

Current State of Services and Supports in Vermont for Individuals with Autism Spectrum Disorder and Their Families

Report of the Vermont Act 35 Autism Plan Profile Committee to the
Steering Committee

November 15, 2007

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Meeting the Needs of Adults with Autism: A BLUEPRINT
FOR THE FUTURE [New Jersey] COSAC October 2006 (28 Pages)

Introduction:

The profile committee was charged with the task of providing a profile and describing the state of services and supports in Vermont for individuals with autism spectrum disorders (ASD) and their families. We looked at who these individuals are, and their needs and challenges across their lifespan. We also identified system gaps that impede or prevent individuals from meeting their basic needs and achieving their full potential.

Among the sources for this report were: public input via the Autism Plan forums and a survey distributed on-line via Survey Monkey; data from the Vermont Department of Education (DOE), the Department of Disabilities, Aging and Independent Living (DAIL), and the Department of Vocational Rehabilitation (DVR); information from the Vermont Autism Task Force; and the joint DAIL-DOE White Paper on Autism Spectrum Disorder (2006). Although the data received was incomplete, and, at times, contradictory, a number of patterns of needs and challenges have emerged. These are summarized in the following pages.

Facts, Key Findings and Recommendations:

Growth Trends

This is a Growing Population with Increasing Needs

- **Approximately one in every 150 children born in the US will have autism.** It is estimated that approximately 1 million individuals in the US have this disorder. This number does not include the additional autism spectrum disorders: PDD-NOS, Asperger's Syndrome and Rett's Syndrome. (The CDC, American Academy of Pediatrics, and other federal organizations endorse these statistics.)
- **A new case of autism is diagnosed nearly every 20 minutes.** There are 24,000 new cases diagnosed in the US per year.
- The economic impact of autism is more than \$90 billion and expected to more than double in the next decade.
- While there were only 13 children identified with ASD receiving special education services in Vermont in 1992, by December 2006, there were 63 children in Vermont with ASD between the ages of 3 and 5 years, and 519 children between the ages of 6 and 21 years receiving special education services (DOE). This represents a significant increase over the past 14 years.
- 316 individuals of all ages with ASD receive developmental services. This only represents approximately 10% of the total population served. However, these individuals also represent 33% of new recipients as of June 30th, 2007. (Developmental Services [DS], DAIL).
- 46 adults with ASD are receiving services through the Adult Mental Health system. (DS, DAIL)
- As compared to national standards, and based on Vermont's current birth rate, Vermont's population of individuals with ASD could potentially double over the next 10-13 years.

Identification

It is difficult to collect accurate, complete data and information about individuals with ASD, especially adults.

- The data that exists is limited to the total number of individuals who have accessed a limited number of programs (special education, developmental services, vocational rehabilitation), without details by age range, severity of condition, specific diagnosis; or related to funding and services.
- Data is not being collected systematically across agencies.
- Existing data likely underestimates the actual number of individuals because of differences in eligibility criteria for services and differing requirements for data collection across age groups.
- Children referred for diagnostic services may be on waiting lists for an appointment for several months.
- Individuals with Asperger's Syndrome or High Functioning Autism (which is not recognized as a separate diagnosis in the current Diagnostic Statistical Manual of Mental Disorders, but is used by some clinically and in research to refer to Autistic Disorder with IQ of 70 or above) may not receive diagnoses until they are well into elementary school, high school, or even adulthood, and have been denied services as a result of late diagnosis.

- Delays in identification limit access to appropriate intervention services and contribute to incomplete data about the true numbers of children and adults needing services.

Recommendations:

- *Develop and implement data collection systems across agencies that provide a census of accurate information about the growing numbers of individuals with ASD in Vermont and their support needs, while maintaining confidentiality.*
- *Using current figures and national statistics, develop projections on the growing autism population in Vermont across the lifespan.*
- *Determine the average age at diagnosis in Vermont and take steps to lower it if necessary.*
- *Create a directory of providers able to diagnose ASD across the lifespan.*
- *Expand the network of practitioners able to provide both diagnosis and assessment of ASD for support planning.*
- *Provide public information about the signs of ASD and training to a range of practitioners. For example: Have a CHAT (Checklist for Autism in Toddlers) screening tool leaflet distributed to parents of children at their 18-month pediatrician visit and/or provide parents with the “Red Flags” handout available at [http: www.firstsigns.org](http://www.firstsigns.org).*
- *Assure adequate reimbursement for developmental and autism screening by primary care providers.*
- *Promote materials, such as those recommended by the American Academy of Pediatrics (October 2007) to educate primary care providers and parents on early identification of ASD.*

Eligibility

Eligibility criteria are driven by availability of funds, not need.

- Eligibility criteria for services range dramatically across systems and across the lifespan and exclude many individuals whose needs limit their ability to function in school, the community, and the workplace.
- Not all children with ASD are found eligible for school-based services despite significant social-development needs.
- Eligibility for community-based services for adults through the Developmental Services program of DAIL is limited to those with the most severe needs.
- Except for funding for students completing school for job placement, System of Care priorities limit funding to emergency situations: homelessness; danger to oneself and others; and loss of caregiver.
- Since 2001 no new children have been eligible for funding and services through Developmental Services Home and Community-Based Waivers, while those found eligible prior to 2001 continue to receive this funding, creating inequity.
- Access to developmental services is controlled at the intake level at designated agencies, and lacks an open and transparent application process.
- Eligibility for access to services such as personal care, mental health, vocational training, and other services varies and information pertaining both to eligibility and the range of available services is not necessarily easy to access or understand.
- Delays in developmental service eligibility prevent timely access to needed supports for students transitioning from K-12 education settings to adulthood (Autism Plan Survey responses).

Recommendations:

- *The application and eligibility process, particularly for developmental services, needs to become more streamlined and transparent.*
- *For children and adolescents, the terminology of “adverse effect” in Vermont special education regulations needs to be re-written to allow for consideration of social skills as a critical basic skill in learning.*
- *Eligibility criteria for adult services need to be based on the real life needs and challenges of those with ASD.*
- *Eligibility for services and supports across the lifespan should be based on the functional profile of individuals with ASD.*

Systems: Access to Information, Navigation & Coordination

It is confusing and extremely difficult to navigate systems of information and services.

- Information about ASD, services, and how to navigate access to those services is scattered, confusing, and difficult to access.
- Across the lifespan, there is a need for a central, easily accessible source of information about ASD, the services available across the lifespan, and how to navigate those services.

Systems of care for individuals with ASD are reactive and crisis driven rather than proactive and aimed at improving real life outcomes across the lifespan, such as meaningful and sustained employment and independent living.

- It is difficult to get school and developmental service systems to work together. Wrap-around services are typically available only when children are in foster care.
- Waiver services, which provide needed clinical support, case management, training and supervision critical to those with ASD are only available when individuals are on the verge of institutionalization.
- Waiver services are available for adults only when they are homeless; a danger to themselves or others; or in the event of loss of a caregiver.
- Due in part to lack of expertise, time, and eligibility criteria that limit access to services, school systems may delay ASD programming until students are thought to pose a safety risk to other students and themselves, often resulting in alternative placements that, likely, could have been avoided.
- Currently, services and supports are severely limited and do not effectively assist adults in meeting basic needs such as housing, employment, and health care, let alone meeting their full potential, achieving their personal goals, and leading lives that are as independent and inclusive or integrated into the community, as possible.

Family members provide a disproportionate level of services and supports

- Families of children receiving personal care services do recruitment, training, and supervision of personal care attendants, without professional expertise to implement treatment plans.
- Aging parents are relied on to provide care for adults.
- 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 rather than being able to act as partners.
- Stress is the number one problem identified for families in Vermont (Autism Plan Survey responses).

