

New Hampshire  
Council on  
Autism Spectrum Disorders:

Activities, Findings, & Recommendations  
*July 1, 2011 – September 30, 2013*

*Submitted: November 2013*

**THE NH COUNCIL ON AUTISM SPECTRUM DISORDERS  
GRATEFULLY ACKNOWLEDGES THE VOLUNTEER PARTICIPATION OF ITS MEMBERS  
AND  
THE GENEROUS COLLABORATION OF THE FOLLOWING AGENCIES AND  
ORGANIZATIONS:**

*Association of Maternal and Child Health Programs  
Autism Bridges  
Autism Society, national organization  
Community Bridges  
Community Support Network, Inc.  
Easter Seals, New Hampshire  
Endowment for Health  
Gateways Therapy Services  
Institute on Disability at the University of NH  
Institute of Professional Practice, Inc.  
Leadership Education in Neuro-Developmental Disabilities (LEND) Program  
Musicians for a Cause  
NH Council on Developmental Disabilities  
Opportunities Now, Inc.  
NH Bureau of Developmental Services  
NH Special Medical Services  
Southeast Regional Educational Services Center  
Special Needs Support Center*

*And*

*The many family caregivers, self-advocates, and other volunteers  
who generously give their time to improve the lives of  
New Hampshire citizens who experience an autism spectrum disorder*

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## EXECUTIVE SUMMARY

Autism Spectrum Disorder (ASD) is a complex neurological condition that impacts one in 88 children, according to the Centers for Disease Control. Given the increasing identified prevalence rate, states throughout the country are seeking ways to better support the individuals and families impacted by ASD. High quality services and supports require specialized training, regulatory revision, increased public awareness with positive messaging, and a realignment of service to address the unique strengths and challenges of these individuals.

In New Hampshire, the advisory board that promotes such changes is the NH Council on Autism Spectrum Disorders. Established in 2008, the Council is a small group with a large mission. Composed of dedicated parents and professionals, the Council has put tremendous energy and time into achieving better outcomes for people with ASD.

This report closes a chapter in the Council's history. It summarizes projects undertaken by the Council over the past two years. It also includes a detailed summary of each of the 43 recommendations that the Council inherited from the 2008 Blue Ribbon Committee that review the impact of autism on Granite State Citizens (Appendix #7). Finally, it provides policy makers with a review of the most current data available out the experiences of individuals and families impacted by ASD in NH.

More importantly, this report also opens new chapter for the Council. NH Special Medical Services (SMS) recently received a planning grant through the federal Health Resources and Services Administration (hereafter "the State Planning Grant"). Funded under the Combating Autism Reauthorization Act (CARA) of 2011, this grant provides modest support of \$75,000 for each of two years for SMS and its partners to develop a comprehensive needs assessment and a measurable and actionable State Plan to address the needs of NH citizens living with ASD and other DDs. The Council will have an advisory role to play in the process.

## SCOPE AND PURPOSE OF THIS REPORT

Pursuant to RSA 171-A: 32, section II (h), the New Hampshire Council on Autism Spectrum Disorders (hereafter, “the Council”) is required, to make a periodic report to the Governor, the Commissioners of the Department of Health and Human Services and the Department of Education, and specified members of the NH House of Representatives and the NH Senate.

This review focuses on the accomplishments and challenges faced by the Council during the period from July 1, 2011 and September 30, 2013. It includes recommendations that will enhance the work of the Council in 2013.

### BACKGROUND

The New Hampshire Council on Autism Spectrum Disorders was created by the state legislature in response to the public health challenges posed by an increase in the identified prevalence of this neurobiological condition. Autism Spectrum Disorder (commonly referred to as “ASD”) is the fastest growing developmental disability, occurring in 1 of every 88 children, according to the most recent estimate by the Centers for Disease Control.<sup>1</sup> Now in its fourth year collecting state-specific data, the NH Registry for ASD records a three year average identified prevalence of 150/year.

Though ASD varies both in how it is manifest and in the severity of symptoms, all subtypes share challenges in both communication and social interaction. ASD is associated with significant stress on family systems, a wide range of co-occurring conditions -- including depression, seizure disorders, and gastrointestinal disorders -- and long term societal cost. For a single individual, the lifetime cost associated with autism has been estimated to be \$3.2 million dollars.<sup>2</sup>

In May 2008, the New Hampshire Commission on Autism Spectrum Disorders published its findings and recommendations. Recognizing the continuing need to bring representatives from many state agencies and stakeholder groups together in addressing the service needs of this population, the Commission recommended establishing an advisory council dedicated to promoting comprehensive and quality education, health care, and services for individuals with ASD. With passage of HB 1634, the New Hampshire legislature established this leadership group.

The Commission’s 2008 report placed strong emphasis on improving the infrastructure that supports service delivery to those affected by ASD and their families. “If New Hampshire is to successfully address the challenges of ASD, it is clear that we must do far more than promote exemplary projects,” the Commission wrote. “A systematic review and redirection of the existing infrastructure will be necessary if we are to deliver effective treatment and supports throughout our community clinics, schools, area agencies, vocational centers, and other front line services.”<sup>3</sup>

### ROLE OF THE COUNCIL ON ASD

The Council is an advisory body that has operated for the past five years without dedicated state funding. As such, it relies on the volunteer participation of many members, especially those who are self-advocates and/or parents. Virtually all Council activities are undertaken in collaboration with other agencies or organizations. In this manner, the Council leverages considerable resources and

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<sup>1</sup> Centers for Disease Control,

<sup>2</sup> Ganz, Michael L. “The Lifetime Distribution of the Incremental Societal Costs of Autism.” *Archives of Pediatrics & Adolescent Medicine* 161.1 (2007): 343-349.

<sup>3</sup> New Hampshire Commission on Autism Spectrum Disorders. “Findings and Recommendations” (2008), p. 16. Report by the NH Council on Autism Disorders, November, 2013.

expertise with a relatively modest investment in operating funds from foundations and participating agencies. (See Appendix 5) Council partners are gratefully acknowledged at the front of this report.

## STRUCTURE AND GOVERNANCE

The Council operates under a set of broad principles set out in the 2008 Commission Report (Appendix 2). Guidelines for governance were adopted during the Council's first year and the Council's quarterly meetings are conducted according to Roberts Rules of Order. All meetings are open to the public.

