



THE GLOBAL CHALLENGE OF AUTISM

TESTIMONY PRESENTED TO THE HOUSE COMMITTEE ON FOREIGN AFFAIRS, SUBCOMMITTEE ON AFRICA, GLOBAL HEALTH, GLOBAL HUMAN RIGHTS, AND INTERNATIONAL ORGANIZATIONS

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Chairman Smith, Ranking Member Bass, members of the subcommittee, thank you for the opportunity to share Autism Speaks' experience working with autism communities around the globe.

My name is Michael Rosanoff, and I am the Associate Director of Public Health Research at Autism Speaks. Since 2007, I have managed the organization's epidemiology research portfolio, particularly research focused on measuring the prevalence and economic costs of autism in the United States and worldwide. I am also a member of the international scientific development team, helping lead Autism Speaks Global Autism Public Health Initiative, currently active in over 50 countries around the world. I am formally trained in public health and epidemiology, and have a personal family connection to autism.

Our mission at Autism Speaks is change the future for all who struggle with autism spectrum disorders. This can mean funding scientific research for those families struggling to understand the causes of autism. It can mean developing strategies to help those struggling to overcome barriers that limit access to effective services. Or it can mean providing support for those struggling to receive acceptance and opportunities to contribute to society.

Because autism knows no ethnic, cultural, or geographic boundaries, neither does Autism Speaks. In 2007, the United Nations adopted a resolution recognizing April 2nd as an annual day of World Autism Awareness. In response to the increase in awareness worldwide, and with it the increased demand for information and support, Autism Speaks launched the Global Autism Public Health Initiative in 2008. The objective: to develop sustainable, broad-reaching, and culturally sensitive programs that build local capacity for autism research and service delivery. This is accomplished through multi-directional knowledge transfer and multi-national collaboration among diverse stakeholder groups.

In just over five years our international team has traveled more than one million miles and spoken with hundreds of affected individuals, parents, professionals, and government officials. Today I would like to offer you some of our experiences and important lessons learned.

The autism community is diverse, with a diverse set of challenges *and* a diverse set of strengths. As autism is a lifelong condition, those challenges and strengths often change over the course of time. Thus, there is no single one-size-fits-all solution to improving lives of those touched by autism. Autism is not simply a health issue, but also an education issue, a social welfare issue, and a human rights issue. The most effective strategies are those that are comprehensive and multi-sectorial. For example, in developing a national strategy for autism in Bangladesh, the government established an inter-ministerial taskforce to implement a coordinated plan of action across eight government Ministries including Health, Education, Social Welfare, Labor, and even Finance. Because to achieve a truly inclusive society, autism is as much a Labor and Finance issue to increase employment opportunities, as it is an education issue to achieve inclusive classrooms.

Across countries, while cultures, belief systems, public health infrastructure, and resources may differ, all families around the world want the same for their loved ones with autism. Improved awareness to reduce stigma, statistics to know they are not alone and to advocate for policies, increased access to evidence-based services earlier in life and throughout life, and more opportunities for individuals with autism to reach their fullest potential in life and society, especially after their caregivers are gone. Common goals mean that common approaches can be effective across diverse settings, which makes cross-country collaboration and idea sharing so important.

Approaches do, however, need to be tailor fit to different country contexts. What may be an effective strategy in one country may simply not be feasible in another. Strategies must be adapted to fit the environment while maintaining their active ingredients. Today, the most practical and effective approach to increasing autism support is through community-based programs. The purpose of these programs is to relieve some of the demand placed on the few highly trained professionals in clinical settings, by transferring skills and knowledge to members of the community such as health workers, teachers, and parents.

To help create a package of care that is transferrable especially in low resource settings, Autism Speaks has teamed up with the World Health Organization (WHO) in developing an intervention guide and training program for the delivery of autism services by community health workers in non-specialized settings. This model is currently being used in Ethiopia as part of a project funded by Autism Speaks. As a result of the initial success of this program, the Ministry of Health of Ethiopia has made autism and mental health in general, national priorities. They are currently organizing a conference on the scaling-up of mental health services in the country. The WHO and Autism Speaks are also exploring models for parent training in the delivery of autism interventions. In fact, my colleague was in Geneva just this week for a working group on this topic.

These activities with the WHO were among those identified as priorities as part of an international consultation on autism spectrum disorders and other developmental disabilities.

