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## *Vermont Legislative Research Shop*

### **Autistic Spectrum Disorder**

Autism Spectrum Disorder (ASD) is characterized by varying degrees of impairment in communication skills, social interactions, and repetitive, restricted and stereotyped patterns of behavior. ASD disorders can generally be detected by the age of 3 – sometimes as early as 18 months. ASD disorders can range from a severe form called autistic disorder, to a milder form called Asperger Syndrome. If the child exhibits symptoms of either of these disorders, but does not meet the exact criteria for either, the child is diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) (National Institute of Mental Health 2008).

Presently, there is no medical test to determine whether a person has autism, and the diagnosis is indicated when an individual displays certain characteristic behaviors as defined by the *Diagnostic and Statistic Manual*, Fourth Edition. The individual must have a qualitative impairment with social interaction, as manifested by at least two of the following:

- marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction;
- failure to develop peer relationships appropriate to developmental level;
- a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people;
- lack of social or emotional reciprocity.

Further, the individual must have a qualitative impairment in communication as manifested by at least one of the following:

- delay in, or total lack of, the development of spoken language;
- in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others;
- stereotyped and repetitive use of language or idiosyncratic language;
- lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

Finally, the person must display restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least two of the following:

- encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; or

- apparently inflexible adherence to specific, nonfunctional routines or rituals;
- stereotyped and repetitive motor mannerisms;
- persistent preoccupation with parts of objects (American Psychiatric Association 2000).

Autism is a spectrum disorder, meaning the symptoms and characteristics may present themselves in a wide variety of combinations, from mild to severe. Two children with the same diagnosis can act differently and can have varying skills. Some autistic children are remarkably gifted in specific areas. Evidence shows that early intervention results in positive outcomes for autistic children (Smith 2001). With the appropriate specialized training, even persons with severe autism may be able to learn functional living skills, such as learning to cross the street safely; making a simple purchase; or asking for assistance when needed. Persons with mild forms of autism are able to live and to work independently in the community (Montgomery 1995).

### **Statistics on ASD**

According to the Center for Disease Control, data released in 2007 shows that about 1-in-150 8-year old children in the United States had an Autism Spectrum Disorder, or ASD. It is estimated that up to 560,000 individuals between the ages of 0 and 21 in the United States have an ASD. From 1994 to 2006, the number of children ages 6 to 17 classified as having ASD and participating in public special education programs rose from 22,664 to 211,610. In 2006, the total number of individuals ages 3 to 21 being served through special education programs was 259,705. The total cost of services provided for autistic individuals is estimated at \$90 billion annually. In Vermont, there are 700 individuals identified as having some type of ASD, and the cost of care for each individual annually is \$82,000 (Center for Disease Control 2007).

While there has been a significant increase in ASD diagnoses, it is important to note that the increase in ASD diagnoses may just reflect an increase in awareness among the general public as well as the medical community, rather than a true increase in the incidence of ASD's (Herbert et al., 2002).

Many population studies show an increase in the autistic portion of the population beyond what is expected based on the general population growth. As mentioned above, it may be that the diagnostic criteria have changed, expanding to include people who weren't previously diagnosed as autistic (Rapin 1997). The criteria will continue to waver until a specific biological cause can be determined. The population data also shows that the individuals diagnosed as autistic today tend to have more mild symptoms and are more likely to be able to adapt to a regular lifestyle with a minor amount of intervention at an early age.

### **Treatment**

The most important factor for any intervention program is its flexibility. In addition, most programs include some elements of communication therapy, social skill development, sensory integration therapy, and applied behavior analysis.

Types of treatment proven effective for autistic individuals include:

- Behavior modification;
- High doses of vitamin B6 and magnesium;
- DMG, folic acid, and other nutrients;
- Gluten or casein free diets;
- Music therapy; and
- Speech and language therapy.

Families are involved in certain stages of the treatment programs to assist them in dealing with the stresses of having autistic children and to better empathize with their children (Rimland 2000).

There is no cure for autism; however, there are treatment programs that may remedy certain symptoms and bring about improvement. According to the Mayo Clinic, the most commonly used therapies are Behavioral and Communication, Drug, and Complementary therapy approaches. Behavioral therapy is used to teach autistic children new skills, how to act in social situations, or how to better communicate with other people. Drug therapies are used to control symptoms—for example, stimulants are used to control hyperactivity and antipsychotic drugs are used to control repetitive and aggressive behaviors. Alternative complementary therapies include art therapy, special diets, vitamin and mineral supplements, or sensory integration (reducing a child's sensitivity to touch or sound). It is important to note that not all therapies will work for all children (Mayo Clinic 2006).

