IDENTIFICATION AND TIMELY ACCESS TO DIAGNOSIS AND TREATMENT

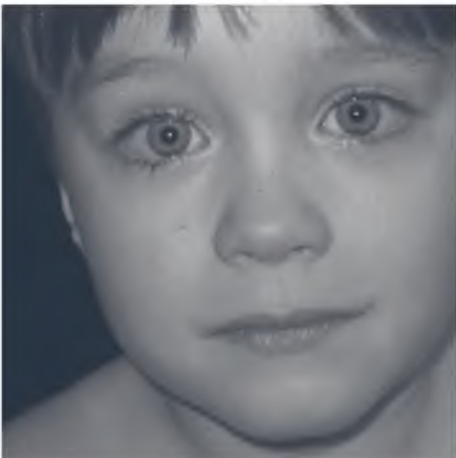
GOAL:

All New Hampshire children will be screened for ASD before age two. All children suspected of having ASD will be referred immediately for early supports and services and undergo a diagnostic evaluation within 45 days. All children with a diagnosis of ASD will have begun a robust program of evidence-based intervention and treatment within 45 days of diagnosis.

UNIVERSAL SCREENING, TIMELY DIAGNOSIS, AND PROMPT REFERRAL

ASD affects one in 150 children in the United States. Among New Hampshire's 15,000 annual births, 100 children per year are destined to experience a condition on the autism spectrum. The tools and systems of care exist so that nearly all of these children could be identified before age two, referred for early intervention and treatment, and provided a future with greater opportunities. Unfortunately, there is a gap between what is and what could be for these children and their families. The average child with ASD is not identified until four years of age, waiting periods of up to six months exist for diagnostic evaluations, and referral for and implementation of intense early services remains inconsistent and inefficient.

In 2008, the American Academy of Pediatrics published new guidelines for primary care physicians and other clinicians providing for a more intense and explicit process of developmental screening during well child visits, including specific screening for ASD at the 18 and 24 months visits.¹⁰ When screening identifies possible ASD,



the new guidelines direct primary care physicians to make an immediate early intervention referral and to arrange for a diagnostic evaluation. These new national professional standards, together with training and tools for their implementation, place universal screening and early referral for ASD among young children within reach. However, delayed access to autism specialists and clinics remains a serious obstacle to timely diagnoses. Shortages of experienced diagnosticians, limited coordination of existing resources, poor reimbursement for team evaluations, and the absence of geographically accessible diagnostic clinics underlie this problem. New sources of funding, new models of collaboration between specialists and primary care physicians, and the implementation of an integrated system of care will be necessary to overcome the diagnosis bottleneck and assure a true continuum of care.

¹⁰ American Academy of Pediatrics. "Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents." 3rd ed. (2008).

KEY FINDINGS

- ▶ Young children are not systematically screened for autism prior to age 2, and their parents' concerns are often ignored or devalued.
- ▶ Intensive supports and services are not provided to children as soon as there is a serious suspicion of ASD, but rather, are delayed until a definitive diagnosis is made. Long waiting times for appointments in autism diagnostic clinics create a cascade of delayed interventions and access to resources.
- ▶ Care and service coordination among families, the primary care medical home, specialists, early intervention services, and school districts is limited or non-existent, and this contributes to poor communication and inefficient use of time and resources.

RECOMMENDATIONS

1. The Department of Health and Human Services, through its Division of Public Health Services, Maternal and Child Health Section, and the Special Medical Services unit of the Bureau of Developmental Services, will develop strong technical assistance for all pediatric primary care settings for the implementation of current nationally accepted autism screening and surveillance guidelines. This effort will include providing information and tools for screening, diagnostic evaluation referral, early intervention and preschool special education referral, individual autism program grants, reporting requirements of the New Hampshire Autism Registry, and connection to available parent-to-parent and family support services, including the Autism Society of New Hampshire. Possible collaborators include the New Hampshire Area Health Education Centers, the Foundation for Healthy Communities, the New Hampshire Pediatric Society, and the New Hampshire Chapter of the American Academy of Family Physicians.
2. The Department of Health and Human Services and Department of Education, through an interagency agreement, will adopt and endorse the two most recent national health care guidelines on ASD: *Medical Home Services for Autism Spectrum Disorders*, published by the United States Maternal and Child Health Bureau through the National Medical Home Autism Initiative, and *Bright Futures*, the guidelines for child health supervision developed by the American Academy of Pediatrics. These guidelines call for universal screening of all children for ASD through continuous surveillance, the use of autism-specific screening tools, and the valuation of parental concerns. They recommend prompt referral for both early intervention and timely diagnosis and endorse a minimum of 25 hours per week of structured programming.
3. The Department of Health and Human Services, through the Bureau of Developmental Services and in collaboration with the Department of Education, will identify and support leadership for a regionalized system of autism diagnostic clinics using or expanding upon available resources to increase access



