

# Growing Supports and Services for Autism and other Related Developmental Disabilities

New Hampshire State Plan to Improve Supports and Services  
for Individuals with ASD/DD and Their Families

2016





## Acknowledgements

Through the Autism Collaboration, Accountability, Research, Education and Support Act, referred to as the Autism CARES Act, the Health Resources and Services Administration's Maternal and Child Health Bureau awarded two year planning grants to 4 states to develop comprehensive state plans to guide the next steps in supporting children with autism and their families. New Hampshire was the recipient of one of these planning grants.

The NH State Plan to Improve Supports and Services for Individuals on the Autism Spectrum and with Other Related Developmental Disabilities and their Families, referred to as the NH State Plan for ASD/DD, is the culmination of the vision, passion and effort of a committed group of planners and stakeholders.

**The Core Planning Group** was a true collaboration of partners who worked together to create the application for funding, plan the project and steward it to fruition.

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## Contents

	Page
<b>Guiding Principles</b>	5
<b>Gathering the Seeds</b>	
• Needs Assessment from Multiple Perspectives	6
• Collaborative Leadership Process	6
• Needs Assessment Summary of Findings	7
• System of Care: Building a Circle of Support	8
• New Hampshire State Plan to Improve Supports and Services for Individuals with ASD/DD and Their Families	9
<b>Branching Out</b>	
• Early Identification, Screening, Referral, and Diagnosis	12
• Family Support	14
• Early Intervention/FCESS	15
• Education	17
• Therapeutic Services	19
• Health Care	20
• Community Supports and Services	22
• Transition	24
<b>Roots: Building a Strong Foundation</b>	
• Awareness	26
• Information Resources	26
• Workforce Development	26
• Financial Support	26
• Public Policy	27
• Monitoring	28







## Guiding Principles for Educational and Community Supports and Services for Individuals on the Autism Spectrum and their Families

*(NH Commission Report on ASD, 2008; updated by the NH Council on ASD, August 2015)*

- ✦ Do no harm
- ✦ Listen to individuals with ASD and their families.
- ✦ Provide support to enable individuals with ASD to communicate their needs and preferences (including but not limited to the use of assistive technology, sign language, picture symbols)
- ✦ Support individuals and families to participate in decisions concerning educational and community supports and services (including but not limited to person-centered planning).
- ✦ Provide identification and intervention as early as possible for children with ASD.
- ✦ Invest in early intensive evidence-based treatment (including but not limited to applied behavioral analysis) to support the best outcomes and quality of life and to potentially reduce the lifetime cost of care associated with ASD.
- ✦ Recognize the dynamic and changing needs of individuals and families and assure that a seamless coordination of services and resources occurs across the lifespan.
- ✦ Assure that comprehensive and coordinated services are available to individuals and their families throughout the state.
- ✦ Assure that all individuals and families, including those with diverse cultural backgrounds, receive information and supports in accessible formats.
- ✦ Provide support to families in order for their children to live safely at home and in their communities.
- ✦ Provide resources to schools, communities, providers, and families to ensure inclusive and meaningful participation in all environments.
- ✦ Adapt physical and social environments in school, service, and community settings to meet the needs of individuals with ASD and their families.
- ✦ Assure that all providers - medical, education, and human services - systematically assess progress and modify services and supports as needed to achieve individual and family goals.
- ✦ Provide quality pre-service and in-service professional development, mentorship, and ongoing consultation on the best practices for treating, educating, and supporting individuals with ASD.
- ✦ Support a workforce capable of meeting the needs of individuals with ASD and their families across the lifespan.
- ✦ Maintain high expectations for individuals with ASD and provide the education, supports, services, and opportunities necessary to achieve a meaningful life, including self-sufficiency for daily living and employment.
- ✦ Identify and endorse disability policy that recognizes the needs and potential of individuals with ASD.



## Gathering the Seeds

New Hampshire (NH) stakeholders have been engaged in a variety of initiatives that served as solid groundwork for the development of this state plan for children and youth with autism spectrum disorders (ASD) and other related developmental disabilities (DD).

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. This state plan focuses on children and youth birth to 21 years and young adults 18-26 years.

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 underserved populations to be addressed through this process.



### Needs Assessment from Multiple Perspectives

Utilizing the State Planning Grants for Improving Services for Children and Youth with Autism Spectrum Disorder and other Developmental Disabilities, U.S. Department of Health and Human Services/Health Resources and Services Administration (HRSA Grant #H6MMC26245), NH completed a comprehensive needs assessment<sup>1</sup> in 2014 that systematically analyzed data from existing data sets and collected additional information from families, young adults, self-advocates, providers, and other stakeholders' regarding their needs.

The data sets reviewed for the needs assessment included:

- ◆ Department of Education Census by Disability (USDE and NHDOE)
- ◆ NH State Registry for ASD
- ◆ The National Survey of Children with Special Health Care Needs
- ◆ NH Needs Assessment Survey 2013

For the State Plan, it should be noted that the data source for each goal included information collected from the Needs Assessment and direct input from stakeholder sessions. Stakeholder Sessions included direct parent input from focus groups held across four major areas in the state, as well as key informant sessions with pediatricians and family practitioners, mental health providers, and special education providers.

