

# STATE OF VERMONT AUTISM PLAN

## GOALS AND PROJECTIONS COMMITTEE REPORT

### PRESENT CHALLENGES

The Goals and Projections Committee identified four broad areas of need in the current system of care for Vermonters with autism spectrum disorders: services, service coordination, equity, and workforce.

#### I. Services

- Vermonters with ASD and their families experience intense stress in their daily lives. The available services may not provide adequate support, and the process of accessing services itself frequently adds to the stress.
- There is no comprehensive system for early screening for ASD. When young children receive an ASD diagnosis, they often do not have access to appropriate and sufficient early intervention services, either at home or in school settings.
- Because of eligibility criteria, some Vermonters with ASD do not have access to services.
- Transition services to help Vermonters with ASD move from one phase of life to another, or one service system to another, are often inadequate.
- Many adults with ASD do not have sufficient and appropriate community-based services to promote independence and community inclusion.

#### II. Service Coordination

- Autism services come from a variety of agencies and public entities. Effective coordination between these service providers is often lacking.
- Vermonters with ASD and their families often do not know where to go for information and assistance in moving through the various service systems.
- Accessing services requires people with ASD and their families to negotiate multiple funding sources, further complicating the process of receiving adequate services.

#### III. Equity

- Supports accessed by Vermonters 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.
- Service levels for Vermonters with ASD are not consistent across the life span.
- Vermonters with ASD face challenges in advocating for their needs and protecting their legal rights.
- People with ASD often find themselves isolated within their communities, and have limited access to employment, housing, and social outlets.

## IV. Workforce

- Support for Vermonters with ASD requires a highly specialized workforce. There are not enough service providers in the workforce to meet current needs. In the future there will be a need for even more trained providers, while the overall size of the workforce is predicted to go down.
- Low compensation levels make it difficult to recruit and retain service providers at all skill levels.
- Service providers, both direct care providers and other professionals who have more limited contact, do not receive sufficient training in ASD-related issues.

## KEY FINDINGS

### Goals

In response to these needs, the Goals and Projections Committee identified the following broad goals for Vermont's statewide system of care for autism services. The goals, in turn, are the basis for the recommended action items that follow. These goals should underlie planning for all changes to the current system of care.

- **Services:** Statewide autism services are effective, comprehensive, and individualized to meet the needs of all Vermonters with ASD. Vermonters with autism spectrum disorders have access to a wide variety of interventions and services built around their individual needs, and informed by evidence-based practices. Services work to maximize independence, engagement and community inclusion for Vermonters with ASD, and provide them with ongoing support throughout their lives.
- **Service Coordination:** Statewide autism services are provided in a coordinated, comprehensive, and holistic manner. Vermonters with ASD and their families have access to a single agency for information, referral, and service coordination. Funding for autism services is seamless, and does not require individuals and families to negotiate multiple funding systems.
- **Equity:** The system of care ensures that Vermonters with ASD have equal access to services and to their communities. Vermonters with ASD have equal access to a full range of services, regardless of where they live or their economic condition. Vermonters with ASD have access to appropriate services throughout their life spans, including community-based services for children and transition services. Vermonters with ASD are included and welcomed in their communities, have effective resources for self-advocacy, and have effective and timely remedies to combat discrimination and abuse.
- **Workforce:** There are sufficient 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. Service providers receive sufficient compensation to allow them to pursue long-term careers in the field, and to encourage new providers to enter the field. Training about ASD is provided throughout the broader community, with a focus on training those who come into contact most frequently with individuals with ASD.

