

NH Statewide Autism Spectrum Disorder Needs Assessment

Executive Summary 2014



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Introduction

The NH Statewide Autism Spectrum Disorder (ASD) Needs Assessment Report is the result of significant effort by a committed group of stakeholders. Families, advocates, and providers have sought to improve the services and supports available for children, youth, and young adults with ASD and related Developmental Disabilities (DD) for over a decade. Significant policy and practice have been achieved and through a Maternal and Child Health Grant has now had the opportunity to develop a coordinated state plan informed by a comprehensive needs assessment.

Autism spectrum disorder (ASD) is a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. ASD is characterized by persistent differences in communication and social interaction across multiple settings and restricted and repetitive behaviors, interests or activities. Characteristics of ASD affect an individual's functional abilities related to communication, social interaction, occupations, and other important areas of development. The observed differences are not explained by intellectual disability or global developmental delays. Signs of ASD begin during early childhood and usually last throughout a person's life¹.



The population addressed through this needs assessment was defined as children and youth with ASD and related DD between the ages of birth to 21 years and young adults between the ages of 18-26 years and their families. The methodology used for this needs assessment consisted of collaborating with state partners, reviewing existing data, and collecting additional data with needs assessment activities.

Partners included representatives from Special Medical Services (SMS), NH Family Voices (NHFV), NH Council on ASD, NH Leadership Education in Neurodevelopmental Disabilities (NH LEND), and Child Health Services as part of a core work group. Additionally the NH Council on ASD created a Needs Assessment Work Group (NAWG) to support the needs assessment process.

The needs assessment work group reviewed available data sets including:

- (a) Department of Education – Special Education Census Data (federal and state),
- (b) NH Registry for ASD,
- (c) National Survey of Children with Special Health Care Needs, and
- (d) Needs Assessment Survey of NH Families and Young Adults with ASD completed by SMS in 2012.

Services

**Information
about Services**

**Coordination of
Care**

Transition

Resiliency

Following the review of data, the NAWG identified five broad focus areas. These focus areas were used to drive the data collection to further inform the needs assessment. Data was collected at family focus groups, a young adult discussion, and stakeholder forums. This executive summary highlights findings in each of the five areas. A total of eight parent focus groups, including two conducted in Spanish, were held across the state. Additionally, one young adult forum was held. Flyers and information were distributed on various list serves, through social media, and through the NH Council and NAWG. Families of individuals across the age-span were recruited to ensure broad representation of families' experiences. All participants were given an incentive to support their participation in the focus groups.

¹ American Psychiatric Association. Diagnostic and statistical manual of mental disorders, Fifth Edition. Arlington, VA: American Psychiatric Association; 2013.

Services

Participants were asked to provide information about the services they currently receive and if there were any services they felt they needed but were not currently receiving.

Many families mentioned the need for qualified providers who are knowledgeable about ASD, including teachers, childcare providers, in-home support providers, and paraprofessionals. Families frequently mentioned the need for provider training and concerns about high provider turnover as it related to qualified providers for their children. Regional differences were evident, with families in the North Country and Central Southwestern regions describing a lack of available clinical services such as speech-language and occupational therapies as well as health care providers who are knowledgeable about ASD. Families and stakeholder expressed concerns about transportation. It is hard for families in different geographic areas of the state to access services. Equal access to ABA services and reimbursement for these services was consistently identified by families as a high need. The need for crisis intervention and support was also raised by families and stakeholders alike as a high area of need.

Themes emerged regarding needed services to support the transition to adult life. Families described needs related to support for college job training, career counseling, and general support for the transition to adult services. Some families described housing needs and the need for varying levels of support for living independently in the community. Finally, another important need identified by families was related to funding and the allocation of financial resources in schools, within Area Agencies, and through Medicaid. Concerns were raised regarding Medicaid funding for ABA and other services, such as technology and therapeutic riding. Families expressed a need for more information about what funding resources exist, confusion over eligibility requirements, and felt that such information is not readily shared with families. Many families described the financial hardship they endured, including the need for one family member to quit their job to care for their child or youth.

Information About Services

Participants were asked to “think-back” to a time when they were seeking services for their child and family, themselves or a family they worked and how they typically learned about supports, services, or resources.

Families and stakeholders agreed on the importance of families having access to information about specific services and next steps at the time of diagnosis. They also thought having information regarding transitions, such as the IEP process as they entered the school system, and information about adult services, was important for families as well. Stakeholders recognized families and providers find information in different ways and through different resources.. Families reported having a good resource coordinator in their Area Agency was very helpful in gaining information. Stakeholders also identified families are often given no information about next steps beyond the initial diagnosis. Families described wanting information about respite, educational opportunities (such as conferences), services, funding, and support groups.

Much of the responsibility lies with families to find and verify information. Many families are referred to the Internet to find information, including using social media sites to ask other families for information. Support also needs to be given to families that may have limited reading and comprehension skills. Participants expressed the importance of families having access to printed materials as well as online resources.

Latino parents described consistently not having access to information and services, particularly regarding behavior supports. They advocated for better information and easier, less expensive access to necessary services. Latino parents are anxious and eager to learn about how to help their children. Lack of appropriate, easily accessible information was a commonly heard concern in the Spanish-speaking Family Focus Groups. Families noted the “absence of Spanish speaking interpreters or staff who answer the phones or help with registration” at providers’ offices.



Participants indicated a number of gaps in finding information about available services. Families and stakeholders felt there was variation across regions regarding where they typically got information. They thought information should come from one primary source, and noted the importance of having regional information available. Additionally they thought families needed to have multiple points of entry at health care facilities, child care centers, schools, and other service providers to get information. Families and stakeholders noted the need for schools to have an Autism Coordinator to support them in where to get information. Some families expressed a need to connect to other families. The rules around privacy were noted as a barrier to being able to connect with other families.