to timely diagnostic evaluations by improving geographic access and reducing wait times for clinical appointments. It may be possible to build upon services provided through the New Hampshire Office of Special Medical Services (Title V—Children with Special Health Care Needs agency) by identifying autism as needing systematic care coordination and service integration among available providers. This effort could follow the models of other SMS clinical services in child development and neuromotor conditions. In addition, new grant opportunities through the US Maternal and Child Health Bureau’s LEND (Leadership Education in Neurodevelopmental and Related Disabilities) program should be pursued.

4. The Department of Health and Human Services and Department of Education will work collaboratively to ensure consistent eligibility criteria for services that include all individuals with ASD, including those with a diagnosis of autism, Asperger syndrome, and pervasive developmental disorder not otherwise specified (PDD–NOS).

THE IMPORTANCE OF WIDESPREAD PUBLIC AWARENESS

Autism spectrum disorders are prevalent, identifiable in early childhood, and treatable using evidence-based interventions. These three facts have an important bearing on the outcomes for young children, on the actions of professionals, and on the willingness of the public and their representatives to invest in needed services. While the public has a better understanding of autism than it did a generation ago, few citizens are familiar with the most common symptoms of ASD in young children; with the understanding that ASDs are neurodevelopmental disorders with a biologic basis; with the fact that early screening and identification is not only possible, but recommended for all children; and with the improved outcomes associated with early diagnosis and robust treatment. Many people have outdated, narrow, deficit-oriented beliefs about autism and fail to appreciate the diversity, potential, and contributions that individuals with ASD bring to their families and communities.

KEY FINDINGS

- Parents of young children, particular those of first children, have limited information about developmental and behavioral expectations in their young children and virtually no information about “warning signs” for autism spectrum disorders.
- The general public is unaware that early identification and intensive, evidence-based interventions substantially improve outcomes for children with ASD and reduce the intensity of intervention that they will need later in life.
- Too few professionals in medicine and education work in partnership with individuals with ASD and their families. In order to provide the most effective services and supports, professionals need to recognize and appreciate the expertise and special knowledge that parents have about their children with ASD.

RECOMMENDATIONS

1. The Autism Society of New Hampshire, in partnership with the New Hampshire Division of Public Health Services and other public and private agencies, will launch the New Hampshire Autism Awareness Campaign for the general public, all families of young children, medical professionals, child care providers, early childhood educators, and therapists. The Awareness Campaign will include multi-tiered messages about the prevalence of ASD, the earliest signs and symptoms, available sources of information and support, diagnostic services, and evidence-based and other promising approaches to treatment and intervention. In addition, the Awareness Campaign will emphasize the importance of family strength and resilience and recognize that families should be included as active partners in all matters regarding their children with autism spectrum disorders. Families and individuals with ASD will be involved in planning and delivering the awareness messages and information. Collaboration to develop and promote the Awareness Campaign will be sought from organizations such as the Preschool Technical Assistance Network, New Hampshire Area Health Education Centers, Institute on Disability, Crotched Mountain Foundation, Easter Seals, the Dartmouth Hitchcock Medical Center Division of Child Development and Department of Psychiatry, Asperger's Association of New England, the Autism Certificate Program of Antioch University New England, the New Hampshire Department of Education, and other public agencies.
2. The Department of Health and Human Services and Department of Education, through an interagency agreement, will develop and periodically publish a report of autism-related data organized by state and by county. These data will be made transparent and publicly accessible in a user-friendly format and will include, but not be limited to, information contained in the New Hampshire Autism Registry.

SUCCESSFUL TRANSITION TO ADULTHOOD

GOAL:

All New Hampshire students and young adults with ASD will be given the opportunities and supports needed to make a successful transition to adulthood and to be engaged and contributing members of their community.

