

## **A Lawmaker's Guide to Autism and Funding**

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Federal and state funding for autism have come a long way in just the past generation. The stream of autism governmental focus started to gain steam in the mid 1990s, stemming from the 1975 federal law stating that every child is entitled to a "free, appropriate education," regardless of ability.

The number of youths diagnosed as autistic has risen dramatically from 1 in 2,500 in the 1980s to 1 in 150 today. As a result, along with the increased commitment to educate autistic children in general, the department of Education indicates that the number of autistic children in public school throughout America grew from 15,580 in 1992 to 193,637 in 2005. There have been numerous causes related to that increase, but without a doubt, more medical focus on the disorder has prompted more federal legislative attention, resulting in more needed funding and educational subsidies for autism directed towards schools across the country.

Autism is characterized by impaired communication, stunted social skills and unusual, repetitive behaviors. Diagnoses have increased dramatically in a short amount of time, possibly because of unknown environmental factors or because the disorder is more widely recognized (Painter, 2003). The official governmental classification of someone who has autism started with only the most severe cases, such as those depicted in those original Hollywood films such as *Rainman* (1988) and *House of Cards* (1993). A big reason for the increased diagnosis and subsequent increased focus by state legislatures and the federal government has been the expansion of the disorder beyond its old stereotypical perceptions, similar to the process of increases in AIDS awareness and subsequent focus in the 1980s. In the 1990s, autism's classification became broader, given the terminology of "autism spectrum disorders" (ASD), which included a group of milder, related conditions. The Social Security Administration followed suit and widened its classification of autism to include Asperger's syndrome and Pervasive Development Disorder. In addition, Congress included autism as a separate disability classification as an amendment to the 1975 federal law that asserting every child is entitled to a "free, appropriate education". The umbrella of ASD now includes many different severities of autism, from extreme autism to milder cases, in addition to some disorders formerly classified under the category of retardation. Dramatic results appeared, and from 1997 -2006, data indicate that autistic children rose from 42,500 to 225,000, while mentally retarded children declined from 603,000 to 523,000 in the same time period (Stobbe, 2007). The US Department of Education likewise classified all those affected with autism under the categorization of "Autism Spectrum Disorders", starting in the 1990s, and consequently increased the number of children in schools associated with autism as well. Although there is no scientific breakdown that is accepted across the board currently, ASD now generally includes Asperger's syndrome and other classifications that were previously included for a child that put them under the category of being mentally retarded (Stobbe, 2007).

### **Legal Battles and Autism Advocates**

During the past decade, legal interpretation has become an important ingredient for those who fight to fund autism to its greatest extent. The Individuals with Disabilities Education Act specifies that public school educators are required to provide an education to all disabled students, which does include autistic children, as well as designing an individualized educational program for each child with special needs. The most accepted treatment as of late has become "applied behavior analysis", which requires 30-40 hours of individual attention and might run up to \$60,000 per year. As of 2002, there is a shortage across the US of 12,000 special education teachers, and the ones currently employed don't necessarily have the training in autism treatment that provides the most appropriate care (Leone, 2002). The lack of qualified professionals has put a strain on many school administrators in their efforts to properly educate those youths afflicted with autism. When the Children's Health Act, the first federal legislation addressing autism, was passed in 2000, the Centers for Disease Control (CDC) stated the prevalence of autism at 1 in 500 children in the United States. By 2004, the CDC revised that figure to as many as 1 in 166 (Autism Speaks, 2007). While funding has been on the upswing, the training and certification of licensed, eligible teachers has not kept up with the sharp increase in diagnosis and constitutes a major current problem facing school funding towards autism.

In addition, autism gained more federal focus through the increased attention from the highly respected National Institute of Mental Health. The National Institute of Mental Health, one of several NIH institutes that support autism research, increased its funding for autism work from \$8.7 million in fiscal 1997 to \$9.6 million in fiscal 1998 as the diagnosis of autism started its sharp upward trend. The Autism Society of America, a parent-advocacy group with 24,000 members based in Bethesda, Md., has been lobbying Congress for more funding for investigation by the Federal Centers for Disease Control and Prevention and the National Institutes of Health. Autism funding has originated from a variety of different federal entities, and by 2003, the combined public funding from the National Institutes of Health that support autism research had increased to \$74 million (Painter, 2003). Since then, that number has continued to climb.