Coordination of Care

Children and youth with ASD tend to have complex needs related to their education, behavior, health, and social relationships. This complexity requires coordination between all of the providers and agencies or organizations involved. Participants were asked how this coordination happens for their family, themselves, or the family members they worked with.

The answer most commonly given by parents, young adults, and stakeholders regarding who coordinates care was that parents are really the ones coordinating their family members' care across systems. The coordination of care is very time consuming for families. Some families described this as a "full-time job" and the task being "exhausting" and "overwhelming. When asked about coordination of services, the young adults also indicated their family was involved in coordination in some way. They all expressed wanting to be more independent with coordinating their health care and other services but would need support to accomplish this.

Families and stakeholders noted the importance of having access to care coordination following a diagnosis of ASD. It is important to them that individualized care coordination focuses on strengths and skills, as well as providing choices. Information needs to be understandable and translated as needed to support families' coordination.

Families and stakeholders noted that many families would like support with coordinating care. When a child has extensive medical needs, families would like to have a health care provider coordinate care through a medical home, including insurance coverage and options. Assistance with applications to programs would also be helpful.

Transition

Participants were asked to describe how their child or family, they themselves, or how the families they worked with have moved through the education and health system. They were asked to touch upon transitions they had most recently or were currently experiencing

Families and stakeholders spoke of different transitions they had experienced, from early intervention to school; transitions within school from preschool to elementary, to middle school or high school; and then the adult system. Having knowledge and understanding of all of their child's rights assisted families to advocate for what their child needed during these transitions. They indicated having a team that worked well with them was important. Likewise, having clear expectations and a voice in the process of transition is most helpful. Families are often focused on what is currently going on in their lives and they need time to prepare for change. The transition process works best when it is started early, new providers are introduced, and everyone involved is prepared. Families noted having a collaborative effort with all people and organizations involved in the process made transitions easier.

The transition to adult services and living in the community received a great deal of attention. Participants had concerns about individuals who graduate at 18 and do not stay in the school system and have no access to adult services until they turn 21. Additionally, concerns about adults who were not found eligible for area agency services were highlighted.

Families and stakeholders alike described transitions as being "hard." This is especially true of the transition from early intervention to school and the transition from school into the adult system. Phrases such as "hitting a brick wall" and "falling off a cliff" were used as descriptors of these transitions.

Early diagnosis was noted as being important to both families and stakeholders. The waiting time to receive an evaluation was noted as a barrier for many families and school systems.

The young adults indicated a concern about a lack of services for individuals over 21 especially if one does not qualify for services outside of school. They also wanted access to training programs to teach about transition, especially to the adult service system. Employment was raised as a concern. The young adults indicated many of the trainings or job opportunities they were offered did not take advantage of their skills. Concerns about employment opportunities especially for young adults with severe ASD were also raised.

Resiliency

Participants were asked to think about what made families strong and have hope for the future – considering their own families or families they have supported. They were asked for suggestions on improving family experiences and outcomes. The young adults were asked what made them strong and what support they needed to have hope for the future.

Families and stakeholders reported access to support, from agencies as well as natural supports, such as extended family, helps families stay strong. Connections with other families either face to face or via social media – having a sense of community – is a huge support for them. Some noted the value of having other families in the area to do things with in the community. Educating others in their community to have awareness and understanding of ASD supported greater acceptance by others, which in turn helped families to be resilient. Many families accessed or created support groups in their region. The young adults indicated having the community embrace young adults with ASD give them a sense of resiliency. They would like to have their neurotypical peers taught about bullying and acceptance.

Another source of support identified by families and stakeholders is having access to a statewide family advocacy training program. Learning how to work within the system and having workshops to gain more information about their child supports their overall resiliency. Staying involved and having access to current information also gives families a sense of hope for the future.

When asked what was needed to support families' resiliency, the importance of having a parent-to-parent network that was continually maintained was highlighted. Some parents in the Spanish-speaking focus groups expressed feeling entirely on their own when it comes to navigating the complicated process of post diagnosis life. Families and stakeholders also wanted an ASD specific organization to return to the state. Families wanted workshops and trainings across the state, not just focused in the central part of the state.

Families wanted to bring awareness to the financial realities they face and the impact that has on their hope for the future. Some parents are not able to work, or have limited employment options because caring for a family member requires flexibility. Conversely, some families do not have the ability to stop working and need support on how to stay afloat. The importance of ensuring low-income families have access to supports was highlighted.

The young adults indicted their parents were definitely a support system for them. However, they do not want their parents to be a "safety blanket " forever. They want the independence to make their own decisions, good or bad, to build self-confidence; the young adults indicated low self-confidence can get in the way for them . Opportunities to learn about and practice conversation skills and knowing what to do to keep up with a conversation would be a support for them. Families expressed the value of feeling heard. Seeing work is being done to improve the system of supports and services for families and individuals with ASD gives them strength and hope for the future.



Next Steps



A State Plan Work Group will be formed to work in conjunction with the Council to inform The creation of a comprehensive state plan. Moving forward, families, young adults, self-advocates, experts in the field, and key stakeholders will review the findings of the Needs Assessment and identify core issues to be address by the Comprehensive State Plan.

Additional focus groups and stakeholder forums will be held to solicit ideas about how to improve systems of care for children and youth with ASD. Stakeholder forums will gather feedback from community-based providers and primary health care providers on the needed components of a comprehensive state plan. A statewide summit with key stakeholders and partners will be held to roll out the state plan with the plan being disseminated widely both in print and electronically.

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