## Projections

In order to implement these goals fully, substantial resources will be needed. The Committee identified the following factors that are likely to impact funding for autism services in the next five years:

- **Increased numbers:** The federal Centers for Disease Control estimates that, currently, the rate of ASD in the United States is 1 in 150. The number of Vermonters diagnosed with ASD has increased at a growth rate of approximately 20% per year, a trend that may continue in the near future. The documented increase does not reflect young Vermonters who have not been diagnosed due to insufficient early screening. It also does not include older Vermonters who have another primary diagnosis, whose ASD may not have been identified. Expanding the eligibility criteria for services will also add to the overall numbers.
- **Insufficient services:** While the current system of care covers a broad range of services, many needs remain unmet. People with ASD need a wide variety of supports. There is no “average” person with ASD, and services must be crafted to meet individual circumstances. The Committee identified particular needs in the areas of early screening for ASD, early intervention services for young children, transition services throughout the life span, adult services to promote further learning, independence and community inclusion, and service coordination for all service recipients. Bringing all of these services up to adequate levels will have a significant short-term financial impact, and new funding will need to be identified. However, some of these service expansions have the potential for being cost-neutral or cost-saving in the long run. For example, research indicates that effective early intervention services can lead to substantially lower need for later services in school and adulthood for a significant number of individuals. Adult services to promote financial and personal independence may lead to less dependence on state services in the long term.
- **Lead Agency and Service Coordination:** The Committee identified a need to designate a lead agency to provide service and financial coordination for autism services. The lead agency will not provide all autism services, but will be the central point for service coordination, data tracking, information and referral. The lead agency will promote inter- and intra-agency cooperation and collaboration, to ensure that services are delivered effectively and efficiently. This change would entail a reorganization of the current system of care, and likely would require the development of new infrastructure to meet these needs. However, not all of the resources needed would be new, and some of this goal could be achieved by restructuring existing resources. Service coordination could likely be achieved by modifying and expanding existing service coordination systems, rather than creating an entirely new system.
- **Increased compensation:** Service providers frequently receive insufficient compensation. This need ranges across the entire pay spectrum, from pediatric neurologists to personal care providers. Service agencies consistently report that they are unable to attract enough workers to fill these positions. For skilled workers, it is difficult to attract new staff to Vermont when other markets offer higher wages. Increasing compensation levels will have

obvious budgetary impact, but without such increase, many positions will go unfilled, even when funding is available.

- **Insufficient data:** As we pursued the legislature’s mandate in the statewide autism study, the Committee found one of the major obstacles to be the inconsistent availability of accurate data. The Committee solicited data both on the number of Vermonters with ASD across the life span, and the amount of money being spent on current services by various agencies. We found significant gaps in this data. We also found that data kept by different agencies was not easily comparable. It is difficult, therefore, to project future needs in an accurate, comprehensive manner. It is essential that the lead agency effectively track this data, to determine future needs and the impact of any changes to the system.
- **Fiscal resources:** Meeting these needs will likely require additional monies from the General Fund. The Committee also considered other possible resources that would help to cover these additional costs. Many other states have adopted legislation requiring private insurance companies to include autism services in their coverage, and such a change could provide significant support for many early intervention, therapy, and other services. Pennsylvania has proposed particularly comprehensive legislation in this area. The state should also ensure that an appropriate percentage of current Medicaid funding is allocated to Vermonters with ASD, and work to maximize available federal Medicaid funding in this area. The state should promote full implementation of Medicaid EPSDT programs for autism services for Vermonters under age 21. 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), and actively pursue any additional federal funding that becomes available. Private grant monies are also available for research and community-based initiatives.
- **Community Resources:** Numerous existing resources can be enlisted to bolster autism services. There are existing programs at the University of Vermont and state colleges to provide support, training and staffing for autism services. Existing training programs for first responders and community organizations can be encouraged to include ASD issues in their training.

## **RECOMMENDED ACTIONS**

The Committee recommends the following actions be taken to improve the current system of autism services. The Committee also identified a range of supplementary recommended actions, which are listed in a separate document.

### **I. Services**

- The state will mandate and prioritize early screening for autism spectrum disorders, in accordance with American Academy of Pediatrics guidelines, at 18, 24 and 36 months, to ensure that children with autism spectrum disorders are diagnosed as early as possible.