<sup>1</sup> New Hampshire Council on Autism Spectrum Disorders. *New Hampshire Autism Spectrum Disorder Needs Assessment 2014*. Available at: <http://nhfv.org/projects/initiatives/improving-services-children-youth-asd/>

## Collaborative Leadership Process

The “core” work group consisted of the Project Coordinator, NH Family Voices, Title V CYSHCN Director, Child Health Services, NH Leadership Education Neurodevelopmental Disabilities (LEND) and a member of the NH Council on Autism Spectrum Disorders. The primary function of the core work group was to provide direction To the State Plan Work Group (SPWG ) regarding the State Plan.

A State Plan Work Group (SPWG) was formed with participation from informed and engaged parents and youth as well as many state and community stakeholders. The SPWG reviewed data sets, forum responses and plans from other states to provide input in the development of NH’s State Plan. The group chose to create a state plan and then have separate action plans to address the recommendations. This was done to give fluidity to the action plans moving forward.

To gather further information for the State Plan, family forums and key informant discussions were held. The key informant discussions included mental health providers, family centered early supports and services directors, educators, and medical professionals.

## Needs Assessment Summary of Findings



### Information About Services

- Families wanted information about respite, education opportunities, services, funding, and support groups.
- Families currently get information from other families, their own research, internet or social media.
- There is variation of information across the state.
- Families wanted information in accessible formats, i.e. readable, easily understood.



### Accessing Services

- Throughout the state there is difficulty in finding qualified providers.
- There was a general consensus of the need for training of providers.
- Both families and professionals acknowledged the high provider turn over.
- There is a perceived lack of consistency in availability and quality of services across the state; in educational systems; community based services; and clinical services.
- Families and professional identified the need for more access to services to support transition to adult life.
- Participants identified resource needs for funding and allocation to schools, community based services and Medicaid.



### Coordination of Care

- Families and stakeholders agreed *parents* are the ones who primarily provide care coordination.
- Participants identified the importance of care coordination following an ASD diagnosis.
- The importance of coordinated medical care within a medical home was confirmed.
- There is a critical need for funding of Care Coordination.
- Parents level of involvement in care coordination directly correlates with their level of satisfaction.

## Needs Assessment Summary of Findings.. continued



### Transition

- Supports were identified as being needed during transitions throughout the lifespan.
- Transitions were often described as “hitting a brick wall” or “falling off a cliff”.
- Families wanted information regarding transitions early in the process.
- Families identified needing extra support during transitions.
- Families and professionals identified a lack of services for young adults over the age of 21.
- Parents and professionals asked about services for those not eligible for Area Agency services system.



### Resiliency

Families felt resiliency happened through:

- Having access to support (funded and natural supports).
- A strong sense of community.
- Social media.
- Connection with other families.
- Parent to Parent.
- Many families expressed concern around what will happen to their family member when they are gone.
- Families felt valued by being heard and involved.

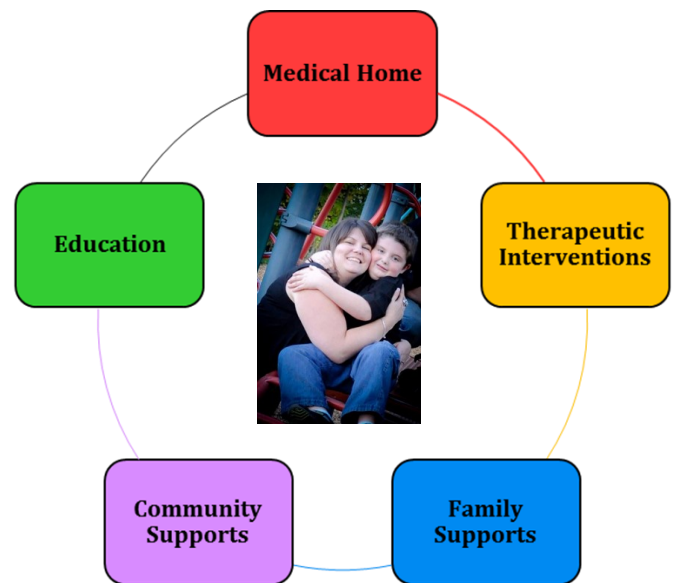
## System of Care: Building a Circle of Support

Families with children and individuals who experience Autism Spectrum Disorder (ASD) /DD receive services and supports from numerous systems that together comprise the “system of care”.

These systems deliver services that include medical, education, therapeutic interventions as well as community and family supports. Some of these systems are considered an "entitlement" under the law and are publicly funded; others must be paid for, in part or in full, by private sources such as insurance or out-of-pocket if a family's situation allows. Some cost nothing at all as they are the natural outcome of being part of a community. Each system maintains independent, and often different, eligibility criteria, service planning, limits to service delivery, and guidelines for quality assurance and consumer protection.

Lack of coordination among systems remains one of the biggest challenges in trying to achieve a unified system of care. More often than not, the parent becomes the glue that holds all these pieces together. The circle of care resource map was developed to support the discussions during the family forums that were completed during the State Plan development process. This tool assisted families to map out systems their family members are using and identify those that may be needed in the future.

It is important to think of these systems of care as "complementary." This means that each part is made stronger by its connection to the other parts that make up a system of care that surrounds a family member with ASD/DD.