### **Causes**

Currently, there is no definitive answer of what causes Autism. Scientists think that the environment and genes are both factors; others suggest there may be many multiple causes that lead to ASD (Center for Disease Control 2007). Autism is a biological brain disorder that occurs in roughly 1 out of every 300 people in the United States (Megson 1997). It is a disorder of the nervous system and of the immune system that affects multiple metabolic pathways. It is possible that autism may be the result of a G-alpha protein disruption, which affects the retinoid receptors which modulate sensory input. It is also documented that many individuals with autism have highly abnormal lipid profiles (Megson 1999). Autism is four times more prevalent in males than in females. Data of autistic individuals suggest that autism may have a genetic component on account of familial patterns of autism and related pervasive developmental disorders (PDD). Tuberous sclerosis is currently the second largest identifiable genetic cause of autism. Subsequently, the US House of Representatives proposed a bill in 2001 to increase awareness of tuberous sclerosis (Kelly 2001).

Recently, a neurologist hypothesized that autism may be categorized into two distinct forms. The first form is an idiopathic autism, resulting from a familial connection. Under this subgroup, some autistic individuals also have other genetic disorders, such as Fragile X Syndrome, Landau-Kleffner Syndrome, William's Syndrome, or Tourette's Syndrome. The second form of autism is characterized by bilateral brain damage in early life, resulting in developmental delays in language, social skills, and organized purposeful activity. Approximately 25 –30 percent of these

people may develop a seizure pattern at some point during life (DeLong 1999).

## **Vaccination Debate**

Recently there has been much public concern regarding childhood vaccines causing autism in some children. The reason for this is that the prevalence of autism has increased dramatically over the past two decades, which coincides with increased childhood vaccinations. Proponents of this theory believe that Thimerosal, a preservative that is frequently added to vaccines, exposes children to a potentially toxic amount of Mercury, which can cause behavioral and neurological dysfunctions similar to those associated with autism (Bernard *et al.* 2000). Thimerosal was removed following an amendment to the Food and Drug Administration (FDA) Modernization Act, in hopes that it would reduce the cases of Autism. Studies, such as one published by the *American Journal of Preventative Medicine* in 2001 (P. Stehr-Green 2001), show that after Thimerosal was removed from vaccines the cases of Autism continued to increase. In 2004, the Institute of Medicine (IOM) reviewed more than 200 studies such as this, relating Thimerosal and Autism, and concluded that there was no relationship between the two (Nelson 2003). Neurological research has also failed to find strong evidence against any such connection. Presently, all recommended vaccines for U.S. infants are available only as “thimerosal-free formulations or contain only trace amounts of thimerosal (less than 1 micrograms mercury per dose), with the exception of inactivated influenza vaccine” (FDA 2008).

## **Programs**

### **Federal Funding for Special Education: IDEA**

The Individuals with Disabilities Education Act (IDEA) is the primary federal program, first adopted by Congress in 1975, that makes funds available to states for services related to children (up to age 21)<sup>1</sup> with disabilities, such as ASD, including early intervention and special education. Such funds are available once states comply with its policy procedures and requirements. IDEA has been amended several times; the most recent reauthorization in 2004 made significant revisions in the law. IDEA ensures that all children with disabilities, no matter how severe, have the right to a “free appropriate public education.” IDEA provides these services that affect more than 6.5 million eligible infants, toddlers, children and youth with disabilities (US Department of Education N.D.).

In 2007, \$10.7 billion were available under IDEA for both public and private school students, teachers, and parents (Cronen 2007). Though states are not required to participate, all states have elected to do so since the inception of IDEA.

A recent study funded by the Policy and Program Studies Service in the U.S. Department of Education’s Office of Planning, Evaluation, and Policy Development found that while almost all public school districts take advantage of the federal funding for special-education services available under IDEA, only 43 percent of private schools had students receiving these services in

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<sup>1</sup> Infants and toddlers (birth to age 2) with disabilities and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B.

the 2004-2005 school year. Education policy researcher Gayle Christensen says that in order to improve this percentage, more information should be provided to private schools (Cronen 2007).