- The state will ensure that all young children who receive an ASD diagnosis have available timely and comprehensive early intensive intervention services, at a level based on a comprehensive, individualized and multidisciplinary evaluation.
- The state will review the current eligibility criteria for autism services as outlined in the Developmental Disabilities Act, Developmental Services regulations and Special Education regulations, to ensure that they are sufficiently broad and flexible to ensure that all Vermonters with autism spectrum disorders have access to appropriate services at home, in schools, and in the community. The state should pay particular attention to the criteria outlined in the federal Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §15002(8), and the federal Special Education eligibility regulation, 34 CFR §300.306 et seq.
- The state will expand services available to adults with ASD. These services should focus on the areas of greatest need: post-secondary education, employment, independent living, community access, social and recreational opportunities, and self-advocacy.

## II. Service Coordination

- The State will identify and designate a lead agency to coordinate autism services. The lead agency will: develop a system of care for all individuals with autism spectrum disorders across the life span; coordinate services between agencies and programs; provide service coordinators to manage clients' cases; serve as a central point for information and referral; track information and maintain a database related to Vermonters with autism spectrum disorders.
- Through the lead agency, the state will provide individual service coordination to individuals with ASD and their families. Service coordinators will assist clients in developing service plans, identifying service providers, and ensuring proper transition services at all points of service change.
- Through the lead agency, the state will ensure coordination between various federal, state and private funding sources to create efficient and seamless delivery of services.
- Through the lead agency, the state will develop a system for accurately tracking data around autism services, to track current costs, project future costs, and determine the impact of any changes to the system.

## III. Equity

- The lead agency will survey autism services throughout the state, to determine gaps in services based on geography. The state will identify local service agencies that can provide services in under-served areas that are equivalent to services available in other parts of the state.
- The state will ensure that adequate and effective transition services are available for all Vermonters with ASD at all major points of transition between service providers or systems.
- The state will restore full developmental services for children to the system of care.
- The state will expand services to adult Vermonters with ASD in the areas of post-secondary education, job development and support, and community access and inclusion.
- The state will develop community education programs to promote understanding and acceptance of Vermonters with ASD.

#### IV. Workforce

- The state will review compensation levels for all autism service providers, and provide funds to increase compensation to levels adequate to ensure full staffing.
- The state will promote and encourage expansion of autism-related training programs in education, therapy, and other areas of service provision.
- The state will develop incentive programs to encourage Vermont college students to enter the field of autism services and to remain in the state to pursue careers in the field, in line with the goals of the governor's Next Generation Commission.
- The state will mandate training for all police, fire, corrections, and other emergency and first responders in the needs of Vermonters with ASD.

#### V. Funding

- The legislature will identify new general funds for autism services, recognizing the yearly increase in the numbers of Vermonters with an ASD diagnosis, and the unmet needs outlined above. Given the complexity of the current system of care, and the many factors that will impact funding, it is very difficult to project an accurate cost for needs over the next several years. However, [INSERT COST PROJECTION FROM CLARE – (It's coming –CM)].
- The legislature will require private medical insurers in Vermont to cover autism services, based on the model currently proposed in the Pennsylvania legislature.
- The governor will work with the state's congressional delegation to pass and expand federal support for autism services.
- The legislature will review the use of Medicaid funds for autism service and ensure that a sufficient percentage of these funds are targeted toward the needs of Vermonters with ASD.
- The legislature will ensure full funding for Medicaid-based developmental services under the EPSDT mandate.

# Goals & Projections Committee

## \*Back Document\*

### Table of Contents

#### I. Supplementary Goals and Action Items

- A list of additional goals and action items to assist in further developing system of care and possible steps for implementation.



