GLOBAL PERSPECTIVES ON AUTISM—A GROWING PUBLIC HEALTH CRISIS

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GLOBAL PERSPECTIVES ON AUTISM—A GROWING PUBLIC HEALTH CRISIS

TUESDAY, MAY 31, 2011

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON AFRICA, GLOBAL HEALTH,
AND HUMAN RIGHTS
COMMITTEE ON FOREIGN AFFAIRS,
Washington, DC.

The subcommittee met, pursuant to notice, at 2 o'clock p.m., in room 2172, Rayburn House Office Building, Hon. Christopher H. Smith (chairman of the subcommittee) presiding.

Mr. SMITH. Good afternoon, everyone. And welcome to our witnesses and those who are joining us for this first ever congressional hearing examining the magnitude and the severity of the global public health crisis of autism.

Autism, as I think more and more people are aware of, is a complex neurodevelopmental disorder that impairs a person's ability to communicate and to relate to others. The condition is often associated with rigid routines or repetitive behaviors. Autism is a spectrum disorder that affects each individual differently. The types and severity of symptoms vary from case to case and range from mild to extremely profound.

According to the Centers for Disease Control and Prevention, 40 percent of children with autism spectrum disorder do not talk at all, and another 25 to 30 percent speak some words at 12–18 months but then lose that speech. Autism occurs in all racial, ethnic and socioeconomic groups but on average affects four to five times more boys than girls.

I actually became involved and immediately concerned with autism back in 1982, when I visited with Dr. David Holmes, the founder of Eden Institute, now Eden Autism Services, in Princeton, New Jersey. I am very pleased that Dr. Tom McCool, Eden's current CEO, will tell us today how Eden is using its 36 years of experience to improve autism service programs around the globe.

I became deeply involved—and even more so—in 1998, when a family in my congressional district, Bobbie and Billy Gallagher, told me of their concerns about a perceived explosion in the prevalence of autism cases in Brick Township. After that meeting, I requested that the Centers for Disease Control and the Agency for Toxic Substance and Disease Registry, or ATSDR, conduct an investigation, which revealed that the prevalence of autism in Brick, 1 in 149, was indeed much higher than what was generally believed to be the prevalence.

As a direct consequence of the Brick study and CDC's admission that there were no recent prevalence studies in the United States with which to make a comparison, I introduced legislation to authorize grants for autism and pervasive developmental disabilities surveillance and to establish centers of excellence in autism and pervasive developmental disabilities epidemiology. This legislation, the Autism Statistics, Surveillance, Research and Epidemiology Act, or ASSURE, introduced in 1999, was incorporated into Title I of the Children's Health Act of 2000, which also established the centers of excellence in autism research in NIH and created the Interagency Autism Coordinating Committee.

To continue to monitor implementation of these new Federal autism programs, I established in 2001, along with my colleague Mike Doyle, the Congressional Autism Caucus to raise awareness of autism and provide a forum for advocacy within Congress. The Combating Autism Act of 2006 reauthorized the autism programs created by the Children's Health Act, but also expanded the Act, calling for research into possible environmental causes of autism and creating an "autism education, early detection, and intervention program" to improve early screening, diagnosis, interventions, and treatment for ASDs.

Just last week, I introduced, along with Mike, a package of three comprehensive autism bills: The Combating Autism Reauthorization Act, or H.R. 2005, which will ensure continuation of the important Federal autism programs for education, early detection, surveillance and research; the National ASD Initiatives Act, or H.R. 2006, makes the HHS Secretary the head of the national autism effort and ties budget authority to the strategic plan for autism research; and the ASD Services Act, or H.R. 2007, which establishes grant programs to provide important research and services for children, transitional youth, and adults, and establishes training programs for service providers.

I would note to my colleagues that on a trip to Lagos in Nigeria in 2007, which was designed to look at an issue that I also work very vigorously on—human trafficking—while there I met with Mr. Chiti Azuwa, the parent of an autistic child. Mr. Azuwa is the Executive Director of the

Public-Private Partnership Resource Centre in Abuja, and his wife, Dr. Doris Azuwa, is the Executive Director of the OLG Health Foundation and Autism Centre in Port Harcourt. They told me of the large numbers of Nigeria, children suffering with autism, and the lack of government or other supports.

As a result of my discussions with the Azuwas, I introduced in February of 2008, the Global Autism Assistance Act, or H.R. 5446, which directs the Administrator for the U.S. Agency for International Development to establish and administer a health and education grant program to support activities by nongovernmental organizations and other service providers focused on autism in developing countries and also establishes a Teach the Teachers Program to train health and education professors working with autistic children in developing countries. I will be reintroducing this legislation later this week.

While this is a first of its kind hearing, I plan on scheduling additional hearings on this escalating health crisis and on the Global Autism Assistance Act when we introduce it later in the week.

I would note the progress that has been made in recent years and increasing awareness, and particularly in some of the more developed countries in improving services and treatment for autism. However, I would note at the same time we must take seriously the World Autism Organization's assessment that in every part of the world the situation for dealing with autism remains inadequate, even in those countries with considerable experience and understanding of autism, because the systems that have been established are being completely swamped by the number of people in desperate need of support.

There are a wide range of autism prevalence figures between countries and individual studies. Here in the United States, CDC estimates that close to 1 percent of the population is affected by NASD. Autism Speaks, the Nation's largest autism science and advocacy organization, describes a scientific consensus that 1 percent of the world's population, or some 67 million people—I repeat, an estimated 67 million people—are affected with some form of ASD. According to the World Health Organization—and I will include their testimony and hopefully at a later date they will testify as well—but in their submission they note that "tens of millions in Africa are affected by autism." Tens of millions.