**Building a Circle of Care Resource Map**

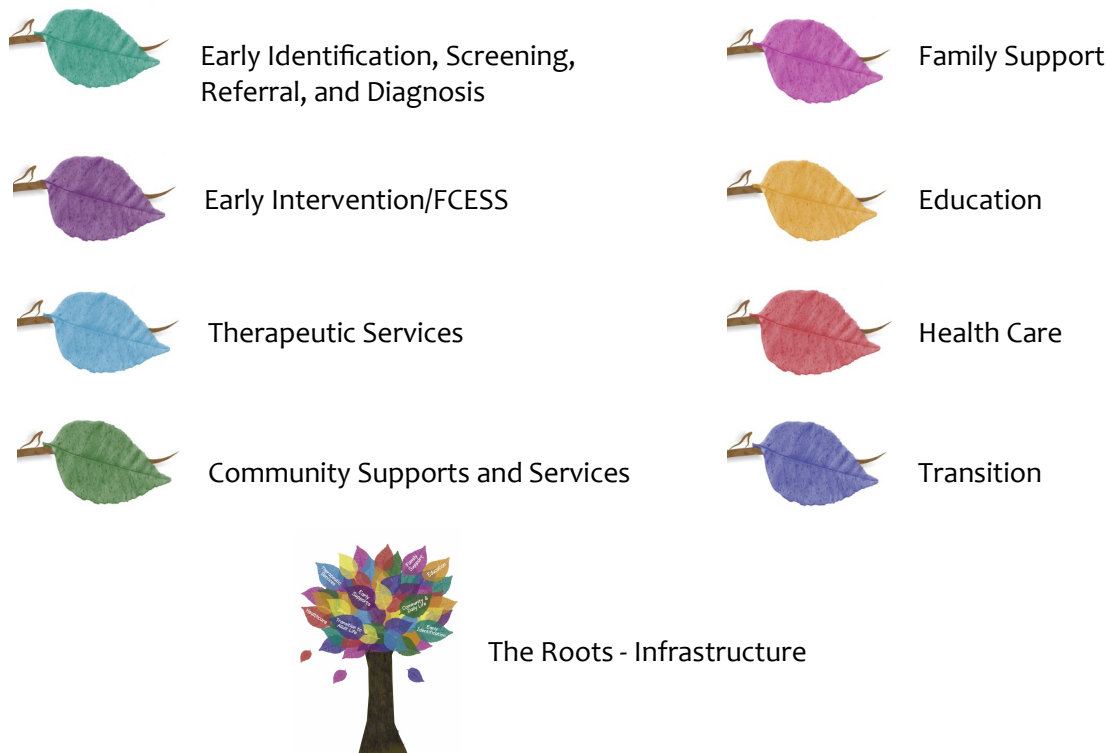
Available at: <http://nhfv.org/projects/initiatives/improving-services-children-youth-asd/>



## New Hampshire State Plan to Improve Supports and Services for Individuals with ASD/DD and Their Families

With all the seeds gathered, the findings from the comprehensive Needs Assessment informed the development of the “NH State Plan to Improve Supports and Services for Individuals with ASD/DD and Their Families”. The workgroup (SPWG) then branched out to identify the priorities and goals for each identified area of need. Many of the supports and services accessed by families of individuals with ASD are similar to those who have related developmental disabilities, therefore the recommendations in this State Plan are beneficial to both populations.

The NH State Plan focusing on the following areas:



Sections are formatted as follows:

- ◆ Each identified area begins with a definition specific to the NH State Plan for ASD/DD.
- ◆ The priority identifies specific issues recognized by stakeholders.
- ◆ Goals clarify the movement needed to address the priority areas.
- ◆ Recommendations identify the steps, partnerships and awareness activities that will be addressed in the Action Plans.
- ◆ Barriers recognize that infrastructure components may have an impact on other sections of this plan and those linkages are identified in the Roots section.





## **Growing Supports and Services for Autism and other Developmental Disabilities**

### **Branching Out**





## Branching Out

### Early Identification, Screening, Referral, and Diagnosis

**Screening:** refers to the use of standardized developmental and ASD specific assessments to identify delays in development that may indicate the need for future evaluations.

**Referral:** means a recommendation that a child, who has been screened through a standardized developmental assessment, be further evaluated for diagnosis and/or eligibility of services through Family Centered Early Supports and Services (FCESS) or other early interventions.

**Diagnosis** is based on the assessment of an individual using criteria from the most current Diagnostic Statistic Manual and/or International Classification of Diseases.

#### ★ **Priority: Awareness and Education for Families**

- Family friendly information about developmental milestones for all ages, needs to be provided in multiple formats that are family friendly, culturally and linguistically appropriate, in real time and easy to access (pictures, verbal, video).
- Families need to be supported and encouraged to express and discuss developmental concerns with professionals including primary care physicians, childcare and others.
- **Goal:** Parents and caregivers are provided resources and information regarding developmental milestones and approaches to pursue and advocate for screening /assessment.

#### ★ **Priority: Awareness and Education for Providers**

- Providers (including child care, health, schools) recognize parents as partners regarding their child's development.
- Providers have a comprehensive understanding of evidence based and best practices to determine surveillance, screening, diagnosis and makes appropriate referrals.
- **Goal:** Providers have the knowledge, skills and resources to facilitate early identification and referral.

