

Report to the Legislature to Address Services for Individuals with Autism Spectrum Disorders

Presented to:

**The Honorable James Douglas
Governor of the State of Vermont**

**House Committees on Appropriations,
Education and Human Services**

**Senate Committees on Appropriations,
Education and Health and Welfare**



Presented by:

**Cynthia D. LaWare, Secretary
Agency of Human Services**

In collaboration with

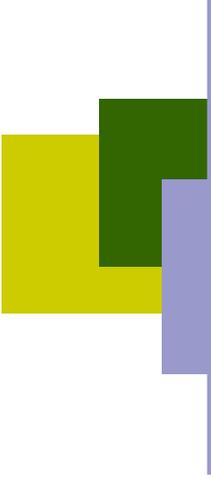
**Richard H. Cate, Commissioner
Department of Education**

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**Thank you to the hundreds of Vermonters whose lives
are affected by Autism Spectrum Disorders for your
contributions to this report.**





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Message from the Secretary of Human Services

As the number of people being diagnosed with Autism Spectrum Disorders (ASD) in Vermont continues to grow at rates consistent with national data, the time has come for the medical, educational and human services communities to rethink, revitalize and reform the way we serve this increasing population. We, at AHS, are developing a new approach focused on the full integration of children's services. This initiative will be managed through the Secretary's office to create a system of care that ensures enhanced coordination and service delivery resulting in better outcomes for our children. Likewise, the same effort to fully integrate adult services through the lifespan is essential.

Conservative estimates indicate that the state spends in excess of \$57 million, exclusive of medical expenses, to serve the currently identified approximately 700 Vermonters with ASD, averaging over \$82,000 per person. Despite this, findings from the public input process conclude that significant improvements are needed to better serve children, youth and adults with ASD. During this tight economic environment, we must rethink the way we support this population, carefully assess the use of existing resources, and determine where we can redeploy services and supports to increase positive outcomes for individuals with ASD.

Vermont will aggressively pursue federal grants under the Combating Autism Act and other federal resources to help address the needs of the ASD population. Additionally, we recognize the importance of identifying appropriate roles for insurance companies, and stand to learn a great deal from states which have already extended coverage for ASD through private insurance.

Family members and advocates support early intervention to reduce long-range costs as children with ASD mature into adulthood. However, as autism is a spectrum disorder, it is likely that individuals with the most severe forms of this disability will need assistance throughout their lives. This report contains a number of recommendations on how the medical, educational and human services communities can better serve those with ASD. It is important to understand, however, that we cannot afford to fully implement all of the recommendations contained in the report. To assist us in rethinking how we do business and in prioritizing the most

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compelling and cost effective recommendations, I have asked that a Steering Committee be continued.

My sincere thanks to the hundreds of individuals who have made valuable contributions to the development of this report. Further, I welcome input from all concerned Vermonters as the Agency of Human Services continues to work with the Vermont Department of Education and our community partners to rethink, revitalize and reform the way we serve individuals with ASD.

Sincerely,

Cynthia D. LaWare, Secretary
Agency of Human Services



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Executive Summary

Act 35, An Act Relating to Autism Spectrum Disorders, signed by Governor Douglas, directed the Vermont Agency of Human Services to work collaboratively with the Vermont Department of Education to develop a plan for providing services across the lifespan to individuals with autism spectrum disorders (ASD) and their families.

Seventy-five stakeholders formed a Steering Committee and five sub-committees to work on the plan. In addition to the work of the committees, five (5) community forums were held to gather public input on the direction the state should take in developing a system of care for people with ASD and their families. Additional opportunities for public input included invitations to provide written comments, and participate in an electronic on-line survey. One hundred and ninety-five (195) people attended the forums, fifty-seven (57) individuals provided written comments, and five hundred and three (503) surveys were completed. Information from these sources was synthesized into this report.

Findings and recommendations are divided into: 1) Best Practices; 2) Identification and Diagnosis; 3) Early Intervention; 4) Coordination of Services; 5) Access to Information 6) Training and Workforce Development 7) Technical Assistance and Consultation; 8) Education Services; 9) Adult Services; and 10) Funding. Recommendations are summarized below.

- 1) **Best Practices:**
 - ◆ A committee should be created to develop, review and regularly update best practice guidelines for a system of lifelong care.
- 2) **Identification and Diagnosis:**
 - ◆ Pediatricians should screen for autism and other developmental disabilities at 18, 24, and 36 months.
- 3) **Early Intervention:**
 - ◆ Intensive, early intervention services should be provided as soon as a diagnosis is considered a serious suspected.
- 4) **Coordination of Services:**
 - ◆ A lead department should be designated to coordinate autism



services across AHS. The role and responsibilities of all departments within AHS must be defined. A Memorandum of Understanding should be developed that will outline respective responsibilities of AHS and the Department of Education.