ENABLING INDIVIDUALS WITH ASD TO REALIZE THEIR POTENTIAL

New Hampshire communities make a significant financial investment to educate their students with special needs, including those with ASD. If this investment is to pay future dividends, it must include a well-conceived and comprehensive approach to supporting these young people to successfully move on to adulthood. Individuals on the autism spectrum and their families often characterize this period of transition as frustrating, stressful, and prolonged. For adults with ASD who were diagnosed after leaving school or who received less than adequate educational supports and services, the journey to adulthood can be especially trying. Even those who have obtained a four year college degree may struggle to find meaningful and sustained employment. For some, it is only at this juncture in their lives that they realize they have been underserved by their education.

Given appropriate training and supports, however, individuals with ASD have demonstrated the capacity to work in the competitive labor force. In fact, despite their many challenges, individuals with ASD often possess striking niche talents that are highly valued when appropriately matched with employer needs. With the provision of specialized teaching strategies, accommodations, and supports, post secondary education can be a reality for many individuals with ASD. Unfortunately, in New Hampshire and nationwide, independence and productivity are not realities for most adults with ASD. The vast majority of adults with ASD are either unemployed or woefully underemployed. Without opportunities or training to acquire the skills that are needed to live independently, most adults with ASD continue to live with their parents or other family members.

The failure to provide quality—or even merely adequate—training and support during the years of transition exacts significant personal and societal costs. The loss of productivity both for unemployed adults with ASD

and for the parents or siblings who give up their jobs to become caregivers, has a profound financial and emotional impact on families. For society, the long term cost of serving individuals with ASD in non-work programs is far greater than offering accommodations and supports to students in post secondary education or providing quality vocational training and careful job matching that will enable these individuals to succeed in the competitive labor market.



KEY FINDINGS

▶ Youth employment is the norm in American society; according to the National Research Council approximately 80% of youth hold jobs during

high school. However, only 15% of youth with ASD are similarly employed, the lowest rate of any major disability category.¹¹

- ▶ A 2002 survey of 405 individuals with ASD living in Massachusetts and Wisconsin found that only 4% lived independently, 73% lived with their parents and 13% live semi-independently; of those old enough to work, 90% could not obtain and/or maintain competitive employment; and a full 95% of those surveyed had difficulty making and keeping friends.¹²
- ▶ Employment of adults with ASD typically requires accommodations and accessibility as outlined in the Rehabilitation Act of 1973 and the Americans with Disabilities Act of 1990.¹³
- ▶ Programs and supports that were designed originally for individuals with cognitive disabilities often fail to address the unique environmental, behavioral, communication, and sensory considerations that make ASD a distinct condition. Many adults with ASD require highly specialized supports delivered in a consistent, predictable manner over a long period of time.

RECOMMENDATIONS

1. The New Hampshire Department of Health and Human Services and the Department of Education will work collaboratively to ensure that, beginning in the early teenage years, individuals with ASD are offered opportunities for a variety of work experiences during typical life and school routines. These will include providing vocational assessment, job development, job training, and employment supports on a time-limited and long-term basis, depending upon the strengths, talents, needs, and choices of the individual.
2. The Governor’s Task Force for Employment and Economic Opportunity for People with Disabilities and Department of Education Bureau of Career Development will work with New Hampshire’s business community to help them identify ways in which individuals with ASD can help meet New Hampshire’s workforce needs.
3. The New Hampshire Council on ASD will work with the Institute on Disability, the Department of Vocational Rehabilitation, and other organizations to pilot innovative supported employment initiatives for individuals with ASD. These programs should take full advantage of existing, evidence-based strategies for effective job development, placement, and retention.
4. The New Hampshire Council on Autism Spectrum Disorders will facilitate efforts to provide individuals with ASD with the supports necessary to participate in the same opportunities for post secondary education, technical school and training, community service, volunteerism, civic involvement, and independent living that are available to their peers.

11 Cameto, C. et al. Reports from the National Longitudinal Transition Study. (2003).

12 Seltzer and Krauss. (2002).

13 Dew, D. W. and Alan, G. M. “Rehabilitation of individuals with autism spectrum disorders.” Institute on Rehabilitation Issues Monograph. The George Washington University, Center for Rehabilitation Counseling Research and Education. 32 (2007).

SAFETY

GOAL:

All providers of emergency services will be aware of the sensory, behavioral, and social differences of individuals with ASD and how to appropriately accommodate their needs.

