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HEARING ON

The Global Autism Challenge

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Committee on Foreign Affairs
Subcommittee on Africa, Global Health, Global Human Rights, and International
Organizations
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Introduction

Thank you, Chairman Smith, Ranking Member Bass and Members of the Subcommittee.

I appreciate the opportunity to be here today to share my view on the global autism challenge. With the growing prevalence of autism and growing costs for care we need to work together to improve the opportunities for individuals affected by autism becoming active and welcomed members of the societies in which they live.

I am grateful for your leadership, Mr. Chairman, on this important issue and for addressing the autism challenge in a global perspective.

My background for discussing the global autism challenge is as a father to a child with autism, as active member in autism organizations, as a business professional and as a social entrepreneur.

In particular I will address my experience in working with SAP, represented by Mr. Jose Velasco, on selecting, training and on boarding individuals with autism in high tech jobs.

Autism

Autism (autism spectrum disorder) is a complex developmental disability that typically appears during the first three years of life and affects a person's ability to communicate and interact with others. Autism is defined by a certain set of behaviors and is a "spectrum disorder" that affects individuals differently and to varying degrees. There is no known single cause of autism.

Some of the behaviors associated with autism include delayed learning of language; difficulty making eye contact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills' and sensory sensitivities. A person on the spectrum might follow many of these behaviors or just a few, or many others besides. The diagnosis of autism spectrum disorder is applied based on analysis of all behaviors and their severity. *(Source: Autism Society of America)*

Autism prevalence in the US

In March 2014, the Center for Disease Control and Prevention issued an autism prevalence report which concluded that the prevalence of autism had risen to 1 in every 68 births in the United States. By the age of eight 46% of children diagnosed with autism in America have normal or above normal intelligence.

In June 2014, researchers from University of Pennsylvania estimated the lifetime cost related to an individual with autism with intellectual disability to average \$2.4 million and \$1.4 million related to an individual with autism without intellectual disability. The costs to the US society related to adults with autism in the US is estimated to be between \$175 billion and \$196 billion per year. A large part of the costs relates to loss of productivity.

Autism globally

Epidemiological data estimate the global prevalence of autism to be one person in 160. This prevalence estimate represents an average figure, and reported prevalence varies substantially across studies. Some well-controlled studies have, however, reported rates that are substantially higher. The prevalence of autism in many low- and middle-income countries is as yet unknown.

The prevalence of autism appears to be increasing around the world. There are many possible explanations for this apparent increase in prevalence, including improved awareness, expansion of diagnostic criteria, better diagnostic tools and improved reporting.

Most individuals with autism and other developmental disorders live in low- and middle-income countries; however, most of the knowledge about these conditions is based on research done in high-income countries.

Worldwide, individuals with autism and other developmental disorders represent a vulnerable group. They are often subject to stigma, discrimination and human rights violations, including unjust deprivation of health, education and social opportunities. Globally, access to services and support for individuals with developmental disorders is inadequate, and families of those affected often carry substantial emotional and economic burdens.

Autism was brought to the attention of Member States and the United Nations General Assembly in January 2008, when the General Assembly adopted resolution A/RES/62/139 designating 2 April each year as World Autism Awareness Day. The subsequent observation of that day has substantially increased international awareness about autism. *(Source "Autism spectrum disorders & other developmental disorders - From raising awareness to building capacity" World Health Organization)*

Autism in Africa

Autism research conducted in Africa has been infrequent and unrepresentative of all African countries, making the prevalence of autism in Africa difficult to estimate. There is a substantial lack of psychiatrists with knowledge on autism.

Examples for Sub Sahara countries from International Association for Child & Adolescent Psychiatry & Allied Professions (IACAPAP) show:

- Liberia has one adult psychiatrist serving populations of 3.4 million respectively
- Gambia's population of 1.7 million people is served by two expatriate psychiatrists on a short term contract
- Nigeria has one adult psychiatrist serving the needs of over one million
- Ghana has one adult psychiatrist serving the needs of over one million people

Accurate national autism statistics in South Africa are hard to come by but with just 9 specifically tailored schools in the entire country, an estimated 135 000 autistic children are not getting the specialized education they need. (*The South African Medical Journey*)

Families

Very often families who have one or more members with autism are constrained in their ability to understand and train the individual with autism to prepare for active participation in society. Individuals with autism risk being bullied in school, dropping out of the education system and being rejected by employers due to challenges in social interaction. The challenges do not only concern the individuals with autism but the whole family where parents often have to reduce their participation in the labor force in order to take care of their family members with autism.