The phrase "appropriate education" resulting from the 1975 federal law stating that every child is entitled to a "free, appropriate education, regardless of ability," has been the source of dispute for those representing youths afflicted with some form of autism. In 1997, The Individuals with Disabilities Education Act was amended and reauthorized and increased its support for the development of a range of assistive instructional technologies (Lloyd, Fuller & Arvidson, 1997a), which broadened the scope of the act and helped facilitate the inclusion of autism and ASD. "Appropriate education" has grown to be a legal lightning rod, as many children, especially those with milder cases of autism, have been represented by lawyers fighting to bring that "appropriate education" to these youths. In 1999, a lawyer representing an autistic child in California sued the California Dept of Education and the school district the child was in, for not providing that "appropriate education" which, according to the lawyer, should have included additional personal reading attention. It took six years of legal squabbling and in 2005 the parties reached a \$6.7million settlement, including \$2.4 million for a family trust. A year later, in LA, it was determined that \$3.3 million would be paid to attorneys of autistic children as reimbursement of legal issues, stemming from lawsuits. There has been a 6 fold increase in autistic children in LA schools from 2003-2006 (Egan, 2007). This legal precedent has greatly enhanced funding to public schools for ASD.

Under the law, in New York, sending an autistic student to a school for autism can run \$100,000 per year, and the bill legally could be sent to the school district for reimbursement. NYC's education department hired ten lawyers to specifically address special education clashes between parents and the school educators, which oftentimes involve autistic children (Egan, 2007). This particular legal precedent has also facilitated in bringing more funding for youths with autism.

"When the federal government created the [1975 law], it said it would pay for 40% of schools' special education budgets. In reality, it's closer to 15%," said Patricia Addison, director of special education for Fairfax County, Va. (Egan, 2007, p. 2). Still, the feds have increased spending on special ed by 68% over the last five years, to \$10.6 billion. With autism diagnoses continuing to rise--Fairfax saw an 84% increase in the number of students with autism from 2003 to 2006. Is there a solution to this? Washington, D.C.'s school district administrators have experimented with caps on the amount it will reimburse parents for their legal bills. After lifting the cap in 2001, the city saw the number of requested hearings skyrocket by 20% in one year. In 2003 Congress (which has a constitutional right to meddle in the city's affairs) reinstated a new cap (it's now \$4,000 per case), and attorney fees dropped by 30%. The school district officials brag that in fiscal year 2003 the \$4.5 million it saved with the cap was enough to pay for 550 new classroom seats at 50 schools to serve special ed schoolchildren (Egan, 2007). If legal wrangling for autism funding can be negated in the future, as it appears will be the case, funding streams might continue to rise even more.

In 2003, an unprecedented, long-term plan to find the causes of autism and treatments was unveiled by federal officials at a government-sponsored conference on the disorder, according to an article in USA Today. Among the ultimate goals from a test that could identify infants at high risk so they could get treatment that would prevent them from developing the disorder. The plan specifies that 25% of cases might be prevented and 90% of people with autism, up from about 50% now, might learn functional speech if research moves swiftly in the next seven to 10 years. The article went on to add that those who have autism are not fully benefiting from what's already known, government officials and advocates at the conference agreed. For example, although experts can identify children with autism by age 2, most are diagnosed later. And while some treatments, including intensive behavioral modification, have been shown to help many children, many don't get effective treatment (Painter, 2003). Early intervention efforts are part of autism funding goals by lawmakers.

### **National Policy Action**

Taking a lead role in the fight to increase support toward autism were US Senators Rick Santorum of Pennsylvania and Senator Christopher Dodd of Connecticut. Their partnership on the issue gave the fight two early figureheads and high-level spokespersons. In 2005, the two senators put forth a bill that authorized \$860 million over 5 years for autism, including education, research, screening, and intervention. In addition, the legislation calls for the reauthorization of the NIH's Centers of Excellence Program in autism, which was created in 2000 (Samuels, 2005).