#### ★ **Priority: Access throughout the years including Middle and High school and for Diverse populations**

- Developmental delays that emerge/express themselves after early childhood need to be accurately identified.
- Outreach, services and screenings will continue to be available after early childhood.
- Families of children within diverse populations should have access to culturally and linguistically appropriate materials and information that assist them in determining their child's emerging developmental needs.
- **Goal:** Developmental screening and diagnostic services are accessible and available in a timely manner.

#### **Recommendations:**

- Emphasize the benefit of parent partnership as a component of Medical Homes.
- Promote / create expert training for providers that is available in a variety of modalities including in person and self-directed/(asynchronous) learning that is easy to access, responsive to time constraints.
- Develop and disseminate tools related to screening and diagnosis as well as state specific resources.
- Develop educational resources that are culturally respectful and available in families primary languages.
- Support education and training for providers (school, health, mental health) regarding age appropriate comprehensive developmental screening at all ages.
- Explore emerging practices that improve quality and efficiency for diagnostic services.
- Expand and improve access to team based diagnosis services for school aged youth .

- Expand stakeholder involvement to ensure that youth and culturally diverse populations are better represented in system design.
- Support a variety of formats and approaches for public awareness regarding developmental milestones throughout the years, including CDC's Learn the Signs, Act Early Materials.
- Support the incorporation of evidence based developmental screening for children beyond early childhood.
- Facilitate stronger family involvement in the statewide developmental screening system, Watch Me Grow.
- Develop a framework to provide educational opportunities to strengthen family knowledge, skills and confidence to collaborate with their family providers.

**Barriers:**

- Currently, there is a lack of developmental providers.
- There can be difficulty in finding funding.
- Cultural and linguistic differences may impact the ability to clearly diagnosis a child at the earliest age.
- When a family identifies a concern screening may be deferred, delaying an appropriate referral for diagnoses.
- Limited availability of providers for diagnosis of middle and high school aged students.
- Difficulty in following up on referrals when the provider is unable to contact the family or families aren't ready or don't respond.







## Branching Out

**Family Support** refers to supports that can help families. The intent is for families to be strong, hopeful for the future, resilient, and to thrive in their communities.

★ **Priority: Connection and Sense of Community**

- Families will feel less isolated, be part of a community and have the availability to access both funded and natural supports. Families will have access to family support offered in a variety of forms which may include in-person support groups, parent-to-parent connections, the use of social media, sibling groups, etc. Family support should be family driven, sustainable and formally supported.

- **Goal:** Families have access to a variety of reliable and consistent opportunities to connect with other families and support a sense of community as a way to increase their resiliency.

★ **Priority: Information Resources**

- Families have a central place to access current information, including current information about respite, educational opportunities, services, funding, and support groups.
- Information for families is available in accessible formats that are offered in various languages and is easily understood.
- **Goal:** Families have access to timely information about supports and services within their local community and region that reflect family culture, needs, values, and preferences.

★ **Priority: System Awareness and Education**

- Families need to understand the array of systems that may be of benefit as their child/ren age out of the education system. Information about adult services and opportunities should be available for both families and youth, in various formats including in person, online webinars, and accessible in all areas of the state.
- Families and youth have training and support needed to initiate and influence transition and futures planning discussions.
- **Goal:** Families have access to parent training and education, including a focus on advocacy, future planning and other topic areas as identified by families. Young adults have access to a support network as they transition to adult life.

### Recommendations

- Support a statewide autism resource network to provide awareness, to improve family and youth supports, and to assist with navigating the system of care.
- Collaborate with partners to create training opportunities for families and individuals.
- Create a system map for transition to be used by young adults, families, and stakeholders to support the transition into adult life.

### Barriers

- Families are often isolated due to geography and the intensity of the child/youth's support needs.
- Providers are limited by confidentiality standards in their ability to make connections between families.
- Families report they do not have enough formal support and are required to identify their own information and resources.
- Resource information is often outdated and it is difficult to discern the accuracy of information, when the source is not easily identifiable.
- Limited availability of peer support and family support groups. Families schedules and respite needs often limit their ability to attend in person support groups.
- The move from the educational system to the adult service system is a significant change in culture and approach, with limited navigation assistance (often experienced as "falling off a cliff").



## Branching Out

**Early Intervention** are interventions that are utilized after the identification of a delay or disability is given, and that are chosen by families to enhance the child or youth's overall development<sup>2</sup>.

**Family Centered Early Supports and Services**, Part C, FCESS (0-3) is a program designed for children birth through age two who have a diagnosed, established condition that has a high probability of resulting in delay, are experiencing developmental delays, or are at risk for substantial developmental delays if supports and services are not provided. Family centered early supports and services are provided within a child's home or where a child spends time. In this way, a child and family are better able to participate and become more actively involved in their community.

★ **Priority: Consistency of efforts across FCESS**

- Explore opportunities within areas for which procedures and approaches could be implemented with consistency across FCESS agencies.
- Develop resources in areas of the state that currently have a limited array of services.
- **Goal:** Regardless of location children receive consistent and high quality services from FCESS agencies.
- **Goal:** Explore procedures and approaches in each FCESS agency to ensure continuity of services across regions.