Under IDEA, schools are required to create for each student an Individual Education Program (IEP) who is eligible for receiving IDEA services. The IEP outlines the services to be provided and includes a description of the student's present levels of performance and how their disabilities affect their academic performance. It also includes the specific modifications and accommodations to be provided for the student.

IDEA also requires children with disabilities be educated in the Least Restrictive Environment (LRE), meaning that children are educated in a setting with other children who have no disabilities, or as near to such a setting as possible (providing that the special help and modifications are provided to those who need it).

On December 1 of each year, the Child Count data is collected at the supervisory union level reflecting the status of children with disabilities eligible for services under IDEA. This collection can be found at the state of Vermont's Department of Education website under Programs and Services: Special Education: Data Reports, Publications and Resources: Special Education Child Count Data Report for 2006. The collection includes demographic information, information regarding educational environment, educational location, and compliance indicators. Data are reported by disability, placement, gender, grade group, and funding category. The Vermont state totals for 2006 show that there are 14,012 active IEP students out of a total 14,088 eligible students (for special education services under IDEA). The total percentage of IEP students out of the whole student population (including students not requiring special education services) is 15.02% (Dept. of Education 12/10/07).

In the Fiscal Year 2006, Vermont failed to meet its target of 80% of youth with IEPs graduating with a regular diploma. The graduation rate for students with IEPs had varied by less than two percentage points from 2004 to 2006. 531 of 679 or 78.2% of IEP students eligible to graduate from grade 12 graduated with a regular diploma in FFY 2006-2007 (See Figure 1, comparable to Figures 2 and 3). Improvement activities have focused on districts with the lowest graduation rates, and while those graduation rates have increased due to this focused channeling of resources, the overall graduation rate has not changed. Because of this, new statewide activities have been added to Vermont's State Performance Plan (SPP) for the 2008-2009 school year (Part B: Annual Performance Report FFY 2006, p. 5).

The reauthorized IDEA of 2004 requires each state to create and disseminate a State Performance Plan (SPP) that contains measurable and rigorous targets relating to twenty performance indicators. The first Vermont SPP was submitted to the U.S. Department of Education on December 1, 2005; it has since been revised as of February 1, 2008, containing new baseline data as well as revisions to targets and activities resulting from analysis of the 2006-2007 Annual Performance Report. This revised SPP for 2005-2010 can be found at the Vermont Department of Education website (<http://education.vermont.gov>), Programs and Services: Special Education: Data Reports and Publications. The website also provides further school data and reports, along with the FY 2009 Special Education Funding Projections at <http://education.vermont.gov/new/html/data/spedfunding.html>.

## **State Funding for Special Education: Act 230**

In 1990 in Vermont, Act 230 was implemented as the state's program for special education funding. This act allows for funds to be used on remedial and compensatory education and for the block grant to be based on the total student membership rather than on special education student counts. This removed incentives to identify students as "special ed" students, a label which carries negative stigma and may impact the children's social interactions, especially in rural areas. The Act appropriated 1% of the state special education money for in-service training grants to school districts. The Act also implemented a school-wide instructional service and school-level instructional support team for identification of at-risk students. According to Act 230, reimbursement for additional special education staff is subject to annual approval and only a portion is reimbursed. The funding formula for Act 230 consists of (1) a mainstream block grant based on the total student enrollment in a district, which states that the local funds must equal 40% of the core service for special education; (2) extraordinary services reimbursed; and (3) intensive services reimbursement which must be annually approved (Montgomery, 1995).

Follow-up data four years after the implementation of Act 230 showed an increase in collaboration between regular and special educators, earlier intervention of at-risk children, more specialized training of individual aides, and less paperwork for teachers. Interviewed teachers stated that the system was now more placement neutral and more predictable. In addition, many teachers commented on the benefit of added resources that special education students brought to the classroom, such as computers and individual assistants. Teachers and families interviewed all stated that special education students educated in a regular classroom setting "clearly benefited" by receiving regular curriculum in a "real world" environment. However, in order for everyone to benefit, the class size must be small and no one child may monopolize the teacher's time. With the growth in the total student population and with subsequent budget cuts, the demands of teachers and the class size are increasing (Montgomery 1995). Some autistic children may monopolize their teachers' time with their special demands and certain behavioral habits; however, most autistic children are not a substantial time concern for the teachers.

With respect to other special education children, the average per pupil expenditure for special education programs for autistic children is the most expensive (Parrish, O'Reilly, Duenas, & Wolman 1997).

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