Senators Santorum and Dodd have launched an attack on autism that has never been seen at the federal level," said Jonathan Shestack, the father of a son with autism, and co-founder of Cure Autism Now, one of the largest private funders of autism research. "The legislation introduced today will cut across federal agency lines to more effectively fund autism research and expand autism treatment and early diagnosis. It is truly the result of the autism community pulling together to focus the nation's attention on this public health crisis," Shestack continued. "As the incidence of autism continues to rise, the proposed legislation introduced today would ensure continued resources to zero in on the cause so we can treat the current generation and develop preventive practices for future generations (Medical News Today, 2005, p.1).

Autism is a profound condition that can have a devastating effect on children and their families," said Senator Dodd. "We as a nation must devote significantly increased resources to finding answers to the many questions surrounding autism. Families struggling to raise a child with autism deserve our support, and they deserve answers. This legislation will help move us toward a better understanding of autism and better supporting those living with this difficult disability" (Dodd, 2006, p. 30).

The increase of autism focus from the US Senate prompted a comprehensive federal legislative package that culminated in late 2006. In December of 2006, President Bush signed into law the "Combating

Autism Act of 2006" which provided funding through 2011 for ASD research, intervention, screening, and education. In response to the Act, the President issued the following statement:

For the millions of Americans whose lives are affected by autism, today is a day of hope. The Combating Autism Act of 2006 will increase public awareness about this disorder and provide enhanced federal support for autism research and treatment. By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and intervention, which is critical for children with autism. I am proud to sign this bill into law and confident that it will serve as an important foundation for our Nation's efforts to find a cure for autism (Therapy Times, 2006, p.1).

This Act increased federal funding by 50% for the disorder, which afflicts 1.5 million people in the US. Congress initially voted to dramatically increase funding to identify the cause of autism, and the Senate authorized \$945 million over the next five years for research, screening, and treatment (AP, 2006). Also, in response to the new law, the White House issued the following declaration.

Since The President Took Office, National Institutes Of Health (NIH) Funding For Autism-Related Research Has Increased By Over 80 Percent From \$56 Million In FY 2001 To An Estimated \$101 Million In The FY 2007 Budget, Including Support For Autism Centers of Excellence. In addition, the Budget includes approximately \$15 million at the Centers for Disease Control and Prevention (CDC) for autism surveillance and research, including five regional Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology. In October, CDC initiated a \$5.9 million study to help identify factors that may put children at risk for autism spectrum disorders and other developmental disabilities (Autism Votes, 2006, p.1).

Still, the 1975 passage of the landmark federal legislation "Individuals with Disabilities Education Act" included a promise to fund 40% of the average per child cost for each special education student, according to the National Education Association. That pledge never materialized in full at the federal level, according to the NEA. It is now financed at 18%, and President Bush's budget proposal for 2007 resulted in a funding at a 17% rate. The federal share was as low as 11% in the mid-1990s and as high as 19% in 2005 (Brown, 2006). The original promise to fund 40% of the average per child has not been legally challenged, but has generally seen enough goodwill that a stream of increases has closed the gap. In March of 2007, Autism Speaks (2007) reported that Sen. Clinton and Sen. Allard revealed the Expanding the Promise for Individuals with Autism Act of 2007, a piece of legislation broadening federal funding for life-long services for citizens diagnosed with autism. The EPIAA would authorize approximately \$350 million in new federal funding, above and beyond all existing federal dollars, for key programs related to treatments, interventions and services for both children and adults with autism. EPIAA would also authorize a variety of grants: \$20 million in annual demonstration grants for the coverage of treatments, interventions and services; \$20 million in annual planning and demonstration grants for services for adults with autism; \$10 million in grants in FY09 (growing to \$20 million by FY12) for the expansion of access to immediate post-diagnosis care; \$13.4 million annually in training grants for the University Centers of Excellence for Developmental Disabilities for training, technical assistance and additional services for individuals with autism and their families; and \$6 million in annual grants to protection and advocacy systems to better meet the needs of families facing autism and other developmental disabilities, including legal representation.