There is a lack of systems for coordination and collaboration between organizations and agencies at all levels.

- Schools, the developmental services system, and other agencies do not have a means for communication and collaboration.
- During the transition from Family Infant Toddler Program (FITP) services to Early Essential Education (EEE) services at age three, there is a lack of collaborative, family-centered, holistic programming. The mechanisms that exist for combining school and community-based supports (such as mental health or community-based developmental services) are hard to access and limited. Families do not have access to a neutral / unbiased case manager or service coordinator to work with them to develop a comprehensive, appropriately individualized service package.
- Parents/caregivers are faced with navigating complex systems to patch together services for which their children are frequently ineligible.
- Families must navigate legal issues such as competency and guardianship. Safety and emergency planning are also serious concerns.
- From adolescence into adulthood, transition from school to work and community living continues to be an area of significant need, including job training and maintenance, the provision of appropriate housing, recreation, community inclusion, and post secondary-educational opportunities.
- Community mental health agencies with ASD- specific programming often do not collaborate with the developmental service department within the same agency to serve children or adults.
- ASD expertise and planning is often not shared across the same school district, within supervisory unions, or across regions.
- There is a lack of attention to needs overall when an individual has a diagnosis of Asperger's Syndrome (Autism Plan Survey)

Recommendations:

- ***Engage in strategic planning to address short and long-term comprehensive needs of individuals and families, including:***
 - *Service delivery, care, and support for individuals with ASD across the lifespan*
 - *Creation of local and regional networks that bridge agencies and school districts to create quality programming.*
 - *Include individuals with ASD and families in this planning.*
- ***Establish an entity with responsibility and accountability to provide ASD-specific coordination, collaboration, and planning across the lifespan and across community, educational, and developmental services at state, regional and local levels.***
- ***Create a central, easily accessible unbiased source of information about ASD, including available services that will:***
 - *Assist individuals with ASD and families navigate systems*
 - *Keep professionals and the public informed.*
- ***Make interagency planning and funding for individuals easy to do. Improve interagency planning and sharing of resources and make this process accessible to family members and other stakeholders.***
- ***Extend FITP services from birth through age three to birth through age six or up until the transition occurs for a child to enter kindergarten.***
- ***Increase the availability and specificity of disability support services for students with ASD in post-secondary education, including within the Vermont State College System.***

Funding and Equity

Funding is inadequate to provide the supports needed for people with ASD to become independent, self-sufficient community members.

- Access to funding is dependent on the ability to navigate complex systems using persistent advocacy skills that individuals with ASD, and possibly their family members, are unlikely to possess.
- Access to funding and services significantly diminishes as individuals leave school and enter adulthood due to eligibility barriers.
- There are issues of equity in funding distribution, regardless of an individual's level of need. One example of this is the 2001 suspension of access to any new community-based waivers for children.
- While children are eligible for personal care services through Medicaid for after school hours, parents receive no support for recruitment, training, or supervision of workers, or access to the clinical expertise that a waiver would provide.
- Because public schools are the only mandated service provider for individuals with disabilities, they are relied on by families for services and supports that might be better provided by community-based service agencies. While Medicaid is the insurer for most children and many adults with ASD, there are a limited number of Medicaid providers able to offer the specialized therapies and interventions needed, and there are regional disparities in access.
- Private insurance generally does not cover services for individuals with ASD.
- Coordination of services across systems and funding for adult services and supports (community living, housing, recreation, employment training and support, etc.) are woefully deficient and limited to those with the most dire need and lowest level of functioning. Therefore, the majority of families of adults with ASD bear the full cost and emotional strain (siblings included) of providing for care for their family members.
- Autism Plan Survey results revealed that 40% of respondents pay for services for the individual with ASD out of pocket and economic issues were the #2 concern noted for families with a family member who has ASD.

There are inequities in access to programs and services experienced by the ASD population across the state.

- There are inequities in funding for services depending on area of residence.

Recommendations:

- *Look at ways to distribute current funding that are equitable and appropriate for all individuals.*
- *Seek access to all available federal funding sources for this population.*
- *Increase funding, especially to provide for the needs of adolescents, adults, and the elderly.*
- *Mandate that private insurance (at least of large employers), pay for research-based services.*
- *Explore redistribution of funding and redefining eligibility criteria for services.*
- *Develop more comprehensive services for adults.*
- *Implement comprehensive, autism-specific services and supports that are proactive and individualized to prevent long-term poor outcomes and negative impacts with significant financial costs to society.*

Specialized Services

Lack of comprehensive, autism-specific program planning and implementation based on research and up-to-date specialized interventions and supports.

- Few options exist 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.
- Lack of resources and expertise at the community school level has resulted in students in alternative learning placements as well as out-of-state residential schools.
- The early intervention system infrequently provides the level of intensive services recommended for positive outcomes.
- For children aged 3 to 6 years, curriculum does not include the development of developmental reciprocity and rudimentary social skills. Older children who qualify for IEPs may not have goals that address the social development issues that are so critical to improve their community and work options as they enter adulthood.
- Children with Asperger's or High Functioning Autism frequently do not qualify for IEPs in Vermont because they do not demonstrate significant deficits ("adverse effect" as described in Vermont Special Education Regulations) in the basic skills areas, which do not include social skills development or social functioning. Therefore they receive limited services at school.
- Adult services are severely constrained by lack of funding and eligibility criteria that direct limited resources to those with the most critical needs (those who are least able to support themselves in any way in the community).
- 67% of Autism Plan Survey respondents rated vocational rehabilitation services as inadequate.

Lack of expertise, quality, consistency, and availability of both professionals and direct support workers across all age groups.

- Projected need for staffing: 2500 professionals, including 150-200 case managers and 50-80 expert consultants (Vermont Interagency White Paper on Autism Spectrum Disorders, March 2006)
- Training, both initial and ongoing, is needed at every level, from school and community-based personnel through regional and state professionals to provide expertise, and keep up with emerging interventions research.
- Only a few of the regional designated agencies that provide developmental services to adults have staff with expertise, and they are limited in availability.
- There is no funding for training or supervision of personal care attendants (PCAs) working with children, nor are families able to access clinical services to support PCAs on the job.
- As more professionals are described as "autism specialists," there is a public interest in state government describing minimum requirements and credentialing for these professionals.
- There is little to no training for parents of children with ASD. Parents are the first and primary caregivers for their children and need to be taught how to develop a relationship based in reciprocal, active engagement with their child.
- A thoughtful effort to increase overall community awareness of ASD is needed.
- Training is needed; especially for the variety of community members who are likely to come into contact with individuals with ASD and their families, including, but not limited to, health and mental health care providers, emergency personnel and first responders, police, legal personnel, employers, general educators, and school administrators.
- 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-morbid conditions; and appropriate treatment. (Autism Plan Public Forums, fall 2007)

Recommendations:

- *As part of a central, ASD-specific information center, provide ongoing information about trainings, review of research into evidence-based practice and research-based and*

promising interventions, and updated information about best practices for support and intervention across the lifespan.