★ **Priority: Consistency of efforts across other Early Interventions**

- Access to specialty providers that accept Medicaid and private insurance.
- Access to early interventions regardless of insurance coverage.
- Looking at ways to improve resources in order to better access expert clinicians.
- Review options for greater efficiency or improving access and increased number of hours based on the recommended number of hours and determine funding components.
- **Goal:** All young children diagnosed with ASD will receive appropriate services based on need, that can be equitably accessed across the state.

★ **Priority: Thorough and reliable process for explaining to families what to expect, service delivery, and resources**

- Whenever individual rights allow, families will be given options of provider choice and location of care.
- Families will understand the components of a comprehensive individualized service plan that incorporates best practices.
- All education, information and services will be provided to families in the family's primary language and in a format that is easily understood.
- **Goal:** Families understand their rights and options.

★ **Priority: Access to information and coordination of services regionally**

- There will be access to a statewide information/resource repository for providers and families.
- Opportunities for the development of a coordinated system of care post diagnosis
- Families of children newly diagnosed with ASD and other developmental disabilities will have access to a consistent support person (preferably a person who has a family member who has experience with ASD/DD) for navigating the system of care within their own region.
- **Goal:** A regional system providing information and coordination will be available to all families whose child is diagnosed with Autism and other DD.

### **Recommendations**

- Early Intervention systems incorporate family and stakeholder input regarding potential design changes to improve consistency of efforts.
- Establishment of an accessible statewide information/resource repository.
- Develop a statewide system to provide supports and navigations across the various sectors that impact children and families with ASD/DD.
- Increase awareness about individual rights regarding service delivery options for providers and families.
- Maximizing the utilization of financial resources available to families in order to cover their individual service plan.
- Establish a process for ongoing exploration of emerging best practice and evidence based practices for incorporation into the system of care.
- Training is available for families and providers around evidence based and best practices that can be incorporated into their service plans.

### **Barriers**

- Early Intervention services have a large degree of variability across the state.
- There is not an established training protocol or competency standard for all Early Intervention providers and others such as child care providers, regarding autism and other DD.
- NH utilizes a multi-disciplinary / transdisciplinary approach that impacts the utilization of consulting clinicians specific to FCESS.
- Lack of sufficient trained clinicians, in NH, results in a struggle for expert consultation in FCESS.
- Families are given information from a variety of sources which can be confusing, difficult to understand and families have a hard time navigating the system.
- Families are given recommendations (for example, a number of hours of services within the home) but families are not sure how to find providers, implement and advocate for the services, and what the family's role might be.



<sup>2</sup> <http://www.dhhs.nh.gov/dcbcs/bds/earllysupport/index.htm>



## Branching Out

**Education** refers to services and supports provided by the local school systems to students with autism and other related developmental disabilities age 3-21. What students are entitled to is driven by the individual education plan or 504 plan aligned with federal and state guidelines for special education.

### ★ **Priority: Evidence Based Educational Practices**

- Educators within schools will use research based curriculum, materials or methodologies that have proven to be effective for students with autism and other developmental disabilities.
- **Goal :** Curriculum, materials and methodologies are research based and proven effective for students with autism and other developmental disabilities.

### ★ **Priority: Individualized Programming**

- Student placements will incorporate individualized needs including when ASD or other developmental disability is a secondary eligibility for special education services.
- Families will be provided with information regarding appropriate options in relation to the least restrictive environment for their child's learning experience.
- **Goal:** Students will receive adequate programming and supports designed for their individual needs resulting in an appropriate and least restrictive education.

### ★ **Priority: Educator Training**

- Develop/adopt a mechanism to ensure teachers, support personnel and related service providers have adequate training to meet the unique needs of students identified with ASD/DD.
- **Goal:** Staff members will have specialized training and therefore will be able to adequately meet the educational needs of students.

### ★ **Priority: Inclusive Education**

- Students will receive their education in the least restrictive environment and will incorporate maximum learning and social interactions with all of their peers.
- **Goal:** Students of all abilities will have the opportunity to develop learning, social, and pragmatic skills by interacting with one another across educational environments.

### **Recommendations:**

- Ensure schools are utilizing curriculum, materials and methodologies that are research based and proven effective for students with autism and other developmental disabilities.
- Ensure schools are providing adequate programming and supports to provide students with an appropriate education that is based on their individualized needs.
- Provide parents with information and resources relative to best practices in educating children with ASD/DD.
- Parents and family members have access to training regarding navigation of the special education process.
- Provide educators, support personnel and related service providers with the opportunity to acquire expertise relative to best practices that allow them to obtain a certification endorsement in ASD/DD.
- All opportunities for inclusion within the school environment will be explored and utilized where appropriate.

## Education ... continued

### Barriers

- The New Hampshire Department of Education does not have a certification endorsement for Autism.
- Students with Autism and other development disabilities may receive their educational instruction in secluded programs with little to no interaction with non-disabled peers. This is due to a variety of factors including, school culture/design, limited professional/families knowledge concerning the benefits of inclusive options.
- Difficulties in achieving and maintaining necessary staff resources including recruitment, training, career incentives and funding.
- Limited awareness on the part of families regarding the availability of trainings pertaining to the special education system.