- 5) **Access to Information:**
 - ◆ Autism resource centers should be created to act as information clearinghouses, provide training, technical assistance, and consultation.
- 6) **Training and Workforce Development**
 - ◆ Competencies and experience expected of professionals and others working with individuals with ASD should be defined.
- 7) **Technical Assistance and Consultation**
 - ◆ Technical assistance should be provided to schools and agencies to develop cost-effective models of service delivery.
- 8) **Education Services:**
 - ◆ Consideration should be given to redefining “*adverse effect*” eligibility criteria to include social adaptability.
 - ◆ The availability of best practice services in local schools/ regions throughout the State of Vermont should be examined.
 - ◆ The reasons why children are not educated in their community schools should be studied.
- 9) **Adult Services:**
 - ◆ Providers of adult services should be trained on effective methods for supporting individuals with ASD at all points of the spectrum.
 - ◆ Post-secondary opportunities for education and community-living skills should be developed.
 - ◆ Job opportunities, training and education of community employers should be ongoing.
 - ◆ A variety of housing options should be developed to address the varying needs of individuals with ASD.
- 10) **Funding:**
 - ◆ The resources necessary to meet the needs of children, youth, and adults with ASD throughout the lifespan should be evaluated including the more effective use of existing

“I don't want to see a separate system of care for each disability...”

Comment from a Parent

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resources to provide for the following:

- ◆ Restoration of access to home and community-based services for children in the developmental services system, fuller access to Medicaid under the federally-mandated Early, Periodic Screening, Diagnosis and Treatment (EPSDT) services and increasing flexibility of Children's Personal Care Services.
- ◆ Expanded access to services for adults including, increasing funding for training, technical assistance and consultation.
- ◆ Increased funding to attract developmental pediatricians to the Vermont Department of Health, Child Development Clinic.
- ◆ Legislation should be enacted requiring large employers to provide insurance coverage for autism services.



Introduction

Process for developing the report:

Act 35, an Act Relating to Autism Spectrum Disorders, was signed by Governor Douglas on May 18, 2007. Act 35 directed the Agency of Human Services to work collaboratively with the Department of Education to develop a plan for providing services across the lifespan to individuals with autism spectrum disorders (ASD) and their families. The legislation required the involvement of key stakeholders in the development of the plan. This legislation was passed in response to the growing number of individuals in Vermont with these diagnoses and the need for the state to develop its infrastructure to meet the needs of this population. This planning work is the next step in addressing the gaps in the system of care identified in the [Vermont White Paper on Autism Spectrum Disorders, Report to the Act 264 Board](#), published in March 2006 (see WWW link 1).

In June 2007, the Agency of Human Services and Department of Education invited individuals with ASD, families, community providers, education professionals, advocates, private practitioners and state officials to participate on committees to help develop this report. Approximately, seventy-five (75) people were organized into a Steering Committee and five additional sub-committees to work on various components of the report. (See list of members under Acknowledgements.) Individual committees met from August through mid-November. Approximately thirty-five (35) committee meetings were held. The subcommittees provided reports to the Steering Committee with their findings and recommendations (see WWW links 2 through 6).

In addition to the work of the various committees, five (5) forums were held to gather additional information from the public on the direction the state should take in developing a system of care for individuals with ASD throughout the lifespan. One hundred and ninety-five (195) people attended the forums which were held in Burlington, Montpelier, Rutland, Springfield, and St. Johnsbury. The attendees included individuals with autism spectrum disorders, family members of individuals with ASD, school personnel, community service providers, college and university staff, state government staff, legislators, and reporters from the media.

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People were also given the opportunity to provide written comments. The questions posed at the forums were also posted on-line. Fifty-seven (57) individuals provided written comments. Additionally, people were provided the opportunity to rate their top three priorities for the state to develop and enhance services to individuals with ASD in Vermont. See a summary of comments from the public forums and the priorities identified in WWW link 7. Additionally, approximately ten (10) adults with ASD were either interviewed or responded to a questionnaire regarding their experiences living with ASD. See WWW link 8 for their comments.

A survey was also developed and sent to individuals with ASD, family members of individuals with ASD, guardians, caregivers and professional staff through Survey Monkey, an on-line survey tool. A total of 503 surveys were completed representing 104 families/caregivers, 2 individuals with ASD and approximately 400 professionals. The results of the survey are included in WWW link 9. In general, most input from professionals, including educators, was obtained through the on-line survey. The high numbers of people involved in this process speaks to the importance of the issue to many Vermonters.

Input from all these sources has been synthesized into this report.

Background:

Autism Spectrum Disorders are developmental disabilities of a neurobiological origin that can have life-long effects on daily functioning, particularly in the areas of communication, social skills and behavior. The symptoms of ASD vary widely, from some people who have intellectual disabilities and severe behavioral problems to people who are highly articulate and may have superior intelligence, but still have major difficulties in social interaction. It affects four times as many males as females. Currently, there is no known cause. Although there is no cure, specialized interventions and educational programs can lead to significant improvements for many people with ASD¹.

Autism Spectrums Disorders have a significant impact on individuals diagnosed with ASD, their families, and the State of Vermont.

