



## **Autism Speaks**

### **2012 Presidential Candidate Policy Pledge Request**

#### **I. About Autism**

Autism is a general term used to describe a group of complex developmental brain disorders – more commonly referred to as autism spectrum disorders – caused by a combination of genetic susceptibilities and environmental influences. These disorders are characterized, in varying degrees, by social and communication challenges, as well as repetitive behaviors. An estimated 1 in 110 children in the U.S. is on the autism spectrum – a 600 percent increase in the past two decades that can be attributed only in part to improved diagnosis and increased awareness.

Even these astonishing prevalence numbers, produced by the national Centers for Disease Control and Prevention (CDC) under the terms of the Combating Autism Act of 2006 (CAA), may dramatically understate the true rate of autism. A recently published study conducted in South Korea using more comprehensive ascertainment methods found the prevalence of autism to be 1 in 38. Indeed the CDC itself concluded in a 2011 report that the current U.S. estimate is very likely to be overly conservative, and is working with Autism Speaks to launch a new study within the U.S. using the same methodology as the South Korea study. The CDC has called autism a national public health challenge; however, given the lack of funds to adequately address the causes, treatment, and services needed to respond to the challenge of autism, Autism Speaks believes it is a crisis.

Autism occurs in all racial, ethnic and social groups and is four times more likely to affect boys than girls. The economic burden of autism on the United States has been conservatively estimated to be at least \$35 billion per year, but more likely is in the range of \$90 billion annually in direct and indirect expenses on our economy. Caring for a person with autism can cost more than \$3 million over the individual's lifetime. More children will be diagnosed with autism this year than pediatric cancer, diabetes and AIDS combined.

Notwithstanding these enormous social and economic costs and notwithstanding the improvements in scale and efficacy of federal efforts resulting from the CAA, autism is still drawing a sorely inadequate response from the federal government.

The recently enacted Combating Autism Reauthorization Act of 2011 (CARA) merely continues, for a short three-year period, the current level of federal investment in autism research which is still inadequate given the magnitude of the problem. Indeed, even within the first CAA funding period, a significant increase in autism prevalence occurred. It is essential that resources be devoted to the growing autism public health crisis.

The seminal 1998 Institute of Medicine (IOM) report on ["Improving Priority Setting and Public Input at the NIH"](#) concluded that disease incidence and prevalence were unrelated to NIH funding levels. A [Yale University School of Medicine review](#) this year of how the NIH responded to the IOM finding concluded that the agency's funding is no better aligned today than it was a decade ago with respect to the U.S. disease burden.

This is abundantly clear with respect to the national public health crisis posed not only by the enormous increase in prevalence of autism among American children, but also by the aging-out of a large cohort of autistic Americans from childhood to adulthood. It is estimated that over the next decade, more than 500,000 children with autism will transition to adulthood.

Insufficient prioritization of federal research dollars for autism is evident not just from the social and economic burden of autism. A consensus is growing within the scientific community that a more substantial and better coordinated initiative – modeled more closely to the Human Genome Project than on conventional NIH funding processes – to unlock the secrets of the human brain would produce dramatic results. This new knowledge would not only improve the quality of life for many millions of Americans (including those with Alzheimer's, Parkinson's and a variety of mental health conditions, including autism), but could mark a critical step in reducing the projected future national debt of the United States.

There are at least three ways that increased research could make a significant and lasting impact on improving the lives of persons with autism and their families:

First, genetic studies of the past decade are paving the way toward the development of novel medicines that can potentially reduce the core symptoms of autism – namely, language, cognitive, and social impairments – even in adults with the disorder;

Second, research on environmental risk factors is discovering new avenues for prevention of the disability associated with autism; and

Third, health services research is needed to identify strategies for disseminating current evidence-based practices, such as early autism screening and intervention, which have been shown to dramatically improve the outcomes of people with autism and generate substantial long term cost-savings as people with autism become productive members of society.

Likewise, the lack of research funding is paralleled by a lack of services addressing the needs of people living with autism spectrum disorder. People with autism often encounter discrimination in obtaining health insurance, have difficulty finding adequate housing and jobs, and face the loss of federal benefits if they save money to meet their life needs.

