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**Advancing the Rights of Persons with Disabilities:  
A US-Iran Dialogue on Law, Policy, and Advocacy**

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# **Autism and Disability Discourse and Policy in the Comparative Perspective**

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## **Introduction**

Over the course of the last decade, the public profile of the autism spectrum has grown at a far quicker pace than that of any other disability category. Public Service Announcements, celebrity charity events, fundraising walks, and all manner of other means of raising money and “awareness” associated with the autism spectrum have increased markedly, tracking rising incidence statistics for the autism spectrum provided by the Centers for Disease Control and Prevention (CDC). It is difficult to think of a television show that has not had a “very special episode” or a movie star that has not lent their name to some facet of “the cause” at one point or another. Over the course of the last decade, hundreds of millions of both public and private dollars have been invested in autism research and autism has been one of only a select few disability categories to have legislation pass Congress specific to a particular diagnosis.

Yet, despite the rising public attention to this particular developmental disability, the national and international conversations on autism have been largely segregated from other disabilities and developmental disabilities. As autism’s public profile has risen, the likelihood of autism issues being considered separately from those relating to the broader developmental disability category has drastically increased. This raises the question: has the relatively high profile autism has received relative to other disability categories within the “developmental disability” space resulted in greater quality of life for individuals on the autism spectrum? This paper aims to answer some of these questions by outlining the major differences in American policy and public discourse with respect to the autism spectrum as compared to policy and discourse related to other disability categories and seeks to ascertain if individuals on the autism spectrum enjoy improved life outcomes as a result of these differences.

## **How does the discourse on autism differ from the general disability discourse in the United States?**

On January 18, 2011, the Inter-Agency Autism Coordinating Committee, a federal advisory committee tasked with providing recommendations to the Secretary of Health and Human Services, met in Rockville, Maryland (Interagency Autism Coordinating Committee). Among the tasks of the Committee on that particular date was to review and finalize its annual Strategic Plan for Autism Research, one of the few duties statutorily mandated

to the IACC by its authorizing statute, the Combating Autism Act.<sup>1</sup> As the discussion commenced, one of the issues under debate was whether or not to include the idea of self-determination—the idea that people with disabilities should be able to make decisions about their own services, supports and public policies—as a cross-cutting theme in the plan. The idea of self-determination is well established in the developmental disability community—in fact, the Developmental Disabilities Assistance and Bill of Rights Act makes reference to it throughout the text of the legislation. Despite this, the concept was resisted by several members of the IACC. In fact, the final vote came very close to defeating the measure—only two defections would have been required to turn the 12-8 vote into a deadlock. How did a concept so universally acknowledged in one part of the disability community become so controversial in another part?

Some explanation may be found in the different character of the public discourse on autism as compared to the general developmental disability and broader disability discourse. The national conversation on autism which has emerged in the United States is very much distinct in tone, values and inclusivity of the population being discussed from dialogues associated with other disabilities. Such distinctions can be observed clearly in American political, policy and legislative proceedings as well as in the character of language around autism and disability at the United Nations.

An instructive example of the disconnect between general disability and autism policy can be found in a cursory review of successful and unsuccessful disability and autism legislation in the United States Congress. The Americans with Disabilities Act of 1990 (ADA) is generally considered the nation's landmark disability civil rights law, outlining not only clear and specific legal non-discrimination protections for people with disabilities, including a right to reasonable accommodations, but also providing a conceptual framework for disability policy writ large. The findings of the ADA clearly communicate the intent of Congress that disability be viewed as a civil rights issue. To quote the last two findings of the ADA's text upon initial passage:

8) The Nations proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and

9) The continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity.