- *A paradigm shift is needed from a reactive, crisis-driven approach to a more proactive, preventative system of education and service delivery. This means providing services that reduce or prevent isolation and crises by providing adequate education and support services to help individuals with ASD reach their full potential in the school, community, and work place. Such a service system would link the individual characteristics of each person with supports and interventions that build on their strengths and address their needs.*
- *Build on the model for students who are deaf and hard of hearing to develop a statewide network of educational placements WITHIN Vermont that provide a range of intervention and expertise needed.*
- *Build on attempts to integrate services (such as the Baird program in Burlington) for creating more collaborative, wrap-around models of service provision.*
- *Develop a system of specialized supports for adults with autism in key state programs (community services, vocational rehabilitation) to achieve success at work and in community participation.*
- *Mandate autism-specific training for teams that work with individuals with ASD at all levels, including schools, developmental services agencies, employment transition, etc.*
- *Define entry-level and continuing education requirements for ASD specific training for professionals and support staff.*
- *Define minimum requirements, continuing education, and credentialing for autism specialists that design and implement programming, including behavior supports, for students and adults with ASD.*
- *Develop and implement mentoring programs for professionals working with individuals with ASD.*
- *Develop and implement ongoing training opportunities for families, professionals, and other community members (such as employers, healthcare workers, first responders, etc.).*
- *Develop and implement community awareness programs.*
- *Develop Guidelines for Remediation / Intervention:* (A gradual, systematic process of correcting a deficit, to the point where it no longer constitutes an obstacle to reaching one's potential.)
 - *Define a remediation program which seeks to restore developmentally appropriate, healthy relationship functioning and active engagement and that empowers parents in establishing the primary relationship through which this can be achieved. Such programming would encompass a long-term approach focused on quality of life goals: genuine emotion sharing, true friendships, community involvement, independent living, etc.*
 - *Outline requirements for Intensity, Frequency, Location and Comprehensive, Individualized, Developmentally Appropriate Evidence Based Approaches.*
 - *Determine means for measuring progress: In terms of dynamic abilities rather than behavioral compliance and static academic knowledge acquisition (i.e. learning color and shape names, saying certain words, making eye contact when told to do so, sitting in a circle without being disruptive).*

WORKGROUP: Ages Birth to 6 Years

Present Challenges	Key Findings	Recommendations
<p>Identification</p>	<p>9 children with ASD diagnoses being served through Family Infant Toddler Program (FITP) in December 2005</p> <p>63 children in Vermont with ASD between the ages of 3 and 5 years (Department of Education Child Count data, December 2006)</p> <p>Data likely underestimate actual numbers of children with ASD in these age ranges because of eligibility criteria for FITP (birth to 3 years) services and for Early Essential Education (EEE) services (3 years to 6th birthday).</p> <p>Most children suspected of having ASD are referred to Child Development Clinics. Children referred for diagnostic services may be on waiting lists for an appointment for several months.</p> <p>Delays in identification limit access to early intervention services.</p>	<p><i>Develop data gathering systems that are sensitive to confidentiality but that improve information about real numbers of children with ASD diagnoses.</i></p> <p><i>Increase the number of professionals and networks of professionals who are trained to make ASD diagnoses.</i></p>
<p>Training Intervention Credentialing</p>	<p>Families need access to information and support as soon as ASD is suspected.</p> <p>Continued lack of awareness across community regarding ASD.</p> <p>Organizations (FITP, EEE, health care providers, for example) providing services to children with ASD may not have anyone with autism expertise on their staff. They may also have limited access to specialists such as occupational therapists, physical therapists, and speech-language pathologists, let alone specialists with ASD-specific training.</p> <p>Early childhood curricula do not include developmental reciprocity and rudimentary social skills development.</p> <p>Lack of community-based family support services (difficulties accessing child care</p>	<p><i>Develop ASD-specific information center providing information about ASD, best practice, research-based and promising interventions, services and funding available.</i></p> <p><i>Monitor and review research into interventions for the birth to 3 population.</i></p> <p><i>Implement recommendations of Autism Task Force sub-committee on Intensive Early Intervention Services for birth to 3 population*(see page 15).</i></p> <p><i>For the 3 to 6-year-old population, implement early intervention recommendations of the National Research Council (2001) in Educating Children with Autism**(see page 16).</i></p>

	<p>or home-based care, for example).</p> <p>Lack of information about services, supports, funding.</p> <p>No intervention guidelines for children birth to 3 with ASD.</p> <p>Early intensive intervention guidelines for children aged 3 to 5 inconsistently implemented.</p> <p>What is an “autism expert?”</p>	<p><i>Provide general information about ASD to community at large to increase awareness and understanding.</i></p> <p><i>Mandate ASD-specific training for key employees in organizations that provide services and support to individuals with ASD and their families.</i></p> <p><i>Training of all doctors, nurses, educational personnel in ASD and warning signs.</i></p> <p><i>Utilize recently published American Academy of Pediatrics algorithm, and recommended screening tools.¹</i></p> <p><i>Work to address critical shortages in specialists such as occupational therapists, physical therapists, and speech-language pathologists.</i></p> <p><i>Create curricula that include the development of reciprocity and social interaction skills.</i></p> <p><i>Define “autism expert” and create a state certification process that provides minimum education, training, and continuing education criteria.</i></p>
Eligibility	<p>To be eligible for FITP (birth to 3) services, a child must:</p> <ol style="list-style-type: none"> 1. Demonstrate a “developmental delay”; or 2. Have a condition leading to a “high probability” for a developmental delay. <p>A developmental delay is defined as:</p> <ul style="list-style-type: none"> • Demonstrating a “clearly observable and measurable delay in” cognitive, physical, 	<p><i>Review eligibility criteria for programs and make sure that they are based on real life function and need and are developmentally appropriate. Make sure that eligibility criteria are driven by need rather than funding levels.</i></p> <p><i>Define and improve data gathering across agencies so that there is a more accurate representation of</i></p>

¹ Johnson, C. J., Myers, S. M., and the Council on Children with Disabilities. *Identification and Evaluation of Children With Autism Spectrum Disorders*. Pediatrics volume 120, number 5, 2007. The American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL 60007

<p>communication, social-emotional, or adaptive development; and Such a delay must be at a level that future success in home, school, and community “cannot be assured without the provision of early intervention services.” (Vermont Department of Education Special Education Regulations, 9/17/07, page 29). A specific medical diagnosis (such as ASD) is not necessary for eligibility. This is beneficial in terms of initiating services, but can be problematic if:</p> <ul style="list-style-type: none"> • No additional evaluation is pursued that may have bearing on type/intensity of service • Gathering data on prevalence of ASD for projecting future service needs. <p>To be eligible for EEE (3 to 6) services, a child must demonstrate at least one of the following:</p> <ol style="list-style-type: none"> 1. Have been determined eligible under FITP prior to the third birthday; 2. Be determined to have a disability “caused by a developmental delay; 3. Have a medical condition (such as “autism”) that could result in significant delays; or 4. Meet eligibility criteria for children aged 6 to 21 years. <p>A “developmental delay” under EEE eligibility criteria is defined as demonstrating at least a 40% delay or performing at or below the 2nd percentile in one important life skill area (such as communication or social and emotional development) or performing at or below the 7th percentile in two of the defined areas of development (Vermont Department of Education Special Education Regulations, 9/17/07, page 36). (It should be noted that, prior to September 2007, criteria for demonstrating developmental delay in a new evaluation of a child between 3 and 6 years of age was limited to showing a 40% delay. This likely artificially limited the number of children with significant</p>	<p><i>numbers of young children with ASD in Vermont. Include data for children identified with ASD who have not been found eligible for the services for which their families have applied.</i></p> <p><i>Increase training for early interventionists, early childhood diagnosticians, and health care providers in identifying ASD, the services available, and the recommendations for services.</i></p>
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	<p>delays who were able to access services. For example, a 5 year (60 month) old child with an 18-month delay in communication would not be eligible for services under the 40% delay model because he/she would only be demonstrating a 30% delay.)</p> <p>No mandate for community-based intervention or family-support services. Families of children who are Medicaid eligible can attempt to access Children’s Personal Care Services, but may not be eligible depending on CPCS Assessment of Need criteria. ASD-specific training is not mandated.</p>	
<p>Systems: Information Access, Navigation of Systems, Coordination of Systems and Services</p>	<p>You don’t know what you don’t know. This means that when a child first receives an ASD diagnosis or is suspected of having an ASD, parents often don’t know what questions to ask about the diagnosis, their child’s needs, interventions, supports, funding, healthcare, or what agencies and organizations to turn to get information and to meet their child’s needs. Not knowing even what to ask about these issues has implications for program design and services for children birth to age 3 because of the manner in which Individualized Family Service Plans (IFSPs) are written through FITP. An IFSP contains in part “a statement of the family’s priorities and concerns related to enhancing the development of the child; a statement of the major family driven outcomes that are expected for the child and the family” (Vermont Department of Education Special Education Regulations, 9/17/07, page 31). Type, frequency, and intensity of services are identified based largely on these priorities. This is an important, family-centered component of early intervention services, but does not provide safeguards for insuring that families have access to all the information that they need in order to make informed decisions about their child’s needs.</p> <p>Each professional (physician, early</p>	<p><i>Central information source, with information provided in a manner that is easy to understand. Information should cover ASD, needs, interventions, best practices, sources of service, funding, support. Information should be available to all stakeholders—families, physicians, educators, etc.</i></p> <p><i>There need to be professionals with up-to-date, ASD-specific training who are involved with or accessible to FITP across the state who can help families understand their child’s needs and current best practice for intervention. Such professionals can help families develop priorities for their child’s development that can drive the development of effective IFSPs.</i></p> <p><i>Statewide coordination of systems needs to be enhanced. Mechanisms need to be developed for providing case management or service coordination across systems and agencies.</i></p> <p><i>The family-centered approach of FITP should be extended to age 6, with development of a system of maintaining consistent case management and service providers</i></p>

