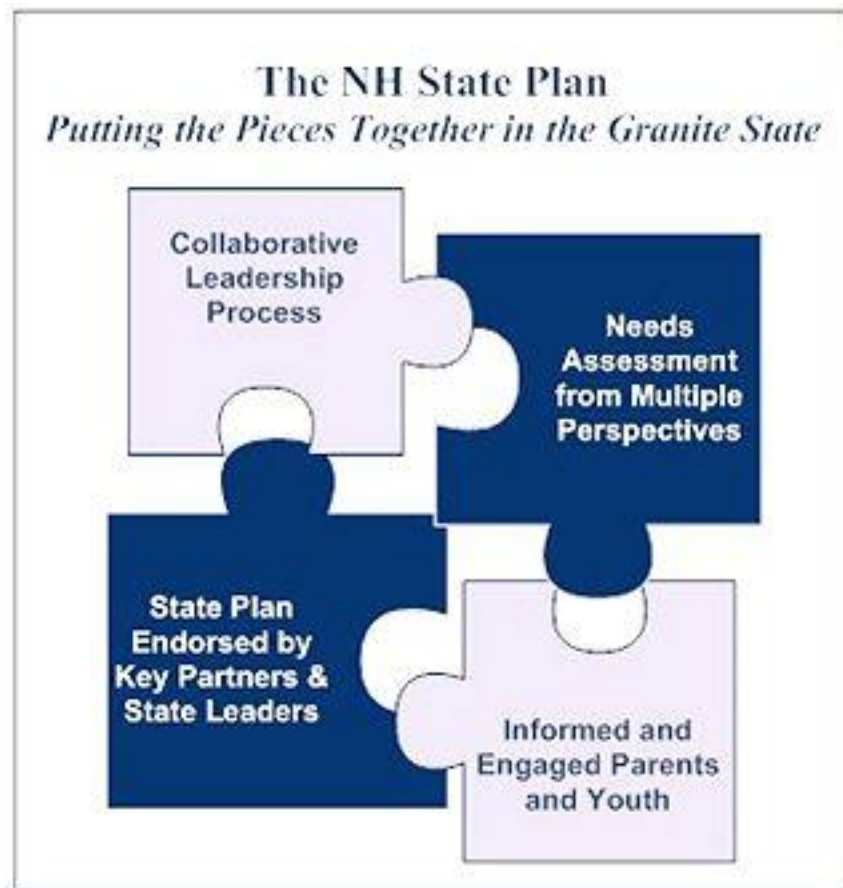


NH Statewide Autism Spectrum Disorder (ASD) Needs Assessment 2014



New Hampshire Council on Autism Spectrum Disorders

Special Medical Services

Child Health Services

New Hampshire Family Voices

New Hampshire Leadership Education in Neurodevelopmental Disabilities

ACKNOWLEDGEMENTS

The NH Statewide Autism Spectrum Disorder (ASD) Needs Assessment Report is the result of significant effort by a committed group of stakeholders. The effort began in 2012 with a statewide survey made possible through the work of Helena Sung an intern supported by the Maternal and Child Health Information Resource Center's Graduate Student Internship Program. The next phase of the Needs Assessment primarily took place in 2014. The vision and design was the result of a truly collaborative Core Planning Group and the process was guided by the Needs Assessment Workgroup, of the NH Council on Autism Spectrum Disorders. However, it was the dedication and concentrated effort of Rae Sonnenmeier and Jennifer Pineo that guaranteed the successful completion of this report.

The development of the Focus Group Moderator's Guide was completed in consultation with Andrew E. Smith, Ph.D., Associate Professor of Practice in Political Science Director of the University of New Hampshire Survey Center.

We would like to thank Natalie Waltner for completing the transcriptions of the audio recordings of the focus groups.

A special thanks goes to Amy H. Frechette, A.S., NH Council on Autism Spectrum Disorders Governor Appointed Self-Advocate, for her assistance in typing notes from the Stakeholder Forums, facilitation of stakeholder forums and young adult group, and proofreading of documents.

We would like to thank our partners in this process: New Hampshire Council on Autism Spectrum Disorders, Special Medical Services, Child Health Services, New Hampshire Family Voices, and New Hampshire Leadership Education in Neurodevelopmental Disabilities

The completion of the comprehensive needs assessment of services and supports for children and youth with autism spectrum disorder and other related developmental disabilities was supported in part by:

This project is/was supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under Grant number H6MMC2624, State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, \$150,000 award. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

A grant from the National Center for Ease of Use of Community Based Services, Maternal and Child Health Bureau Mini-grant Award Project Number S20110000015432

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INTRODUCTION

Families, advocates, and providers in New Hampshire have sought to improve the services and supports available for children, youth, and young adults with autism spectrum disorder (ASD) and related developmental disabilities (DD) for over a decade. Significant policy and practice changes have been achieved, such as the publication of a guide to Assessment and Intervention by the NH Task Force on Autism (2001-2003), creation of a State Council on ASD (2008), implementation of a state registry to track new diagnoses of ASD (2008), and the adoption of a state mandated health insurance provision for ASD (known as “Connor’s Law”, 2012). Despite these efforts, New Hampshire has not yet had the opportunity to develop a coordinated state plan informed by a comprehensive needs assessment.

The rising prevalence of ASD in children and youth is well documented, although exact prevalence numbers are difficult to identify. The Centers for Disease Control and Prevention (CDC) *estimates* the prevalence of ASD based on data collected from the Autism and Developmental Disabilities Monitoring (ADDM) Network. The ADDM network monitors the number of 8-year-old children with ASD living in diverse communities in 11 sites in the United States. Based on 2010 ADDM data, the CDC estimated approximately 1 in 68 children have been identified with an autism spectrum disorder (ASD)¹ *in those 11 sites*. The number of children with ASD identified using the ADDM methodology varied widely by community, with 1 in 45 children reported for New Jersey to 1 in 175 children reported for Alabama. While the CDC notes this does not represent the entire population of children with ASD in the United States, the trend for rising prevalence is clear. There has been an approximate 120% increase in the prevalence in ASD increased by since 2002, when the estimated rate was reported to be 1 in 150.

Prevalence patterns in NH mirror the national estimates. The NH Department of Education (DOE) data indicate there has been a more than six-fold increase during the 13 year period from 2000 to 2013 in the number of children receiving special education services under a code of “autism,” increasing from 397 students (2000) to 2,419 students (2013) (NH DOE Statewide Census by Disability). The significance of this increase is amplified by the fact that overall school enrollment declined slightly during this same period, and the number of special education students remained relatively flat at approximately 30,000 students.

In 2006, recognizing the need to improve data collection to better understand the prevalence of ASD in NH, a small coalition of parents worked with state legislators to establish in statute a registry for diagnoses of ASD. Under RSA 171-A: 30, 31, health care and other providers who are qualified to make a diagnosis of ASD are required to report new cases to the NH Department of Health and Human Services (NH DHHS) when the diagnosed individual is a NH resident. Following applicable rule making, the NH Registry began collecting data in 2008. Five years of data have been collected and analyzed (2008 – 2013) through the Registry. A total of 605 newly diagnosed cases have been reported. Preliminary summaries of these data are consistent with national averages (for example, 4 boys:1 girl).

¹ Centers for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network 11 sites, United States, 2010. *Morbidity and Mortal Weekly Report* (MMWR) 2014; 63 (No. SS 2):1-21.).

Understanding the needs of children and youth with ASD/DD and their families involves more than understanding prevalence and demographic data. Examination of parents' responses to National Survey of Children with Special Health Care Needs (NS-CSHCN) 2009/2010² provides a broader understanding of families' needs regarding involvement in decision-making, access to coordinated care within a medical home, adequacy of public and private insurance, screening services, organization of services for ease of use, and services to support transition. Examination of responses revealed families of children and youth with ASD generally experienced more challenges with accessing family-centered, community-based, coordinated care than did families of children and youth with other special health care needs. For example, fewer family caregivers with children and youth with ASD (61.8%) indicated that they were a partner in decision making at all levels and were satisfied with the services they received than those who supported a child with a special health care need other than ASD (78.8%).

While NH stakeholders have begun to understand the demographic patterns, characteristics, experiences, and needs of children and youth with ASD and their families, the need for a more complete understanding of the challenges experienced by families, as well as the needs of providers and other stakeholders remain. A comprehensive needs assessment was completed to systematically analyze data from existing data sets and collect additional information from families, young adults, self-advocates, providers, and other stakeholders' regarding their needs. The findings of this comprehensive needs assessment will inform the development of an effective state plan to improve the overall system of care for children and youth with ASD and related developmental disabilities and their families.

AUTISM SPECTRUM DISORDERS

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 life.³

Previously, the term "ASD" collectively referred to the following three conditions that were diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Aspergers disorder. Now, a single diagnosis of "autism spectrum disorder" encompasses all of these conditions. The term "spectrum" in ASD means that each person can be affected in different ways and symptoms can range from mild to severe. People with ASD share some similar characteristics, such as difficulties with social interaction, difficulties with communication, and highly focused interests and/or repetitive activities. How the characteristics affect a person's functioning depends on the severity and combination of those characteristics.

² National Survey of Children with Special Health Care Needs. 2009/2010. Retrieved at: <http://childhealthdata.org/learn/NS-CSHCN>

³ American Psychiatric Association. *Diagnostic and statistical manual of mental disorders*, Fifth Edition. Arlington, VA: American Psychiatric Association; 2013.

Since ASD is a developmental disability, the results of this needs assessment will be applicable to individuals with related developmental disabilities. Many of the services and supports accessed by families of individuals with ASD are similar to those who have related developmental disabilities. As a growing population, insights resulting from this needs assessment will serve to inform a state plan that will be of benefit to all individuals with developmental disabilities, including ASD, and their families.

Population Addressed

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. These age groups were chosen based on available state data sets and the age parameters for existing data collection systems. The age range was extended to 26 years given the Affordable Care Act allows young adults up to that age to remain on their parent's health insurance. It was recognized that the available data on young adults is not as robust as available data on younger children. State data for adults based on specific diagnoses are not easily accessible for analysis at this time. Additionally, families of lower income and non-English speaking families were identified as an underserved population to be addressed through this needs assessment process.

METHODOLOGY

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, NH Family Voices, 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 Special Medical Services in 2012.

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 were collected at family focus groups, a young adult discussion, and stakeholder forums.

PARTNERS

The needs assessment process was supported in part by the *State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities* (the “ASD State Planning Grant”) funded by the U.S. Department of Health and Human Services/Health Resources and Services Administration (HRSA) grant #H6MMC26245. The grant was a collaborative effort among five key partners who formed the Core Work Group including representatives from Special Medical Services, NH Family Voices, NH Council on ASD, NH Leadership Education in Neurodevelopmental Disabilities (NH LEND), and Child Health Services. The Core Work Group provided oversight and organizational leadership to the

needs assessment process and worked closely with the NH Council on ASD to frame the information that was gathered, support understanding of the findings, and facilitate keeping the process moving forward. Family members and self-advocates were actively engaged in all aspects of the needs assessment process.

Special Medical Services. Organizationally, Special Medical Services (SMS) is an agency within the Bureau of Developmental Services (BDS), under the administrative umbrella of the NH Department of Health and Human Services (DHHS). BDS is charged with maintaining a statewide service system for individuals with Intellectual Disabilities (including ASD and other DD) and Traumatic Brain Disorders. Additionally, BDS operates NH’s early intervention program – Family Centered Early Supports and Services. SMS is the State agency responsible for services to Children and Youth with Special Health Care Needs (CSHCN) through the federal Maternal and Child Health Bureau’s (MCHB) Title V Block Grant. SMS provides leadership in building and promoting a community-based system of services that is family-centered, comprehensive, coordinated, and culturally and linguistically sensitive. SMS provides oversight and support to a network of child development clinics across the state. These clinics provide comprehensive diagnostic evaluations for young children whose parents have concerns about their child’s development or behavior, including ASD and related DD. SMS places the highest priority on integrating public and private health services with education, social services, mental health, and family support programs. SMS is the recipient of the ASD State Planning Grant and provides administrative oversight to all grant activities, including completion of the comprehensive needs assessment.

New Hampshire Family Voices. NH Family Voices (NHFV) is the state’s Family-to-Family Health Information and Education Center. NHFV is directed and staffed by parents of children, youth, and adults with a wide range of special healthcare needs, including ASD and related DD. They provide free technical assistance and emotional support to families of children and youth with special health care needs and the professionals who serve them. With the support of a national network they provide families with tools to make informed decisions, advocate for improved public and private policies, and build partnerships among professionals and families. NHFV serves as the contract agency for the ASD State Planning Grant and supports the project coordinator.

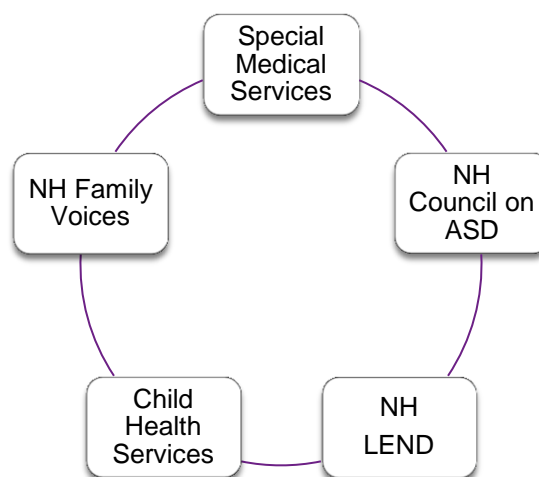


Figure 1: Key Partners for the Implementation of the ASD State Planning Grant

New Hampshire Council on Autism Spectrum Disorders. Established by the NH legislature in 2008, the NH Council on Autism Spectrum Disorders (“the Council”) is charged with “providing leadership in promoting comprehensive and quality education, health care, and services for individuals with autism spectrum disorders and their families” (RSA 171-A:32, I). Its work has been informed by the findings, recommendations, and principles published in May 2008 by a

previously established Commission on Autism Spectrum Disorders. The Council has a history of strong family and self-advocate involvement. It has consistently been chaired by a parent member, with parents and a self-advocate comprising approximately half of the active membership. The other half of the membership consists of representatives from key state agencies and professional organizations serving individuals with ASD and their families. A complete listing of the members of the Council is included in Appendix A

The Council serves as the Advisory Board for the completion of the Comprehensive Needs Assessment. Members of the Council contributed topics to be explored during the needs assessment process, provided feedback on recruiting participants for the needs assessment activities, and reviewed and provided feedback on the preliminary findings.

The Council formed a work group to guide the needs assessment process. The Needs Assessment Work Group (NAWG) included representation of families, a self-advocate, early intervention, education (including public and private schools), and community-based services. Families and self-advocate representatives on the NAWG received an incentive to support their participation in this process. A complete listing of the members of the NAWG is included in Appendix B

The NAWG was responsible for reviewing data sources, designing the specific needs assessment procedures, collecting and analyzing new data, and compiling the information into a comprehensive needs assessment report. This group met monthly to review data and make decisions about the process of completing a needs assessment. The NAWG used consensus as the primary decision making process (see Appendix C).

New Hampshire Leadership Education in Neurodevelopmental Disabilities. The NH Leadership and Education in Neurodevelopmental and Related Disorders (LEND) program, funded through Maternal Child Health Bureau (MCHB), is a collaboration among the Geisel School of Medicine at Dartmouth, the Institute on Disability (a University Center of Excellence on Disability [UCED]) at the University of New Hampshire, and the Center for Community Inclusion and Disability Studies/UCED at the University of Maine. With the support of MCHB over the last 22 years, NH LEND has provided graduate level interdisciplinary leadership training in family-centered, culturally competent, interdisciplinary care for over 300 long-term trainees. Many NH LEND graduates are recognized national, state, and local leaders. Beginning in 2008, with funding from the Combating Autism Act Initiative (now known as the Autism Collaboration, Accountability, Research, Education, and Support Act of 2014 or Autism CARES), NH LEND initiated a variety of projects related to improving the system of care for children with ASD. These projects have included: continuing education and technical assistance for primary health care providers regarding early identification and diagnosis of ASD; training emergency responders; collaboration with Watch Me Grow; Learn the Signs Act Early Campaign Awareness; Open Forums on early identification and diagnosis; and advocacy efforts. NH LEND continues to have strong partnerships with Title V programs and other MCHB funded initiatives in New Hampshire and Maine that contribute to ongoing improvements in the system of care for children and youth who experience ASD and related DD. NH LEND faculty and trainees provided technical assistance related to the collection, analysis, and interpretation of the needs assessment data.