Having an ASD significantly impacts a person's ability to function in his or her home, school and community. It can impact a person's ability to



communicate, learn, and form relationships. Some individuals who are able to speak about their experiences report that life with autism can be challenging. Almost all the adults who provided input said that they have felt isolated, bullied or excluded in school. Many report difficulties finding jobs and support for living independently as adults. Several adults reported that despite having a college degree, they were unable to find employment. A number of adults reported having additional mental health problems such as depression or anxiety as a result of their challenges in life. There are many people with ASD who cannot speak for themselves and their parents responded on their behalf. They reported challenges for their children with making friends, frustrations with schools who could not provide adequate support for learning and social integration, difficulties being included in their communities after school and lack of options for adults for employment and independent or supported living.

Families caring for their children with ASD also experience significant stress. Caring for a child with ASD includes many extra responsibilities above that required for caring for typical children including: more frequent medical appointments; frequent meetings with and training of school staff, specialists, care providers and medical professionals; coordinating care with multiple providers; researching, applying for and managing support services; ongoing advocacy; extraordinary care giving; teaching; and, supervision for safety. Results of the on-line survey conducted in Fall 2007 (see WWW link 9 for full results), show the following impact on parents:

"In elementary school I had friends but after that I didn't interact with people. I had problems socializing. Being lonely has been a source of terrible anxiety for me."

Comment from an Adult with ASD

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Description of Impact	Percent of Parents Affected
Stress	100%
Social Isolation	61%
Economic	61%
	(of these, 40% of families reported paying for services out of pocket ranging from \$600 to over \$10,000 annually)
Depression	57%
Marital Difficulties	52%
	(nationally, similar to other disabilities, 80% of parents with a child with ASD divorce)
Sibling Issues	51%
Extended Family Relations	38%
Job Loss	35%
(Parents may report being impacted in more than one area.)	

Based on statistics from the U.S. Department of Education and other governmental agencies, the number of individuals diagnosed with ASD has been estimated to be growing nationally at a rate of 10%-17% a year². The U.S. Center for Disease Control and Prevention recently published a report indicating that 1 in 150 children have an ASD diagnosis³. Vermont's data supports similar prevalence rates.

Data from the Vermont Department of Education indicates that in 1992, 13 children between the ages of 3 and 21 identified with ASD were receiving special education services, and that by December 2006, 582 children identified were receiving services. Likewise, in the Agency of Human Services, data show that in 1992, 68 children and adults with ASD were receiving either Mental Health or Developmental Disability services, while the number had increased to 671 by 2007. This represents an average annual rate of increase of 16% over the past ten years.



The growing number of individuals with ASD has a significant impact on Vermont's schools and human services providers. Services for individuals with ASD are provided through schools, primarily in special education, and through various programs in the Agency of Human Services. Based upon available data, it is estimated that the State of Vermont is currently spending at least \$57 million annually between education and human services, and by 2012 these costs are estimated to increase by 81% due to increased numbers of people with ASD.

The table on the following page illustrates the estimated number of individuals with ASD and approximate cost of services ***already being spent*** to assist individuals and their families. Both the numbers of individuals and the cost estimates should be viewed as giving the reader a sense of the scope of current resources being used to benefit individuals with ASD and should not be viewed as precise. One of the reasons that data is not available is that autism spectrum disorders may not be a person's primary diagnosis being treated, even though it may be a disability present. For example, someone being treated for a substance abuse problem will not necessarily list autism as a secondary diagnosis while being treated for substance abuse. It became apparent during the process of preparing information for this report that the state and local data systems do not easily identify individuals served and related costs in a consistent way and recommendations are made to rectify this situation.



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AGENCY OF HUMAN SERVICES					
Department and Program	Ages Served	Number Served FY 07	Average Cost /Ind. FY 07	Total Spent FY 07	Projected Cost for FY 12*
Department for Children and Families					
Family, Infant and Toddler Program	Birth - 3	64 point-in-time during the year ending 10/31/07	\$23,775	\$1,521,568	\$2,282,352
Children's Upstream Services	Birth - 6	24	\$6,000	\$144,000	\$216,000
Healthy Babies, Kids and Families	Birth - 6	Not available	Not available	Not available	Not available
Foster Care/ Residential Placements	Birth - 21	Not available	Not available	Not available	Not available
Department of Health					
Children with Special Health Needs	Birth - 21	Not available	Not available	Not available	Not available
Substance Abuse	Not available	Not available	Not available	Not available	Not available
Department of Mental Health					
Children's Mental Health	Birth - 22	309	\$22,249	\$6,852,737	\$10,279,105
Adult Mental Health	18 and up	46	Not available	Not available	Not available
Department of Disabilities, Aging and Independent Living					
Developmental Disabilities Services	All ages	316	\$47,849 in FY06	\$15,120,284	\$22,680,426
Children's Personal Care	Birth - 21	582	\$9,167	\$5,335,194	\$8,002,791
Vocational Rehabilitation	Transition age youth and up	137	\$9,383 in 2006	\$1,285,471	\$1,928,207
EDUCATION					
Special Education	3 - 21	582 on 12/1/06	\$47,109	\$27,417,759	\$58,972,824
TOTAL				\$57,677,013	\$104,361,705

*Presented in 2007 dollars, based on current levels of service with no changes in access.