	<p>interventionist, etc.) with whom the family has contact may have some information to offer, but don't have knowledge about all of the scattered sources of support and information that may exist.</p> <p>There is little or no system coordination in most regions of the state. There is a lack of cross-system case management or service coordination. Families must self-manage or access services from different agencies on their own.</p> <p>Transition between the FITP system and EEE at age 3 is difficult. Case managers and service providers are usually different. Types of services available are frequently different from those provided by FITP and service locations are generally school-based. Inclusion in a preschool classroom may be assumed to be an important part of a child's program without fully assessing an individual child's specific developmental needs. Service delivery and program planning are general less family-centered at an age and developmental stage when family-centered intervention in natural settings (which can include, but should not necessarily be limited to, preschool) are still vital to a child's growth.</p>	<p><i>throughout these years.</i></p>
<p>Funding</p>	<p>Currently, families with children who are Medicaid eligible can, possibly, access Children's Personal Care Services. However, if their children are not eligible, they must pay for care and respite out of pocket. Care providers have generally not received ASD-specific training. Families usually must provide this themselves.</p> <p>Funding for FITP services (including child find, evaluations, and service provision and coordination) is complicated and includes financial and administrative responsibilities shared by the Agency of Human Services and the Department of Education. Sources of funding include federal IDEA Part C and some other federal funding, state and local</p>	<p><i>More funding is needed to provide respite care for families and for personal care services. Funding is also needed to provide for training for respite providers and personal care assistants.</i></p> <p><i>More funding, and more secure funding, is needed for early intervention services, especially for FITP. Continue working to streamline sharing of funding across different sources.</i></p>

	<p>funding, Medicaid, and, sometimes, private insurance. Rules state that federal funds (Part C) “are used to supplement state and local funds expended to eligible children and their families; federal funds are not to be used to supplant state and local funds” (Interagency Agreement with Vermont Agency of Human Services and Vermont Department of Education Pursuant to Part C of the Individuals with Disabilities Education Act 2004, June 27, 2006, revised April 16, 2007, page 12). There are concerns that there is less than optimal federal commitment to funding for early intervention.</p> <p>Funding for EEE is provided through grant funds to local school districts. These funds include federal IDEA Part B funds, and state funds. Grants are calculated based on the “estimated number of children from 3 through 5 years of age in the school district” (Vermont Department of Education Special Education Regulations, 9/17/07, page 107). This estimate is based on the number of children enrolled in the district in grades 1 through 3. If any funds are left over from meeting obligations to 3 through 5 years olds, they may be used to help meet the needs of children receiving services through IFSPs.</p>	
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*Intervention recommendations for the birth to 3 population were based on discussion of National Research Council recommendations for early intervention (primarily for 3 to 6-year-old children), Connecticut and New Jersey guidelines, the Lovaas Young Autism Program, and meetings with FITP staff. Intervention and support suggestions include:

- Active engagement during waking hours similar to that experienced by typically developing peers
- Recognition that some children may need 25 hours per week or more of services
- Trained personnel to provide systematically planned engagement
- Training and support for families to provide active engagement in activities and daily routines
- For 18 to 36 month old children
 - Systematic, planned activities with trained personnel
 - Amount of individual intervention increases over time, beginning with 10 to 15 hours for the youngest children
 - An additional 5 to 10 hours per week to train and support family members/caregivers in increasing active engagement in play and daily routines

- As children reach the age of 3, direct individual intervention time with the child increases as family training/support time decreases.

(Vermont Autism Task Force Sub-Committee on Intensive Early Intervention services for Young Children with ASD, Meeting Minutes, May 16, 2006)

**The National Research Council report, *Educating Children with Autism*, can be accessed online at http://www.nap.edu/catalog.php?record_id=10017. Recommendations include 25 hours per week or more of thoughtfully planned programming to build active engagement.

NEWS RELEASE

Below is a news release on a press briefing at the 2007 National Conference and Exhibition (NCE) of the American Academy of Pediatrics (AAP). Co-authors Chris Johnson, MD, MEd, FAAP, Clinical Professor of Pediatrics at University of Texas Health Science Center at San Antonio and Scott Myers, MD, FAAP, neurodevelopmental pediatrician at the Janet Weis Children's Hospital/Geisinger Medical Center in Danville, Pennsylvania, will present the new AAP clinical reports, "Identification and Evaluation of Children With Autism Spectrum Disorders" and "Management of Children With Autism Spectrum Disorders" on Monday, October 29, at 10:00 a.m. (PT) in Hall E of the Moscone Center.

Andy Shih, PhD, vice president of scientific affairs for Autism Speaks, will join Drs. Johnson and Myers for the press briefing.

For Release: Monday, October 29, 2007 12:01 am ET

NEW AAP REPORTS HELP PEDIATRICIANS IDENTIFY AND MANAGE AUTISM EARLIER

SAN FRANCISCO – Two new clinical reports from the American Academy of Pediatrics (AAP) will help pediatricians recognize autism spectrum disorders (ASDs) earlier and guide families to effective interventions, which will ultimately improve the lives of children with ASDs and their families. The first clinical report, "[Identification and Evaluation of Children With Autism Spectrum Disorders](#)," provides detailed information on signs and symptoms so pediatricians can recognize and assess ASDs in their patients. Language delays usually prompt parents to raise concerns to their child's pediatrician – usually around 18 months of age. However, there are earlier subtle signs that if detected could lead to earlier diagnosis. These include:

- not turning when the parent says the baby's name;
- not turning to look when the parent points says, "Look at..." and not pointing themselves to show parents an interesting object or event;
- lack of back and forth babbling;
- smiling late; and
- failure to make eye contact with people.

Most children, at some time during early development, form attachments with a stuffed animal, special pillow or blanket. Children with ASDs may prefer hard items (ballpoint pens, flashlight, keys, action figures, etc.). They may insist on holding the object at all times.

The report advises pediatricians to be cognizant of signs of ASD, as well as other developmental concerns, at every well-child visit by simply asking the parents if they or their child's other caregivers have any concerns about their child's development or behavior. If concerns are present that may relate to ASD, the clinician is advised to use a standardized screening tool. The report also introduces universal screening, which means pediatricians conduct formal ASD screening on all children at 18 and 24 months regardless of whether there are any concerns.