BEHAVIORS ASSOCIATED WITH ASD PUT INDIVIDUALS AT RISK OF BEING MISUNDERSTOOD AND EXPLOITED



Safety is a critical but often overlooked issue for individuals and families affected by ASD. For a number of reasons, this population is at high risk for encounters with police and other first responders. Like people with Alzheimer's, there are children and adults with ASD who wander, often oblivious to the dangers posed by traffic, water, deep woodlands, or other people. Individuals with ASD may be unable to provide such basic information as their name and address, especially if they are in stressful situations or unfamiliar environments. Their inability to respond appropriately to simple questions is particularly problematic, as some behaviors associated with ASD are often mistaken as indicating drug or alcohol use and the lack of eye contact typical for individuals with ASD may be misinterpreted as guilty intent. In addition, their poor understanding of social cues and confusion about social situations and interpersonal relationships makes this population especially vulnerable. Children and adults with ASD can be easily manipulated by others and are often the victims of bullying, exploitation, and more serious crimes.

Fortunately, our state has begun to lay the groundwork for safety awareness. A training curriculum for police has been developed and piloted in a number of New Hampshire towns. Training is provided bi-monthly to 911 dispatchers and a process for registration in the 911 Data Base has been established. A booklet for families, *Safety First*, has been developed, although it needs to be more widely distributed. New Hampshire would benefit greatly from expanding these initiatives and making basic training and information on this topic available throughout the state as soon as possible.

KEY FINDING

- Individuals with ASD are four to seven times more likely to have an encounter with law enforcement than the general population.¹⁴ Police, search and rescue personnel, and other first responders all confirm that they have encountered serious situations involving individuals with ASD here in New Hampshire.

¹⁴ Debbaudt, D. and Rothman, D. "Contact With Individuals With Autism: Effective Resolutions." FBI Law Enforcement Bulletin, 7.4 (2001): 20-24.

RECOMMENDATIONS

1. The New Hampshire Department of Safety Police Standards and Training Council and Division of Fire Standards and Emergency Medical Services, collaborating with interested organizations and state agencies, will work to ensure that training about autism spectrum disorders is widely available to all first responders and included in the curriculum of the New Hampshire Police Academy.
2. The Autism Society of New Hampshire, in collaboration with the New Hampshire Department of Health and Human Services, the Department of Education, and the New Hampshire Pediatric Society, will undertake an ASD safety awareness initiative. This effort will include distribution of *Safety First* and related materials to families and collaboration with primary care and mental health practitioners, educators, and childcare providers to encourage the discussion of safety issues in the routine care of children and youth with ASD. Other audiences for this awareness initiative will be school nurses, emergency room personnel, and search and rescue providers.
3. The Department of Education will work in partnership with local schools to ensure that information about autism is included in educational and prevention programs that address bullying.



PROFESSIONAL DEVELOPMENT

GOAL:

Expand evidence-based, high quality pre-service and in-service professional development, technical assistance, and mentoring opportunities to ensure that New Hampshire has a workforce that is capable and confident in its ability to support individuals with ASD to be fully included in all aspects of their community.

IMPORTANCE OF HIGHLY QUALIFIED PERSONNEL

New Hampshire's workforce has not kept pace with the dramatic rise in the number of individuals affected with autism spectrum disorders. In all disciplines, at both professional and paraprofessional levels, there are critical shortages of workers qualified in the area of ASD. There simply are not enough educators, direct support professionals, health care providers, and other specialists to meet the needs of this population. Not only is there a shortage of personnel, those who are in the workforce often lack the necessary knowledge and skills to deliver high quality services to individuals with ASD and their families.

Several studies have documented this workforce crisis. In its 2004 report, the Center on Personnel Studies in Special Education found that 98% of the nation's school districts report shortages of special education personnel. A recent report by the US Department of Health and Human Services predicts that by 2020 the nation will need 37% more direct support professionals in order to meet the long-term support needs for citizens with intellectual and developmental disabilities.¹⁵ New Hampshire's developmental services system is already feeling this squeeze with up to one third of its direct care workforce leaving within a year.¹⁶

In order for New Hampshire's children and adults with ASD to achieve positive outcomes, those who work in our state's public schools and community service programs need to be well versed in evidence-based and other best practices. With support from highly qualified personnel, students with ASD are more likely to be fully included in regular classrooms with access to the general curriculum. When youth and adults with ASD receive appropriate supports and services, they are more likely to go on to post secondary education, to be gainfully employed, and to be actively engaged in civic and community life. The realization of these positive outcomes will require a commitment to provide quality professional development, training, and mentoring opportunities for the professionals and paraprofessionals who support individuals with ASD.