During its first year of operation, the Council assigned each of the 43 recommendations in the 2008 Commission Report to one of eight work groups, depending upon the area of focus. These were: Human Services, Education, Early Screening and Diagnosis, Independent Living and Employment, Safety, Public Awareness, Data Collection, and Health Insurance and Funding.

The Commission's recommendations varied widely in their specificity and in how actionable they ultimately proved to be. Some were time sensitive and are no longer applicable. Others have successfully moved forward as funding opportunities and favorable partnerships have become available. This report includes a review of each of these original 43 recommendations (Appendix 6), rating each as accomplished, partially accomplished, not accomplished, or "found impractical to implement". This document is provided both for historical record and to inform the development of NH's State Plan for ASD.

• **NH Registry for ASD:**  
**INDIVIDUALS WITH ASD IN NH** Diagnoses of ASD since November 2008. N=563 (9/2013)

What do we know about individuals and families impacted by ASD in NH?

• **DOE Census:**

The Department of Education annually tracks special education students by the code under which they receive services.

NH’s application for the HRSA planning grant included a preliminary needs assessment based on existing data sets (See sidebar). The composite picture that emerges shows significant gaps in our understanding of the experiences and needs of this diverse population.

• **SMS Survey:**

A 2012 survey conducted by Special Medical Services (SMS). N=238

However, the broad outline suggests the scope and urgency of the challenges presented by the growing number of children, youth, and adults who seek services and supports from many publicly funded systems, including developmental services, special education, behavioral health, and Special Medical Services.

• **CSHCN:**

The NH estimate from the 2009-10 National Survey of Children with Special Health Care Needs. N=4994

**GENERAL INFORMATION**

- The NH Registry reported 505 diagnoses of ASD over three and a half years. Consistent with national findings 19.2% were female and 80.8% were male.
- One third of diagnoses were made before age 3 and 83.5% before age 9, according to the Registry. These figures, which reflect 3.5 years of data, are consistent with the Registry’s most recent annual report (Attachment 5).
- The Registry recorded 286 diagnoses of autistic disorder (56.63%), 133 diagnoses of Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) (26.34%), and 84 diagnoses of Asperger Disorder (16.63%). There was a single diagnosis each of Rett Syndrome and Childhood Disintegrative Disorder, which are both very rare conditions.
- In NH, a diagnosis of ASD is most commonly made by a neurologist (24.8%), a developmental pediatrician (15.1%), or a clinical team (13%), according to the SMS Survey.

A particular concern is the steadily increasing number of students in NH who receive special education services under a code of “autism.” With a more than fivefold increase in a decade, this group of complex students now represents 7.5 % of all special education students, up from 1.3% in 2000 (Figure 1).<sup>4</sup>

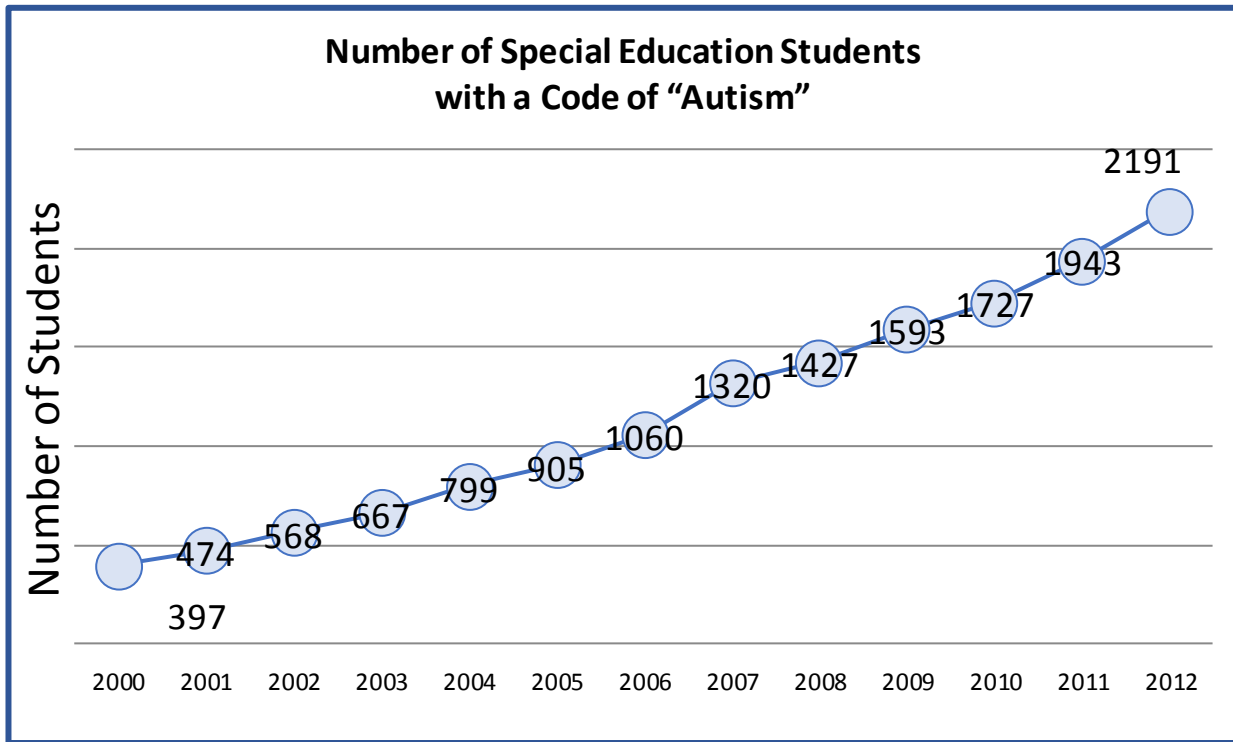
It should be noted that there are a number of limitations to the DOE Statewide Census. Many children with a medical diagnosis of ASD use an alternative code for special education, including “other health impaired,” “specific learning disability,” or “speech language impaired.” In other words, the data under counts the total school-age population with ASD by an unknown amount.<sup>5</sup>

<sup>4</sup> From [http://www.education.nh.gov/instruction/special\\_ed/census\\_by\\_disability.htm](http://www.education.nh.gov/instruction/special_ed/census_by_disability.htm) (10/1/13).