"Red Flags" that are absolute indications for immediate evaluation include: no babbling or pointing or other gesture by 12 months; no single words by 16 months; no two-word spontaneous phrases by 24 months; and loss of language or social skills at any age. Early intervention can make a huge difference in the child's prognosis. "Autism doesn't go away, but therapy can help the child cope in regular environments," said

Chris Plauche Johnson, MD, MEd, FAAP, and co-author of the reports. “It helps children want to learn and communicate.”

Educational strategies and associated therapies, which are the cornerstones of treatment for ASDs, are reviewed in the second AAP clinical report, “[Management of Children With Autism Spectrum Disorders](#).” Early intervention is crucial for effective treatment. The report strongly advises intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made. The child should be actively engaged in intensive intervention at least 25 hours per week, 12 months per year with a low student-to-teacher ratio allowing for sufficient one-on-one time. Parents should also be included.

Pediatricians who treat children with ASDs should recognize that many of their patients will use nonstandard therapies. The report says it’s important for pediatricians to become knowledgeable about complementary and alternative medicine (CAM) therapies, ask families about current and past CAM use, and provide balanced information and advice about treatment options, including identifying risks or potential harmful effects. They should avoid becoming defensive or dismissing CAM in ways that convey a lack of sensitivity or concern, but they should also help families to understand how to evaluate scientific evidence and recognize unsubstantiated treatments.

“Many parents are interested in CAM treatments such as various vitamin and mineral supplements, chelation therapy, and diet restrictions. It’s important for pediatricians to maintain open communication and continue to work with these families even if there is disagreement about treatment choices,” said co-author of the reports Scott M. Myers, MD, FAAP. “At the same time, it’s also important to critically evaluate the scientific evidence of effectiveness and risk of harm and convey this information to the families, just as one should for treatment with medication and for non-medical interventions.”

Although use of the gluten-free/casein-free diet for children with ASDs is popular, there is little evidence to support or refute this intervention. More studies are in progress, and it is anticipated that these studies will provide substantially more useful information regarding the efficacy of the gluten-free/casein-free diet.

Tantrums, aggressive behaviors, and self-injury are common among children with ASDs, and medical factors may cause or exacerbate these behaviors. Behavior management strategies are often the most effective treatment for challenging behaviors. In some children, medications are effective in addition to the behavioral strategies. The report addresses the medical issues that some children with ASDs encounter such as seizures, gastrointestinal problems, and sleep disturbance, and provides guidance for medication management.

Both reports will also be part of the new AAP practical resource for pediatricians "AUTISM: Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians," which includes screening and surveillance tools, guideline summary charts, management checklists, developmental checklists, developmental growth charts, early intervention referral forms and tools, sample letters to insurance companies and family handouts.

The American Academy of Pediatrics is an organization of 60,000 primary care pediatricians, pediatric medical subspecialists and pediatric surgical specialists dedicated to the health, safety and well being of infants, children, adolescents and young adults.

WORKGROUP: Ages 6 to 16

Present Challenges	Key Findings	Recommendations
Identification and Definition of Autism Spectrum Disorders	<ol style="list-style-type: none"> 1. Lack of Expertise in screening, diagnosis. 2. Incomplete data gathering among Vermont State Agencies 	<ol style="list-style-type: none"> 1. Training of all doctors, nurses, educational personnel in ASD and warning signs. 2. Designate Lead Health Agency to organize collection of data for Programmatic Planning.
Intervention and Treatment Guidelines	1. Lack of Comprehensive Individualized Developmental Plans upon diagnosis	1. State agency intervention plan that initiates a team based approach similar to school based IEP team approach upon diagnosis
School based Autism Curriculum— customized for ASD students based on individual and inclusion of family.	<ol style="list-style-type: none"> 1. National Academy of Science recommends Intensive early intervention program. 2. Vt has lack of developmental, relational educational model that treats deficit of communication and reciprocity/rudimentary social skills. Lack of comprehensive educational VT adverse effect (vs. Vermont framework of standards) limiting children receiving services (i.e. aspergers syndrome) 	<ol style="list-style-type: none"> 1. <i>Inclusionary Model limits the appropriate Placement of children in educational settings that meets their developmental needs for intensive early intervention.</i> 2. <i>Immediate recruitment and training of autism trained SLPS, OT paraprofessionals, etc.</i> 3. <i>ASD training of all related school administrators, teachers</i> 4. <i>Placement Continuum for schools to be in compliance IDEA.</i>
Lack of ASD expert providers and autism trained interventionists	intervention guidelines, defined expertise providers, supports for training necessity	linking individual characteristics of children with interventions expertise—credentialing, education and training— parents, providers, caregivers, medical, etc
Funding	School is only mandated source (for many, it is only source of funding) Medicaid dollars not directly benefiting this class of children. Medicaid waiver post 2001 inequitable. Inequity of Services regionally. Private Insurance providers not covering related services for this population of children causing Educational system	<ol style="list-style-type: none"> 1. Mandate private Insurance that covers asd children. 2. Revise Medicaid personal care hours program- i.e. lift rate cap and allow flexible usage by parents for approved in state /out of state ASD expenses 3. Medicaid waiver flexibility to

	<p>to carry majority of financial burden. Respite program administration inadequate (\$ 10.00 per hour rate cap deems program useless resulting in unused hours</p>	<p>ease financial strain on parents</p>
<p>system coordination</p>	<p>Equity of services across school's across state—i.e. Baird Center, Stern Center limited to certain regions of State. Lack of seamless agency coordination among state health, education and health departments.</p>	<p>1.Wrap Around Service plan needed to provide comprehensive treatment</p> <p>2.Transition between systems</p> <p>3.general case management/service coordination</p> <p>4.Information access</p>
<p>Lack of inclusion and Autism awareness across all domains -Education, community and societal.</p>	<p>Community inclusion limited support in school settings</p>	<p>1.Statewide campaign to promote autism awareness , community inclusion</p>

Profile Committee Workgroup: Ages 16 and Up

OVERALL CRITICAL CHALLENGES AND NEEDS:

- Numbers of individuals identified with ASD are increasing every year and the educational, mental health and developmental services workforce is not adequately prepared.
- Better systems are needed to track data for current and unmet needs and to identify trends in order to plan services for the population across the state.
- There is a lack of information about what the situation is for adults re jobs; housing; higher education; health care; life skills; leisure & recreation -- especially for people who do not have waivers.
- Information is needed to help navigate a confusing developmental service intake and delivery system, especially around eligibility and the range of options for services and supports.
- The developmental disability definition and system of care plan priorities leave out all new children, and adults with significant functional impairments from eligibility for key supports and services.
- There is a lack of coordination and collaboration between schools and developmental services agencies.
- There is a disconnect in planning between the educational system that begins transition services at age 16 and developmental services, which does not decide eligibility until school is completed.
- Programs have been created in a patchwork fashion around the State but there are still unmet needs as evidenced by data, waiting lists and input from individuals and families.
- There is a lack of specialized services, programs, activities and well trained staff that would promote individualized supports and community inclusion for the range of people with ASD
- There is a lack of expertise, quality, consistency and availability of both professionals and direct support workers.
- There is an overreliance of systems on parents -- especially aging caregivers -- to support adults
- There is a lack of support for aging caregivers, including help doing planning that addresses parental anxiety (Example: NJ's system of care prioritizes services when parents are 55 or older.)
- Adults with ASD suffer unemployment and underemployment due to lack of training during and after school in employable skills; lack of support to gain and keep meaningful, satisfying jobs that match potential; and lack of proactive outreach to recruit potential employers.
- There is a lack of opportunities for growing social skills (sex education), social interactions, friendships and intimate relationships
- Medical & health care providers lack knowledge & skills for treating people with ASD.
- First responders and law enforcement lack knowledge & skills for encountering people with ASD.
- Transportation: Many (if not most) individuals with ASD do not drive.