KEY FINDINGS

- The lack of teacher training and leadership has direct bearing on outcomes for students with ASD. IDEA (Individuals with Disabilities Education Act) data show that students ages 6-21 with ASD receive their education outside regular education classrooms more often than students who have other disabilities. In New Hampshire the number of out-of-district placements for students with ASD

¹⁵ US Department of Health and Human Services. "Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities: Report to Congress." (2006).

¹⁶ Telephone survey of NH Area Agency Directors. (2008).

is higher than the New England average. Students with ASD also are less likely to graduate with a standard diploma than students who experience other disabilities.¹⁷

- ▶ In its 2003 survey, the Institute on Disability found that only 52% of New Hampshire teachers and administrators felt positively about their experience in educating students with ASD and only 25% reported they were adequately trained to work with this population.
- ▶ The direct care workforce has few opportunities for professional development related to effective practices for individuals with ASD. The Bureau of Developmental Services offers limited scholarships for courses leading to a Certificate in Human Services or Community Social Service. However, the curriculum for this certificate program does not include information on ASD.
- ▶ In the training and/or certification standards for New Hampshire educators and other professionals, there is currently no requirement concerning knowledge or competencies in ASD.

RECOMMENDATIONS

1. The Department of Health and Human Services and the Department of Education will conduct a comprehensive statewide needs assessment of in-service and pre-service education and training opportunities and identify gaps in the current system and will pursue existing and additional resources to fill these gaps.
2. The Department of Education and Department of Health and Human Services will identify resources to develop, deliver, and market pre-service and in-service professional development opportunities that promote nationally recognized evidence-based and other best practices for treatment and support for individuals with autism spectrum disorders. This training will be available to a wide constituency including: educators, service providers, therapists, physicians, public guardians, educational advocates, case managers, and individuals with autism spectrum disorders and their families.



3. Institutions of higher education, in collaboration with the Department of Education's teacher education program, will expand efforts to recruit faculty in post secondary institutions who have expertise in autism spectrum disorders.

4. The Department of Health and Human Services, Department of Education, and institutions of higher education will ensure that pre-service and in-service professional development efforts include opportunities for individuals with autism spectrum disorders and their families to share their knowledge and personal experiences.

¹⁷ US Department of Education. "IDEA." (2006).

5. New Hampshire's institutions of higher education and the Department of Education's Bureau for Credentialing will offer scholarships, loan forgiveness, and opportunities for alternative certification as incentives to encourage students in undergraduate and postgraduate programs to pursue careers in the field of autism spectrum disorders in New Hampshire.
6. The New Hampshire Board of Allied Health will amend professional certification requirements to include knowledge of best practices for supporting individuals with autism spectrum disorders.
7. The Department of Education will amend state teacher certification requirements to include knowledge of best practices for teaching students with educational disabilities, including autism spectrum disorders.
8. The Professional Standards Board and the Council for Teacher Education will develop recommendations for the State Board of Education to address New Hampshire's growing need for behavioral specialists, communication specialists, psychologists, and special educators to work with individuals with autism spectrum disorders and their families.
9. The Department of Health and Human Services and the Department of Education will collaborate with the Board of Allied Health, the Board of Mental Health Practice, and the Professional Standards Board to develop recommendations to address New Hampshire's growing need for occupational therapists, speech and language pathologists, mental health practitioners, licensed assistants, paraprofessionals, and others to work with individuals with autism spectrum disorders and their families.
10. The New Hampshire Community College System will develop and promote a certification program for paraprofessionals working in schools and direct support professionals working in community-based services with individuals with autism spectrum disorders.
11. The Department of Health and Human Services will increase the Medicaid reimbursement rate for paraprofessionals and direct service professionals trained in supporting individuals with autism spectrum disorders.
12. The Department of Education's *Open NH – An Online Professional Education Network*, the state's institutions of higher education, and other professional development programs will expand distance and online learning opportunities that include offerings related to all areas of autism spectrum disorders.
13. The Department of Education will revise its Paraprofessional Certification program to include information on best practices for supporting students with autism spectrum disorders.
14. The Department of Education will revise Education Rules 500 - 610.02 to include the labels of autism and autism spectrum disorders and competencies related to curriculum and instruction.

FUNDING

GOAL:

Funds from multiple sources—public and private, federal and state—will be brought together to ensure that New Hampshire can develop and sustain the infrastructure, workforce, and knowledge-base necessary to meet the public health challenges of ASD, and that the individuals served by this system receive medically necessary treatment(s) and the ongoing support needed to live a productive life of their own choosing.