Child Health Services. A representative from Child Health Services (CHS) joined the Core Work Group to support understanding of the needs of families from low-income communities and speakers of languages other than English. CHS, a National Committee for Quality Assurance (NCQA) Medical Home, is dedicated to improving the health and well-being of children who are at risk from low income families in the Greater Manchester area. With a fully integrated system of physical and psychosocial health care, social services, nutrition services, and behavioral and mental health services, CHS provides specialized care that is adapted to the specific physical and psychosocial needs of the children served. CHS' treatment philosophy and approach are intended to help children and their families reach their full potentials and live healthy, enriched lives. With support from a mini-grant from the MCHB National Center for Ease of Use of Community Based Services, Latino families shared their stories and needs regarding accessing services for their family member with ASD.

EXISTING DATA SETS

A number of data sets were available for review at the beginning of the needs assessment process. These data sets provided preliminary findings regarding the characteristics and needs of New Hampshire's children and youth with ASD/DD and their families. These data sets included: (a) Department of Education – Special Education Census by Disability Data (federal and state) (DOE), (b) NH Registry for ASD (NH Registry), (c) National Survey of Children with Special Health Care Needs, (NS-CSHCN) and (d) Needs Assessment Survey of Families and Young Adults with ASD completed by Special Medical Services in 2012 (NH Needs Assessment Survey).

NH Department of Education – Special Education Census by Disability

The NH Department of Education (DOE) publishes an annual census of special education students organized by each student's primary code for special education services. Although it does not provide a complete count of the number of children and youth with ASD, it does illustrate the trend toward a greater identified prevalence.

Limitations of using the DOE Census data. An individual student's diagnostic profile does not align neatly with their special education code. To be found eligible for special education services under a code of "autism," a student must have a diagnosed ASD. However, having a diagnosis of ASD does not necessarily mean that the student's special education team will choose this code when eligibility is determined. An unknown number of students who have ASD/DD receive special education services using one of several other primary codes, including "speech and language impairment," "developmental delay," "emotional disturbance," "other health impaired," and "multiple disabilities." Additionally, many individuals diagnosed with ASD who do well academically do not qualify for special education services or may receive accommodations under a 504 Plan. In other words, the DOE census likely undercounts the total number of students with a diagnosis of ASD, both nationally and at the state level.

NH State Registry for ASD

In 2008 the NH Registry for ASD was created, requiring physicians, licensed clinical psychologists, and other healthcare professionals who diagnose a NH resident with ASD to report the diagnosis, using an online reporting form. NH was the second state in the nation to

establish a legislatively mandated statewide registry for all new diagnoses of ASD. The NH Registry was carefully designed to track only the information necessary to answer three questions: (a) How many individuals are identified on the registry each year? (b) At what age is the diagnosis typically made? (c) Do patterns emerge? The registry is intended to provide information about new cases of ASD in NH to help guide public health policy toward better outcomes for individuals affected by ASD and their families.

Limitations of the NH Registry. Out of respect for the time constraints of diagnosing professionals, NH rules limited data points collected through the NH Registry. For example, there is not a unique identifier that can be used to track an individual across the systems of care (such as health care, education, community services). Additionally, while reporting of new diagnoses is required, there is no mechanism to ensure each new case is actually reported, resulting in variability in the data reported. As with the DOE census, the NH Registry likely undercounts the total number of new diagnoses of ASD.

National Survey of Children with Special Health Care Needs

The National Survey of Children with Special Health Care Needs (NS-CSHCN) is conducted every five years. At least 750 randomly selected respondents from each state participate in a telephone survey. Trained interviewers ask parents or guardians a series of questions for all children in the household to identify those with special health care needs. Questions addressed in this survey are related to health care and other services. The most current data set available is based on the survey completed in 2009/2010. Examination of the NS-CSHCN data revealed a total of 76 NH respondents identified ASD as a special health care need.

Limitations of the NS-CSHCN data. The conclusions that may be drawn from the NS-CSHCN 2009/2010 survey data are somewhat limited given the relatively small number of respondents (n=76) with a child or youth with ASD. The sample was not large enough to conduct meaningful comparisons between NH respondents with the national sample.

NH Needs Assessment Survey of Families and Young Adults with Autism Spectrum Disorders 2012

A preliminary needs assessment survey of NH families with a child or youth with ASD up to age 18 or a young adult between the ages of 18-26 was conducted by SMS in 2012. This anonymous online survey was designed to gather more in depth information regarding families' experiences and needs. Questions were designed to correspond to those in the NS-CSHCN, yielding useful comparisons. The invitation for families and young adults to complete the online survey was widely distributed through family support contacts, clinics, and existing list serves through SMS, NHFV, special education, and related networks. A total of 238 self-selected respondents to the 2012 Needs Assessment Survey met survey criteria either as a parent of a child with a diagnosis of ASD under the age 18 (204 respondents) or a youth age 18 or older (31 respondents). Three of the respondents were a young adult with ASD between the ages of 18-26. The 2012 Needs Assessment Survey completed by SMS provides a rich data set that describes the perceived needs of NH parents and family caregivers who support a child or youth with an ASD.

Limitations in the 2012 Needs Assessment Survey data. Some limitations of the 2012 Needs Assessment Survey include: (a) respondents were self-selected versus randomly selected; (b) it was not possible to identify if those in rural/medically underserved areas were adequately

represented; and (c) the sample size for parents and family caregivers supporting a young adult with ASD is too small (n=31) to make meaningful inferences regarding the experiences of young adults with ASD. Very few respondents (n=3) were themselves individuals with an ASD, possibly indicating that an online survey may not be the best way to collect information from this group. In addition, questions related to demographics such as race, ethnicity, and socio-economic status were an optional component of the survey; not everyone responded to these questions. This makes it difficult to draw inferences regarding underserved populations.

NEEDS ASSESSMENT ACTIVITIES

A number of limitations were identified with the existing data sets. The existing information was used to guide the design of the other activities to gather additional feedback from families of individuals with ASD, young adults, self-advocates, educators, and community and health care providers.

Identification of Areas of Focus

The first step was to solicit input from key stakeholders regarding the areas of focus for the needs assessment. The Core Work Group engaged both the Council on ASD (as the advisory board) and the NAWG in a guided brainstorming session using a modified “deep diveTM” process originally pioneered by IDEO, a respected process design firm.⁴ Four broad questions were asked:

- What do we need to know from families, young adults, and self-advocates that we do not already know?
- Where do we need to go to ask the families, young adults, and self-advocates?
- What are the biggest unmet needs for families, young adults, and self-advocates?
- How do we reach culturally diverse families?

The information from these modified “deep diveTM” was utilized to create five broad categories to gather additional information from families, self-advocates, and providers.

1. **Information:** How do families learn about services and supports? Where are the gaps?
2. **Services:** What services do individuals with ASD and their families currently receive? What services do families, young adults, and self-advocates need?
3. **Coordination:** How are services and supports currently coordinated? Where are the gaps?
4. **Transition:** What information do families have at the time of transition within and across service systems? Where are the gaps?
5. **Resiliency:** What supports families to be strong and have hope? Where are the gaps?

⁴ Moen, R., “A Review of the IDEO Process,” Robert Wood Johnson Foundation, Toolkit, <http://www.rwjf.org/en/research-publications/find-rwjf-research/2001/10/a-review-of-the-ideo-process.html> (10/25/2001)

Data Collection

Two different methods were used to gather additional information from families, young adults, self-advocates, and providers in the five identified broad categories. **Focus Groups** were determined to be the most appropriate method to gather in-depth information from families and young adults about their experiences. It was determined that focus groups with Spanish-speaking families were needed to understand the needs of this community. **Stakeholder Forums** were determined to be the most appropriate method to gather in-depth information from a representative group of community providers and other key stakeholders.

Focus Groups

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

A Moderator's Guide was developed including a script and specific questions for the focus groups based on the five broad focus areas identified (see Appendix D,E). Each focus group had a facilitator and note-taker. Six of the parent focus groups were held in English and were audio recorded. These recordings were transcribed verbatim. All identifying information was removed to ensure confidentiality. Transcripts were reviewed to identify themes related to the broad focus areas. Notes were taken during the two Spanish speaking and the young adult groups. These two focus groups were not audio-recorded to support the participants' comfort in sharing information.

Parent Focus Groups (8)

Six of the eight parent focus groups were held in five regions of the state based on the five education superintendent regions: North Country, Lakes, Central Southwestern, South Central, and Seacoast regions (see Figure 2). Originally a focus group was planned in each region, however due to a large response in the South Central region, a second focus group was added in the Concord area to accommodate all those who wished to participate.

The NAWG had decided to limit the number of participants for each group to between 8-10 to ensure each participant's active discussion in the group. Families interested in participating contacted

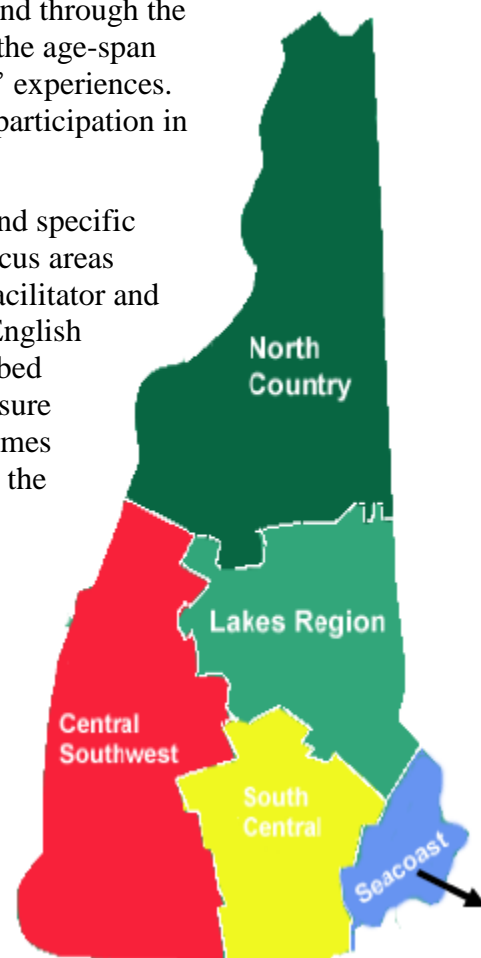


Figure 2: Five Education Superintendent Regions for Parent Focus Groups

the focus group coordinator and provided information regarding their child's age, gender, and diagnosis. Families were then selected to ensure representation of children and youth across the age span and from diverse location within each region. Once selected, families were provided the details regarding the schedule and location of the focus group in their region. There were 42 parents/ grandparents that participated in the six English-speaking focus groups, representing 48 children with ASD (1 family with 3 children, and 4 families with 2 children).

In collaboration with Child Health Services, two parent focus groups were held for Spanish-speaking families. The moderator's guide was translated into Spanish and the sessions were led by a Spanish speaker. There were a total of 12 participants with children aged 2 to 14 and included immigrant families as well as NH natives. Child care, transportation, and food were provided to support families' participation in these focus groups.

Young Adults Forum (1)

The young adult forum was held with three participants. While it was a small number of participants, they did span the age range of 16-26 that was aimed for, including a high school student, a high school graduate preparing to attend college, and a college graduate. The group was facilitated by a Self-Advocate member of the Council as well as a member of the core work group. A note-taker was present. Similar categories of questions were used and framed more toward youth when questions were asked. The young adults self-identified as having Asperger's Syndrome.

Stakeholder Forums (3)

Three Stakeholder Forums were held in three regions of the state: North Country (Littleton), Central (Concord), and Southern (Bedford). A "world café" approach⁵ was used for these forums to gain information at a local and regional level. Participants provided feedback on each of the five focus areas through participation in small discussion groups. Each discussion table included a facilitator and a note-taker. There were a total of five discussion tables, each representing one of the focus areas. After a specified period of time, the participants moved to a different discussion table. A total of five rounds were completed to ensure that each participant was given the opportunity to offer feedback in regards to each topic area.

A total of 42 individuals participated in the Stakeholder Forums representing the following groups: self-advocates (1), parents (14), professionals (21), and parents/professionals (6). A number of community-based organizations were represented as follows: community providers (10), Area Agency staff (5), health care providers (physician, nurse, emergency medical technician) (3), mental/behavioral health (6), government agency (2), and schools (1). The lack of school personnel participation was noted by the NAWG. This could be attributed to a few factors including the timing of the forums in June and the schedules of school personnel at this time of year. It was noted in the future to try to have a stakeholder forum that is specifically geared toward schools.

⁵ The World Café Took Kit. <http://www.theworldcafe.com/tools.html>

FINDINGS

Characteristics of New Hampshire's Population

Prevalence. For more than a decade, the number of individuals with ASD has been steadily increasing. A review of the national census data for students ages 3-21 years served by the Individuals with Disabilities Education Act (IDEA) between 2000-2011 reveals a more than four-fold increase in the number of students identified with the educational code of “autism” (Figure 3). During the 2000-2001 academic year, 94,000 students were reported to receive special educational services based on autism. This number increased to 417,000 during the 2010-2011 academic year. It should be noted that the IDEA data likely underestimates the number students with autism receiving special education since a student with ASD may have a different primary educational code, such as speech-language impairment or developmental delay. However, the trend toward a increased prevalence is obvious.

A review the NH Department of Education Statewide Census by Disability for the years 2000-2013 reveals a similar trend. As shown in Figure X, a six-fold increase in the number of NH students identified with an educational disability of autism, from 397 students in 2000 to a total of 2419 students in 2013.

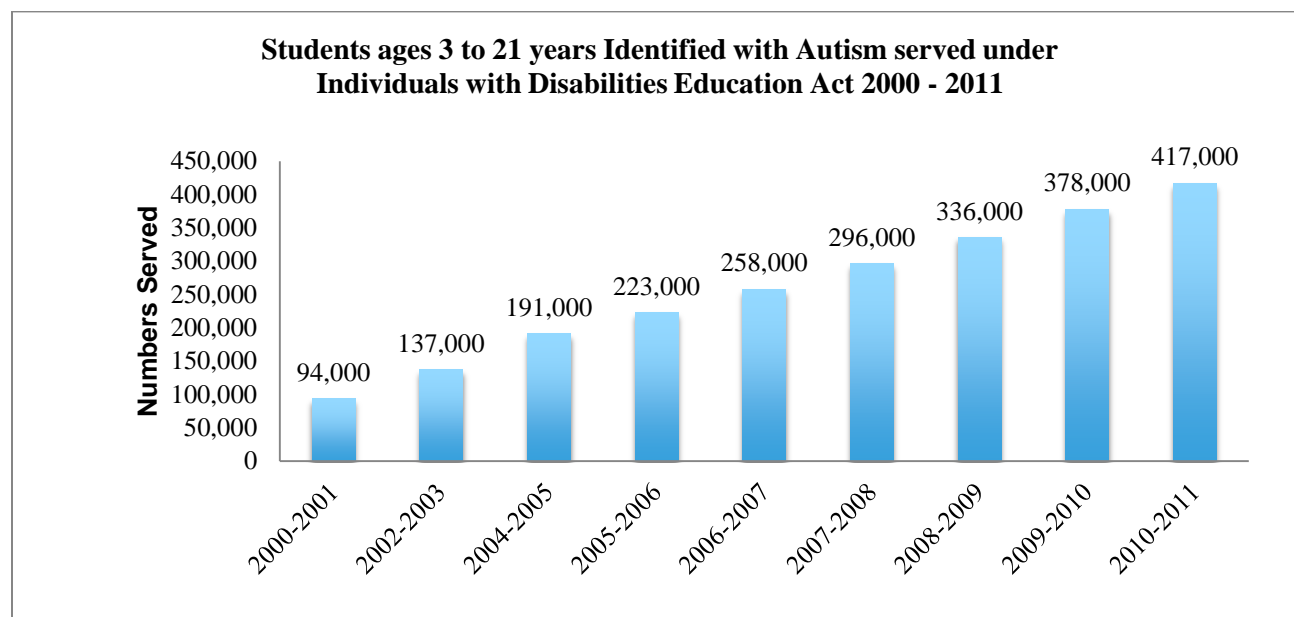


Figure 3: Children 3-21 years old served under Individuals with Disabilities Education Act, Part B, by type of Disability.^{1,2} Retrieved at <http://nces.ed.gov/fastfacts/display.asp?id=64>

Source: U.S. Department of Education, National Center of Education Statics. (2013). Digest of Education Statistics, 2012 (NCES 2014-015), Chapter 2.