SOME OVERALL RECOMMENDATIONS

- Build on involvement of parents as partners
- FOCUS on employment potential: Outreach & training for employers to promote employment; also grow employment skills of individuals that meet VT's shortages.
- Build on increased public awareness of the diversity and potential of people with autism to increase employment and community opportunities.
- Build on VT's transition initiative (Career Start) to incorporate effective autism interventions and expertise and ensure accountability for real collaboration at the local level.
- Create a system of Inter-district planning & support teams
- Use our beautiful state and quality of life to ATTRACT PROFESSIONALS!!

FACTS & KEY FINDINGS	RECOMMENDATIONS**
<p><i>Profile</i> For all developmental stages there is no one source of information on resources related to services for the ASD population.</p>	<p>IN-DEPTH CENSUS needed to: -- Profile what is happening at each developmental stage -- Profile differences in services regionally and within regions (rural/urban etc.)</p>
<p>Education Special education students with ASD: Total of 582.</p> <p>LACK OF PROFILE OF LEARNERS AGED 16 to 22: Data and information is not available on how many students there are at each age; their educational settings; service packages, etc. ** Anecdotally older students more likely to be in alternative educational settings. ** Disparities in available expertise, services & supports both regionally and within regions. ** Whether students get extended school day, summer services, etc. No specific data for transitional youth 16 to 22, although reported anecdotally as being educated outside community schools at higher rate.</p> <p>Some students stay in school until age 22. Some students in the state are graduating early based on credit hours rather than meeting IEP goals -- including transition goals.</p> <p>2006 D-DAS Graduate study reported 24 students with ASD completed school in June 2006. No other information on these students is currently available.</p> <p>Funding: Educational services paid by school district & state. (Residential schools paid by state.) Medicaid collected cannot be used for special education, is "reinvested" in other school programs.</p> <p>Family services can be available through IDIEA related services. Anecdotally, this is rare in VT, as is extended school day. Limited summer services are somewhat more available.</p> <p>INTER-SCHOOL DISTRICT COLLABORATION: Information not available on what school district, inter-district programming and planning teams exist. Appears to be very little regional sharing of expertise within regions and across school districts, and sometimes within the same school district.</p> <p>LACK OF INFORMATION on use of specialized ASD services including specialized programs and services schools are tapping; and criteria used to define autism specialists. No information is available on regional distribution and profile of</p>	<p>USE MODEL OF Birth to 3 Child Count, which tracks what services are provided. ". For e.g., few are known to receive extended day services. Extent of summer services unknown, etc.</p> <p>Look at TRANSITION AS AGES 16 TO 25</p> <p>PROFILE population of TRANSITIONAL STUDENTS and how served, through in depth questionnaire to school districts and special educators/case managers across the state.</p> <p>STUDY and support intra, inter-school district and regional planning as great potential for growing available expertise within a region. .</p> <p>COMPLETE A PROFILE of autism specialized services including definition of expertise; regional distribution of providers' and time spent with school teams; and update regularly.</p>

<p>time spent with school teams.</p> <p>There does not appear to be autism specialists in every region available to be part of teams providing developmental services -- both agency based or self or family managed.</p>	<p>COMPLETE and update a DIRECTORY of available specialized programs and providers of services and supports.</p>
<p>Interagency School-AHS The expanded Interagency agreement between AHS and DOE has been in effect for over a year</p> <p>Interagency Agreement is being used to address crisis situations, for example likelihood of foster care or residential placement. It does not seem to be fostering ongoing local collaboration for all kids so that there is coordination & collaboration between school and home based programs, even at the transition stage.</p> <p>Interagency collaboration at transition varies by school district and region; some work together with VR, local DS agency, others do not. The mechanism for collecting data about transitional students who may be eligible for developmental services is late (only when completing school) and is not uniform across the state.</p> <p><i>TRANSITION AGE GAP:</i> Most often eligibility decisions for adult services happen AFTER school is completed, which undermines the transition planning process. The gap is described as a cliff or chasm.</p>	<p>STUDY utilization of the LIT-SIT process for students with ASD, including impacts and outcomes</p> <p>COMPLETE AN IN-DEPTH review of gaps in mechanisms for collaboration across providers.</p>
<p>Developmental Services Administered by D-DAS: (1) Flexible Family funding up to \$1200 per year. (FFF) (2) Personal Care Services, up to age 21; and (3) Waiver services, that can include service coordination, community supports, and respite as part of waiver package</p> <p>2006 data: 316 children and adults receive developmental services. (approx. 15% of total)</p> <p>Not known: # of children with ASD receiving personal care services # receiving FFF.</p> <p>LACK OF DATA that permits profile of developmental services received across the lifespan: ** No data breakdown for children, adults and families receiving flexible family funding (FFF) or children's personal care services ** Data for adults receiving developmental services does not have breakdown by age, service packages, etc.</p> <p>SYSTEM of CARE plan excludes children, while PCA does not provide any assistance to families with recruitment, training or supervision of direct support workers who really need specialized skills and supervision.</p> <p>Children have not been eligible for new developmental service waivers in VT since 2001 (those with waivers</p>	<p>PROFILE Adults with ASD, and their interface with DEVELOPMENTAL SERVICE SYSTEM, including -- Past 10 year trends in applying, found eligible &/or receiving DS services, compared with total population with ASD. -- Where adults live, including proportion with parents -- How many are supported to work? Supports? Hours worked, etc. -- Range of waivers and supports received ** Projections on # with ASD that will enter adult system in coming years. In depth questionnaire to designated agencies.</p> <p>ONGOING data collection and analysis</p> <p>Consult the New Jersey Center for Outreach Services for the Autism Community document: Meeting the Needs of Adults with Autism: A Blueprint for the Future, October 2006, for a comprehensive plan for meeting the needs of adults with ASD in a state.</p>

continued; some have been added under dire circumstances.

While autism is one of the diagnoses for developmental services, not all people with ASD meet functional criteria, or one of the System of Care priorities that trigger developmental service supports (home & community based.) At 19 youth may meet a waiver priority if they have a paid job lined up. Otherwise, on completion of school priorities, eligibility criteria are basically being a danger to yourself or others, or homeless.

THERE ARE KEY GAPS even when youth & young adults have waivers:

- (1) program managers with expertise in autism working with home & community based teams on a regular and ongoing basis to supervise and train staff and support individuals to gain social, living & job skills, and
- (2) Coordination and collaboration between the school and home programs.

PCA program helps a number of families by providing funding for direct support workers outside school day.

LACK OF ONGOING NEEDS ASSESSMENT FOR DEVELOPMENTAL SERVICES after eligibility to look at intensity of disability related to service needs (family reporting)

Even those with waiver services say it is difficult to understand and find out what the range of options are for services & supports that might help people become more independent

There is a lack of coordination and collaboration between service providers within and across systems.
-- between school districts in regions
-- between mental health and DS divisions of designated agencies
-- between schools and developmental service agencies

SERVICES ARE NOT AVAILABLE even for those who meet narrow state definition for developmental services who do not meet system of care priorities.

Even when there is funding there is a lack of trained professional and direct support staff with expertise to provide services in a range of settings

LACK of appropriately trained in-home and family support, day programs, job supports, out of home residential supports.

LACK OF programs and supports for adults with ASD who do not meet developmental service definition but have environmental, behavior, communication and sensory needs, for self-direction and to build on individual strengths to maximize independence.

STUDY alternative HOUSING options to family: How are they funded, who is served and how, are there models that are working?