Supplementary  
Goal & Action Item

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/supplementary-goal-action-items>

#### II. Other State Legislation regarding Autism and Private Insurances

- A list of states that mandate autism services be covered by private insurances and what coverage or services are mandated for each state



Memo re state  
autism legislation.1

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/memo-re-state-autism-legislation>

#### III. Article from the April 2007 issue of the Archives of Pediatrics & Adolescent Medicine

- The Lifetime distribution of the incremental Societal Costs of Autism

<http://archpedi.ama-assn.org/cgi/reprint/161/4/343>

#### IV. Estimates of numbers and statistics for infants and toddlers in Vermont with ASD

- This report is an estimate the numbers and related statistics of infants and toddlers who have an ASD diagnosis and have received early intervention services through an IFSP during the last 12 months



ASD goals report  
11-11-07 lett...

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/asd-goals-report>

- V. Analysis of the outcomes of children served in four autism collaborative across the state in their first year of programming
- Outcome data collected from four community-based programs supporting children with Pervasive Developmental Disorder or ASD



ASD Program  
erview2.doc (272)

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/asd-program-overview>

VI. Survey Monkey results

- A breakdown of responses from the survey monkey completed by parents, professionals and individuals



surveymonkeyrep  
ort4.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/survey-monkey-report-v4>

VII. Services for Pervasive Developmental Disorder clients in Children's Programs and estimated costs by service type for FY07

- A breakdown of services provided and their estimated costs in FY07 for all DMH Designated agencies for clients with PDD in Children's Programs



PDD\_Cost\_Works  
heet\_FY07\_with\_e.

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/pdd-cost-wrksht-fy07-estimates>

VIII. Cost Scenarios for Early Intervention

- The various cost scenarios related to early intervention for Chittenden County for children 0-3 with ASD



autismgrid.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/autism-grid>

IX. PDD in VT CMH & DS programs 1990 - 2007

- Number of individuals with Pervasive Developmental Disorder Diagnosis on caseload in VT Community Mental Health agency or Developmental Services program
- Chart with numbers based on age group



PDDanalysis\_by  
age.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/pdd-analysis-by-age>

X. Individuals with PDD served by DMH Agency 1990-2007

- Number of Individuals with a PDD diagnosis being served by a Department of Mental Health
- Trend Analysis and 5 year projections



PDDanalysis\_FY19  
90thru2007\_projec

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/pdd-analysis>

XI. Costs of Children with PDD Diagnosis Receiving Intensive Services through Mental Health

- Number of children with a PDD diagnosis that are receiving Intensive Needs Services through the Mental Health System (residential care or Waiver funding) '06 & '07



Costs for Children  
with PDD Diagnosis

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/costs-for-children-pdd-diagnosis>

XII. All active Vocational Rehabilitation Cases in Fiscal Year 2007 by Disability Source

- Individuals with Autism as primary Disability served by DVR in FY2007
- Individuals who have autism as a primary disability that are served by Department of Vocational Rehabilitation in fiscal year 2007



DVR data in one  
place 10-19-07.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/dvr-data-in-one-place>

XIII. FY2005/FY2006 Vermont CMHC Clients with Autism

- Cost analysis of services from Units of service based on service codes



FFS rates FY  
05-06\_032007.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/ffs-rates>

XIV. Children ages 0-6 Served by MH programs in FY2007

- An analysis by cost center and age of children ages 0-6 with PDD that are being served by Mental Health programs in FY2007



Children\_0\_to\_6\_in-  
cluding\_PDD\_2007

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/children-0-to-6-including-pdd>

XV. Geographic Equity in Autism Services

- Immediate and long term suggestions/ideas on how to approach equity in services for individuals throughout the state



Geographic Equity  
in Autism Services

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/geographic-equity-in-autism-services>

XVI. Summary of Themes/Issues from Public Comments on Vermont Services for People with Autism Spectrum Disorder

- A summarization of issues/needs raised by public from the 5 forums that were held across the state



themes from  
forum comments.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/themes-from-forum-comments>