¹Data does not include Vermont, for which 2007–08 and 2008–09 data were not available. In 2006–07, the total number of 3- to 21-year-olds served in Vermont was 14,010.

²Data does not include Wyoming, for which 2010-11 data were not available. In 2009–10, the total number of 3- to 21-year-olds served in Wyoming was 15,098

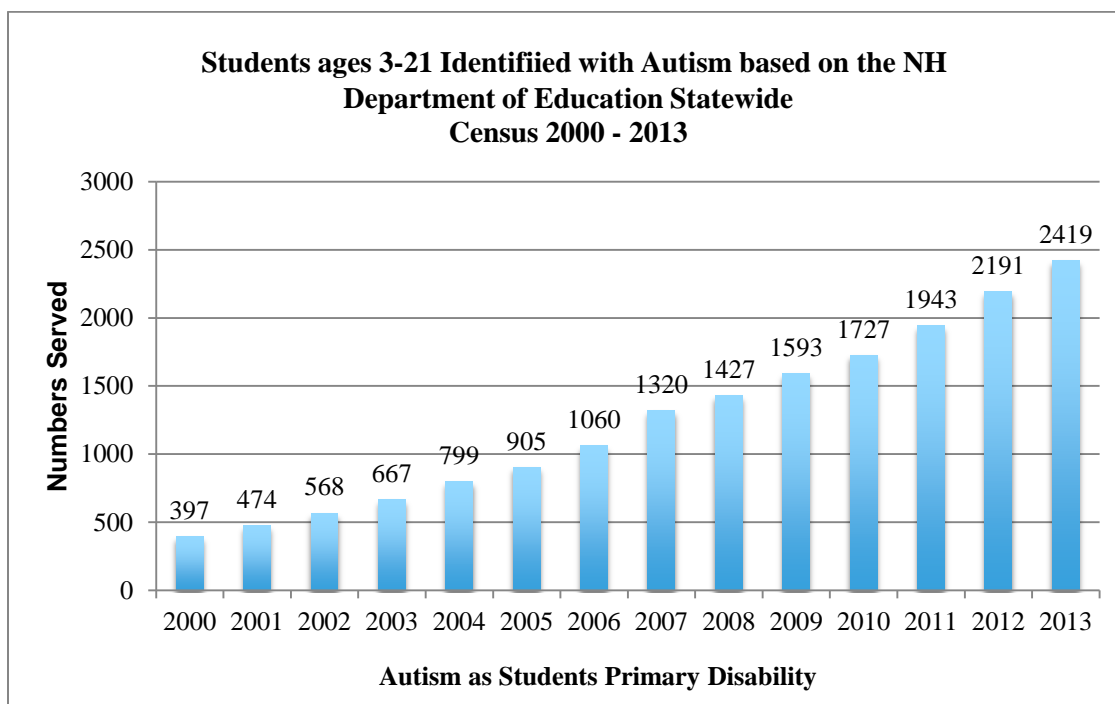


Figure 4: Number of Students identified with an educational disability of Autism between 2000-2013 based on the NH Department of Education Statewide Census by Disability.

Gender Differences. NH’s population reflects nationally reported gender differences among individual diagnosed with ASD, with a ratio of approximately 4 boys to every girl. According to data from the 2009/2010 NS-CSHCN, 80.6 % CSHCN with ASD are boys. This pattern is also reflected in the NH Autism Registry data. The parents participating in the Parent Focus Groups reported similar patterns as well. Of the 48 individuals with ASD represented, 38 were male (78%) and 10 were female (21%) ranging in age ranged from 2.5 years old to 52 years old.

Early Identification. The 2009/2010 NS-CSHCN indicated early identification of individuals with ASD is an area of relative strength for the Granite State. Among NH respondents, 87.4% indicated that they had received early and continuous screening, which is above the national average of 78.6%. Caregivers of children with ASD and those of children with other special healthcare needs did not markedly differ in this indicator. The NS-CSHCN data also indicated that children who are white, non-Hispanic are more likely to be diagnosed early.

Findings from the NH Registry on ASD also provide evidence that children in NH are being identified early. As shown in Figure 5, more than two-thirds (68.1%) of children were diagnosed with ASD prior to the age of six years; nearly a third were diagnosed before age two. Based on the findings of the ADDM Network, children identified with ASD were not diagnosed until after age 4⁶.

⁶ Centers for Disease Control and Prevention (CDC). Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network 11 sites, United States, 2010. *Morbidity and Mortal Weekly Report* (MMWR) 2014; 63 (No. SS 2):1-21.).

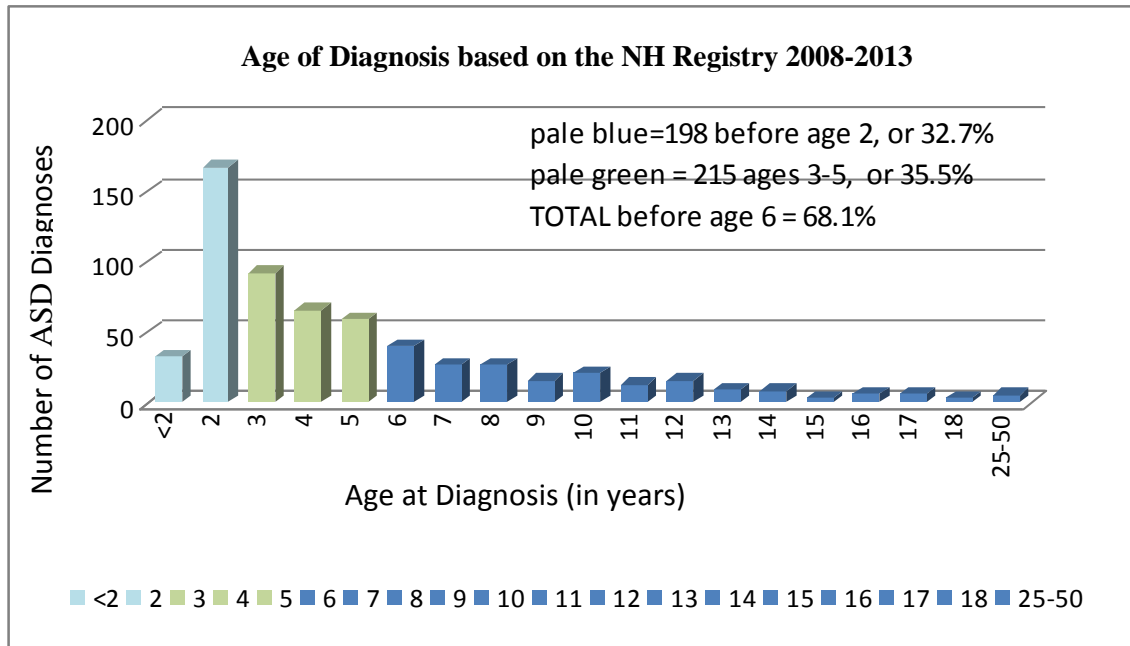


Figure 5: Age of Diagnosis based on the NH Registry 2008-2013

A review of the NH Registry data suggest a lower rate of identification under age 2, even though research has shown a diagnosis of autism at age 2 can be reliable, valid, and stable^{7,8}. This may be related to a time delay in seeking professional opinion when a concern about a child’s development first arises or may be related to a perceived difficulty providing an accurate and definite diagnosis before age 2 by diagnosticians. The NH Registry data also suggest that diagnoses continue to be made with young adolescents. This may be related to the increased in social demands in middle school and the characteristics of ASD for some youth becoming more evident at that time.

The 2012 Needs Assessment Survey included questions related to the child or youth’s diagnostic history. The purpose of these questions was to collect more detailed information regarding screening and diagnosis of individuals not reported on the registry due to the short period of implementation of the Registry (2008-2012) at the time of the survey. A similar trend toward early identification and diagnosis was observed in the 2012 Needs Assessment Survey, with the majority of children receiving an ASD diagnosis by the age of 4 years. Findings are presented in Figure 6.

⁷ Lord, C., Risi, S., DiLavoire, P.S., Shulman, C., Thurm, A., & Pickles, A. Autism from 2 to 9 years of age. *Archives of General Psychiatry*, 2006, Jun:63(6) 694-701.

⁸ Kleinman, J.M., Ventola, P.E., Pandey, J., Verbalis, A.D., Barton, M., Hodgson, S., Green, J., Dumont-Mathieu, T., Robin, D.L., & Fein, D. Diagnostic stability in very young children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 2008; Apr:38(4):606-615.

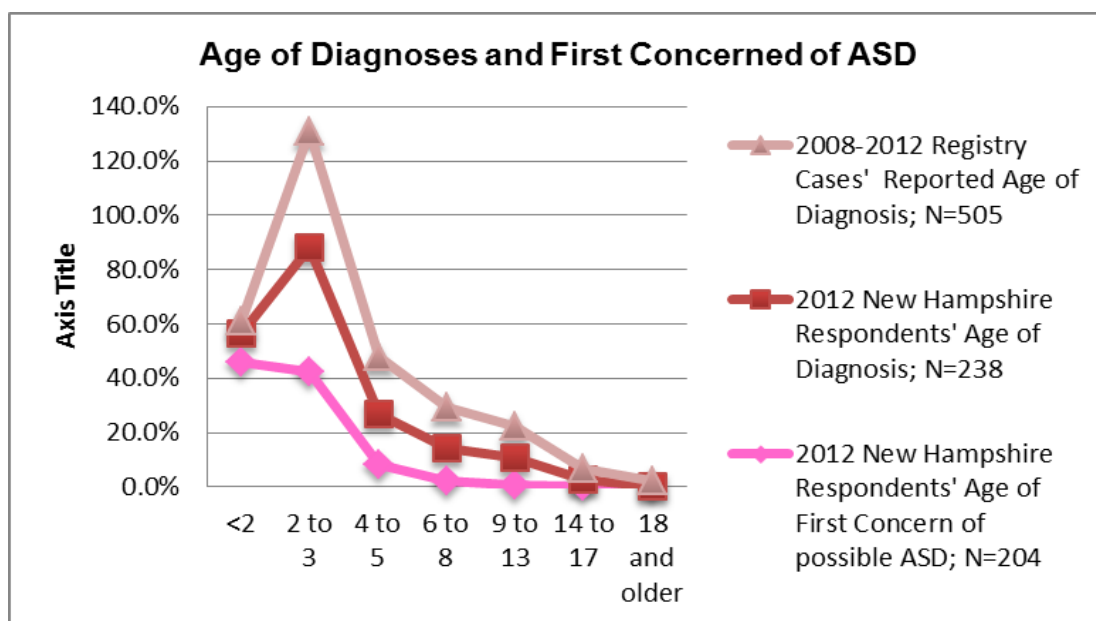


Figure 6: Reported Ages of First Concern of Possible ASD and Diagnosis of ASD based on Responses to the 2012 New Hampshire Statewide ASD Needs Assessment Survey.

Similar patterns by both the NH ASD Registry and the 2012 Needs Assessment Survey indicate the ability of the NH Registry to represent an overview of the New Hampshire ASD population. Similar patterns were reported by the participants in the Parent Focus Groups, with 44% of children receiving an ASD diagnosis by the age of 3 and 63% receiving a diagnosis by the age of 4 years.

Functional Abilities. With respect to perceived level of functional impairment, families were asked to rate the overall “severity” of their child’s disability. Findings from the NS-CSHCN (n=76) revealed nearly half of the parents rated the severity of their child’s disability due to ASD as “mild” (49.5%), approximately a third (36.2%) rated their child’s ASD as “moderate” (36.2%) and 14.3% rated their child’s ASD as “severe” (see Figure 7).

Somewhat different findings are reported by families who participated in the 2012 Needs Assessment Survey. The majority of respondents (62.7%) identified their family member with ASD as experiencing a “moderate level of disability related to their diagnosis of ASD. While the reason for this discrepancy is not clear, it is possible differences in the methodology for recruiting survey respondents is the most likely factor. Respondents to the NS-CSHCN were randomly selected and represented a small number (n=76) whereas the respondents to the 2012 Needs Assessment Survey respondents were self-selected and represented a larger group (n=202).

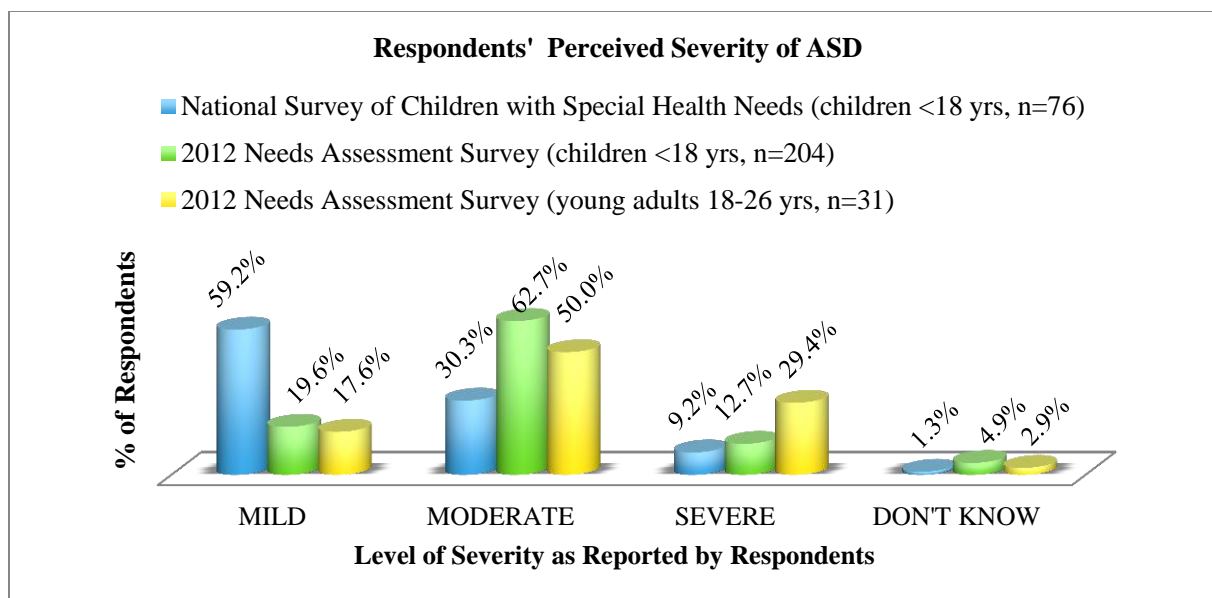


Figure 7: Perceived Level of Severity of ASD based on NH Respondents to 2009/2010 NS-CSHCN and 2012 New Hampshire Statewide ASD Needs Assessment Survey

Co-occurring Conditions and/or Diagnoses. The majority of the NS-CSHCN respondents (93.2%) reported their family member with ASD had at least one other condition or diagnosis. A similar finding was reported by respondents to the 2012 Needs Assessment Survey, with a majority (84.5 %) indicating their family member had one or more additional diagnoses and more than half of the respondents (57.1%) reported two or more additional conditions or diagnoses (see Table 1). It is presumed that the presence of co-occurring conditions is a contributing factor to overall perception of severity of disability.

Diagnoses in Addition to ASD	Percent of Total (n = 235)
No other diagnoses reported	15.5%
1 additional diagnosis	27.7%
2 additional diagnoses	21.4%
3 additional diagnoses	14.7%
4 additional diagnoses	12.2%
5 or more additional diagnoses	8.8%

Table 1: Number of Additional Conditions or Diagnoses Reported by Respondents to the 2012 New Hampshire Statewide ASD Needs Assessment Survey.