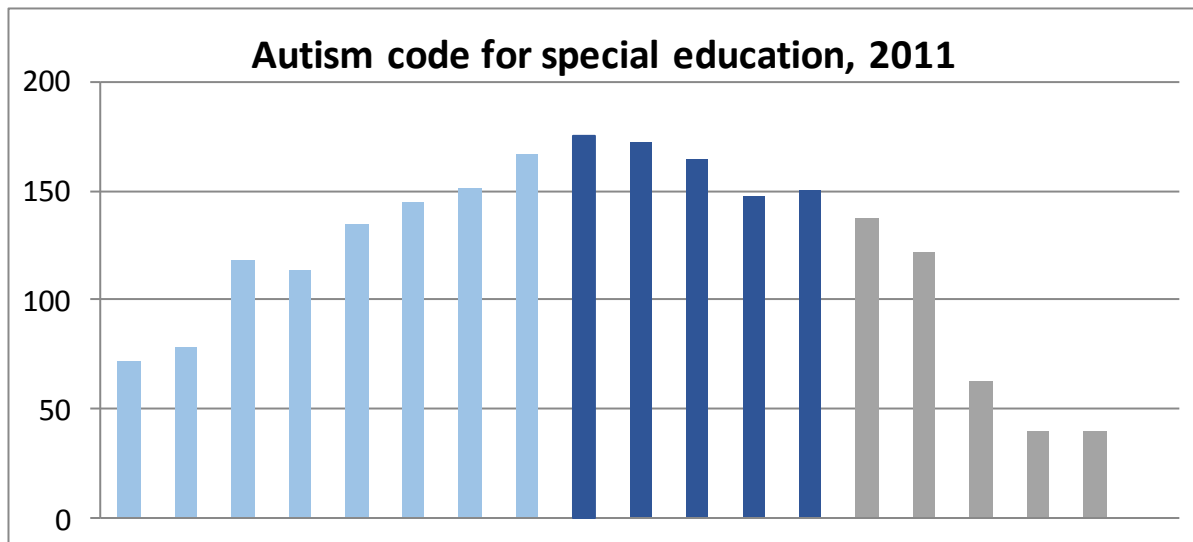
<sup>5</sup> The complexity of the interface between diagnosis and special education eligibility categories was echoed by the data from the SMS Survey, which found that approximately half of respondents receiving special education services do so under more than one educational code.

Figure 2

Dark Blue = 810 students  
However, even if the trend indicates more about coding practices and prevalence, it points to the increasing need for educators, including general educators, to understand the unique learning profile of students who have autism and to make appropriate accommodations.  
Gray = 401



The DOE Statewide Census also illustrates how NH policy makers can expect the increasing identified prevalence of ASD to impact the adult long-term care system and vocational supports. The cohort of individuals who will transition to adult services within the next five will include at a minimum 401 individuals with a special education code of autism. The next five years will add another 810 young adults, many of whom will qualify for developmental services, bringing the total to just over 1200 in the next decade.





Again, there are limitations in what we can infer from the DOE Census. The total number of students with ASD is likely much higher, and it is difficult to predict when each age cohort will exit special education, since a number of special education students with ASD choose to graduate at age 18, rather than waiting until 21. Moreover, because ASD is a highly variable condition, not every student with a code of “autism” will go on to need or qualify for adult long term care services.

However, even when we consider the limitations the data suggest a very concerning trend. Students, who use a primary code of ASD, are more likely to experience a greater number of interfering symptoms due to their autism. They are therefore more likely to enter the adult developmental services system and to have significant support needs. When we consider the fact that in FY '10 the Bureau of Developmental Services database showed that the area agencies were serving only 172 adults with a diagnosis of autism, we should take seriously the possibility that NH will triple this number in just a few short years. At a minimum, this fact has significant implications for staff training, the development of clinical capacity, and state cost.

## ACCESS TO SERVICES AND SUPPORTS

One set of public health criteria by which services and supports to any group of children with special health care needs (CSHCN) are measured is the Six Core Indicators adopted by the Maternal and Child Health Bureau (MCHB Core Indicators) to support *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*. NH's HRSA Planning Grant will build on these national metrics. The following key findings are drawn from the preliminary needs assessment in NH's HRSA Planning Grant application.

*How do NH Services and Supports for individuals with ASD fare when measured against the MCHB Core Indicators for Children with Special Health Care Needs?*

### MCHB Core Indicator #1

*Families of children and youth with ASD partner in decision-making at all levels and are satisfied with the services they receive.*

- o Among NH respondents to the NS-CSHCH, fewer family caregivers with children and youth with ASD (61.8%) reported having a personal doctor than did those supporting a child with a different special healthcare need (78.8%).
- o In the SMS Survey, 21.7% of respondents said that their family member with ASD did not have a personal doctor.

### MCHB Core Indicator #2

*Children and youth with ASD have access to coordinated, ongoing and comprehensive care within a Medical Home.*

- o In the NS-CSHCN, only 28% of NH respondents with a child or youth with ASD reported receiving coordinated and comprehensive care within a medical home. By comparison, 51.5% of NH respondents with a child with another special health care need agreed their care was coordinated and comprehensive within a medical home, which is higher than the national average of 43% of families with a child with a special health care need.

### MCHB Core Indicator #3

*Public and/or private insurance and financing provide adequate access to the services needed by children and youth with ASD*

- o According to the NS-CSHCN, 51.7% of NH respondents with a child with ASD indicated that their public/private insurance was inadequate to cover the services needed; by comparison, 32.3% of NH respondents with a child with another special medical need reported inadequate funding.
- o In the SMS Survey, respondents were asked about 25 different services (including “other”). The four services respondents reported “receiving but needing more” were speech therapy, occupational therapy, social skills training and behavioral therapy -- all therapeutic interventions that can be covered by health insurance given the right policy environment.

### MCHB Core Indicator #4

*Children are screened early and continuously for ASD and other developmental delays.*

- o In the NH-CSHCN, 87.4% of NH respondents indicated that they had received early and continuous screening, which is above the national average of 78.6%.
- o According to the NH Registry, fully a third of children with ASD are diagnosed prior to age three, an important public health goal that provides access to NH’s Family Centered Early Supports and Services program.