## Branching Out

**Therapeutic Services** are services that work toward rehabilitative and habilitative goals to promote functional development and inclusion in the community

★ **Priority: Evidence Based Practices**

- Children and youth with ASD/DD will benefit from services that incorporate emerging best practice and evidence based practice.
- **Goal:** Evidence Based Practices are utilized in New Hampshire by those qualified to provide them.

★ **Priority: Behavioral supports through adolescence**

- Individuals with ASD/DD and their families have access to a continuum of therapeutic supports, including behavioral health services, as the child grows into adolescence and adulthood.
- Families, schools and providers will be trained regarding referral processes.
- Trainings are available regarding how to access, and the purpose of behavioral health supports and the juvenile justice programs.
- **Goal:** The behavioral health needs of children and youth with ASD/DD will be addressed.

★ **Priority: Autism services are available and sufficiently funded as part of the Medicaid State Plan**

- Children eligible for NH Medicaid and in accordance with the Center for Medicaid and Medicare Services' (CMS) guidance on autism services will have access to therapeutic services.
- **Goal:** An ABA benefit will be added as part of the NH Medicaid State Plan benefits.

★ **Priority: Access to appropriate therapeutic providers that are qualified and trained**

- Providers will be trained regarding standards of care, emerging practices and evidence based practice for children with ASD/DD.
- Families will understand their rights to habilitative and rehabilitative services, how to identify the appropriate providers and how it impacts the utilization of funding.
- **Goal:** Families will have access to qualified and trained providers and funding sources (public and private) that meet the habilitative and rehabilitative needs of their children.

### Recommendations

- Establish a process for ongoing exploration of emerging best practice and evidence based practices for incorporation into service delivery.
- Trainings for families and providers regarding behavior health supports, juvenile justice programs, emerging and best practices, utilizing funding sources, habilitative and rehabilitative service options, ability to make referrals and eligibility to the various programs.
- Incorporation of the Center of Medicaid and Medicare Services ASD/DD guidance into the state Medicaid plan

### Barriers:

- As children with ASD grow families may struggle with difficult to manage behaviors and this can often initiate a referral to Juvenile Justice or child protection. Families often have a lack of understanding of the system as well as fearfulness of the implications.
- ABA is often recommended when an ASD diagnosis is first received, yet families may have difficulty accessing funding and finding ABA providers.
- Across agencies there is an inconsistency regarding knowledge of ASD/DD.
- Families and providers do not have access to shared information and resources related to the array of therapeutic services that might be appropriate for their child.
- No licensing mechanism for ASD/DD providers and limited availability of adequate trained professionals across sectors.



## Branching Out

**Healthcare** provides children, youth and adults assurance that their well-being, physical, oral, and behavioral health needs are met. Ideally within a medical home as defined by the American Academy of Pediatrics.

A Medical Home<sup>3</sup> is not a building or a place. It is an approach to providing comprehensive primary care that facilitates partnerships between patients, clinicians, medical staff and families. Care within a medical home should be accessible, continuous, comprehensive, patient and family centered, coordinated, compassionate, and culturally effective.

### ★ **Priority: Health Care Providers have access to training and information**

- Health Care Providers are well informed about how to support the everyday needs of children with autism and other developmental disabilities and their families.
- **Goal:** Trainings and information dissemination will be provided to medical providers on services and supports available to families with ASD/DD.
- **Goal:** Medical providers are confident when referring families to supports and services, particularly following a new diagnosis.

### ★ **Priority: System of Care**

- The system of care incorporates linkages, with Health Care Providers, that promote comprehensive coordination and improve access.
- **Goal :** The system of care for ASD/DD will include medical, behavioral, education, and community components with a focus on coordination of effort starting with screening and following through to individualized service provision at all ages.

### ★ **Priority: Access to Best Practice and Evidence Informed Approaches**

- Providers will integrate new approaches and techniques that have demonstrated improvement in outcomes.
- **Goal :** Screening, assessment, and diagnostic approaches will facilitate early and reliable identification of needs resulting in the design and timely provision of quality supports and services.

### ★ **Priority : Supported Transition into Adult Health Care System**

- Youth/young adults, families and providers will be prepared regarding transition from pediatric to adult health care.
- **Goal:** The transition of youth/young adults into the adult health care system will reflect trained adult providers, prepared families and youth/young adults who are engaged in decision making.

## Recommendations

- Assure training opportunities for providers (medical, oral health and behavioral health) on how best to address the needs of individuals with autism and other related developmental disabilities.
- Create a comprehensive up to date information sharing platform that is available in real time and informs the public and providers about resources available in their communities and state wide.
- Integrate the work of diagnostic clinics with early intervention services to provide rapid access to diagnostic evaluations for very young children and early supports and services.
- All service areas that support children and youth/young adults with ASD/DD, and their families, collaborate to design a framework for coordination across all areas with consideration given to utilizing family navigators.

<sup>3</sup> The Medical Home AAP <https://medicalhomes.aap.org/Pages/default.aspx>

- The system of care will embrace a commitment to evidence informed practices and on going review of emerging and best practices.
- Information from the MCHB National Center on Health Care Transition Improvement should be made available to families and providers.
- Ongoing assistance from the Youth for Education Advocacy and Health Care Advisory Council (YEAH) so youth will have access to information, education, and opportunities to enhance their independent health care decision making.