WWW link 10 provides a more detailed description of available AHS services, eligibility, number of people served and current and projected costs. Lifetime costs for a person on the Spectrum are estimated to be \$3.2 million over the person's life, including costs for education, home and community-based services and lost individual and family income⁴.

As the number of individuals with ASD has increased, some schools and agencies have developed their programs and expertise to meet the needs of people with ASD, however, there is considerable variability around the state in the availability of effective programs and services. The Vermont White Paper on Autism Spectrum Disorders, Report to the Act 264 Board identified the following gaps in services for children⁵:

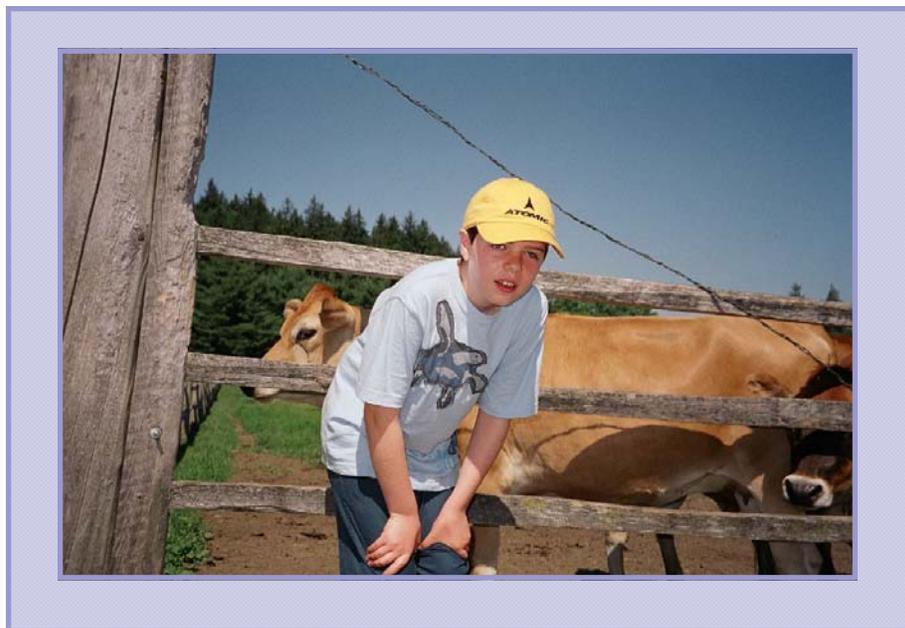
- ◆ Easy access to information regarding diagnosis, prognosis, options for treatment and intervention, available resources, parent support.
- ◆ Sufficient number of staff with experience and training in ASD to provide needed support, including direct support staff, case managers, behavior specialists, psychologists, psychiatrists, occupational therapists, physical therapists and speech-language pathologists.
- ◆ Sufficient availability of training for staff through higher education, conferences and hands-on instruction.
- ◆ Systems and processes to ensure smooth transitions when students change programs, especially transition from high school.
- ◆ Infrastructure of trained personnel and financial resources to provide intensive early intervention as outlined by the National Research Council.
- ◆ Availability of comprehensive services, when needed, for children with ASD in the home and community.
- ◆ Availability of parent training.
- ◆ Best practice guidelines to guide delivery of services in schools, home and community.
- ◆ Systems and processes to enhance collaboration across school and home.

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The information gathered from the public forums, the online survey, information gathered from adults with ASD and the six (6) autism planning committees confirmed that these remain the primary gaps.

Additional information was gathered in the current process regarding the needs of adults. Gaps in services for adults include limited access to support for employment; higher education; social involvement; and, independent living options. These were priority areas identified for system improvement.

The following sections describe the major findings and recommendations for a plan to enhance the Vermont system of care for supporting individuals with ASD in their homes, schools and communities. These findings and recommendations represent a synthesis and prioritization of input gathered from the steering committee, the five subcommittees, and the extensive public input process.



Findings and Recommendations

Best Practices

Findings

1. There currently are no state guidelines for schools and service providers that outline best practices for service delivery for individuals with ASD and their families.
2. The National Research Council stated that while some intervention strategies for individuals with Autism Spectrum Disorders (ASD) have been developed and scientifically demonstrated as successful, no single intervention or approach has proven to be effective for every individual with ASD⁶. Therefore a range of approaches need to be available in the state.

Recommendations

A committee should be created to develop, review and regularly update practice guidelines for a system of lifelong care. These guidelines should adhere to the following overarching values:

1. Supports and services should be provided throughout the lifespan and across all settings;
2. Individuals with ASD and their families should be respected and listened to; supports and services incorporate their values and beliefs; and,
3. Coordination of supports and services should be ensured through cohesiveness, collaboration and clear communication between all service providers to individuals with ASD and families across settings.



Identification and Diagnosis

Findings

1. No established protocol exists in Vermont for early screening for ASD for primary care physicians and screening is inconsistent across the state.
2. Not all primary care physicians are aware of the early signs of ASD.
3. The number of specialized diagnosticians is insufficient, so individuals may be on waiting lists for several months awaiting evaluations.
4. Delays in identification limit access to appropriate intervention services.