### MCHB Core Indicator #5

*Community services are organized so that families can use them easily.*

- o When asked about the reason for service limitations, respondents to the SMS Survey indicated that the lack of information was the single most significant barrier: 107 reported they did not know who to talk to, and 101 said that they believed their child needed more services but that they did not know what to ask for. The cost of services and the lack of service providers in the respondents area were also significant obstacles.
- o In the NS-CSHCN, 39% of NH respondents with a child with ASD indicated that services were easy to use, as compared with 71.5% of respondents with a child with a different special health care need.
- o Respondents to the SMS Survey also expressed considerable confusion regarding school-based services. Although 47.9% agreed that their school provided “evidence-based services,” another 37.8% indicated that they did not know the answer.
- o Similarly, when asked about 6 categories of Family Services in the SMS Survey, very few respondents indicated that they were currently receiving all the services they considered necessary. In particular, more than half said that in two service categories, they were either

receiving no services or inadequate services: Respite (50.3%) and Family Support Groups (52.9%). The primary barrier to family services was “lack of information/don’t know who to talk to.” As with services in general, the other most frequently reported barriers were cost and a shortage of service providers.

MCHB Core Indicator #6

*Children and youth with ASD and other DD receive the services necessary to make transitions to all aspects of adult life, including health care, work, and independence.*

- o A relatively small sample of 34 respondents to the SMS Survey had firsthand experience in seeking employment. Of these, 21 were not working at all, and half of these attributed this to the fact that “the workplace would be too challenging, due to ASD.” Another 9.5% indicated that they would like to work but had not found a job, and 9.5% said they had worked but stopped due to “discrimination or other difficulties with employers, because of ASD”. Among those not working, 13 reported no engagement in vocational services

## SUMMARY

Information about the characteristics and needs of individuals with ASD and their families in NH is incomplete. NH’s Planning Grant will use both quantitative and qualitative approaches to help the Council, its partners, and policy makers better understand the impact of ASD.

Despite these gaps, preliminary indicators signal that children, youth, and families with ASD do not fare as well as those with other special health care needs. Access to critical therapeutic supports appears to be hampered by both funding limitations and by difficulty understanding best practices and service systems. While a primary care provider and/or medical home might improve family access to comprehensive community-based supports and services, there is reason to believe that a significant number of families living with ASD do not experience a close partnership with their child’s healthcare provider.

## ACCOMPLISHMENTS OF THE COUNCIL

Between July 2011 and June 2013, the Council played a central role in completing three projects. In partnership with other organizations, the Council and its work groups also contributed to three additional projects. The Council also completed its review of the 43 recommendation by the Commission on ASD, assessed its membership, structure, and funding, and assisted in developing a successful proposal to HRSA for a two year Planning Grant.

### COUNCIL PROJECTS

#### ❖ Autism Summit, February 2012

##### Outcome:

*Following a year of planning, the Council and its partners conducted a Summit Meeting for special educators, healthcare professionals, and other stakeholders focusing on improving communication and collaboration across systems of care. As a tangible outcome, a group of Summit participants created a communication tool to improve the exchange of information between schools and healthcare professionals. A post-Summit survey also provided data to inform future initiatives.*

##### Collaborators:

- Southeast Regional Resource Center (SERESC)
- Endowment for Health

##### Discussion:

Approximately 60 educators, healthcare professionals, parents and other stakeholders convened at the Southeast Regional Resource Center in February 2012 to discuss improving outcomes for students with ASD by strengthening partnerships between special education teams, parents, and providers of clinical services such as physicians and psychologists. The Summit organizers had prepared this “deep dive” with two goals in mind: (1) To identify short-term projects that could have an immediate impact on communication between schools, families, and clinicians; and (2) to gather stakeholder input regarding specific tools thought to have potential for further improving collaboration, including technology based consultation and training.

Following a “State of the State” presentation by Council Administrative Director Kirsten Murphy, speakers representing four key stakeholder groups shared their perspective on supporting students with ASD.

##### Findings:

A post-summit survey indicated the following:

- 76% of respondents to the survey answered “yes” to “As a result of attending... I received information that has the potential to change how I provide services or care.”
- There was a clear interest in regional hubs and networking as having the most potential for impact- especially in the long term.

- Short-term solutions that were seen as having the most benefit were parent training and parent/professional support, increased wrap-around, increased communication among providers, websites and technology tools.
- Regarding technology:
  - 24% indicated that they participate in web-based assessment, consultation and conferencing on behalf of a child with ASD; 76% indicated that they did not.
  - 58.3% indicated that are interested in using teleconferencing on behalf of their child/student/client/patient; 8.3% said that they were not interested; 33.3% indicated that they were unsure.
  - 95.8 % indicated that they are interested in web-based professional learning and support.

#### ❖ Virtual Resource Center for ASD

##### Outcome:

*Completed Phase I development of a web-based tool to assist parents and professionals seeking information about ASD and the services and support available in New Hampshire to assist those impacted by ASD.*

##### Collaborators:

- The NH Special Medical Services
- Association of Maternal and Child Health Programs (AMCHP)
- Centers for Disease Control's "Learn the Signs. Act Early Campaign"
- Council Work Group on Early Screening and Diagnosis
- Council Work Group on Independent Living and Employment

##### Discussion:

As indicated by the SMS Survey, families continue to experience considerable frustration in accessing high quality information about autism and about appropriate supports and services. With funding from the Association of Maternal and Child Health Programs (AMCHP), the Council developed a website to assist NH families and providers in locating information about services and supports for individuals with ASD. Envisioned as PHASE I of a multi-step initiative, the focus of this project was building a guided experience to early screening and diagnosis. The site highlights materials from the *Learn the Signs, Act Early* Campaign sponsored by the CDC and MCHB. Links include provider training materials and a communication tool developed through the Autism Summit to foster better physician-school communication in NH. The site maintains a categorized list of many types of providers with expertise in ASD.