<p>LACK OF appropriate supports for pursuing post-secondary education which could include vocational or college education.</p> <p>HOUSING OPTIONS are limited. Section 8 can be a funding source but does not provide supports.</p> <p><i>Dept. of Vocational Rehabilitation:</i></p> <ul style="list-style-type: none"> ➤ Over the past 6 years, the percentage of individuals coded as having autism at the point of certification for VR services has gone from .36% (9 of 2484 individuals certified in SFY 2001) to 1.58% (53 of 3346 individuals certified in SFY2007) ➤ Of the 137 served in SFY 2007, 73 cases are still open and 64 cases have closed. ➤ Of those 64 closed cases, 51 were closed after an Individualized Plan for Employment was written. ➤ Of those 51 cases, 42 closed with stable employment, yielding an 83% rehab rate. ➤ 74% of successful closures were with youth under age 25 at the time of closure. ➤ 90% of the successful closures were with individuals under age 35, so it is a young population. <p>THERE IS A LACK OF INFORMATION about job placement and of job retention rates overall.</p>	
<p><i>Misc. Services and Supports</i> Known supports for teens and young adults with Asperger's: Howard Services has a support group for teens; private therapist in Burlington with experience working with adolescents, young adults with Asperser's.</p> <p><i>Health insurance coverage</i> Medicaid is available through Katie Beckett for kids with disabilities whose parents are otherwise over-income. Some youth have therapies paid by CSHN and private insurance. However, many employer policies exclude developmental disability as a "chronic condition", for example UVM, while many private therapists do not or cannot take Medicaid.</p> <p><i>Financial assistance</i> People with ASD may be eligible for SSI monthly payments (after 2 years Medicare kicks in.)</p> <p>LACK OF up-to-date information on specialized services across the state. Examples: psychotherapists; support groups for people with ASD, etc.</p>	<p><i>** NOTE: There are a number of additional 16 & up Workgroup recommendations embedded throughout the Profile Committee report.</i></p>

Autism Plan Profile Committee
DATA ON INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS

1. Compilation of Data & Facts (Source: White Paper, citing multiple sources)**

NATIONAL TRENDS

- 1994 Asperger's Disorder added to the DSM IV
- National prevalence of autism increased at 10-17% yr
- 2003 Autism Society reports incidence of AD 1/166 births
- 2001 National Research Council concludes substantial subset of children make marked progress when receiving intensive early intervention.

PROJECTED VERMONT NEEDS:

- Estimate 2500 professional, 150-200 case managers, 50-80 "expert consultants" needed to meet needs of people in VT (White Paper)
- Estimate: costs to provide special education services to rise an additional \$19 million by 2010 from estimated \$11 million in 2005
- Estimate: annual cost to serve up to 22 children in FITP in 2010=\$1.2 million-estimated savings \$1-2 million over lifespan) (White Paper)
- Estimate additional \$8.1 million needed in Children's Personal Care services

GENERAL VERMONT DATA and trends

- Estimate: average age of diagnosis for ASD is 3yrs; Asperger's 8 years (White Paper from FITP and DOE data)
- 9 children w ASD in state custody and living in foster homes (White paper, from DDAS record review)

EDUCATION: Children with ASD receiving special education

(additional children w ASD may be served only by EST or 504 Plans)

- 1992 13 (White Paper)
- 12/05 child count 540
 - 362 autism
 - 94 PD/NOS
 - 77 Asperger's,
 - 3 Rett's Syndrome
 - 4 Childhood disintegrative disorder
- 12/06/2006 582- (DOE child count- note 7.7% increase from 2005)
 - 397autism
 - 88 PD/NOS
 - 89 Asperger's,
 - 4 Rett's Disorder
 - 4 Childhood disintegrative disorder
- 10/2007 593 (by SU count)
- If average annual increase continued at 20% 12/1/05, as noted in White Paper, 1,343 students 3-22 will be identified with ASD in five years (White Paper)
-

Early Intervention

12/05: 9 children receiving Birth to 3 (Family, Infant & Toddler services)
○ 24 children in past 12 month period increase more than 200%)

Programs

- Three of the designated mental health agencies provide specialized autism programs in schools (Washington Co at capacity with 15, Howard Center-Chittenden Co at capacity w 17 and 4 on (White Paper)
- Supervisory Unions w specialized programs:
 - Newport City (7 elementary to high school students)
 - Bennington School District serving 4 w ASD K-4th grade & preschool serving 7
 - Wilder serving six students from 4 different Supervisory Unions in VT/NH
 - Hartford serving "several" w ASD. (White Paper)
 - Windham Southeast serving 19 students (undetermined # w ASD; 11 at high school)
 - Rutland NE SU program for preschool and elementary-six students
 - Otter Valley Union has 4 programs (for intensive needs, not all ASD)

COMMUNITY MENTAL HEALTH

- 6/30/05 VT Community Mental Health and Developmental Services [CAFMH] programs serving 527 adults and children (White Paper)
 - 245 children under twenty two receiving CAFMH services
 - 39 adults receiving Mental Health Services
- 5 children w Child Adolescent and Family Mental Health Services (CAFMH) waiver live outside family home
- CAFMH support to 3 children to live in residential facilities of schools out of state (White Paper from DOE, Residential Review Committee)

DEVELOPMENTAL SERVICES

- 2004 survey of DS agencies: 218 children served under age 18 (Likely under report due to undiagnosed AS in children with MR who are already served)
- As of 6/30/05: 243 adults and children receiving Developmental Services (children probably duplicated from DOE count)
- September 2005-# receiving DS waiver (White Paper)
 - 86 children and 52 18-22 year olds
 - 66 AD
 - 58 PDD-NOS
 - 11 Asperger's
 - 3 Rett's syndrome
 - Most of the children also had Children's Personal Care Services
 - 9 children on autism spectrum and in DCF custody had DD waivers (unclear if included in numbers above)
- 1996 Eligibility for DS in Vermont expanded to include pervasive developmental disorders
- 2001 DS waiver funding for children under age 18 and new applicants cut except for those at risk of nursing home or psych hospital admission. Children already funded continued with services. Increases in their funding dependent on agency resources or child meets funding priority
- Families w children w ASD eligible for up to \$1122 annually in Flexible Family Funding through VT State system of Developmental Services (White Paper)

MEDICIAD CHILDREN'S PERSONAL CARE SERVICES

- January 2005 1,166 children were enrolled in Children's Personal Care Services w average number hours authorized being 25/wk. 80% were family managed and 20% agency managed. (White Paper)
- Due to lack of appropriate trained individuals only 64% allocated hours used.
- June 2005 245 children and youth under age 22 w co-occurring mental health disorders served by CAFMH (White Paper)

*** Vermont Interagency White Paper on Autism Spectrum Disorders: Report to the ACT 264 Board, March 2006, Vermont Agency of Human Services & Department of Education*

2. Vermont Department of Education, CHILD COUNT INFORMATION on students identified with ASD as of DECEMBER 1, 2006 (Source: Claire Bruno)

AGES 3 TO 5:

In Regular Ed Program at least 80% of time: 30
 In Special Ed Program; Separate Class: 17

Following categories are combined:

Not Attending Special Ed Program; Service at Home

In Regular Ed Program 40% to 79% of time

In Regular Ed Program <40% of time

In Special Ed Program; Separate School

16

TOTAL AGES 3 TO 5 63

AGES 6 TO 21:

In Regular Ed Program at least 80% of time: 275

In Regular Ed Program 40% to 79% of time: 74

In Regular Ed Program <40% of time: 140

Following categories are combined:

Separate school: Public or Private

Homebound/Hospital

Residential Facility

30

TOTAL AGES 6 TO 21: 519

TOTAL ASD CHILDCOUNT 12/1/06 582

ASD CHILDCOUNT INFORMATION BY COUNTY: (as of 12/06)