ELIGIBILITY AND THE PARTICIPATION OF HEALTH INSURANCE PROVIDERS

It is critical that New Hampshire find the resources to meet the needs of individuals with ASD and their families. Investing in treatment and supports—including family supports—will pay future dividends by both lowering the lifetime cost of care for individuals with ASD and ensuring that a far greater number of adults with ASD become productive members of the workforce. There is growing evidence that investment in supports and treatment also will lower the substantial indirect costs exacted by ASD. These include the costs associated with family breakdown, impact on siblings, strain on family finances, and the effect on the physical and mental health of the primary caregiver.



Sufficient monies from state and federal sources must be directed toward the treatment and services for children with ASD who need intensive early intervention services and in-home supports. Not only will providing these services maximize each child's developmental potential, they also will prevent costly out-of-home placements and more expensive lifelong supports. In order to mitigate the long-term economic impact of ASD, New Hampshire must take full advantage of available federal resources; this may require making significant adjustments to the state's enrollment process and eligibility criteria for Medicaid.

Public funds alone, however, cannot carry the up-front cost of providing intensive early treatment. Imagine a balanced and fair approach for funding the care of a child with ASD as a three-legged milking stool: one leg represents public spending for treatment and support, including Medicaid, special education funds, and other government programs; a second leg represents the cost borne by the child's family both directly and indirectly; and the third leg represents private health insurance. It is in the interest of New Hampshire that all health care payers, including private insurers, come to the table to negotiate a more balanced approach to funding the treatment of ASD.

KEY FINDINGS

- Presently, none of the private health insurance companies operating in New Hampshire adequately cover the intensive evidence-based treatments recommended for children with ASD. As a result,

families are unable to access the level or intensity of services recommended by the National Research Council (2001) and other professional groups.

- ▶ Under New Hampshire's current Medicaid program for Children with Severe Disabilities (HC-CSD, commonly known as the "Katie Beckett" option) children with ASD may not be found eligible for Medicaid services. In contrast, children with other neurologically based medical conditions are routinely found eligible for this benefit.
- ▶ Recommended treatment and ongoing support of individuals with ASD often includes health care services such as occupational therapy, physical therapy, speech language therapy, and group and individual psychotherapy. In some cases, private insurers will not provide any coverage for these services if they are related to an individual's diagnosis of ASD.

RECOMMENDATIONS

1. Through the Department of Health and Human Services, Medicaid eligibility under HC-CSD (Katie Beckett) for children with ASD will be brought into parity with other neurologically based medical conditions.
2. Both public and private insurance coverage for the evidence-based, intensive treatment of ASD will mirror coverage for the treatment of other neurological conditions. The New Hampshire Council on ASD will work with the New Hampshire Insurance Commission, the New Hampshire Department of Health and Human Services, and New Hampshire Healthy Kids to identify where coverage and/or the rate of reimbursement is not comparable and shall consider strategies to address these gaps.

SCHOOL AND COMMUNITY SERVICES

Consumer directed models of service delivery have emerged nationally as a cost-effective vehicle for funding the intensive treatment of ASD that is specified in the National Research Council guidelines. This model typically provides families with an annual budget and allows them—within broad guidelines—to decide how to best use these funds to benefit their family member. For children with ASD who need an intensive, structured program of at least 25 hour/week, the consumer-directed model has many advantages. It allows families the flexibility to spend a portion of their budget for professional consultation, equipment and environmental modifications, and parent or provider training. It also enables families to set a wage that will allow them to hire one-on-one providers capable of implementing the program that they have chosen.

Nationally, the principle mechanism for funding consumer-directed services is the Medicaid Home and Community Based Care Program. This model has rapidly gained popularity with over 300 such programs in place nationally; fully one third of these are structured to include individuals with ASD. Six states have Community Based Care programs exclusively designed for the ASD population. In 2003, New Hampshire initiated its In-Home Supports Program for those Medicaid-eligible children three to 21 who have the most intense needs. While need has far outpaced funding, participating families with children on the autism spectrum report a high degree of satisfaction with this program.

In 2005 New Hampshire began a targeted program for children ages birth to three with ASD who are receiving Early Supports and Services (ESS). Known as the Autism Proposal, this program taps a separate pool of federal funds¹⁸ to increase the number of hours of one-on-one treatment that a child can receive. A task force of parents and professionals convened in spring 2007 recommended increased flexibility in the use of these supplemental funds. Subsequently, wage guidelines have been relaxed to allow families to choose their providers, both professional and paraprofessional, at market rates.