In December 2007, Autism Speaks reported that the US House of Representatives appropriated \$162 million to fund autism research, treatment, and services, as was part of the Omnibus Appropriations Act (Autism Speaks Press Release, 2008). In total, Autism Speaks expects a 2008 fiscal appropriation of approximately \$162 million, as authorized by the Combating Autism Act (Autism Speaks, 2007).

In March 2008, Senator Chris Dodd (D-CT), a senior Democrat on the Senate Committee on Health, Education, Labor and Pensions (HELP) and Chairman of its Subcommittee on Children and Families, lauded the passage of his amendment to the FY2009 Budget Resolution that increases funding for autism research, education, and early detection by \$197 million. This increase brings autism funding up to its authorized level and then provides for a doubling of funding research into the causes of and treatments for autism. Senator Susan Collins (R-ME) joined Dodd as the lead co-sponsor of the amendment.

At a time when the number of children and families living with autism has grown exponentially, the President's budget proposes to freeze federal spending on autism at levels that are insufficient to realize the type of scientific breakthroughs in autism that are needed," said Dodd. "I applaud my colleagues for passing this amendment, which redoubles our federal commitment to funding autism, the fastest-growing developmental disability in the U.S (Dodd, 2006, p.30).

### **Grants for Autism/ASD**

Grants awarded to various organizations are an ever-increasing method to fund research, services, and children with ASD. For 2008, a total of \$14 million was given out by the Health Resources and Services Administration through various grants. Six states were awarded grants, totaling \$1.8 million, to provide additional support for existing state programs in efforts to upgrade and improve health care and other services to autistic children. The General Hospital Corp of Boston was awarded nearly \$4 million for research and health related issues for autistic children, a scholar society in Los Angeles was awarded \$2 million for research related to autism, The Association of University Centers on Disabilities in Md., gets a grant of approximately \$500,000 for the National Interdisciplinary Training Resource Center, and The Association of Maternal and Child Health programs was awarded \$250,000 to create the State Public Health Coordinating Center for Autism. Also, twenty-one universities and research organizations were awarded grants worth \$5.6 million.

Autism is a condition that presents special challenges for many families and the providers who treat these special children," said HRSA Administrator Elizabeth M. Duke. "These grants, funded by HRSA's Maternal and Child Health Bureau, demonstrate our commitment to improving the care of children with autism spectrum disorders" (Autism Speaks, 2007, p.1).

### **Public Schools and Action from Individual US States**

An editorial by Fran Smith in September 2008, looked into how public school educators are coping with providing quality education to more and more children with needs, amidst shortfalls in budgets. Smith explained, "A small but growing number of districts are creating innovative programs based on the latest research in autism and modeled after some of the most highly regarded -- and expensive -- private schools. These pioneering programs may change the future for special-needs children, and not only for the children fortunate enough to get into one. If these experiments prove successful, they may change the future of autism education throughout the United States, and not a moment too soon. She referenced a study by the Special Education Expenditure Project, which was carried out for the US Department of Education. The results of that study indicated that all costs of education associated with a child with autism is about triple the cost for a mainstream student, and in many cases, that amount can be near \$75,000 per year for all intensive services (Smith, 2008).

While various federal governments, national organizations, states, and provinces have made much progress in a short amount of time for autism funding, no matter where the source, the process has been an arduous one. The *Augmentative and Alternative Communication, Handbook of Principles and Practices* looked at the process to locate funding sources for related efforts and stated "Efforts to secure funding are frequently exercises in patience, because no one systematic funding avenue currently exists" (Lloyd, Fuller & Arvidson, 1997b). Several US states have been at the forefront of increasing funding toward autism and ASD, and have provided inspiration for the federal government in their increased efforts to bring much-needed money to the disorder.

These state officials, as well as school system administrators in the US, have utilized various strategies to educate children with autism, with some states doing more than others. In an innovative program developed in a five-county area of California near the Sierra foothills, a free intensive behavior programs for up to 40 hours per week has been available for autistic youths. The total number of children under seven has increased to 170 total children (Smith, 2008).