The ultimate goal for most families is for the family member with autism to achieve a meaningful and productive job and through the job establish a fruitful and independent life situation.

Few families have the resources themselves to create better opportunities for their family member so they seek to organize their own efforts through autism organizations. However – when resourceful parents have the right conditions to make a change the impact can be amazing, making a positive change in society. I have seen a huge power in the grass roots of parents with family members with autism.

If we can empower families to understand and train their family members and to advocate for or start initiatives within education and employment we can tap into the power of the grass roots and improve the opportunities for individuals with autism around the globe.

Education

Education opportunities are often inadequate and costly for society and/or families. The success of including students with autism in a traditional class room very much depends on well-educated and compassionate teachers.

A large part of individuals with autism who succeed to graduate from higher education will face a major challenge in meeting recruiters and qualify for jobs. The labor market expects

social skills in addition to professional skills and employers very often lack the understanding and accommodation needed to take advantage of the skillsets of individuals with autism.

My experience tells me that transition from education system into the labor market is one of the biggest challenges for individuals for autism. The labor market requires strong social skills for most jobs and the recruitment meeting often turns into a bad experience for individuals with autism as they are measured according to a social skills paradigm. The stigma in the labor market is huge and we need to form common ground between the individuals comfort zone and the work zone.

To lower the barriers from the education system into the labor market internships are great tools by which individuals with autism and managers will have a longer period of time to ensure that the individual with autism will have a fair opportunity to excel and demonstrate value for the company.

Autism seen as untapped talent pool

Individuals with autism often finds their self-esteem in the work they do. As such a job is of utmost importance for the individual to establish a positive life situation.

In particular the high tech sector can benefit from skill sets often related to autism like a good memory, attention to detail, structured way of working, ability to perform repetitive jobs with high accuracy and innovation. Examples of tasks like quality control, analysis, data entries and logistics can be found in several business areas.

Despite the potential talents and the attractiveness for the labor market it is expected that up to 70% of adults with autism are unemployed or under employed according to Autism Society of America.

The inability for societies to provide and thereby develop the talent among individuals with autism combined with the inability for the labor market to make use of the talent is a major global challenge that calls for action.

Social entrepreneurship

A social entrepreneur is an individual who develops an innovative business model to solve a social challenge. Social entrepreneurs are mostly people who have a deep insight in a social challenge and a strong motivation to make a substantial change in society to eliminate the challenge. Amazing changes are carried out across the world by social entrepreneurs who often are supported by global organizations like Ashoka Innovators for the Public and Schwab Foundation for Social Entrepreneurs (who are affiliated with the World Economic Forum). A number of Ashoka Fellows work on education and employment of individuals with autism and other disabilities across the world.

Social entrepreneurs have the innovation and flexibility to find solutions in their local community and to partner with stakeholders to scale the solution and make a substantial change.

The Specialisterne experience

When my youngest son was diagnosed with autism in 1999 I learned about the challenges for a family to prepare a member with autism for a meaningful and productive life situation as adult. A combination of family drive, experiences from being chairman of a local branch of Autism Denmark and a position as technical director in an IT company made me challenge society by claiming that stakeholders in our society should work together to include individuals with autism and similar challenges in the labor market.

As an attempt to remove the divide between talented individuals with autism and the need for talent in the labor market I founded Specialisterne (The Specialists) in Denmark in 2003 as a social enterprise. The ambition is to assess, train and employ individuals with autism based on understanding and accommodation. Specialisterne has for more than 10 years been working with the local government to train and educate adolescents and adults with autism and with the corporate sector to provide services where individuals with autism can provide competitive tasks within coding, quality control, analysis, data entries and logistics.

Specialisterne has expanded to 12 countries. In 2013 I relocated with my family to the US to lead the activities in the US with the aim to enable 100,000 jobs for individuals with autism within 10 years through partnerships and knowledge share. Specialisterne US is a non-profit organization operating in DE, NY, PA, CA and ND. We have partnered with companies like [SAP](#) and [CAI](#) and NGOs like [The Arc](#) and [ExpandAbility](#) to match talented individuals with autism with corresponding jobs.

Working with Specialisterne for more than 10 years I have seen how individuals with autism have unfolded talent and brought it to good use in meaningful and productive jobs. I have seen what it means to quality of life when individuals with autism are appreciated and respected for the work they do. I have met many parents who feel relieved by the new independent life situation for a family member with autism.