As shown in Figure 8, the top five additional conditions or diagnoses identified by the respondents were: developmental delays, anxiety disorder, ADD/ADHD, learning disability, and other diagnoses. Respondents included a variety of “other additional diagnoses” including Bipolar Disorder, Obsessive-Compulsive Disorder, Tourette’s, and sensory processing differences. One limitation in verifying these findings regarding co-occurring conditions relates to the lack of a consistent data entry system across service systems within NH.

These findings are consistent with those reported in the research literature. For example, Joshi and colleagues⁹ reported on a study of 217 youth ages 3-17 years with ASD compared to age-matched youth without ASD who were referred to the same psychopharmacology program. These authors concluded that youth with ASD experience significantly higher number of co-occurring conditions and experienced more functional difficulties than their peers. They found that 95% of youth with ASD had three or more co-occurring psychiatric disorders and 74% had five or more co-occurring disorders.

Impact of ASD on the Family. Related to understanding the functional abilities of children with ASD is understanding the impact on families. Based on findings from the NS-CSHCN 2009/2010, families of children with ASD reported a greater impact on the family than experienced by families of CSHCN without ASD. Families of children with ASD generally reported their children experienced a greater burden of illness and other special health care needs they have as well as the number of functional difficulties and co-occurring conditions when compared to families with CSHCN without ASD.

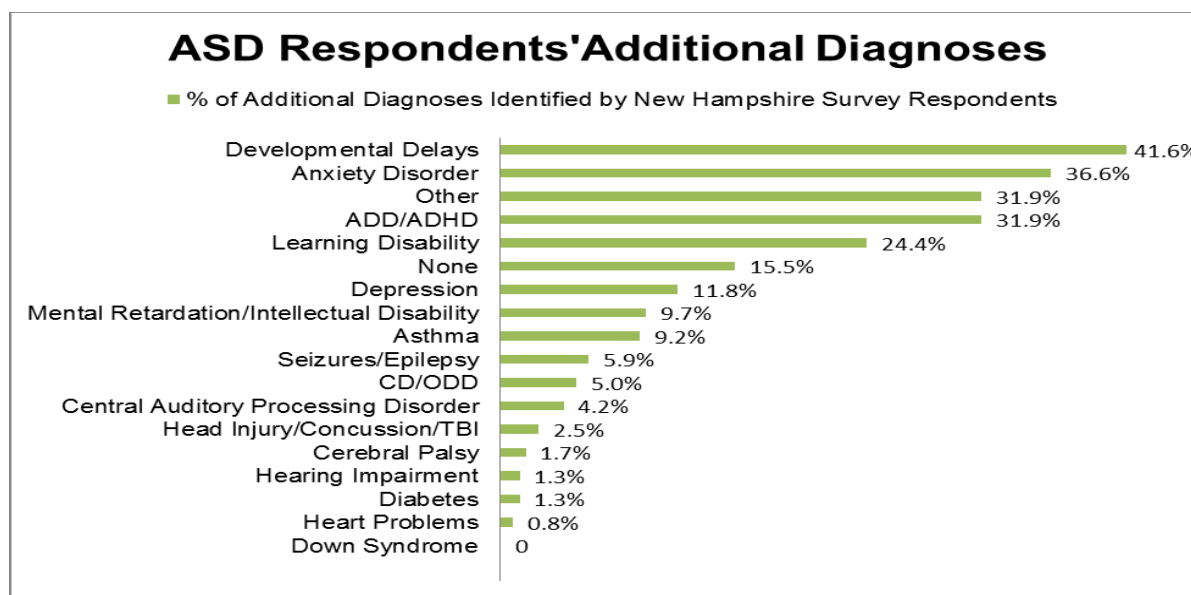


Figure 8: Additional Diagnoses based on Responses to the 2012 New Hampshire Statewide ASD Needs Assessment Survey

⁹ Joshi, G., Petty, C., Wozniak, K., Henin, A., Fried, R., Galdo, M., Kotarski, M., Walls, S., & Biederman, J. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. *Journal of Autism and Developmental Disorders*, 2010; 40:1361–1370. DOI 10.1007/s10803-010-0996-9

More than half of the NS-CSHCN respondents with a child with ASD (57.1 %) reporting having to cut back or stop working, and 30.6 % reported avoiding changing jobs in order to maintain health insurance for the children as compared to CSHCN without ASD at 21.6% and 16.5 % respectively (see Figure 9). Families of CSHCN with ASD reported a higher prevalence of financial problems for the family – 43.0% compared to 19.6% without ASD. Additionally, 33.5% of CSHCN with ASD reported paying more than \$1000 annually of out-of-pocket medical expenditures as compared to 21.2% without ASD. It should be noted the NS-CSHCN respondents indicated the severity of their child’s disability as being “mild”. It is likely the reported impact on the family would be much higher for families who perceive the severity of their child’s ASD as “moderate” or “severe”.

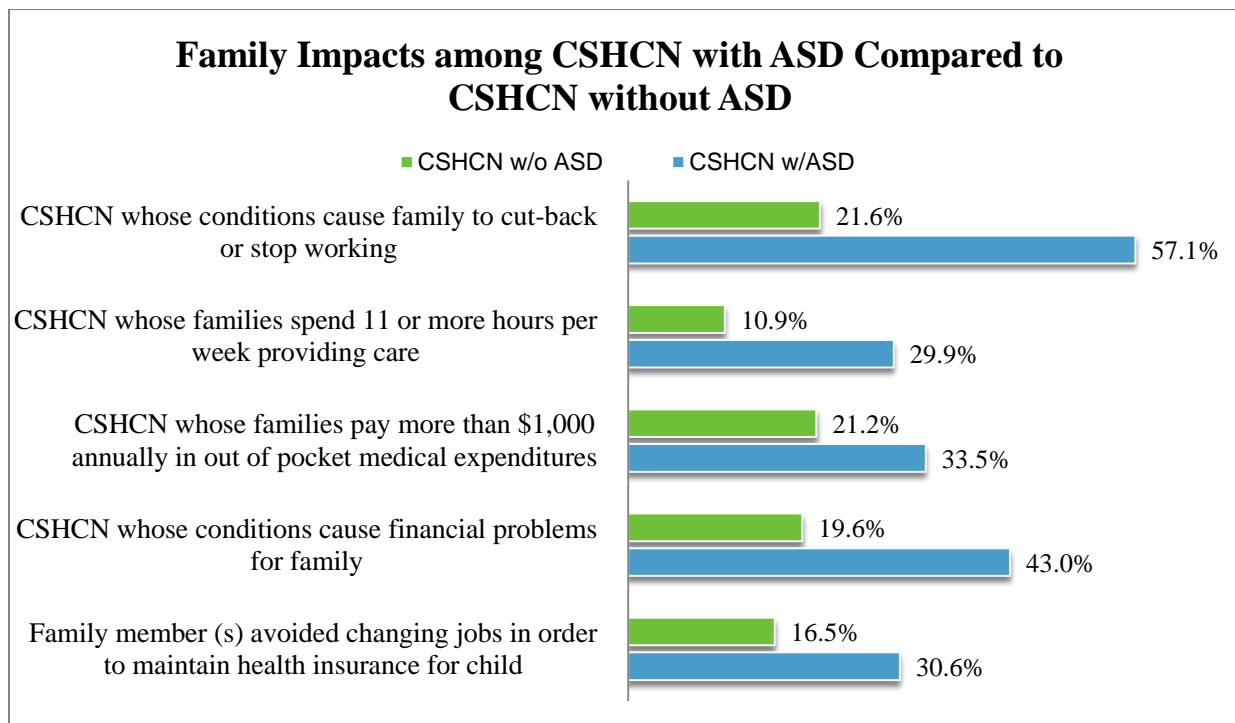


Figure 9: Family Impacts of Children with ASD as Compared with Children with other Special Health Care Needs without ASD. Data Source 2009/2010 NS-CSHCN

Health Care Coverage. Nearly all of the respondents (99%) to the 2012 Needs Assessment Survey indicated they had at least one type of insurance coverage; 30.6% of respondents reported having two or more insurance coverage (see Figure 10).

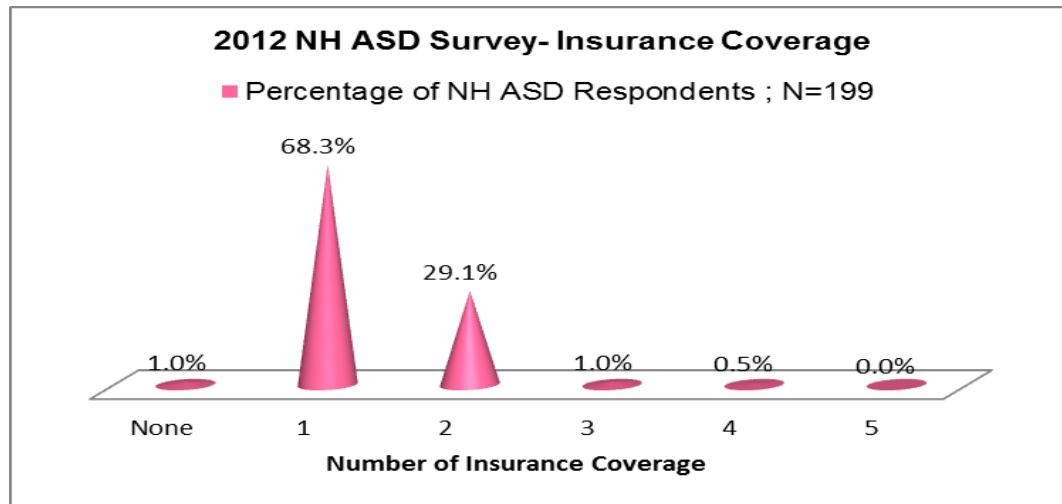


Figure 10: Health Care Coverage as Reported by Respondents to the 2012 New Hampshire Statewide ASD Needs Assessment Survey

Families were asked about the adequacy of their health care coverage based on the following measures: (a) insurance offers benefits that meet the needs of the individual with ASD, (b) costs not covered by insurance are reasonable, and (c) insurance allows individual with ASD to see needed providers. Respondents rated each measure as: Always, Usually, Sometimes, Never, or Don't Know.

Results from the 2009/10 NS-CSHCN and the 2012 Needs Assessment Survey demonstrated issues in all three categories regarding insurance adequacy in New Hampshire. Based on the NS-CSHCN, 41.9% of the respondents reported their insurance benefits "Always" met their child's needs and 33.8% reported their insurance benefits "Usually" met their child's needs, accounting for three-quarters of those responding (75.7%) (see Figure 11). In comparison, only 10.4% of respondents to the 2012 Needs Assessment Survey indicated their insurance benefits "Always" met their child's needs. Approximately half (46.2%) indicated their insurance benefits "Usually" met their child's needs. More than a third (37%) of the respondents to the 2012 Needs Assessment Survey indicated their insurance benefits only "Sometimes" met their child's needs in comparison to 18.9% of NS-CSHCN respondents. Differences in perceived adequacy of health insurance benefits is likely related to the perceived severity of disability, with the majority of NS-CSHCN respondents indicating "mild" severity in comparison to the "moderate" severity by the majority of the 2012 Needs Assessment respondents. Another contributing factor is the complexity of the child's overall health needs in light of the data on co-occurring conditions.

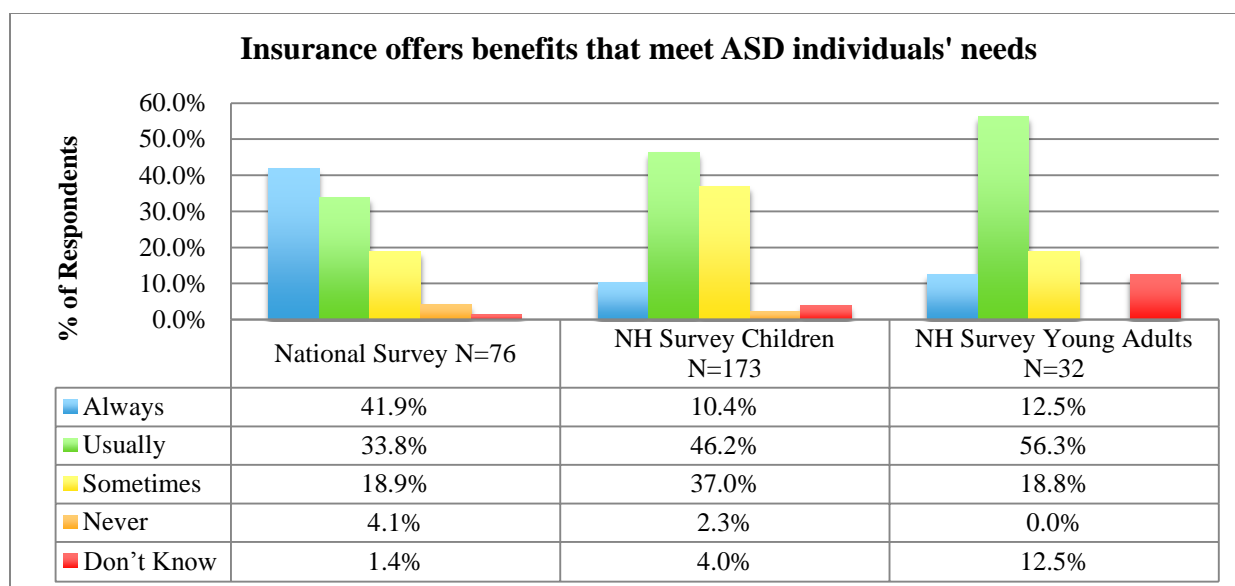


Figure 11: Insurance offers benefits that meet ASD individuals' needs as Reported by Respondents to 2009/10 NS-CSHCN and 2012 New Hampshire Statewide ASD Needs Assessment Survey

More than half of the respondents to the NS-CSHCN (51.5%) and nearly two-thirds of respondents to the 2012 Needs Assessment Survey (64.5%) indicated costs not covered by insurance were “Always” or “Usually” reasonable. Approximately a third of respondents to each survey (36.4% NS-CSHCN; 29.7% 2012 Needs Assessment survey) reported costs not covered by insurance were only “Sometimes” reasonable. These findings support the impression of increased financial burden on families with a child with ASD.

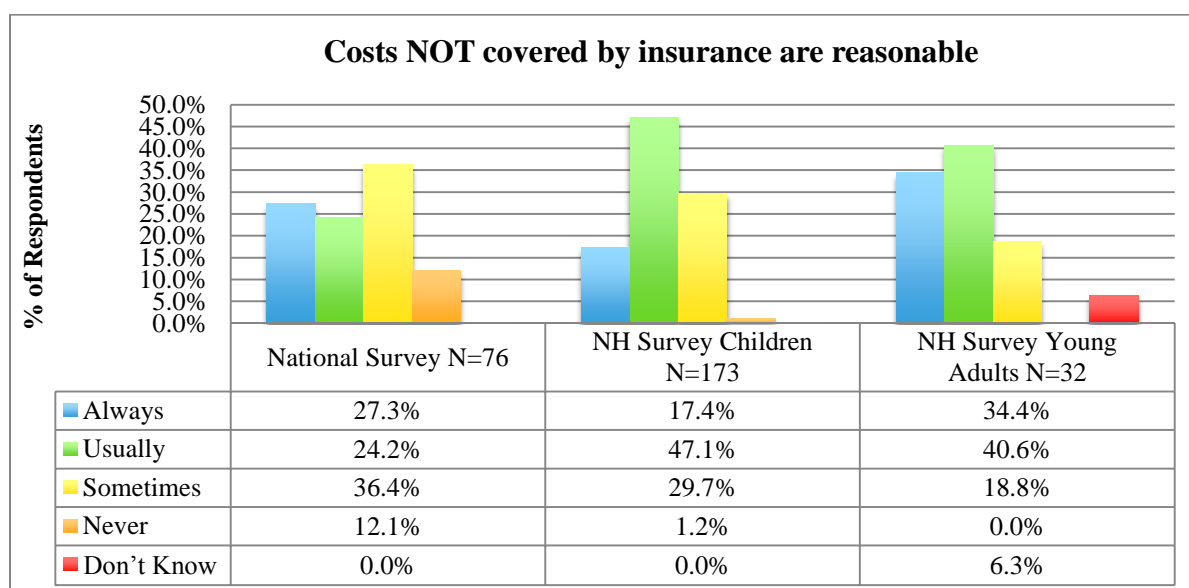


Figure 12: Health Care Costs Not Covered by Insurance are Reasonable as Reported by Respondents to 2009/10 NS-CSHCN and 2012 New Hampshire Statewide ASD Needs Assessment Survey.

