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"The Global Challenge of Autism"

House Hearing of the Subcommittee on Africa, Global Health, Global Human Rights and International Organizations Excerpts of Remarks Chairman Chris Smith, NJ-04 July 24, 2014

The global incidence of autism is steadily increasing. About 1 in 68 children has been identified with autism spectrum disorder, or ASD, according to estimates from the Center for Disease Control's Autism and Developmental Disabilities Monitoring Network. ASD is reported to occur in all racial, ethnic, and socioeconomic groups, but is almost 5 times more common among boys (1 in 42) than among girls (1 in 189).

Studies in Asia, Europe, and North America have identified individuals with ASD with an average of about 1% of the population. The prevalence of autism in Africa is unknown, but there is no reason to believe that it is any different than other parts of the world. A new study recently found that each case of autism costs \$2.4 million over a lifetime, including the expense of special education and lost productivity for their parents. Meanwhile, 85 percent of autistic adults are jobless or underemployed.

It is, therefore imperative that people with ASD are empowered to be self-sufficient so that they can not only earn money to meet their own needs, but also so they can utilize the talents they possess to contribute to society at large. This hearing will examine some innovative strategies to achieve this goal.

SAP, a global software company, is working to rectify this problem. SAP partnered with Thorkil Sonne, CEO and Founder of Specialisterne, to develop its highly successful "Autism at Work" program. Mr. Sonne, whose 17-year-old son Lars is autistic, realized that, while those with autism might lack the social skills recruiters are looking for, they possess many attributes high on their radar as well: intelligence and memory, the ability to see patterns and attention to detail on repetitive tasks. He reasoned that it would be phenomenal if we could use skills like we see among people with autism in software testing, data analysis, and quality control. He says that there is no reason why we should leave these people unemployed when they have so much talent and there are so many vacant jobs in the high-tech sector. SAP and Mr. Sonne will provide further details of their extraordinary program here today.

Theresa Hussman of Autism Society of America says, "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."

Pulitzer Prize-winning journalist, Ron Suskind will testify in part about success with an "affinity" approach, and he says, "for every visible deficit, there is an equal and opposing strength. This population is just like the rest of us, only less so and more so. The question increasingly is not "if" these "more so" qualities exist, but "where"?"

Autism used to be described as a disorder characterized by delays or abnormal functioning before the age of three years in social interaction, communication or restricted, repetitive and stereotyped patterns of behavior, interests and activities. More recently, behavioral scientists describe a range of such behavior now referred to as autism spectrum disorder, which includes a more high-functioning version known as Asperger syndrome.

It is medically possible to diagnose someone with ASD as early as 18 months or even younger, and a reliable diagnosis can be made by the age of two. However, symptoms might not present themselves until later in life. Those with some form of autism may never be diagnosed at all.

This has led to a debate over famous, productive people, often considered geniuses, who appear to have symptoms of autism, especially Asperger syndrome. In the April 30, 2003 issue of *New Scientist* magazine, writer Hazel Muir revealed the debate over whether geniuses Albert Einstein and Isaac Newton had Asperger syndrome.

Simon Baron Cohen, an autism expert based at Cambridge University, and Oxford University mathematician Ioan James speculated that Newton, the noted English physicist and mathematician, exhibited Asperger traits such as hardly speaking, forgetting to eat and giving scheduled lectures even to an empty room. Einstein, the German physicist, was said to have obsessively repeated sentences until he was seven years old and was a notoriously confusing lecturer. Both were highly productive scientists, perhaps because of the kind of focus ASD produces rather than in spite of it.

In a February 2, 2005, report on *CNBC*, anchor Sue Herara presented an interview with 2002 Nobel laureate Vernon L. Smith in which he spoke of the way in which his autism has allowed him to excel.

"I can switch out and go into a concentrated mode and the world is completely shut out," Smith is quoted as saying. "If I'm writing something, nothing else exists."

During the interview, Smith, who won the Nobel Prize for inventing the field of experimental economics, admitted that he is sometimes "not there" in social situations. He said that teaching had forced him to be more social, but it was only because he was talking about issues on which he was already focused.

I raise the issue of intelligence and functionality because we too often see people with ASD as victims who must be cared for when the focus their condition produces may allow them to highly successful in certain endeavors. When we begin to look at people with ASD in this light, we can better see how they can be enabled to contribute to society. It just requires understanding of their potential as well as their limitations.

Many fields involving mathematics and science would allow for the intense focus exhibited by many people with ASD to be quite useful. Think also of fields of analysis – intelligence, actuary science and other positions requiring what we commonly call "numbers crunching." The ability to analyze data and see patterns most people would not recognize would be invaluable in analytical jobs.

As Nobel laureate Vernon Smith said, his disconnection from social relationships enables him to think outside the box, as it were, without concern for violating social norms. Smith found his condition to be an advantage in enabling greater creativity. In our increasingly technical world, people with ASD actually are becoming more valuable, if we can help them overcome social disconnection and allow them to find fields in which what we have thought to be their disability is actually their advantage.

We hope today's hearing can be instructive in at least initiating a change in perspective on what people with ASD can do to help themselves and to make a contribution to society as a whole. We must not continue to waste the talents of people who could make their lives and ours much better.

Finally, I'd like to welcome an amazing group of individuals who have—and are—making a historic difference in the lives of those on spectrum.

As Michael Rosanoff puts it in his testimony "our mission at Autism Speaks is to change the future for all who struggle with autism spectrum disorders." Each of you on this expert witness panel are doing just that.