In addition I have seen employers been taken by surprise by the skillsets of individuals with autism and puzzled by how individuals with a disability can be able to perform as good as or better than non-disabled employees. Besides appreciating the professional skills of the new colleague managers among corporate partners have told me how they have grown as managers from working with new colleagues with autism. The value based management style is based on respect, accommodation, clarity and accessibility has turned out to have a positive impact on the work climate in the department where the new colleague works.

In order to lower the barriers between education and jobs we established Specialisterne Youth Education to work with the transition of adolescents with autism into an active adulthood. We have experienced the importance of working with students to improve life skills and to bring them into internships among corporate partners.

Experiences from addressing the global autism challenge

Since I founded Specialisterne I have been contacted by families with members with autism from 90+ countries with requests to bring education and employment opportunities to their community.

In order to respond to these requests I founded the non-profit Specialist People Foundation with the goal to enable one million jobs for people with autism and similar challenges throughout the world.

In 2006 I had the opportunity to speak at the World Autism Congress in South Africa. Through listening to testimonies and interacting with participants I learned about the vulnerable situation for most families with members with autism in Africa. Through my work with WHO, Ashoka and World Economic Forum I have met people working with the autism challenge in countries like Egypt, Morocco, Nigeria, Ghana, Lesotho and South Africa.

My impression is that the lack of understanding of autism in Africa is pervasive with South Africa as an exception. It will take decades before adequate capacity in identification, care and education for individuals with autism.

Experiences from partnership with SAP to create jobs globally

SAP announced May 2013 that it will work globally with Specialisterne to employ people with autism as software testers, programmers and data quality assurance specialists. SAP sees a potential competitive advantage to leveraging the unique talents of people with autism, while also helping them to secure meaningful employment. By 2020 1% of the SAP global work force will be represented by individuals with autism through the Autism at Work program. In the partnership SAP has so far employed individuals with autism at SAP locations in India, Germany, Ireland, Canada and USA.

This year I have worked with SAP, the Philadelphia Chapter of The Arc, Office of Vocational Rehabilitation Pennsylvania, ExpandAbility and Department of Rehabilitation California to search, select, train and on board individuals with autism through the Specialisterne model in Newtown Square and Palo Alto. SAP has been very dedicated to combine the work zone with the comfort zone of the new colleagues. As an example an internal and external support organization has been established to ensure that the new colleagues will feel welcome and be given the best possible opportunities to excel. With this support structure in mind we are not just talking about jobs but start of careers.

The experience of working with SAP has been very successful and has generated a lot of interest from companies across the US. Thanks to SAP's position as a global role model I foresee a large number of national and global partnership with leading companies which will create jobs and become role models not just in the US, but globally.

Mr. Jose Velasco, SAP, will in his testimony give an insight in the background, motivation and experiences of SAP.

Conclusion

Chairman Smith, Ranking Member Bass, Distinguished Members of the Subcommittee:

With all this in mind, permit me to conclude by citing UN Secretary-General Ban Ki-Moon from the UN World Autism Awareness Day Message 2013:

"Autism is not limited to a single region or a country; it is a worldwide challenge that requires global action. This international attention is essential to address stigma, lack of awareness and inadequate support structures. Now is the time to work for a more inclusive society, highlight the talents of affected people and ensure opportunities for them to realize their potential."

The corporate sector has the capacity to act as a role model for employment of individuals with autism in the US, globally and in particular in societies with low awareness about autism as in Africa. In particular global companies have the advantage of bringing experiences from employing individuals with autism in the Western World to Africa.

As drivers in job creation, corporate companies and social entrepreneurs should be encouraged to work together to find the best way to develop the talents of individuals with autism globally and locally. Social entrepreneurs will be well positioned to work with other stakeholders like families, NGO's, local governments and education providers to facilitate assessment, training and education which will reduce the barriers between individuals with autism and employers.

My experiences from Specialisterne and partnerships with companies like SAP and CAI gives me hope that we can make a difference in dealing with the global autism challenge.

We can deal with the global autism challenge by

- helping families with members with autism to become advocates for change and provide support to establish schools and small businesses through social entrepreneurship
- providing knowledge on autism and education services from the rich world to the medium and low income world through virtual platform for any family and school with access to the internet
- encouraging global companies to work as role models in job creation and facilitate partnership with social entrepreneurs and NGOs
- developing a platform for match making between individuals with autism and jobs
- encouraging academic partnerships by which universities can document and disseminate best practices

Mr. Chairman, Committee members

The vision of Specialisterne is a world where people are given equal opportunities in the labor market and the goal is to enable one million jobs for people with autism and similar challenges.

We can get far by taking a partnership based job creation approach to deal with the global challenge of autism.

I thank you for your attention and will be happy to answer questions.