The Virtual Autism Resource Center also serves as a repository for the information and resources collected by the Council's work group on Independent Living and Employment. Phase II development of the site will include expanding these pages and improving user interface in this section of the site. Additionally, the Council hopes to partner with adults on the autism spectrum to build a third portal to information specifically tailored to the needs of individuals with ASD. A final state of the project will focus on improving the user

experience by addressing software limitations such as the lack of a site specific search feature. Funding is needed for Phase II and III.

#### Findings:

There have been 1650 visits to NH's Virtual Autism Resource Center since Phase I was completed in November 2012. A user survey should be developed now that the site is better established.

### ❖ Preserving Connor's Law for the Evidence-Based Treatment of ASD

#### Outcomes:

*The Council developed materials to educate providers, carriers, and consumers about new benefits available for the treatment of ASD under RSA 417-E:2, also known as "Connor's Law." At least 47 children have received coverage for therapeutic treatment under this consumer protection measure. The benefits established under Connor's Law were preserved, despite several legislative challenges.*

#### Collaborators:

- Autism Bridges
- Endowment for Health
- Gateways Therapy Center
- Institute of Professional Practice, Inc.
- *Ready, Set, Connect* at Crotched Mountain

#### Discussion

Connor's Law requires that state-regulated group health insurance policies cover evidence-based treatments for the interfering symptoms of autism, including a therapy called "Applied Behavior Analysis" or ABA. The American Academy of Pediatrics includes ABA as one of its recommended interventions for young children with a diagnosis of ASD. Traditionally, carriers have declined coverage for ABA, arguing that it is "experimental," despite more than 30 years of peer-reviewed research supporting its efficacy. Thirty-two states have adopted consumer protection measures similar to Connor's Law.

With funding from the Endowment for Health, the Council Director met on alternate months with a group of providers of ABA to monitor the implementation of the new benefit. Group participants provided information to interested carriers about how ABA programs are conducted and how patient progress is assessed. With provider input, the Council also developed consumer information, including a website and brochure, to assist families in understanding whether their policy was subject to Connor's Law. The Council Director provided education to legislators during the 2012 session, when two bills were introduced that would have overturned the autism benefit; neither bill moved out of committee.

#### Findings:

As of January 1, 2013, ABA programs had been successfully funded through a number of carriers operating in NH's small group market, including Harvard Pilgrim, Aetna, and Tricare, which insures members of the United States military. Although not an exhaustive study, the

Council is aware of 47 children having received this best-practice intervention under the new regulations.

The Council remains concerned, however, that Connor's Law has limited applicability. For example, two thirds of families seeking behavioral therapy for their child from a Concord-based clinic have been turned away due to the fact that their child's health insurance policy does not include the benefits secured under Connor's Law. The majority of these children have Medicaid as either primary or secondary insurance. There are two reasons for this:

1. Large companies that self-insure are not subject to state health insurance regulations. Nationally, an increasing number of self-insuring companies have voluntarily written coverage for ABA into their health benefit. However, no NH-based company has yet elected to do so, including our state's major hospitals and the State of NH itself, which also self-insures.
2. As is the case in most states, including those with an autism benefit, NH Medicaid does not cover ABA. Recently, this has been challenged successfully by advocates in four states, where ABA is now covered by state plan Medicaid, either by court order (Florida and Ohio) or by virtue of an out-of-court settlement (Washington and Michigan). The basis of the legal action was a federal standard known as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) provision. EPSDT, which sets an unusually broad definition of medical necessity, requires states to cover any "necessary health care, diagnostic services, treatment, and other measures" that are needed to "correct or ameliorate defects and physical and mental illnesses and conditions."

## PARTNERSHIPS TO FURTHER COUNCIL GOALS

The Council and its work groups also participated in a number of other initiatives that furthered goals and objectives set out by the 2008 Commission on ASD. In these activities, another organization or agency provided leadership.

### ❖ Open Forums on Early Periodic Screening and Diagnosis

#### Outcomes:

*NH has hosted four trainings for early childhood educators, healthcare professionals, and families to learn about tools for early screening, conveying concerns to parents, and making appropriate referrals when further evaluation is needed. These multi-disciplinary conversations have helped promote improved regional partnership and linked providers to high quality public health information and materials – both those created in NH and those used nationally in the Learn the Signs, Act Early Campaign.*

#### Collaborators:

- o Special Medical Services (SMS)
- o The Association of Maternal and Child Health Programs
- o The NH Pediatric Society
- o The NH Institute on Disability and NH LEND
- o SPARK New Hampshire

### Discussion:

The Centers for Disease Control and Prevention (CDC) now estimate that 1 in 88 children has been identified with an autism spectrum disorder (ASD). More generally, about 1 in 6 children between the ages of 3 and 17 has a developmental disability. In other words, developmental challenges, including ASD, are common. They are also highly treatable, especially when intervention begins early in life.

The CDC and its national partners have designed an extensive catalogue of free materials that promote a shift in how the public views early childhood development: Just as height and weight are familiar measures of physical growth, certain predictable signs of social and emotional development give us important information about how a child is maturing. For example, smiling, pointing, and enjoying social play are some of the skills that every child should reach within a certain range of time. Failure to achieve these milestones may indicate the presence of a developmental disorder such as autism for which treatment is indicated.

The Council is an active partner in a robust network of early childhood professionals who have promoted the idea that screening for developmental delay should be conducted routinely and in a number of settings. With grant support from the Association of Maternal and Child Health Programs, the Bureau of Special Medical Services and the Council Work Group on Autism Spectrum Disorders hosted four open forums on the importance of early, periodic screening for developmental delays, including those associated with ASD.<sup>6</sup> These trainings, which were held in Plymouth and in Bedford, brought together early childhood educators, pediatric healthcare professionals, and family support providers to share information and resources that can assist in moving children suspected to have a developmental difference quickly into appropriate diagnostic and educational services.

The Council and its partners have disseminated *Learn the Signs Act Early* materials widely, including online through NH's Virtual Autism Center, and created a "Road Map" specific to NH.<sup>7</sup> Remaining grant funds were used to purchase screening kits for providers.

The Council is pleased to note that data from the NH Registry for ASD indicates that fully one third diagnosed on the autism spectrum in NH are made before the age of three. The average age of diagnosis for children under nine is 3.94 years. This is earlier than the national average of 4.85 years, and suggests that NH's collaborative effort to identify children early is having a positive result.