Recommendations

1. Pediatricians should implement the recommendations set forth by the American Academy of Pediatrics that prioritize screening for autism and other disabilities at ages 18, 24, and 36 months⁷.
2. Collaboration with the Department of Health's "medical home" initiative should be explored to promote the use of nationally-recognized developmental screening for all primary care physicians.
3. A directory of providers who are skilled at diagnosing ASD across the lifespan should be created. In addition, the network of practitioners able to provide both diagnosis and assessment of ASD for support planning should be expanded.

"Primary care physicians really need more training. Many times I am told, 'This isn't my area of expertise', which is very frustrating."

Comment from a Parent

Early Intervention

Findings

1. Research indicates that, for a significant number of individuals, effective early intervention services can substantially lower the need for later services in school and adulthood. The National Research Council reported that up to 48% of children birth through 8 who received early intervention made substantial progress⁸.
2. Intensive, early intervention services are not available in many locations in the state.

Recommendations

1. Intensive, early intervention services should be provided for young children with ASD as soon as a diagnosis is seriously suspected. Services should include a minimum 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, developmentally-appropriate educational activities aimed toward identified objectives⁹.



Coordination of Services

Findings

1. Services for individuals with ASD are provided by a variety of state agencies, schools and local providers.
2. Responsibilities of a lead agency for developing, coordinating and implementing a system of care for people with ASD need to be defined. The Part B Interagency Agreement between AHS and DOE addresses roles and responsibilities of each agency in the provision and funding of services for all students eligible for special education. It covers coordination of services, agency financial responsibility, conditions and terms of reimbursement and resolution of interagency disputes. A separate MOU is needed that specifically addresses agency roles and responsibilities for individuals with ASD.
3. Systems for coordination and collaboration between organizations and agencies at all levels — local and state — is lacking.
4. Many families do not have access to a case manager or service coordinator to work with them to develop a comprehensive, appropriately individualized service package.
5. While there is an established interagency coordinated service planning process available in the state, there is a perception that the process is being used to address primarily crisis situations, for example, likelihood of foster care or out-of-home residential placement.
6. There is no centralized agency responsible for creating and managing a strategic plan for awareness and training at a variety of levels for service providers, parents and individuals with ASD. A coordinated vision or framework for training and resources does not exist at this time.





7. It is difficult to collect accurate, complete data and information about individuals with ASD because of the way data are collected by various state agencies and local providers.
8. There are numerous transitions between programs for school-age children, youth and adults. Barriers to successful transitions across the lifespan include lack of communication within and among agencies, difficulties accessing various types of funding, and lack of clearly defined roles and responsibilities.

Recommendations

A recommendation was made to designate a lead agency in the state by most of the autism plan subcommittees. Earlier in 2007, the Secretary of the Agency Human Services (AHS) designated the Department of Disabilities, Aging and Independent Living (DAIL) as the lead department for coordinating autism services across AHS. With that in mind, a Memorandum of Understanding should be created between the Department of Education and AHS that will outline responsibilities of each department in developing a system of care for individuals with ASD across the lifespan. The role and responsibilities of the lead agency within AHS with respect to the other AHS departments should be further defined and agreed to by the other departments. It is recommended that the lead agency:

1. Ensure that there is continued planning for implementation and oversight of a system of care for all individuals with autism spectrum disorders across the lifespan.
2. Coordinate services between agencies and programs at the individual, regional, and state level using existing coordinated service plan processes; and create or expand local and regional networks that bridge human service providers and school districts.
3. Ensure that there is a central point for information and referral within AHS.
4. Coordinate between various federal, state and private funding sources to create efficient and seamless delivery of services.

"I have found case management to be lacking and contact greatly diminished since I began working full time."

Comment from a Parent

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5. Develop a system for accurately tracking and analyzing data around autism services including the number of individuals with ASD, their needs and the costs to serve them in order to plan for further developing the system of care.
6. Establish data sharing protocols among state agencies and departments to provide accurate information for planning of services for school-age children and youth with ASD.
7. Provide funding for service coordination for individuals with ASD and their families to help them access services, train workers and transition across systems throughout the lifespan.





Access to Information

Findings

1. Individuals with ASD and their families often do not know where to go for information and assistance in moving through the various service systems. Access to information pertaining both to eligibility and the range of available services such as personal care, mental health, vocational training, and other services varies and is not necessarily easy to access, understand or navigate. The process of accessing services itself frequently adds to family stress.
2. Families need access to resources geared towards individuals of all ages with ASD to teach social skills, health, sexuality, safety, drug awareness, and what to do about bullying and abuse.

Recommendations

1. Autism resource centers (see WWW link 11 for draft proposal to create autism centers) should be created to act as an information clearinghouse and that promote collaboration among school staff, families, state agencies and community service providers and build capacity in all areas of Vermont to address the needs of individuals with ASD and their families. The centers should include capacity in the following areas:
 - ◆ Provide updated information about best practices for support and intervention across the lifespan.
 - ◆ Create a directory of providers able to diagnose ASD and provide consultation across the lifespan.
 - ◆ Disseminate information about available trainings.
 - ◆ Using an informational phone line and other technology, provide information about available resources and assist individuals with ASD and families to navigate systems.