This is as much a fiscal as a moral imperative.

## **II. The Blueprint for an Appropriate Federal Response to Autism**

### **A. Increased and More Accountable Research Spending**

Because of the huge and growing prevalence of autism, the present and future social and fiscal burden of the condition, the lack of appropriate prioritization by the NIH, and the great scientific promise if sufficient resources are applied, Presidential leadership is required to ensure adequate federal autism research spending is appropriated to address the current public health crisis that autism poses and to ensure maximum return on the investment of taxpayer dollars.

Specifically, the next President should ensure a clear line of accountability for the management of taxpayer dollars in autism research efforts through a budgetary and structural mechanism equivalent to the Office of AIDS Research (which requires the NIH to spend research dollars according to a strategic plan approved by the President) and through such a line item appropriation, **double autism research funding** within his/her first term in office.

To those who argue that funding for biomedical research should be allocated without any involvement by the elected representatives of the American people – including the President, the only official elected to represent all Americans – it must be noted that every Institute and Center of the NIH is a creation of Congress, signed into law by the President, reflecting an assessment of public priorities and public health needs. The NIH is also replete with additional directives from Congress, which have occurred only after the NIH proved unresponsive to public health concerns. These include the Office of Women's Health and the Office of AIDS Research.

### **B. Equitable Insurance Coverage**

In recent years, a wave of justice has swept across 28 state legislatures – north, south, east and west, "red" states and "blue" states – to end the historic discrimination against people with autism in the health insurance marketplace. As of this writing, approximately 70 percent of Americans live in states where lawmakers have enacted legislation requiring medical coverage for evidence-based treatments for autism, including early intervention based on applied behavior analysis, speech therapy, and other evidence-based and well-established interventions that are known to improve outcomes. Empirical evidence has convinced a majority of state governments, containing the vast majority of the American people, that the benefits of equitable insurance coverage for these autism treatments are great while the dollar cost of coverage per policy is low (generally between \$0.50 to \$1.50 per month per member).

However, state regulation of insurance is limited by the Employee Retirement Income Security Act of 1974 (ERISA), which preempts states from regulating self-funded plans. According to Kaiser Family Foundation estimates, nearly 60 percent of private sector employees at companies that offer health insurance are enrolled in self-funded plans.

It is simply inexcusable that two American families facing autism with employer-provided private health insurance literally could live as neighbors, yet only one receives essential and effective therapies for their child (because their state government has enacted an autism

insurance reform law) while the other goes bankrupt paying out-of-pocket for the same therapies because the federal government has not taken the same necessary and proper action.

Presidential leadership should **ensure insurance marketplace discrimination against people with autism and their families is ended**. The next President should, on his/her first day in office, order that autism coverage under the military health insurance system (TRICARE) and the Federal Employees Health Benefits (FEHB) program be made equivalent, with respect to autism, to the [national model state autism insurance reform statutes](#). Those who serve our country deserve better. It is particularly shameful that children of militarily retired veterans are denied access to effective autism treatment.

Further, there is concern that implementation of the Affordable Care Act may make families worse off under the new law than they are today. Specifically, the [IOM report to HHS](#) discounts the role of state legislatures in establishing a fair marketplace. Should HHS accept the IOM's recommendation, the will of a majority of the nation's citizens expressed through their legislators, in almost 30 states will be countermanded by bureaucratic dictate.

The next President should send legislation to Congress that ends the present inequity in autism insurance coverage by requiring such coverage under ERISA and other federal law, including Medicaid. Meaningful healthcare reform must ameliorate the challenges faced by individuals with autism. The actions taken by state legislatures across the country should be the building block for our nation's autism policy.