ADDISON:	27
BENNINGTON:	33
CALEDONIA:	30
CHITTENDEN:	140
ESSEX:	12
FRANKLIN/GRAND ISLE:	52
LAMOILLE:	27
ORANGE:	34
ORLEANS:	18
RUTLAND:	63
WASHINGTON:	52
WINDHAM:	39
WINDSOR:	55
TOTAL:	<u>582</u>

AUTISM:	397
PDD/NOS:	88
ASPERGER'S DISORDER:	89
RETT'S DISORDER:	4
CHILDHOOD DISINTEGRATIVE DISORDER:	4

3. AHS, Department of Disabilities, Aging & Independent Living [DAIL] (Source: Clare McFadden as of October 25, 2006)

- DOC: Corrections does not have information.
- Adult Mental Health: Serving 46 adults with ASD as of June 30, 2007. (Includes CRT, outpatient and substance abuse.)
- Developmental Services: Serving 316 people of all ages with ASD. (Accuracy in question.) (No breakdown yet on numbers for adults and children.) [Total served is 3224 (ASD approximately 10% of those served.) Source: Annual Report 2007, Developmental Disability Services, DAIL].
- One in 3 current applicants is a person with ASD. Source: Theresa Wood 11/7/07

4. AHS, DAIL, Department of Disability & Aging Services [D-DAS] (Source: Jennie Masterson.)

In its 2006 Graduate Tracking Report, there were 24 youth with ASD out of a total of 128 completing school who were identified as likely to be eligible for developmental services. (See attached report at page 30.)

5. AHS, DAIL, Department of Vocational Rehabilitation [DVR] (Source, Alice Porter, September-October, 2007) (See attached report at pages 31-32.)

- Over the past 6 years, the percentage of individuals coded as having autism at the point of certification for VR services has gone from .36% (9 of 2484 individuals certified in SFY 2001) to 1.58% (53 of 3346 individuals certified in SFY2007)
- Of the 137 served in SFY 2007, 73 cases are still open and 64 cases have closed.
- Of those 64 closed cases, 51 were closed after an Individualized Plan for Employment was written.
- Of those 51 cases, 42 closed with stable employment, yielding an 83% rehab rate.
- 74% of those successful closures were with youth under age 25 at the time of closure.
- 90% of the successful closures were with individuals under age 35, so it is a young population.

Individuals with Autism as primary disability served by DVR in SFY 2007

cell values of 5 and under are suppressed

District	Total Individuals Served	Applicants in SFY	Eligible in SFY
Barre	16	**	6
Bennington	8	**	**
Brattleboro	7	**	**
Burlington	27	12	13
Middlebury	**	**	**
Morrisville	**	**	**
Newport	11	**	**
Rutland	16	**	**
Springfield	11	**	**
St. Albans	6	**	**
St. Johnsbury	9	**	**
White River Jct	20	9	7
Total	137	54	53

Age Group	Total
Age 0-5	0
Age 6-17	44
Age 18-21	57
Age 22-30	22
Age 31-50 & 51-65	14
Total	137

DDAS 2006 Graduate Tracking Report

(with annotations)

agency	Projected**		actual #	in-eligible	stayed in school	declined svcs	# graduated	MR	PDD	Funded by			SE	CS
	# on survey	add ons								employed on 5/25/06	grant VR	waiver DS		
	10/1/2006		1/1/2006											
CA	10	0	9	3	1	1	8	4	2	7	1	3	3	3
CAP	12	3	15	6	0	0	15	5	1	0	3	6	2	4
CDS	2	6	8	0	1	0	7	5	1	0	3	4	4	4
HCS	20	2	22	5	1	1	21	11	5	9	1	12	7	7
HCRS	32	3	35	6	3	8	31	14	6	14	4	11	10	4
LCMH	6	2	8	0	4	0	4	8	0	2	n/a	4	4	0
LSI	4	0	4	0	1	0	3	3	1	3	0	3	3	0
NEKHS	27	3	30	4	9	1	21	21	7	17	2	15	13	1
NCSS	4	2	6	2	1	0	3	3	0	4	0	2	2	0
SAS	2	2	4	0	0	0	4	4	0	2	0	3	3	0
UCS	8	0	8	0	3	2	5	7	0	1	1	2	2	3
UVS	7	0	7	0	1	2	6	4	1	3	0	1	0	1
totals	134	23	156	26	25	15	128	89	24	62	15	66	53	27

survey Of 1/06	added	actual	in-eligible	stayed in school	declined	graduated	MR	PDD	employed	grant	waiver	SE	CS
budget built from this count		130 DS eligible	open w/ DVR or will refer		7 DS eligible	102 DS eligible			53 DS consumers				# waivers not people
				5 age 18		29 age 18			9 ineligible				
				11 age 19		27 Age 19			7 stayed in school				
				3 age 20		11 age 20							
				7 age 21		26 age 21							
						9 age 22							

** Survey: By October each designated agency reports on youth expected to finish school June 30 & be eligible for developmental services.

Vermont Department of Vocational Rehabilitation: Active cases by Disability Category

All Cases Active in State Fiscal Year 2007 (July 2006 to June 2007) by Disability Source

Excludes individuals determined ineligible for VR Services (for whom no disability information is recorded)

all values <10 suppressed

Disability Category	Disab Source	Cases	% of Cases in Disability Category
Developmental Disability/MR	Attention-Deficit Hyperactivity Disorder (ADHD)	268	13%
	Autism	129	6%
	Cerebral Palsy	75	4%
	Congenital Condition or Birth Injury	***	
	Mental Retardation	601	30%
	None/Cause Unknown	77	4%
	Specific Learning Disabilities	878	43%
HIV	HIV and AIDS	***	100%
Mental Illness	Accident/Injury (other than TBI or SCI)	***	
	Anxiety Disorders	477	17%
	Congenital Condition or Birth Injury	***	
	Depressive and other Mood Disorders	1651	59%
	Eating Disorders (e.g. anorexia, bulimia, or compulsive overeating)	15	1%
	Mental Illness (not listed elsewhere)	155	6%
	None/Cause Unknown	94	3%
	Personality disorders	101	4%
Schizophrenia and other Psychotic Disorders	287	10%	
Physical Disability	Accident/Injury (other than TBI or SCI)	694	26%
	Amputations	27	1%
	Arthritis and Rheumatism	264	10%
	Asthma and other Allergies	13	0%
	Blood Disorders	21	1%
	Cancer	58	2%
	Cardiac and other Conditions of the Circulatory System	101	4%
	Congenital Condition or Birth Injury	194	7%
	Cystic Fibrosis	12	0%
	Diabetes Mellitus	79	3%
	Digestive	26	1%
	End-Stage Renal Disease and other Genitourinary System Disorders	12	0%
	Epilepsy	67	3%

	Immune Deficiencies excluding HIV/AIDS	23	1%
	Multiple Sclerosis	55	2%
	Muscular Dystrophy	21	1%
	None/Cause Unknown	403	15%
	Parkinson's Disease and other Neurological Disorders	25	1%
	Physical Disorders/Conditions (not listed elsewhere)	423	16%
	Polio	11	0%
	Respiratory Disorders other than cystic Fibrosis or Asthma	44	2%
	Spinal cord Injury (SCI)	64	2%
	Stroke	34	1%
Traumatic Brain Injury	Accident/Injury (other than TBI or SCI)	***	
	Congenital Condition or Birth Injury	31	100%
Grand Total		7542	

APPENDIX 2

Meeting the Needs of Adults with Autism: A BLUEPRINT
FOR THE FUTURE [New Jersey] COSAC October 2006 (28 Pages)

<http://www.njcosac.org/cosac2/PDF/whitepaper.pdf>