Additional discrepancies between the results of the two surveys were noted regarding whether health care coverage supported individuals with ASD to see needed health care providers. The majority of respondents to the NS-CSHCN (79.8%) indicated their insurance benefits “Always” or “Usually” allowed the individual with ASD to see needed providers (see Figure 12). In contrast, less than a third of the respondents to the 2012 Needs Assessment Survey (28.5%) indicated their insurance benefits “Always” or “Usually” allowed access to needed providers. And more than half (56.6%) of the respondents to the 2012 Needs Assessment Survey indicated their insurance only “Sometimes” or “Never” allowed access to needed providers. Again, this is likely related to perceived severity and complexity of their child’s needs.

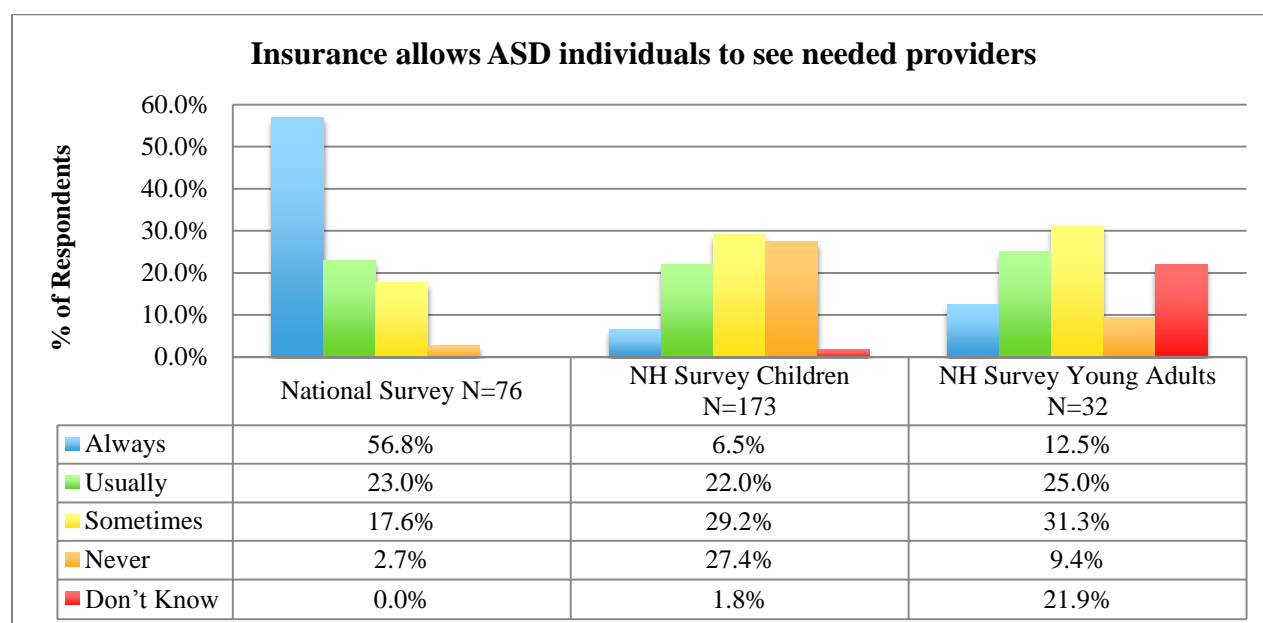


Figure 13: Insurance allowing ASD individuals to see needed providers as Reported by Respondents to 2009/10 NS-CSHCN New Hampshire ASD Respondents and 2012 New Hampshire Statewide ASD Needs Assessment Survey

Examination of the adequacy of insurance findings for young adults revealed interesting results. On all three measures, there were a higher percentage of “Don’t Know” responses than for responses about insurance coverage for children. For example, 12.5% indicated they did not know if their insurance met the needs of the young adult (Figure 13) and 21.9% indicated they did not know if their insurance allowed the young adult to see needed providers (Figure 13). These findings support the importance of engaging young adults in learning about and managing their own health care.

A limitation of the data from both the 2009/2010 NS-CSHCN and 2012 Needs Assessment Survey is the under representation of individuals who speak a language other than English. It is anticipated that there will be an ongoing need to continue to conduct state specific surveys to evaluate the overall adequacy of health insurance to meet the health care needs of children and youth with ASD.

FINDINGS REGARDING SERVICES

Parents and caregivers of children and youth with ASD 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. This information provides a snapshot of the types of services children and youth receive as part of their educational program at school, in the community, and at home as well as health-related services. Questions related to services were included on the 2012 Needs Assessment Survey, as part of the eight Parent Focus Groups, the Young Adult Forum, and the three Stakeholder Forums.

Information about Services - Current

School-based Services

Once children turn three years of age, the education system assumes primary responsibility for providing services and supports for children and youth with ASD. Not surprising, more than 80% of the families responding to the 2012 Needs Assessment Survey indicated that their child had an educational disability code of autism (see Figure 14). Other educational disability codes were also used, including speech/language impairment (27.5%), developmental delay (24.4%), and other health-impaired (17.1%). Nearly half of the respondents (48.2%) indicated that autism was the only educational disability category identified and 47.4% of respondents indicated two or more educational disability categories were identified.

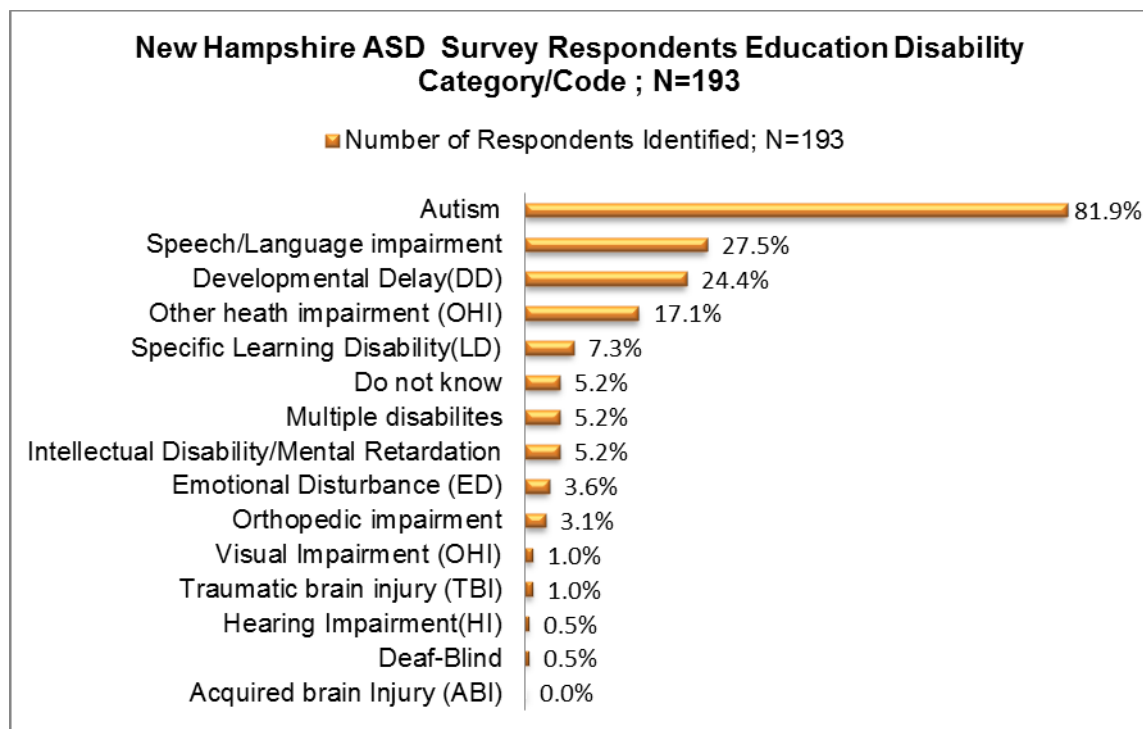


Figure 14: Education Disability Category/Code for Children and Youth with ASD based on the 2012 New Hampshire Statewide ASD Needs Assessment Survey Respondents

Most of the families responding to the 2012 Needs Assessment Survey (92.3%) indicated their child or youth was currently receiving special education services based on an Individualized Education Program. A small number of families (4.8%) reported their child or youth was receiving services based on a 504 Accommodations Plan. Participants in the young adult forum indicated that they did not qualify for special education services in school nor for a 504 Accommodations Plan. More than half of the respondents (51.7%) indicated the diagnosis of ASD had an effect on their school choices.

Families attending the six English-speaking Parent Focus Groups described the school-based services received by their child or youth between the ages of 3-21 years, (a total of 36 school-aged children with ASD), all of these children and youth were reported to be receiving special education services based on an IEP. As shown in Table 2, nearly two-thirds (61%) of the children and youth received support from a paraprofessional for at least part of the day and a third (36%) of the families specifically mentioned individualized instructional supports, such as support for reading, math, and homework. The majority of children and youth (83%) received speech and language services and two-thirds (67%) received occupational therapy. A smaller proportion of children and youth received school-based physical therapy (19%).

School-based Services	Number (n=36)	Percentage
Individualized Education Program	36	100%
Speech and language services	30	83%
Occupational therapy	24	67%
Paraprofessional support	22	61%
Instructional supports (such as support for reading, math, “Homework Club”)	13	36%
Physical therapy	7	19%

Table 2: School-based Services Reported by Participants in the 2014 Parent Focus Groups

With regards to other school-based services, there was greater variability in the types of other services reported by the families who participated in the six English-speaking Parent Focus Groups. Additional school-based services described included: (a) ASD Specialist, (b) case management, (c) applied behavior analysis (ABA) services in school, (d) behavior specialist / behavior support, (e) counseling, psychology services, guidance, (f) social skills (including lunch bunch), (f) technology support (e.g., auditory trainer), (g) music therapy, (h) Virtual Learning Academy (online learning), (i) school internship and other community-based program, and (j) sports (including unified sports).

Community-based Services

Participants in the six English-speaking Parent Focus Groups described services provided outside of the school setting for their children and youth with ASD. Some regional differences in the types of community-based services mentioned were noted.

Families from the Seacoast and South-Central regions highlighted accessing specialty services such as therapies (including speech-language and occupational therapies), ABA services, social skills groups, behavioral health (such as counseling, psycho-therapy, psychiatry), and other specialized services (such as therapeutic horseback riding, gymnastics, and music therapy). In comparison, families from the North Country, Lakes, and Central Southwestern regions primarily highlighted accessing services provided by their local Area Agency (such as respite, family support funds to attend workshops, campership funding), their Community Mental Health Center (for social supports and counseling), and local community recreation programs. One parent described the involvement of a swim coach and personal trainer to support her youth's recreation.

To a lesser extent, families from the North Country, Lakes, and Central Southwestern regions accessed specialty services such as speech-language and occupational therapy, noting the need to travel a great distance (more than an hour) to take advantage of those services. A few families mentioned having their child or youth participate in Special Olympics.

Home-based Services

Several families from the six English-speaking Parent Focus Groups described in-home service including the following:

- Respite, after-school care
- Home accommodations (such as alarms on exits for safety concerns)
- 20 hours per week of a behavior-based program that emphasized carry-over of skills from school, activities of daily living, and community services;
- Home-based ABA program, support from a case manager, and home consultation with a Board Certified Behavior Analyst (BCBA)
- Home-based family counseling and support for behavioral issues

For some of these families, these services were provided through the In-home Support Waiver funded through Medicaid to support individuals with disabilities to live in their home versus an institutional setting. One family described receiving in-home nursing support (her child had an identified seizure disorder, safety concerns and other health conditions). A licensed nursing assistant (LNA) provided 45 hours per week (when school is in session, 60 hours per week when school is out of session) of in-home nursing support.

Health Related Services

A few families from the six Parent Focus Groups reported on specific specialty health care services they accessed on behalf of their child or youth with ASD. One parent described working with a Defeat Autism Now (DAN) doctor who specializes in ASD. Several families reported seeing a neurologist, gastroenterologist, and a feeding specialist.

Services – Needs

Respondents to the 2012 Needs Assessment Survey reported on services their child or youth was currently receiving and their needs regarding more services. As shown in Table 3, the highest areas of need with respect to services were related to social skills, recreational supports, and other social supports including peer mentoring and peer support groups. Three-quarters of the respondents (75.2%) indicated the need for more social skills training. More than half of the respondents reported needing more behavioral therapy (56.1%), occupational therapy (54.1%), and speech-language therapy (51.2%).

ASD Individuals Needed Services	Receiving all that is needed	Receiving, but needs more	Not receiving, but needs more	Do not need
Social Skills Training ; N=213	7.0%	31.5%	43.7%	17.8%
Recreational Therapy ; N=208	6.3%	14.9%	42.3%	36.5%
Peer Mentoring/ Social Supports; N=209	4.8%	16.7%	39.7%	38.8%
Peer Support Groups ; N=214	4.2%	15.4%	38.3%	42.1%
Behavioral Therapy; N=212	14.6%	25.0%	31.1%	29.2%
Occupational Therapy; N=214	27.1%	37.9%	17.3%	17.8%
Speech Therapy; N= 215	30.2%	41.4%	9.8%	18.6%
Physical Therapy ; N=211	16.6%	14.7%	14.2%	54.5%
Communication Services; N=209	16.3%	17.2%	11.0%	55.5%
Services Animal ; N=206	1.0%	1.0%	15.5%	82.5%
* Surveyed both families of children (under age 18) with ASD and young adults (age 18 to 26) with ASD				

Table 3: Service Needs of Children and Youth with ASD based on the 2012 New Hampshire Statewide Needs Assessment Survey

Participants in the six English-speaking Parent Focus Groups described very similar needs related to services. Social skills program and supports for social relationships as well as recreational activities both in and outside of school were consistently described as needs.

Many families mentioned the need for qualified providers who are knowledgeable about ASD, including teachers, child care 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. Several parents described how they sought their own ABA training and becoming certified as a behavior analyst to meet their child's needs.

Several families mentioned the need for consistency of the availability and quality of services across the state – within the educational system, Area Agency system, and community-based clinical services. The need for crisis intervention and support was also raised by families and stakeholders alike as a high area of need.

With regards to needed health-related services, a third of respondents to the 2012 Needs Assessment Survey indicated their greatest need was for more mental health therapy services (32.5%) and nutritional support services (30.7%) (see Table 4). Themes related to health care identified by families in the English-speaking Parent Focus Groups included access to quality health care, dental and vision services, and the need for care coordination.

ASD Individuals Needed Health-Related Services	Receiving all that is needed	Receiving, but needs more	Not receiving, but needs more	Do not need
Mental Health Therapy; N=209	21.5%	15.8%	16.7%	45.9%
Traditional Nutritional Support; N=209	12.9%	4.3%	26.3%	56.5%
Non-Traditional Nutritional Support; N=211	12.3%	8.1%	20.4%	59.2%
HealthCare/Services Transitional Planning; N=209	2.9%	9.1%	12.4%	75.6%
Neurology Services ; N=212	29.2%	9.0%	12.3%	49.5%
Home Health Care; N=210	5.7%	5.7%	11.9%	76.7%
Alternative Health Care/Treatment; N=207	2.4%	4.3%	9.7%	83.6%
Medical Equipment ; N=184	13.0%	3.3%	7.6%	76.1%
Medication; N=211	46.9%	8.1%	5.7%	39.3%
* Surveyed both families of children (under age 18) with ASD and young adults (age 18 to 26) with ASD				

Table 4: Health-related Service Needs of Individuals with ASD based on the 2012 Needs Assessment Survey

With regards to young adults, identified needs related to vocational planning and career counseling (28.3%), supported employment (18.5%), and housing assistance (11.%).