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2. Provide information to the public about Autism Spectrum Disorders through the creation of a Speakers Bureau of practitioners, families, and/or individuals with ASD who are willing to share information with others.

Training and Workforce Development

Findings

1. Due to the shortage of specialized programs and staff in Vermont, parents are often put in the position of having to gain and provide the expertise needed to train team members for home and school programs.
2. Families are responsible for securing and training respite and personal care workers, acting as their child's case manager.
3. There is little to no training for parents of children with ASD. Parents are the constant and long-term caregivers for their children and are the bridge to often changing school and agency staff.
4. There is limited public awareness of ASD, especially for the variety of community members who are likely to come into contact with individuals with ASD and their families. They include, but are not limited to, health and mental health care providers, emergency personnel and first responders, police, legal personnel, employers, general educators, and school administrators.
5. There are insufficient numbers of trained professionals in all areas of autism services to support the needs of Vermonters with ASD and their families in their homes, schools and communities. Parents report that, in their experience, many professionals working with their children were not adequately trained.
6. Service providers do not receive sufficient compensation to allow them to pursue long-term careers in the field, or to encourage new providers to enter the field.
7. Many health care professionals do not have the training or expertise to work with individuals with ASD and their families and appear uncomfortable working with them. Families report that this limits healthcare options, identification of co-occurring conditions, and appropriate treatment.
8. Training and resources are not readily accessible across geographic regions or due to financial limitations of those in need.

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9. There are high turnover rates in front line support staff due to poor compensation, lack of benefits and lack of training.
10. Due to the broad and often complex needs of individuals with ASD, there is a wide range of interventions that are potentially effective. It is difficult for staff to become proficient in many different interventions. The most common types of training, educational and technical assistance resources currently available are at the introductory or intermediate level and occur through workshops or conferences. These modes of training are not always accessible to people who need to be trained. Training at all levels is typically brief with no mechanism in place for sufficient pre-service or follow-through with the teams working with individuals with ASD. Only a limited number of in-state agencies/organizations provide training.
11. There are no state minimum requirements or credentialing for professionals. Few incentives for completing a training program in ASD are in place because there is no career path that leads to certification or licensure.
12. There is a lack of sufficient interdisciplinary training and funding in higher education to support the development of the multiple disciplines that can benefit individuals with ASD.

Recommendations

1. Define the competencies and experience expected of professionals (such as behavioral specialist, communication specialist, autism specialist, etc.) to provide quality services to individuals with ASD across the life span and across settings.
2. Develop a statewide campaign, using Vermont Department of Health media resources, to promote autism awareness and to educate the public about ASD and available resources.
3. Ensure the inclusion of perspectives/voices of individuals with ASD and their families in all training.

4. Provide pre-service, in-service and job-embedded training in best practices, including mentoring, supervision and coaching, to all people working with individuals with ASD.
5. Provide scholarships or incentives to professionals to engage in on-going professional development.
6. Develop training expectations for allied health professionals and others who interact with people with ASD (medical/dental professionals, EMT's, police, community helpers, etc.)¹⁰.
7. Promote materials, such as those recommended by the American Academy of Pediatrics (October 2007) to educate primary care physicians and parents on early identification of ASD¹¹.
8. Support higher education to work collaboratively with multiple disciplines to develop undergraduate, graduate and continuing education courses to address training needs of parents and professionals including mental health professionals, regular educators, special educators, and case managers/service coordinators. Specific work should be done to address critical shortages in specialists such as occupational therapists, physical therapists, and speech-language pathologists, including specific training for those with experience and expertise in augmentative and alternative communication.
9. Support a twice/year institute, similar to the BEST Summer Institute, where teams comprised of school personnel, service providers, parents and employers can come together in teams organized around individuals or groups of individuals diagnosed with autism to be trained and to have time to plan and expand the capacity of their respective systems.



Technical Assistance and Consultation

Findings

1. There are a limited number of highly trained professionals available to provide training, technical assistance and consultation in Vermont.

Recommendations

1. Use the model in which interdisciplinary teams of experts can consult to schools or other settings that support individuals with ASD and their families to provide ongoing support, guidance, training, and resources. Within this model create a train-the-trainer program.
2. Technical assistance should be provided to schools and agencies to develop cost-effective models of service delivery.
3. Consultation and training should make use of technology, including websites, interactive television, webcams, and other solutions.





Education Services

Findings

1. While only 13 children identified with ASD were receiving special education services in Vermont in 1992, by December 2006, 582 children with ASD between the ages of 3 and 21 years were receiving special education services (Department of Education, Child Count data). This represents a significant increase over the past 14 years.
2. Based on the current annual rate of increase in children and youth identified with ASD and the estimated cost of services provided by education with allowance for inflation, the cost of educating children and youth in Vermont with ASD could reach \$58,972,824 by 2011.
3. There are limited options in Vermont for specialized ASD school programming due to lack of staff time and resources; lack of expertise in the design and implementation of programming; and lack of intra- and inter-school district planning and coordination of services and support. These limitations result in some students being placed in alternative learning environments, in out-of-state residential schools and for some parents, choosing homeschooling.
4. Quality and comprehensiveness of services is inconsistent from school to school and region to region within the state.
5. Interagency collaboration during the transition years varies by school district and region.
6. Some children with ASD are not eligible for special education services in Vermont because they do not demonstrate "adverse effect" in the basic skill areas as described in Vermont Special Education Regulation 2362(a)(2)(d)¹². A major area of deficit for people with ASD is in social skills, which is not considered a basic skill area. However, the lack of social skills can have a significant impact on their functioning in home, school and community settings.
7. Core elements of effective programs include individualized supports and services for children and families, systematic instruction,

"...we are the inclusion state and we need to continue being the inclusion state; we've moved away from inclusion in some schools..."