Funding for autism in the state of Indiana peaked in the early 1990s, but there is still no certification process for teachers in order to be qualified to teach children diagnosed with autism, as special education teachers in the state are licensed in mild or intense intervention. In 2006, federal funding for the Individuals with Disabilities Act of 1975 was funded at 18 percent in Indiana, resulting in an overall

deficit of \$139.9 million, which ends up being 65,911 total students being shortchanged. The number of children in Indiana with autism has been said to be one in 143.

The reality is we have been dealing with decreased funding for sending people to training events," said Cathy Pratt, director of the Indiana Resource Center for Autism at Indiana University in Bloomington." The education budget has really gone down, whether it's in general or special education," she said (Brown, 2006, p.1).

The state of New Jersey issued a Prevalence Report from 1992-2003 and spelled out the eligibility criteria for autism, and although the report notes that each state's eligibility criteria may differ, New Jersey did indicate that each state started to record the number of autistic students for ages 3-5 in 2000. In all, trend calculations the 3-5 age group is excluded so as to not upwardly bias the trend results. Difficulty in recognizing autism in younger children (age < 5) can lead to ascertainment bias, which will lower the number of cases of autism, autism incidence and autism prevalence for specific birth years and ages < 5 (New Jersey, 2004).

Schools designed to educate youths with autism have faced many funding challenges along the way that have not always been successful. In 2008, the state of Vermont set up a school for children with autism in Brattleboro, VT. The Vermont Board of Education decided that the school would accept students ranging in ages 11-22. Because the approval of the school went through the Board of Education, this independent school is able to obtain public school funding, if it is determined that a child should attend (Boston Globe, 2008).

Overall, school system officials in various states have had mixed results when attempting to designate funds for ASD. Gwinnett County Public School Administrators, Georgia's largest school system, had eight classrooms for teaching autistic youngsters 13 years ago; today there are 180 (Fox News, 2007). An idea in Illinois has been launched in which specialty state license plates may be purchased in order to raise awareness and assist in providing research related to the disorder. The program was a result of a project created by Governor Rod Blagojevich, who in efforts to bring awareness to autism, launched the Autism Task Force in 2004. At this time it was announced that 22,000 in the state had ASD and means of addressing these youths were brainstormed. In 2006, the governor signed legislation creating the Autism Research Fund, which subsequently increased state focus on this issue allowed total state funding for The Autism Program, led by The Hope Institute for Children and Families, to double in the FY08 budget from \$2.5M to \$5M. Provisions for toddlers with autism included a transition from an early intervention program to the Illinois State Board of Education's Early Childhood Program. Started in January 2008, where residents are able to buy these plates, and proceeds go to the Autism Awareness Fund. Any citizen of Illinois who agrees to buy the specialty plates get \$2 of the \$25 renewal fee and \$15 of the original \$40 issuance fee sent to the Autism Awareness Fund (Adams, 2008).

The dialogue on autism issued in the most recent presidential election underscores the increased importance of autism funding and is indicative of how far ASD state and federal funding have come in a short amount of time. It remains to be seen what legislative and policy efforts are in store for lawmakers who have been at the forefront in the fight for autism during the upcoming years, but trends do seem to be moving in the right directions.

## References

- Adams, C. (2008, January). *New law to generate funds for autism research and awareness*. Retrieved on September 12, 2008 from: <http://www.dhs.state.il.us/page.aspx?item=35776>
- AP. (2006). *Bush signs autism research bill*. Retrieved on September 20, 2008 from: <http://www.cbsnews.com/stories/2006/12/19/politics/main2281401.shtml>
- Autism Speaks. (2007). *HRSA awards \$14 million to help children with autism spectrum disorders*. Retrieved on November 1, 2008 from: [http://www.autismspeaks.org/inthenews/hrsa\\_awards\\_14\\_million\\_dollars\\_for\\_autism.php](http://www.autismspeaks.org/inthenews/hrsa_awards_14_million_dollars_for_autism.php)
- Autism Speaks Press Release. (2008). *Autism advocacy community applauds U.S. congresswomen Mary Bono (R-CA) and Diana DeGette (D-CO) for introducing the combating autism act of 2005*. Retrieved October 12, 2008 from: [http://www.autismspeaks.org/press/combating\\_autism.php](http://www.autismspeaks.org/press/combating_autism.php)

