

[Address to Florida Autism Task Force on World Autism Day](#)

Category : Self Advocacy and Representation

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Thank you for this opportunity to address the first meeting of the Florida Autism Task Force on today, the first World Autism Day. My name is Ari Ne'eman and I am here today in my capacity as the President of the Autistic Self Advocacy Network (ASAN), a volunteer non-profit organization run by and for adults and youth on the autism spectrum. ASAN works to promote the autistic culture movement and other opportunities for individuals on the autism spectrum to interact with each other as well as work to improve the representation of the autistic community in public policy deliberations about autism and disability affairs.

The autism spectrum is broad, diverse and subject to many stereotypes. Just as we work to combat generalizations about racial, religious, national or other minorities, it is only right to avoid a stereotyped view of autism. There are speaking and nonspeaking people on the autism spectrum; people currently capable of living independently and holding competitive employment and those with more significant support needs before those goals are conceivable to them. There are those of us who have held diagnoses since childhood and those of us who were identified later in life, serving to correct an inaccurate previous diagnosis that had placed us in the wrong educational or service-delivery infrastructure. To claim, as some continue to do, that we on the autism spectrum are all incapable of speaking for ourselves is an ignorant and damaging falsehood. Equally harmful is the idea that autistic people are all geniuses or savants, with Rain Man-esque abilities. As someone with an autism spectrum diagnosis myself, I hope to address some of these misconceptions, explain a bit more about our community and inform those assembled here today about the public policy priorities – and concerns – of the autistic self-advocacy movement. In doing so, I hope to communicate to you that, contrary to the unfortunate paradigm that has pervaded the media discourse about us, autism is not a tragedy. We are, as with any other minority, a community with unique needs, strengths, challenges and aspirations that are often distinct from the parent or professional voices that speak about us, without us. The true tragedy is the persistent discrimination, abuse and lack of access that continues to govern society's approach to us. On this, the first ever World Autism Day, we assert that it is this prejudice – not autism itself – that we have a true interest in combating, in the interest of ensuring for every person the rights of communication, inclusion, self-determination and respect.

I was diagnosed on the autism spectrum, specifically Asperger's Syndrome, at age 12. Growing up, I spent time in both inclusive and segregated educational placements. My own negative experiences with segregated educational environments led me to become an advocate for my own educational inclusion and later for the inclusion of other students with disabilities. These experiences motivated me to found the Autistic Self Advocacy Network, an international grassroots advocacy organization of adults and youth on the autism spectrum. ASAN's work has involved me in a number of areas of public policymaking that are important to people on the autism spectrum, some of which I will outline here.

In determining how best to develop a system that provides for the educational, service-delivery and other needs for individuals on the autism spectrum, it is imperative that self-advocates be recognized as the central stakeholder in this discussion. I'm happy to see Florida creating an Autism Task Force

to identify what needs to be done in the areas of education, services, supports and research, however I am saddened that the task force did not provide for representation from people on the autism spectrum ourselves. During my time in Florida, I will be working to create a chapter of the Autistic Self Advocacy Network. I encourage the members of the Task Force to communicate with us in their deliberations. Future policymaking bodies relating to the autism spectrum and disability issues more generally must include self-advocates. We know our own needs best and no policymaking process can be legitimate without including those who it purports to serve. Nothing About Us, Without Us!

One of the key areas of unmet need for the autistic community – the community of those of us actually on the autism spectrum, as opposed to the parents and professionals who make up the frequently discussed autism community – is in the area of diagnosis. As many of you familiar with the autism field are aware, we have been seeing a steady increase in the reported incidence of the autism spectrum, with the most recent update pointing to an incidence of 1 in 150 from a previous 1 in 166. The reason for this increase in reported incidence is not an "autism epidemic" or any other causation theory that seeks to promote the false idea of autism as a contagion or a force that "steals" an otherwise normal child. This disease-oriented model is not supported by either science or our own experiences. What we are seeing is an increase in awareness of the autism spectrum, resulting in more accurate diagnosis identifying individuals who previously were placed within the mental retardation, mental illness, learning disability or other educational and service-delivery infrastructure. This is a situation that I myself experienced, having been diagnosed on the autism spectrum after having an inaccurate ADD diagnosis for years prior. It is also something that is experienced by many other adults and youth on the autism spectrum in a far more damaging fashion, as a result of the frequent institutionalization and presumption of cognitive inability that far too many autistics continue to suffer from today.