Comment from a Parent

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comprehensible and structured learning environments, specific curriculum content, functional approach to behavior issues, and family involvement¹³.

8. Data are not currently collected on programmatic or cost effectiveness of various programs, models or placements.



Recommendations

1. The “*adverse effect*” eligibility criterion in Vermont special education rules should be reconsidered to allow for consideration of social skills as a critical basic skill in learning for individuals with ASD.
2. The availability of educational services that represent best practices should be examined in local schools in order to ensure consistency throughout the state and to explore models of service that provide the full continuum of supports and services to address the range of needs.
3. The reasons why children are put in more restrictive environments or are being removed from school for homeschooling should be studied and recommendations made for developing the full continuum of



supports and services to maximize access to least restrictive educational environments in Vermont.

4. Use of models to integrate services, such as autism collaboratives, should be expanded to create more collaborative, wrap-around service provision.
5. The effectiveness and outcomes of educational programs for students with ASD should be assessed.
6. Statewide and supervisory union training and technical assistance should take into consideration disaggregated data for children and youth with ASD, on student outcomes from the Annual Performance Report.
7. Models for ongoing assessment of functional and academic skills of children and youth with ASD should be explored and a centralized tracking and dissemination system for this assessment data should be created and shared with AHS.

“...I am working to create a program pre-K through 12th grade based on need...create a seamless system through transitions”

Comment from a Professional



Adult Services

“The real world is jobs.”

“I like having people to show me the ropes of living independently”

“Getting involved with self-advocacy because it teaches us how to advocate for ourselves so we can go for our goals”

Comments from Adults with ASD

Findings

1. Access to services and supports such as housing, employment, and health care for adults is limited. Even for those receiving services, funding may not be sufficient or the types of services currently being provided may not assist people in achieving their personal goals, and leading lives that are as independent and inclusive or integrated into the community as possible.
2. As with other developmental disabilities, parents are relied on to provide care for adults with ASD.
3. Support for transition from school to work and community living is an area of significant need.
4. Opportunities for training in self-advocacy skills are limited.
5. There are limited peer and support groups to facilitate social inclusion.
6. Good jobs are important to adults with ASD. Limited training is available for individuals to find and keep jobs. Skills and knowledge about hiring and supervising a person with ASD for employers and vocational support staff are also limited.
7. There is limited access to continuing education and skill building opportunities for adults with ASD.

Recommendations

1. Training should be provided to high school case managers, individuals with ASD and their families about the funding priorities for individuals leaving high school in the State System of Care Plan for Developmental Disability Services.
2. Consistent participation in transition planning by adult service providers should be promoted, including Developmental Disability, Mental Health, and Vocational Rehabilitation services.

3. New post-secondary opportunities for education and community living skills (e.g., college support; peer mentoring/coaching; living coaches, etc.) should be developed.
4. Peer- and professionally-led support and counseling groups that will lead to independent social interaction should be developed. Social and leisure opportunities should be developed throughout the lifespan.
5. Availability of affordable housing by collaborating with public housing financiers and private developers should be increased. Availability of cooperative housing and including the use of technology to support people in independent living should be increased.
6. Job opportunities, training, and resources for people with ASD should be increased. Training to Vocational Rehabilitation counselors, supported employment staff, current and potential employers, and job supervisors should be pursued to increase knowledge about the unique needs of employees with ASD and the skills for hiring and successful ongoing employment.
7. The development of job opportunities should be funded that match the skills of individuals with ASD.
8. A variety of creative and flexible service, support, and case management options from which adults with ASD can choose should be available. Adults should be able to purchase those services using public, private or insurance funds.
9. Consideration should be given to creating a pool of money, for access by application, to private agencies providing support for peer training, parent support, and self-advocacy.