Such language clearly places the onus for change on society and identifies the problems associated with disability as caused by discrimination and prejudice, rather than necessarily by particular medical conditions themselves. Contrast this approach with the language surrounding autism legislation. In 2006, Congress passed legislation known as the “Combating Autism Act,” allocating funding primarily to the National Institutes of Health

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1 Full Disclosure: The author is a member of the IACC and participated in this discussion, as reflected in the minutes of the meeting on that date.

around medical research aimed at developing a “cure” for the autism spectrum. In the words of one ardent advocate for the legislation, the co-founder of Cure Autism Now, a national parent group which would later merge with Autism Speaks, “this bill is a federal declaration of war on the epidemic of autism” (Autism Speaks, Inc., 2006). The bill focused almost entirely on research and epidemiological surveillance, with few investments in improved service-provision. At least part of the explanation for this singular focus on medical cures can be found in how those advocating for the Combating Autism Act defined the problems associated with autism. To quote the Autism Speaks website, “Autism costs the nation over \$35 billion per year, a figure expected to significantly increase in the next decade.” This approach, unlike the ADA approach which defines costs on society as resulting from “the continuing existence of unfair and unnecessary discrimination and prejudice,” leads to an exclusive emphasis on eliminating autism rather than improving the lives – and thus the opportunity to contribute to society – of individuals on the autism spectrum. Indeed, while subsequent autism legislation taking a civil rights focus, such as the Expanding the Promise for Individuals with Autism Act of 2007, was introduced, it failed to advance through the Congress in part because of the lack of interest in advancing it from the autism non-profit establishment as compared to priorities relating to medical research.

To further explore the comparison, it may be valuable to compare the Combating Autism Act and the Developmental Disabilities Assistance and Bill of Rights Act (heretofore referred to as the DD Act). Unlike the ADA, the DD Act is a funding bill rather than one creating legal rights—as is the Combating Autism Act. Furthermore, both the autism spectrum and the developmental disability categories include significant numbers of individuals with significant impairments in communication and intellectual capability. In fact, the autism spectrum is generally considered to fall within the scope of the developmental disability category. The DD Act, first passed in 1970, created a network of public interest law firms (called “Protection and Advocacy programs”), Planning Councils and university-based research programs aimed at enhancing the quality of life of individuals with developmental disabilities from childhood to adulthood. The DD Act also makes available funds for “projects of national significance,” typically used for innovative research and service-provision with the ability to develop models that can make a practical impact on the lives of people with developmental disabilities and family members. In short, the DD Act is focused on both research and services and explicitly acknowledges the needs of individuals with developmental disabilities across the lifespan.

By contrast, the Combating Autism Act is far more limited in its goals and scope. The act primarily funds research and surveillance activities aimed at identifying causes and etiology of the autism spectrum. In so far as the act does focus on services—through the expansion of the Leadership and Education in Neurodevelopmental Disorders programs (which existed prior to the CAA)—it does so only in the context of young children. Indeed, the Health Resources Services Administration’s autism work is done within the context of its Maternal and Child Health Division – meaning that addressing the needs of adults on the autism spectrum is outside of its mandate. This is a marked difference from the policy direction set out by the DD Act.

These distinctions have emerged in international forums as well. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is structured around eight guiding principles:

1. Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
2. Non-discrimination;
3. Full and effective participation and inclusion in society;
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
5. Equality of opportunity;
6. Accessibility;
7. Equality between men and women; and,
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

These abstract concepts are carried out in specifics through the various articles of the Convention, including Article 8—which calls for public awareness campaigns promoting positive perceptions of and greater recognition of the skills, merits and abilities of people with disabilities, and Article 29—promoting the inclusion of people with disabilities in non-governmental organizations and in self-advocacy organizations run by and for people with disabilities (CRPD). Although the majority of the convention deals with more concrete matters of policy such as the availability of reasonable accommodations or the provision of services and supports in integrated community settings, the Convention also addresses the importance of including people with disabilities in all aspects of the public discourse on them and stresses the need for public conversations on disability which are respectful, inclusive and in keeping with the values of the Convention.