The first of its kind meeting in the history of the WHO took place in Geneva last September. More than 75 representatives from nearly 50 different international organizations participated. Among the most discussed and highly prioritized issues were community inclusion and adult employment. This comes as no surprise considering that based on current best estimates of autism prevalence, every year, tens of thousands of children with autism become adults with autism. How are we preparing them for society and is there adequate opportunity for them to pursue employment and independent or assisted living?

In Geneva, we heard about innovative models for identifying unique talents of individuals with autism that would make them a valuable asset to an employer. Two of those models come from Specialisterne and SAP, both of whom you will hear from today. But there is nothing like seeing successful models of community inclusion in practice. In Bangladesh, I visited a center for individuals with disabilities in a small rural community on the outskirts of the capital city Dhaka. The community itself, surrounding the center, was one unlike any I had seen before. It looked like other roads I had seen elsewhere in Bangladesh with small shops and markets selling clothing and groceries. The difference was that individuals with disabilities, including intellectual disabilities and autism, staffed all of the shops. Not only were these individuals learning employable skills such as counting money at the register, but they were also bringing money into the community and, most importantly, raising awareness of disabilities.

I also had the great fortune to travel to Lima to visit the Centro Ann Sullivan de Peru, or CASP. CASP is a center for individuals with different abilities – not disabilities. It first opened its doors over 30 years ago in a garage and now has hundreds of current students and past graduates. The curriculum is community-based where 30% of services are delivered at CASP and 70% are delivered at home and in real-world settings. Students learn real-world tasks needed to survive in a city environment such as using mass transportation. That is a skill they will need to be able to get to and from a job. A goal for all of their students is to get a job. This is not just true for those with autism who are less severely affected. Even those with greater challenges often have or can learn skills that are attractive to employers. And these individuals can be successful in a career with the right support. Importantly, the staff at CASP works with members of the community, such as bus drivers and employers, to educate them about autism which in turn perpetuates a more inclusive society. In a resource poor country like Peru, it is not uncommon for graduates of CASP to actually become the family breadwinners, earning enough money to help support the entire family. Why couldn't this model work elsewhere?

This brings me to another lesson learned. We must not overlook that knowledge transfer goes both ways. We can learn as much as we can teach, if not more by working with autism communities from around the world. Countries and regions with limited resources and professional capacity have been for years developing innovative solutions to overcome the gap in autism services, and the challenges to community inclusion, that we experience even here in the United States.

In just the last few years the pace of development for autism has accelerated rapidly and globally. A new United Nations General Assembly resolution adopted in December of 2012 increased the commitment and accountability of governments worldwide to address the social and economic challenges of autism. And following the WHO consultation, the World Health

Assembly adopted a resolution that provides a framework for the enhancement of national health systems to include autism services. Many countries have since developed national autism action plans and passed autism legislation. For example, in Africa, the country of South Africa for the first time has a framework for mental health including developmental disabilities and autism. Earlier this year, 14 African nations participated in an autism congress sponsored by Autism Speaks in Ghana, where the First Lady of Ghana and the Minister of Health of Tanzania committed to enacting change for the autism communities of their countries.

Worldwide, governments are listening and the commitment is there. However the knowhow and capacity are often not. The final lesson learned I would like to share today is that legislation does not necessarily translate into action. Many of the autism laws passed in recent months around the world are well-intentioned but lack the strategy and resources to implement properly. In some cases, poor execution leads to unsuccessful programs that may actually hurt the chances for future support. More concerning is that hope can turn to helplessness for members of the autism community under these conditions.

In India, there have been inclusive education laws in effect for many years, yet true school inclusion has not been achieved. I just returned last week from a consultation in New Delhi with the World Bank, working with the disabilities and education communities to develop an improved strategy for inclusive education in India. It is clear that you cannot simply put children with autism into a classroom without properly training the teacher and educating the students. Furthermore, in a place like India, you cannot simply train a teacher only on autism when there are many children with other disabilities that also have a right to inclusion. It is important that we consider working with and learning from other disability advocates as we aim for acceptance and inclusion for our loved ones with autism.

Autism is a highly prevalent and highly costly condition to societies around the world. At least 1 in 68 children in the U.S. has an autism spectrum disorder and research suggests that prevalence may be the same or higher elsewhere around the world. A recent study estimated that autism costs U.S. society \$236B per year with much of the cost due to adult residential care and loss of productivity for caregivers and adults with autism, many of whom could be earning greater income.

The time to act is now and there are already models available that are improving access to services and promoting community inclusion around the world. By working together, and learning from one another, we *can* change the future for all who struggle with autism worldwide. Thank you for your time, and thank you to the many families, professionals, and government officials who have welcomed Autism Speaks to their countries to learn from their experiences.