While the Bureau of Developmental Services is to be commended for its efforts to increase service dollars and to allow families greater flexibility in the use of these funds, much more remains to be done. First and foremost, the availability of intensive supports should be extended to all children with ASD. The number of children and youth in need of intensive, structured supports far exceeds the capacity of New Hampshire's current developmental services system. Similarly, the state's educational system is overwhelmed by the increased demands placed upon it by a rapidly growing ASD population. Local school districts have neither the expertise nor the resources to provide the level of intensive one-on-one support and sophisticated behavioral interventions that families are seeking for their children with ASD.

KEY FINDINGS

- ▶ Currently, the Autism Proposal provides \$4500/six-month period; on average, this would be sufficient to cover about 10 hours/week with a paraprofessional and 2-3 hours/month of professional consultation. Along with other ESS supports, funding at this level remains well below that required to support the minimum 25 hour/week intensive program that is recommended by the National Research Council.
- ▶ There are 230 In-Home Supports Programs active in New Hampshire, with just over half (51%) assigned to children with ASD. All area agencies have waiting lists for this program; roughly half (54%) of the families requesting In-Home Supports have children on the autism spectrum.
- ▶ Transition at the age of three from Early Supports and Services to school is complicated by changes in the funding stream that supports a child's program, often resulting in service gaps, conflict, and a decline in the number of hours of one-on-one, behaviorally oriented treatment. Some families must wholly change the approach used in the treatment program for their child.
- ▶ Additionally, there are many children who are not identified or diagnosed prior to age three and who have not received the early supports and services that they need. For these children intensive autism school services will need to be initiated.

RECOMMENDATIONS

1. The Department of Health and Human Services Bureau of Developmental Services, will request or identify additional funds to provide intensive autism treatment for children birth through age three.

18 These funds are available under Part C of IDEA.



2. The Department of Education will issue a memo to the state's local school districts regarding national guidelines for recommended intensive supports and intervention for children with ASD.

3. The Department of Health and Human Services Bureau of Developmental Services will request or identify additional funds to expand the number of In-Home Supports Programs.

4. The New Hampshire Council on ASD will advocate for improving the capacity of the area agency system and eliminating the waiting list for developmental services by July 1, 2010 as set out in SB 138.

FUNDING SPECIFIC TO THE IMPLEMENTATION OF THESE RECOMMENDATIONS

The New Hampshire Commission on ASD has identified two immediate funding needs and is committed to assisting the Department of Health and Human Services in securing these resources.

RECOMMENDATIONS

1. In collaboration with Department of Health and Human Services and the Autism Society of New Hampshire, the Commission will seek grant funding to initiate the New Hampshire Autism Awareness Campaign.
2. In collaboration with Department of Health and Human Services and other stakeholders, the Commission will identify and secure funding for an Executive Director for the New Hampshire Council on ASD; this will be a full-time position housed within the DHHS Bureau of Developmental Services. With the Council, the Executive Director will provide leadership in pursuing the recommendations of this Commission.

ACKNOWLEDGEMENTS

In its 2007 Session, the state legislature established the New Hampshire Commission on Autism Spectrum Disorders to study the impact that ASD has had on our state and to make recommendations concerning the care, treatment, and quality of life for individuals with ASD and their families. Those on the Commission brought wisdom and compassion to this work and gave generously of their time and talent. For their contribution to the Commission and, more importantly, for their ongoing commitment to New Hampshire citizens with ASD we are sincerely grateful.

NEW HAMPSHIRE COMMISSION ON AUTISM SPECTRUM DISORDERS

COMMISSION CHAIR
Rep. Suzanne S. Butcher
Parent
State Representative

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GLOSSARY

Applied Behavior Analysis (ABA): ABA is an individualized and intensive treatment that includes a variety of assessment and intervention strategies. This evidence-based approach seeks to build upon adaptive behaviors and reduce the frequency of challenging behaviors.

Asperger Syndrome (AS): One of the autism spectrum disorders, essentially the same as autism except there is no early language disturbance. Individuals with this syndrome have problems understanding how others view their behavior and often experience difficulties in forming friendships. As in autism, unusual preoccupations and interests characterize people with AS. Many individuals with AS have a strong need for predictability.

Autism Spectrum Disorders (ASD): Includes autism, Asperger syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). All autism spectrum disorders include difficulties in communication and social interaction. Individuals with ASD also exhibit restricted or repetitive behaviors or interests and often have unusual responses to sensory experiences. The extent and severity of these difficulties varies among the diagnoses and among individuals.