Funding

Findings

1. As of December 1, 2001, services funded through the developmental disabilities Medicaid waiver are only available to children who are new applicants based on their risk of institutionalization. Previously this funding source provided needed clinical support, case management, training and supervision critical to those with ASD. This change resulted in some children still receiving these services (if approved prior to December 2001) and others who need services, but can no longer access them due to changes in the System of Care Plan funding priorities.
2. Access to Medicaid waiver funding for adults is limited to System of Care priorities such as: risk of homelessness; risk of abuse, neglect or exploitation; loss of a caregiver; or risk to public safety as examples. While promoting independence is a goal once *already in* services, it is not a funding priority *to get into* services.
3. Some adults with ASD are not eligible for needed services even though they are unable to function independently in the community and the workplace.
4. Supports for people with ASD vary depending on local availability of services, the type of medical insurance coverage they have, and their ability to navigate a complex system of care.
5. Families unable to access adequate home and community-based supports, often turn to schools for additional services beyond what is provided during a typical school day with limited and/or unpredictable success.
6. There are gaps in the federal entitlement to Early, Periodic Diagnosis, Screening and Treatment (EPSDT) services for Medicaid-eligible children, including those with ASD.
7. The Global Commitment waiver could be a potential Medicaid funding source for autism services provided through EPSDT, Success Beyond

Six, Developmental Disabilities Services waiver, Children's Mental Health waiver and Adult Mental Health services. Private insurance could also be a potential funding source for intensive early interventions.

8. Most private insurance plans in Vermont do not cover autism services. Roughly 20 states have already laid the groundwork for increasing insurance coverage for the treatment of ASD by passing laws that intend to require the expansion of covered services. A more limited number have enacted legislation that mandates the coverage of specific treatments such as behavioral therapy, nutrition supplements, habilitation, or case management. An insurance law targeting large group employers (over 50 employees) in Vermont who do not self-insure would affect approximately 180,600 Vermont citizens, based on 2002 data. Passage of this law could impact insurance coverage for ASD services for families covered by this group of employers.
9. The lifetime costs of a single individual with ASD are estimated to be \$3.2 million/individual. At current incidence rates, this translates into \$35 billion annually for the US economy¹⁴. There is the potential that lifetime costs can be reduced with early diagnosis and intensive intervention.





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“...I did not know what Asperger’s was, thank you for educating me; a resource center would be wonderful...”

Comment from a Community Member

Recommendations

1. The targeted use of professional development money available to schools and providers should be investigated to pay for training, technical assistance, and consultation.
2. The gaps in Medicaid EPSDT programs for autism services for Vermonters under age 21, such as speech/language therapies, occupational therapy, case management, and behavior therapies should be closed.
3. Access to the home and community-based developmental disability Medicaid waiver services should be restored in Developmental Services for children to cover services not eligible under EPSDT such as respite and parent training.
4. Access for adults to Medicaid-covered services such as speech/language therapies, augmentative and alternative communication devices, occupational therapy and other services should be improved.
5. The Medicaid Children’s Personal Care Program should be revised to allow flexible use of the funding by parents.
6. Funding should be available to increase access to recreation, summer programs, and community opportunities. This should be coordinated with the Governor’s Fit and Healthy Kids initiative.
7. A pool of dollars targeted for people to attend training should be available to individuals with ASD, families, and front-line support workers.
8. Funding to support the availability of regionally located interdisciplinary teams of experts who can consult with families and staff in schools or other educational settings should be expanded.
9. Compensation for developmental pediatricians at the Child Development Clinic should be increased in order to attract a sufficient number of practitioners for diagnosis and ongoing medical treatment.
10. Changes to the special education funding rules should be considered to allow financial incentives for regional models of training and service delivery in schools.



11. The State should actively support new federal legislation, such as the “Expanding the Promise for Individuals with Autism Act of 2007” (HR 1881/S937) and “IDEA Full Funding Act” (S1159).
12. Legislation should be enacted to require large group employers in Vermont who do not self-insure, to pay for medical services for children with ASD including, but not limited to: full diagnostic evaluation, primary care in a medical home setting, physical therapy, occupational therapy, speech/language services and intensive one-on-one therapy using individually-appropriate interventions. Also, reimbursement for ASD-related services must be at a rate commensurate with that of other medical conditions.
13. Legislation that clearly defines ASD as a neurologically-based medical condition should be enacted in order to access private insurance coverage.
14. The implications of changing eligibility for developmental disability and mental health services to focus on functional supports necessary to help individuals with ASD lead lives that maximize their independence should be evaluated.

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WWW links:

1. Vermont White Paper on Autism Spectrum Disorders; Report to the Act 264 Advisory Board -
<http://ddas.vermont.gov/ddas-publications/publications-autism/publications-autism-documents/dds-autism-white-paper-march-2006>
2. Best Practice Guidelines Subcommittee Report -
<http://ddas.vermont.gov/ddas-boards/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/practice-com-rprt>
3. Profile Committee Subcommittee Report -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/profile-committee-rpt>
4. Public Education Subcommittee Report -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/public-ed-com-rprt>
5. Goals and Projections Subcommittee Report -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/goals-projections-report>
6. Outreach, Education and Workforce Development Subcommittee Report -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/outreach-ed-wrkfrce-dev-com-rprt>
7. Summary of Public Forum Comments -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/themes-from-forum-comments>
8. Summary of Comments from Adults with ASD prepared by Green Mountain Self-advocates -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/focus-forum-person-with-autism-responses>
9. Results of the on-line Survey Monkey tool -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/survey-monkey-report>



10. Detailed description of available AHS services, eligibility, number of people served and current and projected costs -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/ahs-asd-spending>
11. Proposal to Create Autism Resource Centers -
<http://ddas.vermont.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/regional-autism-centers-proposal>