### ❖ SAFETY

#### Outcome:

*Over 350 cadets at the NH Police Academy have received a two-hour training about autism as part of their basic curriculum. At least 1000 NH families have been provided with information and encouragement to flag their address in NH's emergency assistance data base and to provide information about their family member with ASD should emergency responders be called to their residence.*

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<sup>6</sup> Two of these trainings were held during the period covered by this report. Two were held earlier.

<sup>7</sup> [http://nhvirtualautismcenter.homestead.com/RESOURCESfamily/FAMILYfiles/NH\\_FamilyRoadMapFollowingScreening.pdf](http://nhvirtualautismcenter.homestead.com/RESOURCESfamily/FAMILYfiles/NH_FamilyRoadMapFollowingScreening.pdf)



Collaborators:

- o NH Easter Seals Autism Family Support Specialist
- o The NH Police Training and Standards Council
- o Numerous local law enforcement personnel
- o NH LEND

Discussion:

There is an increasing appreciation of the unique safety issues associated with ASD, especially elopement. In a study published last in October in the journal *Pediatrics*, researchers from the Kennedy Krieger Institute found that nearly half of children with autism spectrum disorders (ASD) are reported to wander or “bolt”, and more than half of these children go missing. New Hampshire has been fortunate, in that there are no known fatalities due to elopement among children with autism in our state. But there have been close calls.

Beginning in 2009, Easter Seals Autism Family Support Specialist and two police officers have provided a two-hour training about autism to cadets training at the NH Police Academy. Today, over 300 cadets have participated, raising their awareness of the symptoms of ASD and how to deescalate situations involving someone with this condition.

In partnership with parent volunteers and trainees from the Leadership Education In Neuro-Developmental Disorders (LEND), Easter Seals Autism Family Support Program has also sponsored 911 registrations events Londonderry, Pembroke, Dover, New London, and Manchester in the past 18 months. Easter Seals Autism Safety Specialist has trained town police officers in Bow, Derry, and Geoffstown, and Emergency Medical Technicians and Fire and Rescue Personnel in Hampstead, Bow, and Portsmouth. EMT’s in Claremont received a similar training by the Administrative Director for the Council.

❖ **AXIS, AN INDIVIDUALIZED COACHING PROGRAM FOR ADULTS WITH ASD**

Outcomes:

*NH was introduced to the use of “coaching” as a best practice for adults with ASD. The NH Council on ASD’s Administrative Director developed a small pilot project designed to meet the unique needs of VR customers with ASD. With funding and staff from Community Bridges and VR, the project successfully supported five of the six individuals enrolled. Project partners are reviewing lessons learned and making plans for gradual expansion.*

Collaborators:

- o Community Bridges, NH’s Region 4 Area Agency
- o Vocational Rehabilitation (VR)
- o Council Administrative Director

Discussion:

Policy makers and providers have only recently begun to appreciate and address the challenges faced by transition age youth and young adults with ASD. Half a million young people with ASD will age into adulthood in the next decade, according to Autism Speaks.<sup>8</sup>

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<sup>8</sup> From <http://www.autismspeaks.org/advocacy/advocacy-news/adult-employment-new-allies-come-board>, (10/3/13)

Research indicates that in terms of “real life outcomes” such as employment, adults with ASD are struggling. Data from the National Longitudinal Transition Study 2 (NLTS2), a 10-year prospective study of youth receiving special education services, found that 34.7% of young adults with a diagnosis on the autism spectrum reported that they had attended college and 55.1% had held paid employment during the first 6 years after high school. This is relatively good news, in that less comprehensive studies have suggested unemployment for this population is 80% or more. However, when narrowed to young adults less than 2 years from their high school graduation, more than 50% of those with ASD reported that they had had no participation in employment or education, a rate far higher than that seen in any of eleven other disability groups.

Overall, almost half of the youth with autism earned less than the federal minimum wage and reported that the majority of their co-workers were people with disabilities (42%). In addition, only about a third of youth with autism received paid vacation or sick leave (29%), and even less received health insurance (11%) or retirement benefits (10%). The researchers concluded “It appears that youth with an ASD are uniquely at high risk for a period of struggling to find ways to participate in work and school after leaving high school. These findings point to potential gaps in transition planning specifically for youth with autism and barriers to participation that may be specific to this population.”<sup>9</sup>

A partnership between Community Bridges, Vocational Rehabilitation, and the Administrative Director for the Council resulted in a small pilot project over the past 18 months. AXIS offered person-centered planning and one-on-one coaching for each of six adults with ASD. Modeled after similar programs in other states, AXIS is designed to “jumpstart” adults who are highly motivated to work toward employment and personal goals, but who lack the “soft skills” necessary to be successful with less intensive and more traditional VR counseling. Preliminary results are promising, and program partners are discussing a gradual expansion of the model.

#### ❖ Certified Autism Parent Specialists (CAPS)

##### Outcomes:

*There are 26 new parent-to-parent volunteers who have received advanced training in ASD and NH service systems. Certified Autism Parent Specialists remain in close touch with one another and continually access up-to-date information about ASD to share with other families. There are CAPS from every region of the state, including Coos County.*

##### Collaborators:

- o Easter Seals Autism Family Support Specialists
- o Leadership Development in Neurodevelopmental Disorders (LEND) Program
- o Bureau of Developmental Services

##### Discussion:

For at least a decade, parents and caregivers who support a family member with an ASD have consistently reported that they struggle with a lack of information and confusion

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<sup>9</sup> Shattuck, Paul T., et al “Postsecondary Education and Employment among youth with an Autism Spectrum Disorder.” *Pediatrics* (May, 2012).

regarding insurance, evidence-based practices, and access to services. The pace of basic research in the field of autism is certainly a contributing factor, as is the sheer volume of information available on the Internet. However, the problem is compounded by factors unique to NH, especially the decentralized nature our educational, developmental and mental health services.

Department of Health and Human Services initiatives -- for example, developing a single point of entry ("No Wrong Door") -- may offer some relief in coming years. However, it is likely that families will also need support in finding resources specifically designed to address the needs and strengths associated with autism. In a pilot project funded by BDS and NH Easter Seals, Council members developed a parent training series leading to certification as a "Autism Parent Specialist." The course was given over a 6-week period in 2011 and in two weekend-long retreats.