Autism Votes. (2006). *White House Fact Sheet: Combating Autism Act of 2006*. Retrieved on January 5, 2009  
 from: [http://www.autismvotes.org/site/c.frKNI3PCImE/b.3944503/k.E16C/White\\_House\\_Fact\\_Sheet\\_Combating\\_Autism\\_Act\\_of\\_2006.htm](http://www.autismvotes.org/site/c.frKNI3PCImE/b.3944503/k.E16C/White_House_Fact_Sheet_Combating_Autism_Act_of_2006.htm)

Boston Globe. (August 23, 2008) Retrieved on September 15, 2008  
 from: [http://www.boston.com/news/education/k\\_12/articles/2008/08/23/state\\_expected\\_to\\_approve\\_new\\_autism\\_school/](http://www.boston.com/news/education/k_12/articles/2008/08/23/state_expected_to_approve_new_autism_school/)

Brown, S. (2006). *Autism surging; funding falling*. Retrieved on November 2, 2008  
 from: [http://www.thetimesonline.com/articles/2006/11/13/news/top\\_news/0109ea3cb63fc5a2862572250002cfd5.txt](http://www.thetimesonline.com/articles/2006/11/13/news/top_news/0109ea3cb63fc5a2862572250002cfd5.txt)

Combating Autism Act. (2006). *December 2006 fact sheet*. Retrieved on October 28, 2008  
 from: <http://www.whitehouse.gov/news/releases/2006/12/20061219-3.html>

Dodd, C. (2006.) *US Senate page Dodd Legislation to Help Combat Autism Clears Key Committee*. Retrieved on October 28, 2009 from: <http://dodd.senate.gov/index.php?q=node/3548>

Egan, M. (2007). *A costly education*. Retrieved September 12, 2008,  
 from: <http://members.forbes.com/forbes/2007/0409/088.html>

Fox News. (2007). *Autism "epidemic" follows increase in special education funding, shift in diagnosis*. Retrieved on September 19, 2008  
 from: <HTTP://WWW.FOXNEWS.COM/STORY/0,2933,307997,00.HTML>

Leone, J. (2002). *Autism on the rise and in need of attention*. Retrieved September 19, 2008  
 from: <http://www.yaleherald.com/article.php?Article=1350>

Lloyd, L, Fuller, D, Arvidson, H (1997a). *Augmentative and alternative communication, a handbook of principles and practices, chapter 20, Professional Concerns and Issues*. Needham Heights, MA: Allyn and Bacon.

Lloyd, L, Fuller, D, Arvidson, H-2 (1997b). *Augmentative and alternative communication, a handbook of principles and practices, chapter 21, Service and Funding*. Needham Heights, MA: Allyn and Bacon.

Medical News Today. (2005). *Autism advocacy community applauds U.S. senators Santorum (R-PA) and Dodd (D-CT) for introducing combating autism act of 2005*. Retrieved on January 12, 2009  
 from: <http://www.medicalnewstoday.com/articles/23170.php>

New Jersey. (2004). *Public schools autism prevalence report*. Retrieved September 30, 2008  
 from: <http://www.fightingautism.org/idea/reports/NJ-Autism-Statistics-Prevalence-Incidence-Rates.pdf>

Painter, K. (2003). *Agencies draft plan to study autism*. Retrieved September 30, 2008  
 from: [http://www.usatoday.com/news/health/2003-11-19-autism-study\\_x.htm](http://www.usatoday.com/news/health/2003-11-19-autism-study_x.htm)

Samuels, C. (2005, April 27). Senate bill would target autism for more research. *Education Week*, 24 (33), p.27.

Smith, F (2008). *Overcoming autism: Public schools deal with a growing problem*. Retrieved November 1, 2008 from: <http://www.edutopia.org/autism-school?page=1>

Stobbe, M. (2007). *Several factors explain explosive growth in the diagnosis of autism*. Retrieved October 15, 2008 from: <http://www.foxnews.com/story/0,2933,307997,00.html>

Therapy Times. (2006). *Autism appropriations*. Retrieved January 5, 2009  
 from: <http://www.therapytimes.com/content=5901J64E485EBE841>

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