### Barriers

- Healthcare providers may not have specific autism/DD training and their work schedules often make it difficult to incorporate participation in conferences and other training opportunities.
- When scheduling appointments families may need additional time that is not communicated to or anticipated by staff.
- Resource information is not always easy to navigate and often online resources are not up to date or incorporate appropriate reference information.
- Currently there is not a coordinated approach to the system of care that effectively connects parents across service areas. Additionally, families may be given resource information or referrals that do not have on going support and follow up.
- Families express feeling isolated and lack support as they manage the responsibilities for assuring their child's needs are met. They also identified concern regarding the lack of coordination and collaboration across service agencies.
- Healthcare providers may not have the time and support necessary to review and evaluate research and emerging practices.
- Incorporating new evidence informed practices requires a commitment to change and often requires an investment in infrastructure.
- Health care transition requires an approach that starts early to assess readiness and provide education and training to the family youth and provider. Typically there is not enough time for providers. Parents often prefer to have their child remain with a trusted health care providers, and youth are not given/nor interested in opportunities to develop health care decision making skills.





## Branching Out

**Community Supports and Services** promote and provide strength based supports to encourage, engage, refer, and educate families and community members.

★ **Priority: Community Awareness**

- The community, including providers such as police, EMT's, retail, daycares and other professionals encountered in the community at large will have an understanding of autism and other developmental disabilities.
- **Goal:** Through a public awareness campaign and other events communities are aware, empowered, and supportive of ASD/DD individuals.

★ **Priority: Families aware of services available.**

- Families have a clear understanding of the services and supports available to them, as well as eligibility requirements.
- **Goal:** Families and Providers are given information on how to best access services and supports for their child/ren throughout the lifespan.

★ **Priority: Access to trained personnel**

- Families will have the ability to find trained personnel (Respite and DSP) to fill vacancies, in order to utilize funding.
- Personnel will have access to training regarding autism and other developmental disabilities and how to best support the individual with whom they are hired to work.
- **Goal:** Families have access to trained respite providers and direct support personnel.

★ **Priority: Providers have an understanding of the system of care**

- Providers and professionals within the systems of care have an understanding of services and supports available to families, who are responsible for providing services, eligibility requirements, and resources to work with families as equal partners in the process.
- Providers have information and education on best practices for concepts, values and principles for creating a family driven system with families and individuals with ASD as equal partners within the treatment process.
- **Goal:** Providers and professionals will collaborate to assist families to access supports and services needed.

★ **Priority: Access to Community Supports**

- Families will have access to community supports and recreational programs.
- **Goal:** Families of children, youth and adults with ASD/DD will have access to services and supports that promote independence at home and in the community. Families will be able to access supports with well trained staff, including after school programs, child care, and adult programs.

### Recommendations

- Community Awareness Events are planned in partnership with community organizations and the NH Council on Autism Spectrum Disorders across the state to promote awareness and education throughout the year, along with a yearly event in April for Autism Awareness Month. Include training for families on how to increase awareness and educate community providers such as police, EMT's, retail, childcare, and other professionals encountered in the community.
- Respite providers and direct support professionals (DSP) will be given access to training resources specific to supporting individuals with ASD/DD.

- A database of trained providers will be created.
- Providers and professionals within the systems of care create a systems map of resources available to families identifying who is responsible for providing supports, eligibility requirements, and resources to work with families as equal partners in the process.
- A terminology guide will be created to support cross system collaboration.

### Barriers

- Families are unsure of how to obtain information on services and supports available to them and lack clear understanding of what services and supports they are eligible to receive.
- Providers reported needing clarity on where to send families to access services.
- Similar functions across systems have different terminology and acronyms.
- When families are given funding they often have difficulties finding personnel to fill the vacancy to utilize funding.
- Inequity in access to services and supports across geographic regions.







## Branching Out

**Transition** refers to experiences and supports including both academic and non-academic courses, that will assist individuals in achieving their goals for adulthood. These may include life skills, post-secondary education or vocational skills.

★ **Priority: Families and Professionals are knowledgeable of transition supports available to them.**

- Transition plans for students with autism and other developmental disabilities will include the student, family and professionals that are knowledgeable regarding available programs and/or services that may be available beyond the school system to support the development of life-long skills for self sufficiency.
- Families will have an understating of what is available to the individual with autism as they transition from school based services into the adult based service system.
- **Goal:** Students, parents, educators, and agency professionals will be knowledgeable about ASD/DD and work collaboratively to develop transition plans that are aligned with the student's interests and skills.
- **Goal:** Families and providers have access to supports to plan for the future of the individual with ASD/DD. This includes estate planning, housing, and services as an adult.

★ **Priority: Multiple forms of assessment during transition process**

- Multiple forms of assessment will be used when developing transition plans for students.
- Educators and families will be aware of assessments that are appropriate for students.
- Students will be included in transition planning meetings.
- **Goal:** Student specific transition plans will be based on multiple forms of assessment and include direct student input.