The existence of this volunteer network is particularly important in light of the fact that NH has lost several more formal autism-specific family support resources over the past year: In late 2012, the Autism Society of NH chose to file for dissolution. Easter Seals, NH discontinued its support for two Autism Family Support Specialists in 2013.

## ASSESSMENT OF COUNCIL MEMBERSHIP AND FUNDING

Internally, the Council has struggled with two issues: First, insuring meaningful and consistent participation by Council members; and second, securing funding for a staff member to represent the Council between quarterly meetings, apply for funding, provide basic administrative support, and orchestrate Council sponsored activities.

At the Council's November, 2012 meeting, members endorsed a plan to seek revisions to its enabling statute. In partnership with lead sponsor, Representative Laurie Harding (D, Lebanon), HB 236 sought to achieve greater flexibility for named officials to appoint a voting member of the Council and to broaden participation by individuals with ASD and by professionals from fields not previously included, such as nursing and speech language pathology. HB 236 was signed into law in June 2013, allowing for new members to join the Council this fall. (Appendix #4)

In connection with developing this report, the Council also reviewed its funding sources over the past five years. The Council has received \$114,652 over that time period, an average of just under \$23,000 annually. Funding had been heavily reliant on federal sources (62%) and private foundations/fundraising (31.45%). Less than 7% of support for this legislatively established body has come from state dollars. Funding has been staggered unevenly, creating further limitations on activity. In fact, for a five-month period (August 15, 2011 to January 15, 2012) the Council was without any paid support. (Appendix #6)

## CONCLUSIONS

The Council and its partners have worked diligently and productively despite a lack of funding and other resources. While Council members are proud to have moved several initiatives forward over the past 18 months, they also recognized the relatively modest scope of these activities in comparison to the complex and extensive needs of individuals and families impacted by ASD in our state. Many of these needs are as yet unmet.

The receipt of a HRSA-funded State Planning Grant and revisions to the Council's enabling statute promise to provide the Council with greater participation, stronger partnerships, and some part time administrative support. The grant provides \$75,000 for each of two years in order for NH to create a comprehensive needs assessment and State Plan for Services and Supports for Individuals with ASD. The Council will play an advisory role in this process.

The timing is significant. Prompted by the legislatively mandated move to managed care and by opportunities available under the Affordable Care Act, the NH DHHS is engaged in the most significant redesign of its Medicaid-funded services in state history. Throughout their lifetime, individuals with ASD will access Medicaid through many programs, including acute care (State Plan Medicaid), Medicaid to Schools, and long-term care (waivered Medicaid). Consumers with a diagnosis of an ASD will become an increasingly significant component of the population served by Medicaid. To be effective, advocates will need to engage in conversations that are taking place at multiple levels including the Balancing Incentive Program (BIP), a Governor appointed commission, and through the Community Support Network, Inc. (CSNI). For these reasons and many others, cited already in this report, it is imperative that there be informed representatives from the autism community consistently involved in the ongoing development of NH's Medicaid program.

However, the Council's charge is broader than either Medicaid redesign or the terms of NH's State Planning Grant. In the coming year, the Council is committed to continuing and expanding upon some of the projects described above, including improving access to insurance through Connor's Law, strengthening the link between early diagnosis and active participation in therapeutic interventions, and improving the very limited means by which families access information about autism and support services.

# Appendices

## Appendix #1

### Guiding Principles for the Development and Delivery of Supports and Services For Individuals with Autism Spectrum Disorder, *adopted by the Council Oct. 2008*



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

CHARGE TO THE NH COUNCIL ON AUTISM SPECTRUM DISORDERS, *as revised 7/1/13*<sup>10</sup>

RSA 171-A:32, section II (a-g), The council shall:

- (a) Provide leadership on training, policy, research, and coordination of supports and services for individuals and their families.
- (b) Provide information to families and individuals with autism spectrum disorder about evidenced-based and promising practices for community-based education, support, and treatment.
- (c) Collaborate with schools and other service systems to identify exemplary supports and services and promote successful practices throughout New Hampshire.
- (d) Increase resources for individuals with autism spectrum disorders and their families by accessing federal and state grants and pursuing development opportunities through foundations, corporations, and planned giving.
- (e) Serve as an information clearinghouse for individuals, families, and providers seeking diagnosticians, behavioral specialists, speech pathologists, occupational therapists, psychologists, and others who have expertise in working with individuals with autism spectrum disorders.
- (f) Encourage the establishment of regional collaboratives with representation from educational, health care, and community service providers to ensure that individuals with autism spectrum disorders and their families receive necessary services.
- (g) Make an annual report beginning on April 1, 2009 to the governor, the speaker of the house of representatives, the president of the senate, the commissioners of the department of health and human services and department of education, the members of the house committees on education, health, human services and elderly affairs, and finance, and the members of the senate committees on education, health and human services, and finance.

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<sup>10</sup> HB 236 removed a charge that the Council “Provide mediation, when needed, to ensure that individuals with autism spectrum disorders receive appropriate supports and services.” This has not been an activity that the Council undertook or considered consistent with their scope of authority as an advisory body.

MEMBERSHIP OF THE NEW HAMPSHIRE COUNCIL  
ON AUTISM SPECTRUM DISORDERS  
*Roster, June 30, 2013*

COUNCIL LEADERSHIP

BRIAN HUCKINS, Chair *Parent, appointed by Governor John Lynch*

KIRSTEN MURPHY *Administrative Director (Ex officio)*

COUNCIL MEMBERS

BRIAN BALKE *Representing the New Hampshire Association of Special Education Administrators*

TERESA BOLICK, PHD *Representing the NH Psychological Association*

VIRGINIA BARRY, PHD *Commissioner, Department of Education*

--VACANCY-- *Representing the Autism Society of New Hampshire*

MARY ANNE COONEY *Deputy Commissioner, Department of Health & Human Services*

MATTHEW ERTAS *Bureau Chief, Bureau of Developmental Services*

ADRIENNE EVANS *Representing the NH Council on Developmental Disabilities*

AMY FRECHETTE, A.S. *Self-Advocate, Appointed by Governor John Lynch*

VIKI GAYHARDT *Appointed by Governor John Lynch*

LISA HATZ *Director, Division of Career Technology & Adult Learning, Department of Education*

