



The Autistic Self Advocacy Network

**Dear President-elect Obama:**

On behalf of the Autistic Self-Advocacy Network, we would like to provide your office with the attached policy recommendations addressing our top three public policy priorities for the new administration, as per the request made by your transition team. The Autistic Self-Advocacy Network is an international civil rights advocacy organization of autistic people across the lifespan advocating for our community in public policy, service-delivery, research and media representation. Our organization is unique amongst autism advocacy groups in that we are run entirely by and for autistic people, the all too often unheard stakeholder in autism policy.

We want to applaud your efforts to ensure that this will be a fully inclusive and transparent transition process and hope that the same spirit will govern the upcoming administration. As 2009 begins, autistic people across the country and the world continue to face many obstacles preventing the full realization of quality of life, communication, rights and opportunity. The public conversation about autism continues to be one that is held largely without autistic people, who should be the central stakeholder. It is necessary to implement the central tenet of the disability rights movement, "Nothing About Us, Without Us," in our community. Furthermore, numerous service-delivery and rights protection infrastructures designed to protect individuals with disabilities are not yet proficient at meeting the needs of autistic people across the lifespan. This must change. At the same time, it is also important that we not disconnect autism issues from the values and principles of the cross-disability rights movement. With that in mind, we have been active participants in the consumer-led Disability Leaders Caucus alongside other disability rights organizations such as the American Association of People with Disabilities, the National Coalition for Disability Rights, the Special Olympics and other groups. We wholeheartedly endorse and are proud to have helped to develop the recommendations of that coalition alongside our own more specific recommendations focusing on the top three priorities of the autistic community.

Our top three priority areas are as follows:

- 1. Support and Empower Autistic Adults**
- 2. End School Abuse and Ensure a Free and Appropriate Public Education for All Students on the Autism Spectrum**
- 3. Balance the Research Agenda to Support Quality of Life**

We have included a one page description of each priority area as well as recommendations on specific means of policy implementation. Please feel free to write to us if you have any follow up questions and we look forward to continuing to be a part of the policy process under the incoming Obama Administration.

Regards,

Ari Ne'eman  
President  
The Autistic Self Advocacy Network  
1660 L Street, NW, Suite 700  
Washington, DC 20036  
<http://www.autisticadvocacy.org>  
[info@autisticadvocacy.org](mailto:info@autisticadvocacy.org)  
732.763.5530



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## **Support and Empower Autistic Adults:**

Current CDC statistics estimate the ratio of autism spectrum diagnoses amongst children at 1 in every 150. Systems designed to meet the needs of adults with disabilities are unprepared to deal with the large numbers of identified students on the autism spectrum preparing to transition into secondary and post-secondary environments. We must work to help high schools and adult services infrastructures meet the needs of autistic adults.

Furthermore, a growing number of studies analyzing factors such as diagnostic trends, IDEA statistics and other factors suggest that rather than an "autism epidemic" what we are seeing is increasingly accurate diagnosis of previously un- or mis-identified individuals due to better diagnostic criteria and awareness. As such, there exists a large population of un-diagnosed or only recently diagnosed autistic adults whose needs must be met.

We recommend the following:

- ***Ensure that autism health insurance reform addresses the needs of all autistic people – including coverage of methodologies such as speech and occupational therapy and Augmentative and Alternative Communication (AAC), as well as adult needs such as mental health services and vocational counseling programs.***
- ***Increase capacity of existing disability service-delivery and rights protection infrastructures to meet the needs of adults on the autism spectrum by:***
  - Ensuring that future re-authorizations of the DD Bill of Rights Act, the Rehab Act, IDEA and other major disability service-delivery and rights protection laws incorporate language requiring covered infrastructures to increase capacity and expertise needed to serve individuals on the autism spectrum across the lifespan.
  - Work with Congress to Pass and Implement an Emerging Needs Protection & Advocacy Program as well as other initiatives discussed in Sen. Clinton's Expanding Promise for Individuals with Autism Act. (S.937)
  - Fund pilot programs to develop models for emulation on issues like employment supports, housing, social supports, post-secondary transition, community integration and other issues of importance to autistic adults.
  - Appoint individuals knowledgeable in autism spectrum issues to lead OSERS, OSEP, ODEP, the DOJ Disability Rights Section and the EEOC.
- ***Aggressively enforce disability discrimination laws in regards to autistic people across the lifespan.***
  - Direct the EEOC and DOJ to develop technical assistance materials outlining the rights of and frequent accommodations for autistic adults in contexts such as employment and interaction with police.
  - Fund an extensive outreach program to inform autistic adults and families about relevant rights.
  - Convene an inter-agency advisory group on the civil rights of autistic people across the lifespan, including representatives from self-advocacy and family organizations.
- ***Work to address the lack of physicians knowledgeable enough to accurately diagnose adults on the autism spectrum by providing funding to improve medical education about the autism spectrum across the lifespan.***
- ***Provide states with incentives to address the needs of autistic adults of all kinds across the lifespan. Models to explore include the Pennsylvania Bureau of Autism Services and the Florida CARD system.***
- ***Ensure that all task forces, commissions, committees and other entities tasked with making autism policy include substantial representation from autistic self-advocates.***



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## **End School Abuse and Ensure a Free and Appropriate Public Education for All Students on the Autism Spectrum**

Our nation is facing a critical civil and human rights issue with respect to the education of students on the autism spectrum. The frequent use of restraints, aversives and seclusion place students with disabilities, including those on the autism spectrum, in the position of being abused in the name of treatment. Students with disabilities are at risk and students on the autism spectrum, who often have significant challenges in communication and social interaction, are at particular risk of many kinds of abuse. States across the country continue to allow methods that include prone restraint, electric shock, slapping, seclusion and other unethical and dangerous methods. This must end.