The rapid increase in autism spectrum diagnoses has accompanied repeated broadening of the diagnostic criteria for the autism spectrum, incorporating more information about the diverse manifestations of our neurological type. In addition, the past few decades have resulted in a decrease in the stigmatization of parents of autistic children, as a result of the medical community moving away from the odious and damaging inaccuracy that autism is the result of "refrigerator mothers". This, combined with increased services and supports available for the autism spectrum, has resulted in more autism spectrum diagnoses. These increasing numbers, however, fail to take into account the substantial number of individuals on the autism spectrum who, as a result of a lack of health care access and/or professionals trained in the diagnosis of adults as well as problems with inaccurate diagnostic criteria, are unable to find the resources to acquire the diagnosis that would accurately describe their characteristics and enable them to qualify for services. It is necessary that we increase the availability of accurate information relating to the autism spectrum in reference to adults and youth.

There remains a shocking lack of awareness for the needs – and even the very existence – of autistic adults. In many circles, it is assumed that autism is something relevant only to children and as a result legislation and policymaking has been focused mostly on early childhood. However, there is a large population of adults and adolescents on the spectrum with needs that are not being met. In areas like employment accommodations and other aspects of disability service-delivery, adults on the spectrum are frequently unable to access the supports that are currently available, due to a lack of knowledge of our particular needs. Many of us, as is the case for others with less obvious, "invisible" disabilities, face pervasive employment discrimination as a result of communication difficulties. Vocational Rehabilitation agencies in many states are unaware of how to address these

issues, due to the fact that while many of us have the skills for competitive employment, difficulties with transportation, the interview process and the social aspects of the workplace can often interfere with holding a job. It is important not only to educate the general public about autism, but also disability service-delivery professionals who are too often unfamiliar with our population.

Many adults on the autism spectrum continue to suffer in institutions, despite the Supreme Court decision of *Olmstead v. L.C.*, promising community living options for adults with disabilities. In my work on New Jersey's Olmstead Implementation and Planning Advisory Council and with ASAN chapters across the country, I have seen a consistent lack of knowledge of the unique needs of adults on the spectrum when planning community living options. Many of us have difficulties with certain kinds of sensory environments – a lack of awareness of these issues on the part of those planning and implementing the transition into the community can result in problems with the de-institutionalization process. These and other aspects of community living show the need for significant representation of self-advocates in the policymaking process, to ensure both the legitimacy of the process and the creation of the most effective possible public policy strategies.

Autism training for law enforcement (as well as other emergency personnel) remains a key issue. Many of us possess significant difficulties with communication, particularly in high-stress and anxiety-provoking situations. What happens when a person who cannot speak out loud when under stress is approached by a police officer and asked for personal information? What about when a person fails to understand instructions given to stop or engages in an activity that is interpreted as aggressive? There have been numerous incidents of serious injury and even death as a result of a lack of knowledge on the part of law enforcement personnel about autism and other disabilities. This must be rectified and has been the source of legislation in a variety of states across the country. High-quality training for law enforcement and other emergency personnel does exist and it should be utilized in every locale.

For many adolescents on the spectrum and our families preparing to transition out of the school is a process with little guidance or support. When I was preparing to leave high school, my school did not provide sufficient information on the college applications process because it was assumed that as a special education student, my options were limited. While it is certainly the case that not every student on the spectrum – or every student generally – will be able to attend university, more of us are having that opportunity. It is necessary to see more of a focus on college transition for students on the autism spectrum in both high schools and universities. One of the areas that is frequently ignored in this process is that of "soft skills" related to day to day living. Many of ASAN's parent members frequently are told that issues relating to life skills are not the obligation of school districts, despite the fact that this type of education is just as necessary for students to succeed as the more traditional forms of academics. The communication and executive functioning difficulties that those of us on the spectrum face compound the traditional difficulties that new college students face. In fact, these issues – as well as the matter of transition more generally – are relevant for all students on the spectrum, whether or not college is a possibility. For a successful transition to a post-secondary environment of any kind, basic life skills need to be understood. It is essential that steps be taken to incorporate these elements into the school curriculum in an inclusive fashion.