★ **Priority: Real life opportunities**

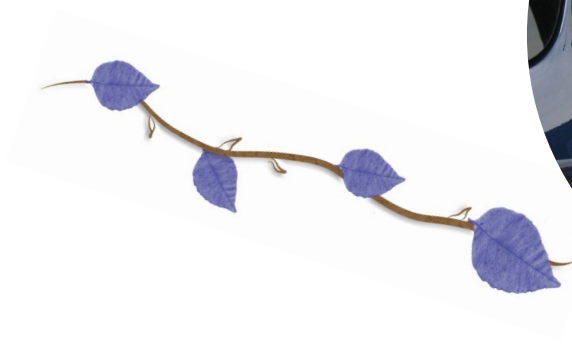
- Students will be provided real life opportunities to practice skills, including domestic, vocational, and leisure opportunities, with appropriate supports prior to transitioning from school based special education.
- Students with autism who have learned skills in isolated settings are not provided with real life opportunities to practice those skills with appropriate supports prior to transitioning from school based special education services.
- Community based activities that are practiced with appropriate supports prior to exiting special education services should include vocational, domestic, and leisure opportunities.
- **Goal:** Students with autism will be provided with real life opportunities to develop: academic skills embedded in functional life activities, job skills (paid or volunteer), domestic living skills, and community based leisure skills.

### Recommendations

- Ensure participation from students, parents, educators, and outside professionals in school transition meetings for students with ASD/DD aged 14 and older.
- Ensure all student transition plans meet guidelines for the use of multiple assessments and include direct student input.
- Ensure students have facilitated opportunities to practice educational, vocational, domestic, and leisure skills in community/real life locations with the supports necessary to be successful.
- Create a no wrong door approach with staff that is informed and knowledgeable about services and supports including education around roles and responsibilities of professionals and agencies to support system collaborations. Include training on eligibility requirements for services.
- Provide access for families and providers to support person centered planning for individuals with ASD/DD. This includes estate planning, housing, and services as an adult.

## Barriers

- Transition plans for students may not include agency professionals who may have knowledge of appropriate programs or services that may be available to the student.
- Students are not always included in their own transition planning meetings to provide direct input.
- Parents and educators may not know how to best obtain the student's input if they are non-verbal or have cognitive challenges.
- Educators and parents may not be aware of assessments that are appropriate to use with students who have ASD/DD.
- Parents may not be aware of the supports and services, beyond the school system, that are available to help their students develop lifelong skills for self sufficiency.
- Multiple forms of assessment are not always used when developing transition plans for students with autism. Educators and parents may not be aware of assessments that are appropriate to use with students who have ASD/DD.
- Students may have learned skills in isolated settings with no real life opportunity to practice these skills.





## Roots: Building a Strong Foundation

**Infrastructure:** basic foundation or underlying framework of the statewide system of care (public policy, data monitoring, financial support).

### ★ Priority: Workforce development, training, and retention

- Adequate number of qualified and trained providers to support individuals with ASD/DD.
- **Goal:** Potential and current workforce personnel are appropriately educated to provide services needed, have access to information for on-going development and advancement, and are available in numbers to meet the need.

### ★ Priority: Cross system collaboration and coordination

- Providers, in areas of education, family support, mental health, health care, and other agencies, collaborate across the systems.
- **Goal:** Providers in all areas are supported with work cultures, policies, procedures, and resources that foster collaboration and coordination of services.

### ★ Priority: Funding and Investment in Infrastructure

- Identification and/or development of adequate funding streams and payment methodologies.
- **Goal:** Supports and Services for ASD/DD will be sufficiently funded to effectively meet the need.

### ★ Priority : Public Policy

- The System of Care for ASD/DD be recognized as a public policy need.
- **Goal:** Public Policy supports a long term commitment to the development and maintenance of a system of care for ASD/DD.

### ★ Priority: Data Systems and Monitoring

- Accurate data that can inform decision making and demonstrate outcomes.
- **Goal:** Comprehensive accurate data will be collected and evaluated resulting in reporting that reflects the system of care's accomplishments, needs, quality, and impact.

## Recommendations

- Consideration of creation of a State of NH staffed position that will be identified to act as the ASD/DD System of Care Specialist.
- Creation of an integrated data system that has identified resources for ongoing monitoring and evaluation.
- Collaboration of provider network to develop a framework for cross system coordination with consideration of incorporation of Family Navigators.
- Adopt and/or incorporate policy recommendations, at all levels, regarding a comprehensive coordinated system of care for ASD/DD.
- Leverage agency, local, state, and national funding opportunities to adequately support the system of care for ASD/DD.
- Foster the development of training, employment opportunities, and conditions that increase the skills and satisfaction, along with recruitment and retention of the workforce.

## Barriers

- There are often differences in terminology, regulations and funding streams that create barriers to smooth coordination and collaboration across the systems.
- Service providers across systems lack an agreed upon framework for effective collaboration and coordination.
- Without formal policies and guidelines there is concern regarding the investment of time, energy and resources at all levels of the system of care.
- Currently there is not a staffed position within the Department of Health and Human Services that is identified specifically to be responsible for supporting the ASD and DD system of care.
- While the NH Council on Autism Spectrum Disorders existence is supported by statute, the lack of committed funding limits its ability to impact the system of care.
- The current direct service and respite workforce experiences instability and inadequacy related to insufficient pay rates, inconsistent schedules, limited access to appropriate training, and complexity of job requirements.



The collaborative work will continue with the creation of Action Plans to address the goals and recommendations outlined in this State Plan.



This State Plan has been endorsed by the NH Council on Autism Spectrum Disorders





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