Despite a requirement that all students with disabilities be educated in the “least restrictive environment”, students on the autism spectrum continue to face rates of school segregation over three times higher than those faced by other students with disabilities. For too many students, the promise of inclusion remains far away. Not only has enforcement of relevant special education law civil rights provisions been lax to non-existent in many jurisdictions, but recent judicial decisions have weakened the ability of parents to fight for the rights of their children.

We recommend the following:

▪ ***All federal laws and regulations which protect persons - of all ages - with disabilities from abuse in institutional and treatment settings must also be applied to schools - all schools: public, private, day, residential.***

-Issue an Executive Order implementing circuit court decisions stating that the Developmental Disabilities Bill of Rights Act applies to schools and should be enforced through all available measures. Clarify that aversives, seclusion and non-emergency restraint are in violation of the DD Bill of Rights Act.

-Place responsibility and budget funds for enforcement of laws protecting students with disabilities from abuse in HHS rather than USDOE, as HHS is better equipped to ensure proper enforcement.

-Fully fund the Protection & Advocacy (P&A) system. Have USDOE instruct state DOEs not to retaliate in funding against P&A agencies for seeking to enforce the law against schools that violate it.

▪ ***Transfer responsibility and budget for enforcement of IDEA complaints from USDOE Office of Civil Rights to the USDOJ Civil Rights Division. Failing this, transfer responsibility for complaints including acts of retaliation and intimidation against parents by school districts to USDOJ to address the more egregious illegal activity.***

▪ ***Ensure that IDEA is fully funded and that implementation of said full funding comes along with program and fiscal audits of IDEA funds to ensure effectiveness, quality and freedom from abuse in implementation. Precedent for program and fiscal audits of federal education funds exists from similar auditing in NCLB.***

▪ ***Create a National Technical Assistance Center on Autism Education within USDOE to provide technical assistance to school districts on effective and inclusive educational practices for students on the autism spectrum and to develop teacher training programs to help prepare teachers for all subjects and grades on the needs of students on the autism spectrum.***

▪ ***Restore IDEA’s due process rights, allow reimbursement to prevailing families for expert fees, and place the burden of proof in IDEA challenges on school districts.***

▪ ***Instruct the Office of Special Education Programs to issue a “Dear Colleague:” letter clarifying that students should be eligible for an Individualized Educational Plan on the basis of social as well as academic challenges.***

▪ ***Instruct USDOE to embark upon a nation-wide bullying prevention program through the use of technical assistance to schools and the funding of studies on effective means to reduce bullying, harassment and violence.***



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## **Balance the Autism Research Agenda to Support Quality of Life**

The autism research agenda has been near-exclusively focused on causation and cure, two priorities out of step with the needs and desires of the autistic community. In the year 2008, only approximately 1% of the NIMH autism research budget was allocated towards services-research. In the private foundation sector, the situation is similar, with autism services and education research vastly underfunded in favor of causation and cure research with little impact on quality of life. The priorities reflected in the current autism research agenda send a concerning message.

Research that focuses on discovering and eliminating autism both enters the dangerous and unethical realm of eugenics and avoids addressing the social barriers that autistic people face that prevent quality of life and full participation and inclusion in society at large. Balancing the autism research agenda to focus on quality of life will pay dividends by providing evidence on the most effective methods of delivering services and providing for an effective education across the lifespan. Such a research agenda would compliment other aspects of federal disability policy, such as de-institutionalization mandated under *Olmstead v. L.C.*, the IDEA and NCLB requirements for evidence- and research-based methodologies, the IDEA “Least Restrictive Environment” right and increased numbers of individuals with disabilities, including the autism spectrum, in the workforce.

We recommend the following:

- ***Require that no less than half of the federal autism research budget across all departments and agencies, including NIH, CDC, HRSA, HHS, DOL and others, be allocated towards services-research.***
- ***Pursue a vigorous quality of life autism research agenda focused on issues such as improved service-delivery methodologies, social barriers to full participation and quality of life, effective systems change models, means of effectively and respectfully addressing social, behavioral, emotional and other challenges, empowering communication and other priorities.***
- ***Mandate that the Inter-Agency Autism Coordinating Committee (IACC) include representation from autistic self-advocacy organizations, such as the Autistic Self-Advocacy Network, and that there exist parity between the number of parent, provider and self-advocate representatives in the public membership to the IACC.***
- ***Fund research into Augmentative and Alternative Communication (AAC) options for autistic people across the lifespan, including Assistive Technology, so as to empower all autistic people to meaningfully communicate.***
- ***Establish a moratorium on federally funded autism-related genetics research until ethical concerns surrounding a possible pre-natal test and eugenic abortion are addressed to the satisfaction of the autistic community.***
- ***Allocate no less than one third of the federal autism research agenda towards the needs of adults on the autism spectrum, addressing the near total lack of research funding towards the needs of this population to date.***
- ***Fund Community-Based Participatory Research (CBPR) models including autistic self-advocates as full partners at every stage of the research process, from topic selection to study design and implementation. Look to existing projects as models, such as the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE – <http://www.aaspireproject.org>).***
- ***Provide for Student Loan Forgiveness for services-related and quality of life/participation-based researchers that is comparable to the loan forgiveness offered for researchers who work on basic science research.***
- ***Look to research funded by the National Institute of Disability and Rehabilitation Research (NIDRR) as a model for autism research priorities.***