In contrast, autism discussions at the United Nations have proceeded from a very different framework. While the General Assembly Resolution establishing April 2<sup>nd</sup> as World Autism Awareness Day did make reference to the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities, the content of much of the autism conversation at the United Nations has been through a public health rather than a civil rights framework. In addition, it seems that the standards of respectful discourse are very different when discussing autism as compared to other disability groups. For example, in September of 2009, a gathering of First Spouses at the United Nations were shown a video pulled together by Autism Speaks, the largest and best-funded autism advocacy group in the United States, entitled, “I am Autism” (Autism Speaks, 2009). The video consisted of a disembodied voice announcing:

“I am autism. I'm visible in your children, but if I can help it, I am invisible to you until it's too late...I speak your language fluently. And with every voice I take away, I acquire yet another language....I work very quickly. I work faster than pediatric aids, cancer, and diabetes combined. And if you're happily married, I will make sure that your marriage fails. Your money will fall into my hands, and I will bankrupt you for my own self-gain. I don't sleep, so I make sure you don't either. I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without

embarrassment, without pain.... I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness...I will fight to take away your hope. I will plot to rob you of your children and your dreams.” (Autistic Self-Advocacy Network, 2009).

The video sparked a horrified response amongst autistic adults and youth, leading to nationwide protests of Autism Speaks fundraisers, and an advocacy campaign utilizing bloggers, social media and on the ground advocacy leading to the successful removal of the video from the internet (Biever, 2009). However, it is surprising and instructive to see that a video which could spark such a strong response from the individuals with the disability it aimed to represent would have been placed in such a position of honor in an international forum. One possible explanation may relate to the different processes that autism and general disability policy conversations have taken at the United Nations and elsewhere. While a wide array of different non-governmental organizations, including many run by people with disabilities, participated in the United Nations Convention on the Rights of Persons with Disabilities, most autism discussions at the UN have been driven by a single parent organization, Autism Speaks, which lacks any autistic individuals on its board of directors or amongst its senior leadership (Wallis, 2009).

### **What does the data tell us about the outcomes of autistic people in the United States?**

The National Core Indicators Consumer Survey Report is designed to provide data on the experiences of individuals with intellectual and developmental disabilities receiving publicly financed service-provision in twenty states. The NCI Survey reveals a number of concerning differences in the service-provision experiences of adults on the autism spectrum as compared to those with other developmental disabilities. For example, while the percentage of autistic persons with a co-occurring diagnosis of mental illness (18 percent) was far lower than that of persons without an autism diagnosis (28 percent), autistic people were vastly more likely to be taking every variation of psychotropic medications. The percentage of autistic adults under guardianship was twenty-one percent higher than people with other developmental disability diagnoses (NCI Data Brief, 2011). Autistic adults were also significantly more likely to receive labels such as “uncooperative” and “disruptive behavior” than individuals with other developmental disabilities and had substantially less choice and control over their own day- to-day lives (NCI Data Brief, 2011).

The aforementioned inequities also exist for younger autistic individuals. According to US Department of Education data, over a third of autistic students spend less than 40 percent of their day inside the general education classroom, as compared to under 10 percent of students with other disabilities (IDEA Data, 2011). Indeed, a national survey of high school students with disabilities found that autistic students spent over 70 percent of their academic courses in segregated settings (Institute of Education Sciences, 2007). Despite far greater public attention and political capital, autistic adults and youth face significantly worse educational and service-provision outcomes than other groups of people with disabilities in the United States. What can explain this inequity and is it related to the differences in societal approaches that exist when comparing autism to other disabilities?

## **What are some possible causes for the divide between autism and general disability discourse, policy, and outcomes?**

At this point, it may be worth considering the ways in which autism and disability policy have been shaped by the process of their development, specifically, the constituencies they were intended to serve. Passage of the ADA—and its predecessor the Rehabilitation Act—was the result of a broad-ranging effort which included family members, professionals and a wide range of supportive allies but was primarily led by disabled individuals. Section 504 of the Rehabilitation Act of 1973—an earlier law applying only to entities receiving federal funds which the ADA extended to the public at large—was enforced only by virtue of mass direct action led by groups of disabled people in 1977 to pressure the federal government into promulgating strong regulations implementing the law (Shapiro, 1994). While the Developmental Disabilities Act was passed mainly due to strong family advocacy, the community of families who led the effort was broad-based and included many who had adults with developmental disabilities in their families rather than just children.