ASD Individuals Needed Services	Receiving all that is needed	Receiving, but needs more	Not receiving, but needs more	Do not need
Vocational Planning/Career Counseling; N=212	3.3%	12.3%	16.0%	68.4%
Supported Employment; N=211	1.4%	7.1%	11.4%	80.1%
Housing Assistance; N=210	2.9%	3.3%	8.1%	85.7%
Sexual Health Education; N=213	4.7%	3.3%	11.3%	80.8%
Drug and Alcohol Counseling ; N=210	2.4%	1.9%	1.0%	94.8%

Table 5: Young Adult Service Needs of Individuals with ASD based on the 2012 Needs Assessment Survey

Similar 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.

FINDINGS REGARDING 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.

Information about Services - Current

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. Some families learned about services through their early intervention provider, Area Agency, Community Mental Health Center, school, or other community programs. Some families also received information from the child development clinic professionals who made the diagnosis. 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

Many families described receiving information about referrals from their health care provider, although this was not typically where they gained information about services. They noted health care providers often do not have information for where to send families, and there are few health care providers specializing in ASD.. Families described wanting information about respite, educational opportunities (such as conferences), services, funding, and support groups.

Families reported often being left to find information regarding services on their own, most often through conversations other families or through their own research. Much of the responsibility lies with families to find and verify information.

Stakeholders recognized parents as critical information sources. Parents often find each other by chance or by asking the right questions at the right time. Success with support groups has not been consistent.

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.

Many families are referred to the Internet to find information, including using social media sites to ask other families for information. Stakeholders also noted not all families have access to the Internet and the Internet can be overwhelming. Many families are not comfortable going to the library to access the Internet and some families may also need childcare (even if they are at home to access information). Some families can be given a website and be fine and other families need more support to access resources. 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.

Information about Services – Needs

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.

Families described often being given specific recommendations for services (such as 40 hours of ABA or other therapies) but not having information about locating such services in their area or information about funding options for these services. Families also expressed concern about not getting consistent information or being informed of available services. Some families felt as if information was not shared openly, such as information about the Medicaid in-home support waiver.

The need to ensure information regarding resources was kept up to date was brought up by families and stakeholders. It was agreed information needs to be shared with families in accessible formats that are readable and easily understood, particularly for parents for whom English is not their primary language or those who have low literacy skills. 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. Additionally, stakeholders noted having a translator in place does not necessarily mean families understand the information shared. It is important for providers to ensure understanding by families. Stakeholders noted our current system is not designed to easily support families whose cultural views and experiences regarding parenting, child development and behavior are different .

FINDINGS REGARDING 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.

Coordination of Care - Current

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. It was noted by families and stakeholders that families felt there was no coordination among schools, area agencies, health care, and service providers - resulting in families assuming the primary responsibility for coordination. 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 were asked to estimate the average amount of time they spend arranging or coordinating care for their family member with ASD each week. The majority of the respondents to the 2009/10 NS-CSHCN (93.4%) reported spending an average of 0-10 hours per week (see Figure 15). In comparison, more than a third (37%) of the respondents to the 2012 Needs Assessment Survey with children under the age of 18 years and 43% of respondents with young adults ages 18-26 reported spending more than 11 hours per week on coordinating care. The differences between the survey findings is most likely related to the perceived severity and complexity of

their child's needs; respondents to the 2012 Needs Assessment survey identified a higher level of need than respondents to the 2009/10 NS-CSHCN.

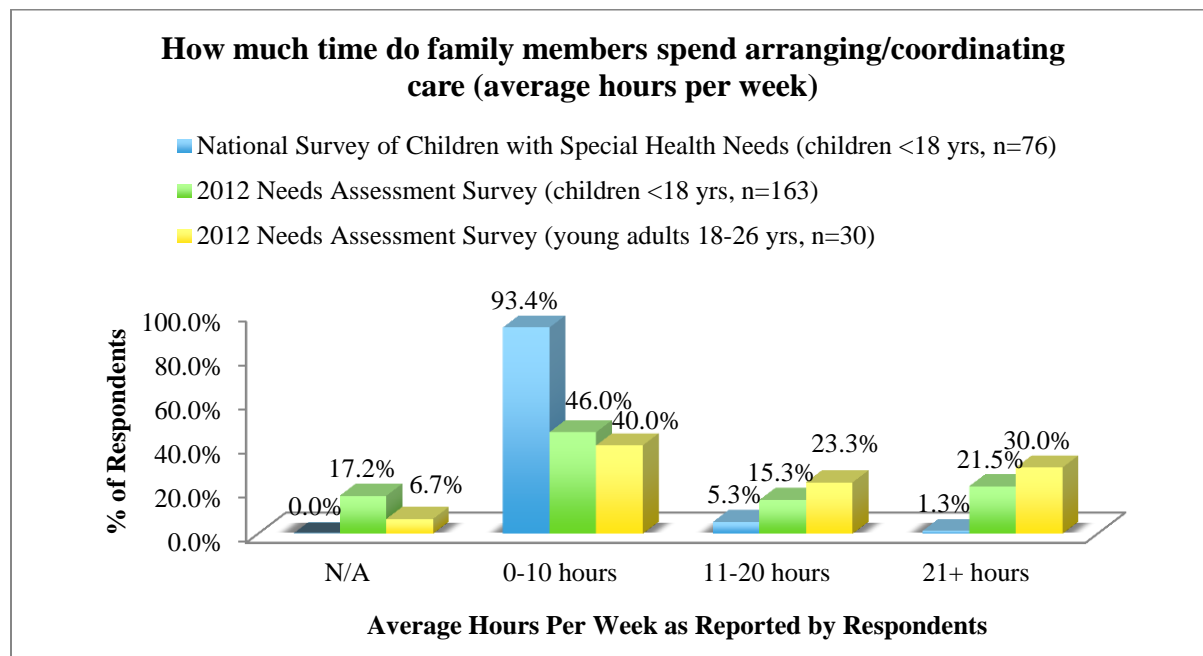


Figure 15: Estimated time Families Spend on Arranging/Coordinating Care for a family member with ASD based on responses to the 2009/10 NS-CSHCN and 2012 Needs Assessment Survey

Coordination of Care - Needs

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. Stakeholders felt that schools expect parents to coordinate and parents have difficulty understanding the IEP process. However, families expressed concerns about having one agency person to coordinate all components, given a high turnover rate of caseworkers. Families found it difficult to access medical providers and agencies providing care coordination. It was suggested that common language across systems (including medical, community mental health, advocates, providers) would be helpful. Families reported varying experiences across regions(??)

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.

A parent's level of involvement in care coordination directly effects satisfactory level of coordination. It was suggested to develop an outline of the services available throughout the life span as a general guideline to support coordination. Funding for care coordination was identified

as being critical, especially given the wide range of potential services. There was also great concern about how to coordinate care and services for individuals with ASD not found eligible for Area Agency services.

FINDINGS REGARDING 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.

Transition - Current

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 importance of families understanding the special education process, including the process of developing an Individualized Education Program (IEP) during transitions was highlighted by families and stakeholders. Starting early also gives time for individuals with ASD to be involved, especially in middle and high school.

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.

The young adults indicated they had programs at school to assist with career development, including internships and a program to assist them in determining what career field they wanted. One young adult had applied for jobs without direct support from the school. The school had referred them to the area agency, however they were not found eligible for services.

As part of the 2012 Needs Assessment Survey, young adults and family members of young adults were asked about employment, including current employment status and possible difficulties faced. A total of 34 respondents (either young adults or families of young adults with ASD) responded to the employment section. While the sample is small, useful information may be gleaned from their responses.

Type of Employment among currently working young adults; N=12	
Regular employment (with no help or support from the workplace)	66.7%
Supported employment (you may have a job coach, other special help at work or receive employment assistance such as vocational rehabilitation)	16.7%
Enclave employment (you may work in a business with a group of other people with special needs, all under supervision of an agency serving people with disabilities)	8.3%
Day Program that includes work or vocational activities	8.3%
Internship or work study program	0.0%
Other	0.0%

Table 6: Type of Employment of Young Adults based on responses to the 2012 New Hampshire Statewide ASD Needs Assessment Survey

As shown in Figure 16, only 5.9% of the respondents reported being employed full time and 29.4% reported being employed part-time. Nearly two-thirds of the respondents (61.7%) indicated they were not currently employed. Some of the respondents were engaged in related activities, such as participating in vocational rehabilitation (5.9%) or volunteer activities (17.6%)

Of the young adults who were employed, two-thirds (66.7%) indicated having no help or support from the workplace (see Table 6). Of the remaining respondents who were employed, 16.7% reported having supported employed such as a job coach, 8.3% reported working in an enclave with others with special needs, and 8.3% reported working in day program that focused on vocational activities.

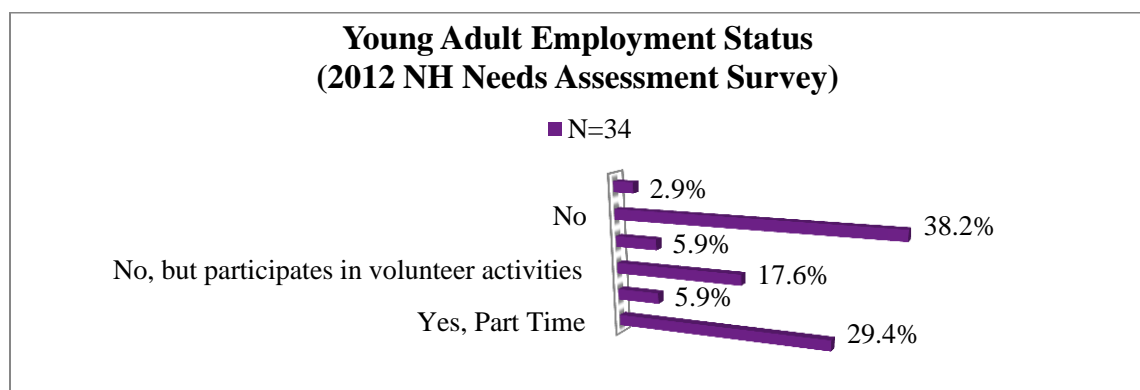


Figure 16: Employment Status of Young Adults based on Responses to the 2012 New Hampshire Statewide ASD Needs Assessment Survey

When asked the reasons for not working among not employed young adults, 52.4% cited “unable to work”, because the workplace would be too challenging due to their ASD. This suggests a young adult with ASD’s main obstacle to becoming more financially independent is finding ASD accommodating employers.

Not Employed young adults’ reasons for not currently working? N=21	
Not able to work, because the workplace would be too challenging, due to ASD	52.4%
Other	19.0%
Full/Part time student	14.3%
Wanted to work, but can’t find work	9.5%
Have tried work, but faced discrimination or other difficulties with employers, because of ASD	9.5%
Do not wish to work at this time	9.5%
Not able to work, because it would interfere with federal or state benefits	9.5%

Table 7: Reasons for Unemployment among Young Adults based on the 2012 New Hampshire Statewide ASD Needs Assessment Survey

Transition to adult health care services is major aspect of the transition to adult services and living in the community. Families and young adults were asked about the transition to adult health care services as part of the 2009/10 NS-CSHCN and the 2012 ASD Needs Assessment Survey. A total of 100 respondents had a youth between the ages of 12-26 years. Of those, 91 respondents answered questions about health care transition.

As shown in Figure 17, two-third (67 %) of respondents to the 2009/10 NS-CSHCN and less than half (43.9%) of respondents to the 2012 ASD Needs Assessment Survey said their doctors or health care providers usually or always encouraged their youth age 12-17 to take age-appropriate responsibility for their health care needs. More than half (51.2%) of the respondents to the 2012 ASD Needs Assessment Survey expressed their providers never encouraged such responsibility. Again, this difference in reporting is likely related to the perceived severity of the youth’s needs.

Among young adults surveyed, responses were evenly dispersed among all five categories (Always, Usually, Sometimes Never, Don’t Know). A quarter of the young adult respondents (24.2%) responded they did not know whether or not their providers have encouraged them to take responsibility.

The differences in reporting suggest the 2009/10 NS-CSHCN may not be representative of of New Hampshire’s ASD population regarding health care transition issues. More emphasis needs to be relayed to providers regarding transitional issues to provide a more supportive environment for this population.

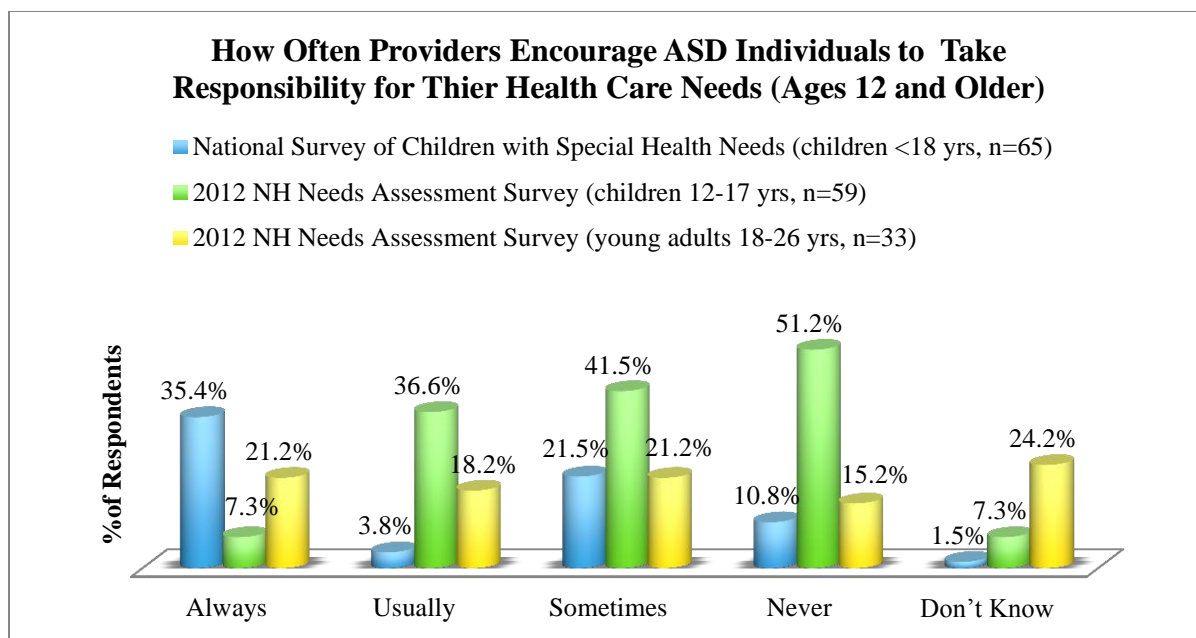


Figure 17: Reported Encouragement for Youth and Young Adults (ages 12-26) to Assume Responsibility for Health Care based on response to 2009/10 NS-CSHCN and 2012 Needs Assessment Survey

Transition – Needs

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 to describe 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. When transitioning from early intervention into the school system, many families expressed apprehension about changing from services being provided 1:1 in the home environment to a larger school environment. Families noted having less access to those working with their child in school in comparison to when providers came to their home. Families expressed concerns about receiving less services in school than they did in early intervention. Some families felt unsupported in advocating for their child during this transition.

Similar concerns were raised regarding transitions from elementary school to middle and high school. Families wanted more information and time to prepare for transitions to assist their child in having a smooth transition. Cultural perspectives about disability can vary greatly. Families need information in formats they can understand.

Families and stakeholders recognized the transition from the services provided during the academic year to the extended school year program during summer months is often difficult especially if the same level of services is not provided. It is challenging for families to locate supports in the summer and to maintain routines for the individual and family. Participants also spoke of other transitions, such as having a new special education director or new team

members. Any of these changes need careful planning and a period of time for everyone to adjust. Families expressed the need for more support, especially during transition from school into adult services, as they thought school focuses primarily on academics. Parents do not have access to someone to advocate for them in meetings, especially around transition. Families suggested having an autism coordinator within school systems to support transitions.

“So we keep talking about, how do we get [adolescent] involved with the process, which is pretty complicated to do effectively and therefore it never gets done. So though we've been talking about bringing him to the table for a year, he's still not made it to the table because we're always reacting to what's going on presently.”