Priorities by  
Roles.xls

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/priorities-by-roles>

XVII. Howard Center: Developmental Services

- Demographics for ASD receiving Developmental Services through the Howard Center



Autism Data  
9-07.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/autism-data>



ASD Chart.xls

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/asd-chart>

XVIII. Autism Supports In Vermont (incomplete at this time)

- A description of what systems or departments in VT pay for or provide services to individuals with ASD across the lifespan



AHS ASD  
spending.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/ahs-asd-spending>

XIX. List of 'Ideals' for the needs of the Autism community in Vermont

- A brainstormed list by category of issues and/or needs of individuals with ASD or their families



Ideals by  
categories.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/ideals-by-categories>

XX. Lists of 'Ideals' for the needs of the Autism community in Vermont

- A brainstormed list by age of issues and/or needs of individuals with ASD or their families



Ideals list by  
age.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/ideals-list-by-age>

- XXI. DOE/AHS Interagency Agreement Users Guide Act 264 (reference material)
- Interagency agreement between Department of Education and Agency of Human Services based on Act 264 from April 2006

[http://education.vermont.gov/new/pdfdoc/pgm\\_interagency/interagency\\_users\\_guide\\_06.pdf](http://education.vermont.gov/new/pdfdoc/pgm_interagency/interagency_users_guide_06.pdf)

- XXII. VT Interagency White Paper on Autism Spectrum Disorder (reference material)
- A report to the Act 264 board from March 2006 created by the Department of Education and the Department of Human Services on the status of autism in the state of Vermont

[http://education.vermont.gov/new/pdfdoc/pgm\\_sped/data\\_reports\\_pubs/autism/interagency\\_autism\\_white\\_paper\\_06.pdf](http://education.vermont.gov/new/pdfdoc/pgm_sped/data_reports_pubs/autism/interagency_autism_white_paper_06.pdf)

- XXIII. Vermont State System of Care Plan for Developmental Services FY08 – FY10
- A three year plan determining criteria for services as well as set priorities for individuals with a developmental disability in the state of Vermont

<http://ddas.vermont.gov/ddas-policies/policies-dds/policies-dds-documents/policies-dds-documents-soc-plans/sscp-dds-3yr-fy08-fy10>

- XXIV. Proposal For Regional Autism Centers

- A draft proposal to the state for the effectiveness of creating regional autism centers throughout the state of Vermont



final proposal.doc

<http://ddas.vt.gov/ddas-boards/autism-boards-committees/vt-autism-planning-committees-documents/regional-autism-centers-proposal>

- XXV. “IDEA Full Funding Act” (S.1159)

- Federal legislation currently being proposed. The bill seeks to fully-fund IDEA in seven years through mandatory annual phased-in spending increases, until federal funding reaches \$30.8 billion in Fiscal year 2015

[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110\\_cong\\_bills&docid=f:s1159is.txt.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:s1159is.txt.pdf)

- XXVI. “Expanding the Promise for Individuals with Autism Act of 2007” (H.R.1881/S.937)

- Federal legislation currently being proposed that will authorize approximately \$350 million in new federal money for initiatives related to treatments, interventions and services for both children and adults on the spectrum

[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110\\_cong\\_bills&docid=f:h1881ih.txt.pdf](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=110_cong_bills&docid=f:h1881ih.txt.pdf)

XXVII. 42 U.S.C. 15002

- Definition of developmental disability in the federal Developmental Disabilities Assistance and Bill of Rights Act

[http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=browse\\_usc&docid=Cite:+42USC15002](http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=browse_usc&docid=Cite:+42USC15002)

XXVIII. 34 C.F.R. 300.306 and following

- Federal Special Education eligibility regulations

[http://www.access.gpo.gov/nara/cfr/waisidx\\_07/34cfr300\\_07.html](http://www.access.gpo.gov/nara/cfr/waisidx_07/34cfr300_07.html)