

**Testimony by
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Subcommittee on Africa, Global Health, Global Human Rights, and International Organizations

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Congressman Smith and members of the Committee...

It is my pleasure and honor to be asked to appear before you and to talk about what I believe is the most critical and important need for the over 3,000,000 individuals who have an autism diagnosis. My name is Theresa Hussman and I am a dedicated volunteer of the Autism Society of America, the nation's oldest and largest grassroots national autism organization. Our organization's president, Scott Badesch couldn't be here today since he is with over 1000 individuals attending our 45th annual Autism Society national conference in Indianapolis today.

With over 105 affiliates serving close to a 1,000,000 people each year, the Autism Society national network works each day to improve the quality of life for all who live with autism. We do this in ways that are outcome based and I am proud that we are fully inclusive, having individuals with autism, family members, professionals and community leaders in all parts of our governing and advisory boards. In addition to serving as a volunteer with the Autism Society of America, my husband, John and I are the very proud parents of four young adults, one of who has autism. Over the past decade we have been among the largest private funders of autism research and recently established the Hussman Institute for Autism, a research institute founded on the principle that people with autism have far more competence than they may be able to demonstrate or that society allows them to achieve.

I want to commend this committee, and especially the leadership of its Chairman Chris Smith for holding this important hearing.

A few years ago there was a video that went viral of a young man with autism named Jason McElwain who spent his high school years as the manager of his school basketball team, because of his passion for the game. In the last home game of his senior year, he was allowed to play during the last 4 minutes and 19 seconds, in which time he made 7 baskets, six of them as 3 pointers. While millions who watched celebrated that brief moment of opportunity, those of us who advocate for our loved ones with autism also asked why wasn't he on the court the whole season?

In school, at work and in the community, people with autism are often faced with segregation, low expectations, impoverished conditions and denial of opportunity that a society committed to civil rights should find unacceptable.

Today, if you are an adult living with autism, you will likely be unemployed or vastly under-employed, living well below the poverty level, and denied access to affordable housing and so much more. The most agreed-upon rate of unemployment or under-employment among adults with autism is close to

70%. Imagine for a minute if any other group of individuals had such a high rate of unemployment. While companies are now starting to move in the right direction to address this dire statistic including SAP, AMC Theaters, Walgreens, UPS, EMC Insurance and many more, the reality is that behind each of these statistics is the lack of our nation's attention to fully integrate those living with autism into the mainstream of society. Though universal access is often expected of buildings and stairways, our society has yet to build universal access into schools, curricula, workplaces, our hearts, or our minds.

A person living with autism has every right to be included in the mainstream of society. But, it isn't occurring. Ask almost any parent of a school age child with autism about their struggles with public school systems and they will tell you story after story about lack of inclusion, denial of rights, and inadequate educational supports. You will hear about schools that underestimate children with autism and limit their educational opportunities. While we watch the number of children diagnosed on the autism spectrum increase, we fail to prepare educators, paraprofessionals, and school administrators to properly support those students with autism. Yet every one of these professionals will come into contact with a student on the spectrum.

Many school districts and superintendents fight against laws that would regulate the harmful impact of restraints and seclusion on innocent students with autism, even though research has demonstrated that these approaches are entirely unnecessary when people with autism are provided with appropriate, positive behavioral support. Many colleges define their commitment to educational opportunities for a person with a disability as being little more than some extra time to take a test. It is rare to find a school leader who is held accountable by his or her governing board for the success of students with disabilities. Autism creates enough barriers for individuals to demonstrate their ability and to engage with their community. We need our nation to lower those barriers in every aspect of life, not to build them higher.

With respect to employment, too many public school systems and colleges are not addressing the educational and job skill development needs of students with autism, leaving adults with autism untrained or unprepared for employment. Fortunately, many employers are now beginning to advance their hiring of autistic adults, and they demonstrate that if given a chance, an adult with autism will be an outstanding employee.

Often times, the federal government reinforces the perception that individuals with autism, and for that matter any developmental disability, can't work in meaningful jobs. In his State of the Union address, President Obama suggested a \$10.10 minimum wage for workers paid for through federal grants and contracts. But it is so common to underestimate and marginalize workers with a disability, that they weren't originally part of this effort. Fortunately, many organizations, including the Autism Society advocated for inclusion of individuals with a disability in that executive order, and we are proud that the President finally assured inclusion of workers with a disability. Congress still also allows sub-minimal wages paid to individuals with a developmental disability in certain instances, based on archaic and inaccurate perceptions of what a person with a disability can and can't do.

At the Autism Society we believe that educational inclusion, employment opportunities, and equal participation in community life are civil rights. As in other civil rights struggles, our nation needs the moral conscience to embrace people with autism as different, and not less.

The answers are not difficult. First, we must ensure that every government agency and body respects the value and dignity of each person living with autism, or for that matter any disability. Second, we

must ensure that if a government entity is charged with helping all people, it does so in a way that is inclusive of those with autism. We must also ensure that public educational institutions are held accountable for seeing that students with a disability are provided the same level of educational opportunities as those without a disability. We know that those few educational institutions that do provide a high commitment to opportunity for students with a disability are showing that with support, a student with a disability can and will be a true success story.

A strong example is Marshall University, where Evan Badesch, the son of our organization's president attends. With proper support and Evan's amazing desire and commitment to obtaining a quality education, he is succeeding. That is because the university, from their wonderful president Dr. Stephen Kopp to all their faculty, are fully committed to ensuring that every student, regardless of their condition, can succeed. They see the value of such success and they know it is the right thing to do.

The Autism Society believes that we also must change the national discussion regarding autism from simply cause and cure to one of hope, acceptance, support, and opportunity. We can seek to improve the lives of people with autism without sending the message that they are not yet enough to be loved, valued, and accepted as they are.

Finally, and we believe this is critical, we must focus our efforts through a private/public partnership that does not rely on government to do it all. I again want to commend congressman smith who is working with us in addressing adult services in a way that assures maximum opportunities by advancing proven, best practices through a public/private effort. People with autism deserve more than four minutes of the game. Real change that embraces them into the mainstream of our society will only come when we all work together.

I thank you for your very important attention to this critical issue and I would be happy to answer any questions.