In a broader sense, educational needs for students on the spectrum must be given additional focus. There has already been a productive discussion on the issue of early childhood educational methodologies. It is important to keep in mind that any educational intervention should be aimed at the acquisition of skills, not trying to enforce an arbitrary standard of normalcy. Efforts should not be aimed at the undesirable and impossible goal of trying to make autistic individuals non-autistic.

Instead, education should be aimed at addressing the significant disabilities many of us face with the goal of improving quality of life. We also have to ensure that our educational methods avoid utilizing abusive and dangerous techniques in the name of treatment. The use of aversive interventions, the application of pain as a means of behavior modification, should be considered unacceptable in any society that aspires to be termed civilized. As a result of aversives and abusive restraint practices, many students and adults in institutions are injured or even killed each year. This must stop. We need a full ban on the use of aversives and non-emergency restraint as well as an end to out-of-state placements that put students in facilities that utilize these barbaric methods.

We also have to face up to the persistent problem of bullying and its negative effect on the mental health of all students. Students on the autism spectrum are particularly vulnerable to bullies due to the social literacy issues we tend to have. When I was in school, bullying was one of the reasons I spent a period of time away from my home school. This is a common situation for students on the spectrum and represents a grave obstacle to our legal right of a "free and appropriate public education in the least restrictive environment". I know that the success that I have achieved today would not have been possible had I not returned to an inclusive school setting where I learnt more about how to successfully adapt to the world around me. Yet, as a result of bullying, many students face serious emotional or physical injury if they remain in their home schools. This also must be stopped. Florida remains one of a handful of states without true anti-bullying legislation. I urge the legislators and activists here today to address this problem.

Finally, I turn to the more controversial area of research. Here, the autistic self-advocate community holds strong views that may clash with those of some of the interest groups assembled today. The persistent focus on both causation and cure in the autism research agenda has left promising areas of research ignored which could positively impact the quality of life for those of us on the spectrum. Despite extremely encouraging possibilities in the realm of Assistive and Augmentative Communication (AAC) technology for many individuals on the autism spectrum, research in this area is given little to no funding. The development of best practices in service-delivery and education is too often ignored. Mental health needs, restraint reduction, health care access, transition, adult supports and a variety of other educational and service/support needs could all benefit from more research into best practices and effective methodologies. Yet quality of life-oriented research in general is underfunded. If we spent one-tenth of the money and attention we currently lavish on the idea of an autism cure on communication technologies, countless, nonspeaking autistic people would be able to communicate today. The fact that we have not pursued promising avenues of research into communication possibilities should be a source of great concern to us as a society.

There are also concerns that we have about the type of research that is being funded. The autism spectrum represents a natural and legitimate part of human genetic diversity. As a result, efforts to identify genes associated with autism with the goal of developing a prenatal test, enabling the possibility of selective abortion, should be met with opposition from all those concerned about the issue of disability rights. Given the fact that 90% of fetuses that test positive for Down Syndrome are aborted and there exists a similar social stigma against the autism spectrum, I urge both private foundations and government research institutions to re-orient their funding away from research with eugenic applications. While we have no position about the broad issue of abortion, the issue of eugenics is of great concern to us.

Thank you for your time. If we as a society seek to fulfill the values we espouse, we must take practical steps to establish ourselves as a culture that respects neurological diversity in the same way that history has shown us to respect racial, religious, national and other forms of diversity. We

on the autism spectrum can make significant contributions to the world around us and, with the right supports, services and education, we can and should be active and participating members of society. By pursuing the goals of inclusion, respect and access, we can make that a reality. I'd like to end with a quote from Jim Sinclair, the founder of Autism Network International (ANI), the first autistic self-advocate organization and a group from which much of the growing autistic culture developed from. ""The tragedy is not that we're here, but that your world has no place for us to be." Today, on the first World Autism Day, I encourage all of us to think about what we can do to change that unfortunate reality and pursue a policy of autism acceptance, now and into the future.

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Ari Ne'eman
President
The Autistic Self Advocacy Network
1101 15th Street, NW Suite 1212
Washington, DC 20005
<http://www.autisticadvocacy.org>
732.763.5530