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. Families expressed concerns in transition around providing their family member with social emotional skills as well as activities of daily living. They wanted more scholarship opportunities for young adults as they transitioned into college. 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. Findings from the 2012 Needs Assessment Survey suggested that young adults with more perceived need are more likely to be unemployed (see Figure 18).

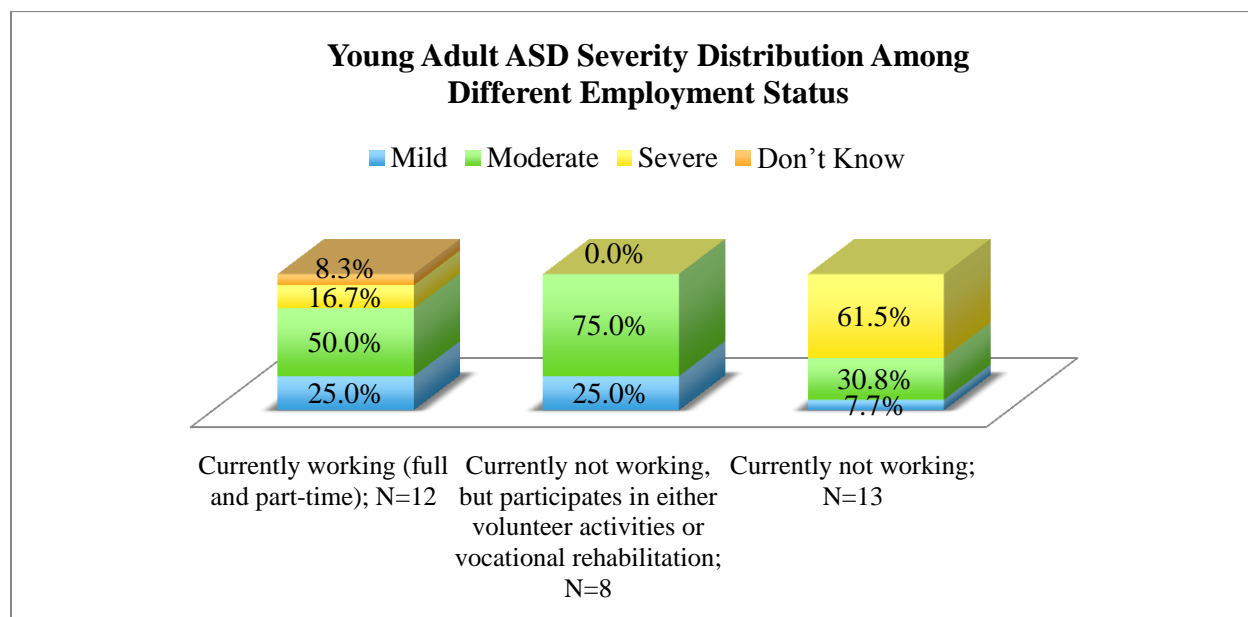


Figure 18: 2012 New Hampshire Statewide ASD Needs Assessment Survey Young Adult ASD Severity Distribution Among Different Employment Status

The young adults, families, and stakeholders also identified transportation as big issue and was needed to get to activities. Stakeholders and families also expressed the need for support

transitioning from a crisis. The young adults recognized the need for supports to more easily transition in and out of school, especially if they are missing school due to being hospitalized. Families and stakeholders also noted the lack of housing options for adults as they transitioned to the adult system.

FINDINGS REGARDING RESILINCY

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.

Resiliency - Current

Families and stakeholders reported that 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. Experiencing success and focusing on the positive helps families to move forward and remain optimistic. Hearing success stories of what worked with other families and being able to connect with someone that has already been through what they are going through is encouraging. Acknowledging it is okay to make mistakes is helpful. Being able to see the future and have hope helped families feel resilient.

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. Some families found it helpful to have someone who understands ASD go to appointments with them. Many families accessed or created support groups in their region. Families also expressed the importance of having someone to talk to and having interests outside of the child who has autism. 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.

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. The young adults expressed wanting support to participate in school sponsored clubs and activities, and having someone they could connect with at these activities. They indicated that having choice about which activities to join is good. Some young adults noted inclusion in typical activities is not always the best model for them. For example, some young adults noted they enjoyed participating in Special Olympics because everyone is nice to them.

Resiliency - Needs

Families expressed concern over their child's future, and if their child would be happy. Many expressed the need to take care of themselves to be around as long as possible for their child,

illustrating the uncertainty many families feel regarding services and support for adults living in the community.

When asked what was needed to support families' resiliency, the importance of having a parent-to-parent network that was continually maintained was highlighted. Families expressed the importance of hearing stories of others' successes, as well as being supported to create their own success story. 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.

Participants noted that families also needed support beyond what is provided through the school system. Families wanted to see counseling offered to families and to couples to support them in maintaining their relationship under stress to help them maintain resiliency. Having support for the entire family would help them greatly. They wanted support how to maintain family including their typical developing children. They also expressed wanting sibling support groups. Families recognized single parents need supports as well. They noted the importance of having the entire family experience recognized.

Participants noted the need for respite care by trained providers as well as assistance in locating them. Low wages for respite providers is another barrier for families. Families and stakeholders report that having an appropriate, reliable service plan in place minimizes opportunities for a crisis, but access to crisis intervention if and when needed, is important to them.

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. Many parents noted needing to be "on-call" in case there was a need to pick up their child from school or other activity when difficulties arose. 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.

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.

The young adults indicated 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.

The young adults want friends that they can be themselves with and not worry about what to say or being judged. Understanding that all individuals with ASD are different supports everyone. They want support to understand and develop healthy romantic relationships. They also want support on how to encourage their parents to give them some independence in this area.

Finally, 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.

LESSONS LEARNED

New Hampshire has always valued involving stakeholders from the beginning, and the Needs Assessment work group reflected this, with participants, both family members and professionals from across the state.

At the beginning of this process the NAWG chose to use consensus as our method of decision-making (See Appendix C), and the NH Council on ASD endorsed this as well. This allowed for the group to move through the process in a way that ensured collaboration, agreement, and support of the decisions made.

As the process moved forward we did bring in Andy Smith, Ph.D., Director of the University of New Hampshire's Survey Center to support the NAWG in creating questions and a document that would lead all of the Focus and Stakeholder Groups.

For the family focus groups, it was decided to keep the groups small, with no more than 10 people. This allowed for all participants to have opportunity for input. The transcripts of the recordings were de-identified to allow for anonymity of participants as well as any organizations they may have identified. There was also only the facilitator and a note taker present to promote families' comfort in providing feedback. This worked well for our process.

We learned that timing had an impact on allowing school professionals to attend. Our Stakeholder groups were held in June and this presented conflicts with end of the school year activities. Some ways to work around this would be to try to coordinate with activities which may already have school personnel in one place, such as a conference or meeting and solicit feedback.

Additionally, we would like to have more feedback from medical professionals. The program coordinator will be attending a NH Pediatric Society meeting to gain information on the best way to engage medical professionals.

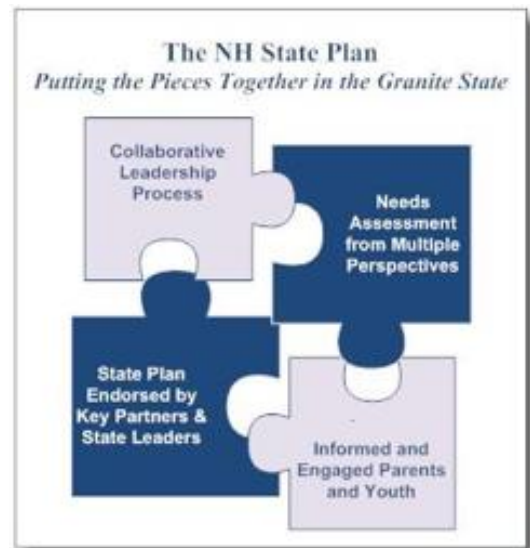
An essential part of this process was having key partners and stakeholders involved throughout the entire process. Having a core team comprised of the partners: Special Medical Services, Child Health Services, NH Family Voices, NH Council on ASD, and NH LEND allowed for a small group to keep the process moving forward and give feedback and direction to the Needs Assessment Work Group as well as the NH Council on ASD. Including Child Health Services gave us access and expertise to include Spanish-speaking families in this process in a way that was most supportive to them.

Including stakeholders was an integral part of this process, however to include stakeholders took time and preparation. It is important as we reflect on this process to note the importance of giving enough time to allow this to happen within the process and allow time for this within timelines and planning.

Families are eager to make connections with other families and promote improvements in the system of care. This was evident in each of the family focus group sessions that evolved into an opportunity for parents to support one another by sharing resources, offering and asking for advice, and exchanging contact information. .

NEXT STEPS

The Needs Assessment Work Group of the NH Council on ASD will sunset upon completion of the needs assessment. 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 Comprehensive Needs Assessment and identify core issues to be address by the Comprehensive State Plan. Metrics will be identified to support monitoring of the implementation of the plan, including measures such as the six MCHB Core Indicators and quality of life indicators including employment, independent living, and social relationships.



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. Focus Groups will be aimed at gaining ideas from traditionally underserved populations or groups not typically well represented in surveys including ethnic and racial minorities, families in NH's most rural areas and youth and young adults with ASD and other developmental disabilities. Stakeholder forums will gather feedback from community-based providers and primary health care providers on the needed components of a comprehensive state plan. Additionally, health care issues facing children, youth, and young adults with ASD will be presented to key health care reform partners regarding ideas about how to integrate relevant aspects of NH's Medicaid Managed Care, the Affordable Care Act, and other health care reforms into the comprehensive state plan. Feedback will be solicited in regards to health insurance and financing services for individuals with ASD and other developmental disabilities.

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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- The World Café Took Kit. <http://www.theworldcafe.com/tools.html>

APPENDICES

New Hampshire Council on Autism Spectrum Disorders

Appendix A

June Adinah, CCC-SLP, Speech-Language pathologist appointed by the NH Speech Language Hearing Association.

Sarah Aiken, Director of Public Policy and Community Outreach, representative appointed by Community Support Network, Inc

Virgina M. Barry, PhD. Commissioner of the Department of Education

Teresa Bolick, Ph.D, BCBA-D Representative appointed by NH Psychological Association.

Ellen Boudreau, NH Council on ASD, Member appointed by the Council

Elizabeth Collins, RN-BC, MS, Title V CYSHCN Director, NH Autism Planning Grant Director Designee for Lorene Reagan, Bureau Chief of the Bureau of Developmental Services, Department of Health and Human Services

Mary Anne Cooney, Designee for Nicholas Toumpas, Commissioner of the Department of Health and Human Services

Pamela DiNapoli, PhD, RN, CNL, Associate Professor UNH, Representative appointed by NH Nurses Association

Adrienne Evans, Representative appointed by the NH Developmental Disabilities Council, appointed by Council

Amy Frechette, AS, LEND Faculty, Individual who has ASD appointed by the governor

Heather Gage, Director, Division of Instruction, Department of Education (DOE)

Viki Gayardt, B.S., 3 family members on the Autism Spectrum, Designee, Honorable Margaret Hassan, Governor, State of NH

Brian Huckins, Chair, A family member of an individual with ASD appointed by the governor

Audrey Knight, Designee for Dr. Jose Montero, Director of the Division of Public Health Services, Department of Health and Human Services

Gregory Prazar, MD, Designee for Dr. Lukas R. Kolm President of the New Hampshire Medical Society

Patricia Reed, Children's Director, Designee for Erik Riera, Bureau Chief of the Bureau of Behavioral Health

Bonnie Rothermel, Vocational Rehabilitation Officer, Designee for Lisa Hatz, Director of the Division of Career Technology, Department of Education.

Rae M. Sonnenmeier, Ph.D., CCC-SLP, Clinical Associate Professor, University of New Hampshire, Designee for Mary Schuh Director of the Institute on Disability, University of New Hampshire

Needs Assessment Work Group

Appendix B

Karen Blake, Parent, Legislative Liaison Northern Human Services

Denise Colby, Parent, NH Developmental Disabilities Council, Lakes Region Community Services Family Support Council, ABLE N

Elizabeth Collins, RN-BC, MS Title V CYSHCN Director, NH Autism Planning Grant Director, NH Council on ASD (Core Team)

Janet Clark, Director of Special Medical Services, Child Health Services (Core Team)

Diana Dorsey, MD, FAAP, Pediatric Consultant, Special Medical Services

Shelly Fagen, Birchtree Center, Director of Special Education

Amy Frechette, AS, LEND Faculty, Self Advocate, NH Council on ASD

Linda Graham, Bureau of Developmental Services, Child and Family Services Administrator

Brian Huckins, Parent, Chair – NH Council on ASD (Core Team)

Esther Kennedy, Director of Student Services SAU 73

Martha Jean Madison, Co-Director, NH Family Voices (Core Team)

Kathy McKechnie, SLP, Special Education Administrator

Jennifer Pineo, BS, Project Coordinator, NH Family Voices, Liaison to NH Council on Autism Spectrum Disorders. (Core Team)

Rae M. Sonnenmeier, Ph.D., CCC-SLP, Clinical Associate Professor, University of New Hampshire, NH LEND Faculty (Core Team)

Kara L. Stanley, Parent, CRPC, Kara Financial

Cathy Wahl, Parent, Community Crossroads Service Coordinator

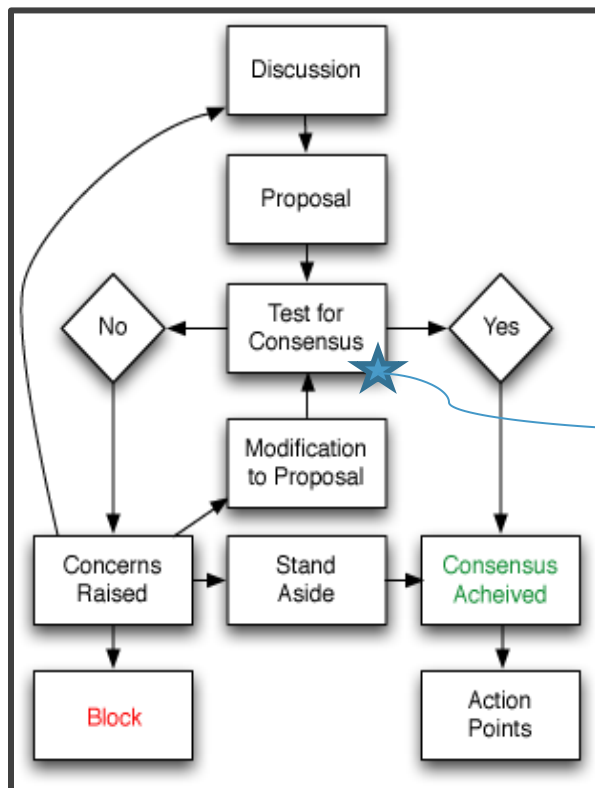
Elizabeth Webster, Parent, Consultant

Active Engagement and Consensus Decision Making

Appendix C

The New Hampshire Council on Autism Spectrum Disorders
Putting the Pieces Together

Active Engagement and Consensus Decision Making



"Consensus" agreement levels

1. **I enthusiastically agree with....**
2. **I agree with...**
3. **I agree with...with a minor clarification and/or edit.**
4. **I disagree, with...but will go along with the rest of the team if they do and I will support the decision (I will not block the work).**
5. **I disagree with...and cannot support it.**
6. **I disagree with...and will actively work against its implementation.**

(Adapted from Kaner, S. (1996). The facilitator's guide to participatory decision-making. Gabriola Island, British Columbia: New Society Publishers.)

Consensus decision-making is a group decision making process that seeks the consent of all participants. Consensus may be defined professionally as an acceptable resolution, one that can be supported, even if not the favorite of each individual.