The Combating Autism Act's passage can be traced back to the founding of Autism Speaks, an advocacy group mentioned earlier in this paper run near-exclusively by the parent and professional constituencies within the autism community. Autism Speaks was founded in 2005 by the then Vice Chair of General Electric and Chairman and CEO of NBC Universal Bob Wright and his wife Suzanne, who were motivated primarily out of a desire to cure their recently diagnosed autistic grandchild—one of the Wrights' first pronouncements upon forming Autism Speaks was, "I want my grandson back" (Wright, 2005). A review of the statements of Autism Speaks' founders show an almost exclusive interest in causation and cure research, as well as interventions aimed at young children. Furthermore, the tactics of the autism movement's most well-financed organization differ significantly from that of the broader developmental disability movement as well. Often, they have more in common with the corporate boardrooms from which Bob Wright emerged. Shortly after its founding, Autism Speaks swallowed up via mergers the two largest autism research organizations prior to its emergence—Cure Autism Now and the National Alliance for Autism Research (Gross & Strom, 2007). Soon after, NBC's television and print media served as effective mechanisms to amplify the organization's message, focusing primarily on the views and experiences of its founders, such as "Suzanne Wright Discusses New Autism Speaks Awareness Campaign on Today Show, MSNBC." (Autism Speaks). The media blitz elevated autism above other diagnoses in the popular mind, leading—along with the lobbying power of Autism Speaks more generally—to the passage of the Combating Autism Act soon afterwards.

This history helps clarify the disconnect outlined earlier. Much of the divide between the disability and autism narratives in the United States can be attributed to the lack of inclusion of Autistic people themselves in the policy and public discussions around the autism spectrum, in contrast to the generally more inclusive discussions in the world of general disability policy. People with disabilities—by virtue of experiencing the challenges of interacting with a world all too frequently designed for the non-disabled—are much more likely to prioritize the gains in quality of life that can be acquired through the civil rights and services/supports framework adopted by the UN Convention on the Rights of Persons with Disabilities. In contrast, parents—particularly parents of young children, who are over-represented in the autism world as compared to in other developmental disability

parent communities—are more likely to prioritize basic medical research and services focused on early childhood. The historic exclusion of self-advocates from autism policy discussions has shaped policy away from the needs of Autistic people living today, with the exception of young children, and towards a focus on causation and prevention. This is reflected in both the autism policy agenda, as described earlier in this paper, as well as in the autism research agenda, where the bias can be reflected statistically.

The IACC's 2009 Research Portfolio, an annual report which tracks the direction of all autism research dollars both public and private, found that only three percent of 2009 research dollars relating to ASD went to research focused on improving services and supports for individuals on the spectrum. A similar inequity existed for research focused around the needs and characteristics of adults on the autism spectrum, which only garnered less than one percent of research funding—as compared to 32 percent for research oriented around causation and prevention (Interagency Autism Coordinating Committee). In light of these inequities, it is unsurprising a recent study found as many as 40 percent of young adults on the autism spectrum lack access to any service-provision, even as public attention to ASD is at its highest (Shattuck et al., 2011). Indeed, reflecting the dominance of the parent narrative in autism policy, the few legislative and policy advances relating to the autism spectrum in recent years have been focused around insurance coverage for interventions in early childhood rather than improvements in service-provision across the lifespan.

In closing, an analysis of the practical results of the increased public attention to the autism spectrum in the United States yields very mixed outcomes and results in terms of meaningful improvements in quality of life for autistic adults and youth. The difference between political and social capital and results can be attributed at least in part to the marginalization of self-advocate voices from the United States' national autism policy conversation and the resulting differences in focus, priorities and values from the general disability and developmental disability movement. As the autism movement in the United States and internationally evolves and grows to reflect a changing population and demands by self-advocate stakeholders for a greater voice, it would be wise for greater consideration to be given to the positive role a more inclusive conversation has played in general disability rights and policy movements.

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