GREGORY PRAZAR, MD *Representing the New Hampshire Medical Society*

JOSE MONTERO, MD *Director, Division of Public Health Services*

--VACANCY-- *Director, Division of Instruction, Department of Education*

ERIK RIERA *Administrator, Bureau of Behavioral Health*

SUSAN ROCKWELL *Representing the Community Support Network, Inc.*

MARY SCHUH, PHD *Representing the New Hampshire Institute on Disability University of New Hampshire*



Revisions to Membership - *Per HB 236 (Revisions are in Red Type)*  
NH Council on Autism Spectrum Disorders,

- (a) The governor, or designee.
- (b) The commissioner of the department of education, or designee.
- (c) The commissioner of the department of health and human services, or designee.
- (d) The director of the division of public health services, department of health and human services, **or designee.**
- (e) The bureau chief of the bureau of developmental services, department of health and human services, **or designee.**
- (f) The bureau chief of the bureau of behavioral health, department of health and human services, **or designee.**
- (g) The director of the division of instruction, department of education, **or designee.**
- (h) The director of the division of career technology and adult learning, department of education, **or designee.**
- (i) The director of the Institute on Disability, University of New Hampshire, or designee.
- (j) A special education director, appointed by the New Hampshire Association of Special Education Administrators, Inc.
- (k) The president of the New Hampshire Medical Society, or designee.
- (l) A representative of the New Hampshire Developmental Disabilities Council, appointed by the council.
- (m) A representative of **the New Hampshire chapter of the national Autism Society, appointed by the chapter.**
- (n) An individual who has an autism spectrum disorder, appointed by the governor
- (o) A family member of a person who has an autism spectrum disorder, appointed by the governor
- (p) A representative of the Community Support Network, Inc., appointed by such organization
- (q) A representative of the New Hampshire Psychological Association, appointed by the association

**New Members Added, per HB 236**

- (r) **The director of the office of Medicaid business and policy, department of health and human services, or designee.**
- (s) **A representative of the Autistic Self Advocacy Network who is a New Hampshire stakeholder, appointed by the network.**
- (t) **One additional member, appointed by the council**
- (u) **A person who has an autism spectrum disorder, appointed by the council.**
- (v) **A representative of the New Hampshire Nurses' Association, appointed by the association.**  
**A licensed speech-language pathologist, appointed by the New Hampshire Speech-Language-Hearing Association, Inc.**

THE NEW HAMPSHIRE COUNCIL ON ASD  
 FINANCIAL REPORT, DECEMBER 2012  
*18-Month Period*  
*July 1, 2011 - December 31, 2012*

## BALANCE SHEET

ASSETS (PLEDGES)		LIABILITIES EXPENSES	BALANCE
Endowment for Health, Public Policy Grant	\$ 30,000		
Association of Maternal and Child Health Programs (AMCHP), portion of grant	\$ 5,100		
NH Council on Developmental Disabilities July, 2011	\$ 1,500		
NH Council on Developmental Disabilities December, 2012	\$ 7,500		
Special Medical Services	\$ 2,500		
Subtotal			\$ 44,100
Salary, Administrative Director		(\$34,611)	
FICA @ .0765, Administrative Director		(\$ 2,648)	
Contracted Work, Web Content Development		(\$ 4,500)	
Clerical Support, Web Content Development		(\$ 600)	
Administrative Fee (5% of EFH grant)		(\$ 1,500)	
Subtotal			(\$43,859)
TOTAL			\$ 241

THE NEW HAMPSHIRE COUNCIL ON ASD  
FIVE-YEAR REVENUE REVIEW

Note: The fiscal cycle for the NH Council on ASD runs from the Council's annual meeting on the second Friday of September until the annual meeting of the following year.

TABLE 1: Revenue collected annually, Five-year period, 9/08 to 9/13

Annual Cycle	Source	Amount	Annual Total
9/2008 - 9/2009	Bureau of Developmental Services	\$ 6,000	
	Council on Developmental Disabilities	\$ 5,000	
	Department of Education	\$ 2,400	
			\$ 13,400
9/2009-9/2010	American Recovery and Reinvestment Act (ARRA)	\$ 33,336	
			\$ 33,336
9/2010-9/2011	American Recovery and Reinvestment Act (ARRA)	\$ 16,664	
	Special Medical Services	\$ 2,500	
	Community Support Network, Inc. (CSNI)	\$ 2,000	
			\$ 21,164
<i>Note: there was a break in funding from 8/15/11 to 1/1/12, during which time the Council had no paid support</i>			
9/2011-9/2012	Endowment for Health	\$ 30,000	
	Fundraising, designated for family support	\$ 1,416	
			\$ 31,416
9/2012-9/2013	Special Medical Services	\$ 2,500	
	Council on Developmental Disabilities	\$ 5,000	
	Association of Maternal and Child Health Programs (AMCHP), grant	\$ 5,100	
	Fundraising, general operating	\$ 2,746	\$15,346
<b>TOTAL over 5 years</b>			<b>\$ 114,652</b>

TABLE #2: SUMMARY of Revenue Sources for the NH Council on ASD  
 Five-year period, 9/08 to 9/13

Source	Type	Amount	Year
American Recovery and Reinvestment Act (ARRA)	federal	\$ 50,000	2009-11
Association of Maternal and Child Health Programs	federal	\$ 5,100	2012-13
Bureau of Developmental Services	state	\$ 6,000	2008-09
Special Medical Services	70% state	\$ 2,500	2010-11
	30% federal	\$ 2,500	2012-13
Community Supports Network, Inc. (CSNI)	private	\$ 2,000	2010-11
Council on Developmental Disabilities	federal	\$ 5,000	2009-10
		\$ 5,000	2012-13
Department of Education	federal	\$ 2,400	2008-09
Endowment for Health	private	\$ 30,000	2011-12
Fundraising, general operating	private	\$ 2,746	2012-13
Fundraising, family support	private	\$ 1,416	2011-12
<b>TOTAL over 5 years</b>		<b>\$ 114,652</b>	

ILLUSTRATION: Distribution of support between federal, state, and private sources.