The following aspects can be effectively applied in any consensus decision-making process:

- ❖ Ground Rules are discussed at beginning to ensure that everyone understands the process
- ❖ Multiple concerns and information are shared until the sense of the group is clear.
- ❖ Discussion involves active listening and sharing information.
- ❖ Norms limit number of times one asks to speak to ensure that each speaker is fully heard.
 - This can be done with a round robin approach or by allowing everyone to speak only once until everyone has spoken. This can be decided/discussed in the ground rules.
 - Individuals can choose to pass in round robin if they choose, but everyone is given the opportunity for input.
 - Each individual speaks only once until everyone is heard.
- ❖ Ideas and solutions belong to the group; no names are recorded.
- ❖ Consensus agreement levels are used to determine where group is in terms of agreement
 - There is a “call to question” to see if the group is at consensus
 - Level of agreement can be shared verbally or with cards.
- ❖ Differences are resolved by discussion. The facilitator identifies areas of agreement and names disagreements to push discussion deeper.
- ❖ The facilitator articulates the sense of the discussion, asks if there are other concerns, and proposes a recording of the decision.
- ❖ The group as a whole is responsible for the decision and the decision belongs to the group.

A key component is the ability to decide together. The goal is "unity, not unanimity." Ensuring that group members speak only once until others are heard encourages a diversity of thought. The facilitator is understood as serving the group rather than acting as person-in-charge. In the consensus decision-making processes, by articulating the emerging consensus, members can be clear on the decision, and, as their views have been taken into account, are likely to support it.

Roles

The common roles in a consensus meeting are:

- **Facilitator:** As the name implies, the role of the facilitator is to help make the process of reaching a consensus decision easier. Facilitators accept responsibility for moving through the agenda on time; ensuring the group adheres to the mutually agreed-upon mechanics of the consensus process and ground rule; and, if necessary, suggesting alternate or additional discussion or decision-making techniques, such as go-arounds, break-out groups or role-playing.
- **Timekeeper:** The purpose of the timekeeper is to ensure the decision-making body keeps to the schedule set in the agenda. Effective timekeepers use a variety of techniques to ensure the meeting runs on time including: giving frequent time updates, ample warning of short time, and keeping individual speakers from taking an excessive amount of time.
- **Note taker:** The role of the notes taker or secretary is to document the decisions, discussion and action points of the decision-making body.

Adapted from Wikipedia: Consensus decision-making Last Revised 28 December 2013
http://en.wikipedia.org/w/index.php?title=Consensus_decision-making&oldid=588088185

Ground Rules/ Gathering Guidelines for Active Engagement

- ❖ Everyone Speaks – actively share your experience and insights
- ❖ Share Airtime - know when to step up/step back.
- ❖ One Conversation (no side bars)
- ❖ Use Parking Lot – Any off topic items will be put into a “parking lot” to be reviewed or discussed at a later time
- ❖ No Beeps, Buzzes, or Ringy Dingies (Silence all electronic devices)
- ❖ Focus on Ideas, Not People
- ❖ Be Respectful
- ❖ Use Person First Language
- ❖ Link and Connect Ideas – Don’t repeat them
- ❖ Focus on the topic at hand (address agenda items)
- ❖ Be Positive – see opportunities, not challenges
- ❖ Have fun
- ❖ Be Flexible
- ❖ Be Non-Judgmental
- ❖ Take A Pause When Needed (Give time to process)
- ❖ Changes or Additions can be made to Ground Rules at any time.

Focus Group Moderators Guide

Appendix D

NH ASD Needs Assessment Focus Group Moderator's Guide Spring 2014

INTRODUCTION (10 minutes)

Introduce moderator

Review purpose of focus group discussion:

Thank you for coming to this discussion. Our purpose today is to get feedback from parents about their experiences getting help and care for their children with autism spectrum disorders or other developmental disabilities. We want to hear from you about what works and what needs to be improved. This work is being done as part of a statewide needs assessment being conducted by the NH Council on Autism Spectrum Disorders. Our goal is to use this information in revising a statewide plan to improve the system of care for individuals with ASD and related disabilities and their families.

We're only going to use first names during our discussions today, and you can be assured that no names will be used in the report. There are no right or wrong answers—your honest feedback is what we are looking for. Occasionally, as your moderator, I will need to move the discussion along, so that we can end on time. Sometimes, I might ask if you agree with what is being said—or if you disagree.

Introduce note taker: _____ will be assisting me today in taking notes and helping with some of the logistics of the session. We are also audio-taping this meeting because neither of us can remember everything said by everyone, and we need all of your input for our report. To help with that, please try to speak loudly and clearly and voice your opinions one at a time.

If you are not able to share all of your ideas in today's meeting, we have provided you with a list of topics. Feel free to jot down additional thoughts related to each topic. If you are interested in sharing these thoughts with us, we will collect the notes at the end of the session. [Distribute notes form; include first name and child's age at top]

Participant introductions: I'd like you to introduce yourselves to the rest of the group by stating just your first name, what town you live in, and the age of your child with ASD or other disability.

1. INFORMATION SOURCES (15 minutes)

I'd like to begin by having you "think-back" to a time when you were seeking services for your child and family. How do you typically learn about supports, services, or resources for your child and family? How helpful have the following services been for your child and family?

- Schools?
- Area Agencies?
- Your child's doctors or people in healthcare?
- What about other parents?
- Statewide organizations, supports, and resources?
- What would be the best way to get you information about available services?
- Have you used electronic or social media resources? How have they worked or you?
- How do you connect with other families, supports/services and resources in the community?

2. SERVICES (15 minutes)

- What services are your child and family currently receiving?
- What other services would be beneficial to your child and family that are not being provided now?
- What is preventing you from getting the services your child and family needs?
- What about services for you as a parent? Such as training, family support, connecting with other parents, respite care?
- And what about crisis support services? (for your child, for your family)

PROBES:

"What are some things that may be preventing access to needed services?"

- Cost? Insurance coverage?
- Location / Distance?
- Awareness of what is available?
- Are services responsive/wait lists?

3. TRANSITION (15 minutes)

We'd like to hear about how you and your child have moved through the education and health system. Tell me about the transition you most recently or are currently experiencing. This could be the transition from early supports (early intervention) and services into the school system; or between grades/schools; or graduation. Or this could be transitions between doctors or therapists or community services.

- Where did you get information about these transitions? Did you get information early enough?
- What gaps were there – either in information or resources?
- What worked for you in moving through these transitions?
- What do you wish you would have known to help you through this?

PROBES:

What worked well for you?

What problems did other people you know have?

4. RESILIENCY (10 Minutes)

I'd like for you to think a minute about families with children with ASD or other developmental disabilities.

- What do you think helps families to be strong and have hope for the future?
- What could be done to support all families' strengths and dreams?
- What suggestions do you have to improve family experiences and outcomes?

5. COORDINATION (10 Minutes)

We know that children and youth with ASD tend to have complex needs with education, behavior, health, and social relationships. These complex needs require coordination between all of the people and agencies or organizations you and your child deal with.

- How does this coordination happen for your family?
- Are you satisfied with the coordination you are receiving?
- What would be the best way to improve coordination?
- Who should be the central person in coordinating care? Why?

6. WRAP UP (5 minutes)

I'd like to thank you again for your time and the information you've provided. Is there anything else you want to add to this conversation that we haven't touched on?

7. NEXT STEPS (after the meeting)

If you have additional information that you would like to share as part of the needs assessment, you may contact Jenn Pineo. Here is her business card.

We will be accepting additional comments for one week following this meeting. If you are interested in connecting with other parents, we have some contact information for you. We also have information about the NH Council on ASD if you are interested. The findings from the needs assessment will be made available via the Council's website in the fall.

Finally, if you have questions about services that are available to you and your child, we'd be happy to talk with you after the meeting.

Thank you for your involvement in this process!

Stakeholder Forum Moderator's Guide

Appendix E

NH ASD Needs Assessment Stakeholder Forum Moderator's Guide Spring 2014

INTRODUCTION (10 minutes)

Review purpose of World Café brainstorming discussion:

Thank you for coming to this discussion. Our purpose today is to get feedback from the community at large about their experiences getting help and care for children with autism spectrum disorders or other developmental disabilities. We want to hear from you about what works and what needs to be improved. This work is being done as part of a statewide needs assessment being conducted by the NH Council on Autism Spectrum Disorders. Our goal is to use this information in revising a statewide plan to improve the system of care for individuals with ASD and related disabilities and their families.

Introduction to the World Café Process

We are going to use a process called World Café. Some of you may have participated in a similar process in other venues. We are using this process to create a living network of collaborative dialog on topic areas identified within the needs assessment.

We have arranged seating in conversational clusters. Each group table will have a question / topic for the group to explore. We will have five progressive rounds of conversation, approximately 20 minutes each.

Each table will have a host who will also be recording your responses on the flip chart. We have also supplied a large sheet of paper on your table, which we encourage you to use for writing doodling or drawing key ideas and comments you would like to add.

As the moderator, I will be watching the time and calling for a rotation to the next table.

Introduce hosts: _____ will be assisting me today in taking notes and helping with some of the logistics of the session.

Participant introductions: I'd like you to introduce yourselves to the rest of the group by stating just your first name, what town you are from, and the capacity that you work with individuals experiencing Autism or a similar disability.

INFORMATION SOURCES

I'd like to begin by having you "think-about" how you work with families/individuals to find ASD related services for a child/youth, adult or family. How do you typically learn about supports, services, or resources?

- "What would be the best way to get you information about available services?"

- Have you used electronic or social media resources? How have they worked for you?
- How do you connect with other supports/services and resources in the community?
- How do you get information to families that may have cultural or linguistic needs?

SERVICES

Based on your experience what services are children/adults with ASD currently receiving? What services are you providing? How is it funded (private insurance/Medicaid.

- What other services would be beneficial to children/adults with ASD that are not being provided now?" If funding was available what services do you wish you could provide families?
- What is preventing children/adults with ASD from getting the services they are seeking?"
- How can we support families whose children have primarily social needs who do not qualify for an IEP or other services?
- What about services for you as a professional?
- What about services for families that may have cultural or linguistic Needs?

TRANSITION

We'd like to hear about how a child moves through the system you are familiar with. Tell us about your recent experiences working with children/families as they transition. This could be the transition from early supports (early intervention) and services into the school system; or between grades/schools; or graduation. Or this could be transitions between doctors or therapists or community services.

What does your agency do to support families with students with ASD during the transition from School to adulthood?

- How can we foster consistency across service systems?
- Where did you get information to assist with these transitions? Did you get information early enough to be of assistance?
- Did families/youth get this information early and with frequent reinforcement?
- What gaps were there – either in information or resources?
- What worked for children/youth with ASD moving through these transitions?
- What do you wish you would have known that would have helped children/adults with ASD through the transition?
- What worked well?
- What problems have you heard about, that you may not have experienced?
- What about Transition for families that may have cultural or linguistic needs?

RESILIENCY

I'd like for you to think a minute about families with children with ASD or other developmental disabilities. What do you think helps families to be strong and have hope for the future?

- What could be done to support all families' strengths and dreams?
- What suggestions do you have to improve family experiences and outcomes?
- What are the preventative/crisis services currently being provided in your community? What are the gaps? What suggestions do you have for improving the system? Caretakers well-being?
- What about for families that may have cultural or linguistic needs?

COORDINATION

We know that children and youth with ASD tend to have complex needs with education, behavior, health, and social relationships. These complex needs require coordination between all of the people and agencies or organizations you and your child deal with.

- How does this coordination happen within the system you work?
- Are you satisfied with the coordination?
- What would be the best way to improve coordination?
- Who should be the central person in coordinating care. Why?
- What about for families that may have cultural or linguistic needs?

WRAP UP

Summary from each table host of the discussion that took place for each topic area.

I'd like to thank you again for your time and the information you have provided. Is there anything else you want to add to this conversation that we haven't touched on?

NEXT STEPS (after the meeting)

If you have additional information that you would like to share as part of the needs assessment, you may contact Jenn Pineo. Here is her business card.

We also have information about the NH Council on ASD if you are interested. The findings from the needs assessment will be made available via the Council's website in the fall."

Finally, if you have questions about services that are available we'd be happy to talk with you after the meeting.

Thank you for your involvement in this process!

Survey Form for Focus Group Participants

Appendix F

ASD Focus Group

PARTICIPANT REGISTRATION FORM

Parent Name: _____

City, Zip Code: _____

Email: _____

Phone: _____

Child's Age (in years): _____

Age when diagnosed with ASD: _____

Please list any other diagnoses: _____

Child's Gender:

- ☐ male
☐ female

Parent Race (optional):

- ☐ White
☐ Black or African American
☐ American Indian or Alaskan Native
☐ Asian
☐ Native Hawaiian or Other Pacific Islander
☐ More than one race

Parent Ethnicity (optional):

- ☐ Hispanic
☐ Non-Hispanic

NOTES:

Invitation to Family Focus Groups

Appendix G



The New Hampshire Council on Autism Spectrum Disorders
Putting the Pieces Together



We want to hear from YOU!

We value YOUR Opinion!

The NH Council on Autism Spectrum Disorders is recruiting parents to be potential participants for a discussion on the current needs facing individuals on the autism spectrum and their families in the state of New Hampshire.

If selected, you will receive a

\$40 VISA gift card for your participation.



Focus Groups will be held as follows:

- Wed June 4 6:00—7:30 pm Dover
- Thurs June 5 6:00—7:30 pm Littleton
- Tues June 10 6:30—8:30 pm Laconia
- Thurs June 12 6:00—7:30 pm Manchester
- Tues June 17 6:00—7:30 pm Claremont

Snacks will be provided

- ⇒ We want to hear from a **variety** of families with individuals across the age span, including young children, school-aged children, middle and high school students, and adults.
- ⇒ ***If selected***, you will be contacted at least one week prior to the focus group. At that time, you will be given directions to the location of the focus group in your area.
- ⇒ ***Your ideas*** will be used to inform a state plan to improve families' access to supports and services in New Hampshire.

Interested in being considered for participation?

Send an email to: asdfocusgroup@gmail.com

OR call 603-862-1860 (leave a message for Rae)

You will hear back within 24 hours

To learn more about the
NH Council on Autism Spectrum Disorders, visit:
www.nhcommissiononasd.org/

Invitation to Stakeholder Forums

Appendix H



The New Hampshire Council on Autism Spectrum Disorders
Putting the Pieces Together

We Want To Hear From You!

World Cafe Discussions on the current needs of families of/and individuals with Autism Spectrum Disorder in New Hampshire are being held throughout the state

We want to hear from all stakeholder and service providers across the age span including young children, school-aged children, middle and high school students, and adults.

Your ideas will be used to inform a state plan to improve families' access to supports and services in New Hampshire.

To learn more about the

NH Council on Autism Spectrum Disorders,
www.nhcouncilonasd.org



Who Should Attend?

Professionals, Physicians, School Personnel, Service Providers, Parents, Stakeholders, Community Members, anyone interested in support and services provided to individuals with Autism Spectrum Disorder in NH

Monday June 9th 4pm-6pm

Littleton Regional Hospital
600 St Johnsbury Road, Littleton

Wednesday June 11th 4pm-6pm

SERESC
29 Commerce Drive, Bedford

Wednesday June 18th 4pm-6pm

Concord Hospital
250 Pleasant Street, Concord
Conference Room 3rd Floor A
(enter via visitor entrance)

Snacks will be provided

Please RSVP to

ASDWorldCafe@gmail.com

or call (603) 271-4525

(leave a message for Jenn)

Invitation to Self-Advocates Forum

Appendix I



The New Hampshire Council on Autism Spectrum Disorders
Putting the Pieces Together

Self Advocates

We Want To Hear From You!

Join members of the NH Council On Autism Spectrum Disorders for a conversation about services and supports in NH. Your ideas will be used to inform a state plan to improve families and individuals access to these services and supports in New Hampshire.

Who Should Attend?

Individuals with an
Autism Spectrum Disorder
ages 16-26.

Please RSVP to

ASDWorldCafe@gmail.com

or call (603) 271-4525

(leave a message for Jenn)

Wednesday

September 10th, 2014

Institute on Disability
56 Old Suncook Road
Concord NH 03301

4pm-6pm

All chosen participants will receive a
\$40 Visa Gift Card
(*RSVP Required to receive Gift Card*)

Please RSVP by Friday Sept 5th
with any accommodations
needed to attend.

To learn more about the

NH Council on Autism Spectrum Disorders

www.nhcouncilonasd.org

Focus Group Participation Distribution

Appendix J