Behavior Specialists: Professionals with expertise in working with persons who have challenging behaviors.

Combating Autism Act: This federal legislation passed in 2006 authorized \$920 million in federal funding for a variety of autism initiatives.

Diagnostic Evaluation for Autism: A full clinical assessment to determine if a child meets the diagnostic criteria for any autism spectrum disorder. There is no medical test for ASD; a comprehensive evaluation is needed. The evaluation may include: physical, neurological, psychological and genetic testing; clinical observations; parent interviews; developmental histories; speech and language assessments; and behavioral observations.

Direct Support Professionals (DSP): Individuals employed to help people with disabilities during daily activities.

Early Supports and Services (ESS): Also known as “Early Intervention,” provides identification and intervention services for children birth to three. This service is provided by New Hampshire’s ten area agencies.

Evidence-based Treatments: Treatment and educational strategies whose efficacy has been validated through published research in peer-reviewed professional journals.

Expanding the Promise for Individuals with Autism Act: Federal legislation (S397/HR1881) introduced to Congress in 2007, but not yet approved, that would dramatically expand federal funding for life-long services for people with ASD.

Extended School Year Programming (ESY or EYP): Refers to special education or related services that are provided beyond the normal school year. ESY may be provided during school breaks, after school, and during

summer vacation. ESY is included in the federal law that entitles all students with disabilities to a free and appropriate education. The student's Individual Planning Team determines whether ESY is provided.

HB 396: The 2007 legislation that established the New Hampshire Commission on Autism Spectrum Disorders to make recommendations for improving services to individuals with autism.

HB 1634: Legislation proposed in 2008 to establish the New Hampshire Council on Autism Spectrum Disorders.

IDEA: *The Individuals with Disabilities Education Act (IDEA):* The federal law ensuring a free and appropriate public education to all children with disabilities. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.

LEND: *The Leadership Education in Neurodevelopmental and Related Disabilities:* A program administered through the Federal Maternal and Child Health Bureau that provides grants to train interdisciplinary health professionals who will work to improve the health status of children with, or at risk for, neurodevelopmental and related disabilities, and their families.

Medical Home: A community-based primary care setting which provides and coordinates high quality, planned, family-centered health promotion and chronic condition management.

Multi-disciplinary Model: An evaluation and intervention approach that involve professionals from several disciplines (such as education, psychology, medicine, occupational therapy, speech-language pathology) working in conjunction with the individual and family. This model also may include multiple public and private agencies.

New Hampshire Autism Registry: A state registry in the Department of Health and Human Services that was established by the New Hampshire legislature in 2006 to record all newly diagnosed cases of autism spectrum disorders that occur in the state.

New Hampshire Task Force on Autism: A group of representative stakeholders convened by the Bureau of Developmental Services in 2001-2002 to make recommendations to the state of New Hampshire concerning the care and treatment of individuals with autism. The Task Force produced a report on assessment and interventions.

Occupational Therapy (OT): Intervention to help individuals in the areas of fine and gross motor development, visual motor integration, visual perception, neuromuscular control, response to sensory stimuli, bilateral coordination, and motor planning. Some occupational therapists have training in sensory integration.

Paraprofessional: A trained worker who is not a member of a given profession, but assists a professional.

Person-centered Planning: An individualized planning process that takes into account the person's unique strengths, learning styles, and circumstances. The person with a disability and the family drive the process and have ultimate responsibility for making decisions about services and supports.

Pervasive Developmental Disorder (PDD): A diagnostic category of disorders that includes autism, Asperger syndrome, childhood disintegrative disorder, Rett syndrome, and PDD-NOS. PDD is often used synonymously with ASD.

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS): Also called atypical autism, includes individuals who have symptoms common with autism, but who do not meet all of the criteria that are required for autism or Asperger diagnoses.

Physical Therapy: Use of therapeutic exercise to restore or facilitate function, improve mobility, relieve pain, and prevent or limit permanent physical disabilities. Some physical therapists have training or certification in sensory integration.

Sensory Integration Difficulty: Differences in integration and organization of sensory input that can result in an inability to interact with people and the environment appropriately.

Speech and Language Pathologists: Certified professionals who treat disorders related to speech, language, cognitive-communication, voice, swallowing, and fluency

Wraparound: A planning process for children and families who have complex and multiple needs that looks to the services and supports in the community, helps families to make connections, and respects family culture and values. It typically involves collaboration of community agencies such as the school system, area agency, community mental health center, and Division for Children, Youth and Families.



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