### **C. Adult Services**

As the number of autistic adults grows daily and will continue to swell (absent fundamental medical breakthroughs) in the years and decades ahead, it is both a moral and fiscal imperative that services be made available which maximize the potential of each unique adult living with autism to contribute to the greatest extent possible to our society and economy. Despite the fact that early intervention can improve outcomes by significantly improving the cognitive, language, and adaptive skills of people with autism, the promise of early intervention is not being realized: close to 80 percent of adults with autism – even those without intellectual disability – are unemployed and living at home with their relatives rather than independently. Research in other disease and disability areas suggests that, by providing adequate services and supports at crucial points in the life trajectory, adults with autism can become tax-paying citizens with productive and rewarding lives. It is imperative that we act now to improve the quality of life for those living with autism, and at the same time, reduce the burden on society of a huge number of unemployed and under-employed adults with autism.

Always favoring accountability and effectiveness in the spending of scarce taxpayer dollars, a first important step toward meeting the needs of adults is the **creation of a demonstration grant program**, authorized and budgeted at the federal level to assist relevant federal, state and local governments, as well as appropriate private institutions, to develop best practice models for the delivery of employment, housing, health, and transportation services to adults with autism.

The next President should send to Congress legislation to create such a program and include funding in each of his/her budget submissions during his/her term in office.

#### **D. Tax-Favored Savings Accounts**

Congress has provided incentives for college savings through qualified tuition programs (section 529 programs) and Coverdell education savings accounts (section 530 programs). Many, if not a large majority of children with autism, however, do not attend college or other post-secondary educational programs. Their life needs are not met by current programs that reward savings for higher education. These individuals need help in financing the services and supports that will enable them to remain productive and independent members of their communities.

Bipartisan support has existed over several Congresses for creating savings accounts for the disabled analogous to the 529 accounts for education. Congressman Crenshaw (R-FL) intends to introduce legislation in November that will create “ABLE” accounts (Achieving a Better Life Experience) as a new subsection within Section 529 of the Internal Revenue Code. This approach is consistent with the House Ways and Means Committee’s prohibition on creating new sections of the tax code. The legislative intent is to provide funding for disability-related expenses that will supplement, but not supplant, benefits provided through the Medicaid and supplemental security income programs. The legislation will follow many of the requirements and regulations of a traditional 529 college savings plan.

Qualified individuals will be eligible to accumulate up to \$100,000 in their accounts without interrupting SSI benefits. Additional safeguards are in place to ensure that Medicaid eligibility is not lost if a beneficiary exceeds \$100,000. However, SSI benefits would be suspended for individuals who exceed that threshold. The legislation will require a Medicaid payback of any funds that remain in a beneficiary’s account upon his death. This common sense concept has been supported by the Heritage Foundation and in the [Washington Post](#) editorial pages and is a first step to ensure that the disabled are not confined to a life of poverty when they require public benefits.

The next President should fully support the enactment of this legislation and sign it when it reaches his/her desk.

### **III. The Pledge**

The public health crisis posed by autism requires an extraordinary response and priority decisions in the allocation of resources, and deserves Presidential recognition as an urgent national public health priority. With every new diagnosis of a child with autism adding another \$3 million in lifetime costs, we cannot afford to rely on “business as usual” practices. The autism crisis demands a focused, coordinated, and accountable response by our public health agencies, similar to the federal response to the AIDS crisis in the 1990s.

Autism Speaks is seeking a pledge by all candidates for President in 2012 to implement the policy blueprint laid out in this statement.

#### **IV. About Autism Speaks**

Autism Speaks is North America's largest autism science and advocacy organization. Since its inception in 2005, Autism Speaks has made enormous strides, committing over \$160 million to research and developing innovative new resources for families. The organization is dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. In addition to funding research, Autism Speaks has created resources and programs including the Autism Speaks Autism Treatment Network, Autism Speaks' Autism Genetic Resource Exchange and several other scientific and clinical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2, which Autism Speaks celebrates through its Light it Up Blue initiative. Also, Autism Speaks award-winning "Learn the Signs" campaign with the Ad Council has received over \$286 million in donated media. Autism Speaks' family resources include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit, a Grandparent's Guide to Autism, and a community grant program. Autism Speaks has played a critical role in securing federal legislation to advance the government's response to autism, and has successfully advocated for insurance reform to cover behavioral treatments in the states. Each year *Walk Now for Autism Speaks* events are held in more than 80 cities across North America. To learn more about Autism Speaks, please visit [www.autismspeaks.org](http://www.autismspeaks.org).