In that context, autism is a developmental disability pandemic. It is largely under-recognized, underappreciated in its impact, and under-resourced. Caring for individuals with autism often takes, as we all know, a very high physical, emotional, and economic toll on families and other caregivers. More severe forms of autism may multiply many times the level and intensity of required care.

In developed countries, autism can overwhelm families, as their lives become consumed with the considerable challenges of identifying appropriate biomedical and psychosocial treatments, schooling, and other needed support systems for their autistic child or children and eventually for an autistic adult.

In less developed countries, the situation is even more desperate. Very often there are no resources outside of the family to help. And rather than a diagnosis of developmental disorder, the child and the family may face cultural stigma and discrimination, pushing the family and the child further into isolation and desperation.

We all know that early interventions are effective in improving the functionality of the child and that the positive outcomes from early interventions can last throughout the life of the individual. But very few children in Africa, for example, as well as in other developing countries, have access to such interventions. Even in more economically developed nations there are large disparities in the quality of care. Concerted actions are required to overcome the global challenges to effectively address autism and other developmental disabilities. We need to continue to help increase awareness of autism at all levels, and in all countries, to advocate for the inclusion of developmental disabilities in national and state health policies to increase the availability of quality of services across a continuum of care and across the life span, and to continue to sup-

port scientific research that will lead to more effective treatments and one day to effective strategies for prevention.

The benefits of international collaborations and cooperation are multidirectional. In fact, I am looking forward to learn about Northern Ireland's Autism Act of 2011 from Arlene Cassidy, CEO of Autism Northern Ireland. I am pleased we will have Ms. Cassidy join us today, and she will be speaking to us very shortly. I and the other congressional autism cochair, Mike Doyle, signed the memorandum of understanding with the Northern Ireland Assembly to share information to support common interests regarding autism.

In addition to Tom McCool and Arlene Cassidy testifying today will be Brigitte Kobenan, founder of the Autism Community of Africa, and Dr. Andy Shih, vice president of scientific affairs for Autism Speaks. We are all looking forward to hearing the valuable perspectives that each of our witnesses brings to this discussion. And although they are not here today, I would like to recognize the Autism Society, who will testify at a later hearing, for their invaluable work in advocating on behalf of individuals with autism both within the United States and in the international community.

I have been informed that Don Payne, who is our ranking member, is en route, will be here hopefully within a half hour to an hour. I guess he ran into some delays at Newark Airport. But he will be here and we will be joined by other members as the hearing progresses.

I would now like to ask our distinguished witnesses to come to the witness table and I will begin with their introductions at this point.

We will begin with Mr. Andy Shih, who is the vice president for scientific affairs at Autism Speaks. Autism Speaks, as I think many people know, is the Nation's largest science and advocacy organization dedicated to funding research into the causes, prevention, treatments, and cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals and their families. Mr. Shih works closely with members of Autism Speaks' board, scientific advisory committee, senior staff, and volunteer leadership to develop and implement the organization's research program. He focuses on things that include genetics, environmental sciences, and epidemiology. He also leads Autism Speaks' International scientific development efforts, including the Global Autism Public Health Initiative, an international advocacy effort that integrates awareness research and scientific development.

I would note parenthetically, in 2005 and 2006, when the reauthorization was very much in limbo whether or not it would actually occur, Autism Speaks moved heaven and Earth to make sure that that legislation was enacted. And I congratulate you on your extraordinary advocacy. Senator Santorum's bill, which did become law, and which passed both the House and Senate, obviously, was a great credit to your organization as to how well you helped to bring that about. So I congratulate you.

We will then hear from Ms. Arlene Cassidy, who is the CEO of Northern Ireland's autism charity known as AutismNI. She has specialized in autism spectrum disorders for 20 years and has pro-

vided the research, service development, and strategic lead for AutismNI, or Northern Ireland, in the development of an internationally acclaimed early intervention program for autism, including a catalog of academic research and published journal articles. She has also led the establishment of the charity as an accredited training agency, as well as an effective agent for social change through a community development and partnership ethos, which has provided the foundation for the charity's family support services and an effective political lobby for a dedicated Northern Ireland Autism Act, which was signed into law in Northern Ireland.

We will then hear from Ms. Brigitte Kobenan, who was born in Cote d'Ivoire and moved to the United States over a decade ago. In 2004, Brigitte's first child Vinny was diagnosed with an autism spectrum disorder. Despite a well established life in DC, she and her husband moved their family to Phoenix, Arizona, so their son could receive the appropriate treatment for his condition. Vinny subsequently improved and was able to live a much better life. Back in Maryland, Brigitte founded the not-for-profit organization Autism Community of Africa in 2008 to create a platform to share her experience and help African families in need by providing them with information and resources. Brigitte also represented Cote d'Ivoire and was elected Mrs. Congeniality World 2008. This title has given Brigitte a rare opportunity to speak around the world about autism awareness in Africa. Thank you so much for being here.

Then we will hear from Mr. Tom McCool, who is president of Eden Autism Services, a New Jersey-based nonprofit organization that works to improve the lives of children and adults with autism and their families. Eden Autism Services provides a range of community-based services to meet specific needs throughout the lifespan. Mr. McCool is also founding commissioner of the National Commission on Accreditation of Special Education Services and founding member and current vice chair of the National Association of Residential Providers of Adults With Autism. He served on the Medical Investigation of Neurodevelopmental Disorders' Institute Advisory Board. He currently is a member of the Autism Society of America, and is serving as Treasurer of the National Association of Private Special Education Centers. He is also the chairman of the Board of Autism Services Group. I don't know where he gets the time.

Mr. Shih.

STATEMENT OF MR. ANDY SHIH, VICE PRESIDENT OF SCIENTIFIC AFFAIRS, AUTISM SPEAKS

Mr. SHIH. Thank you, Congressman Smith and members of the subcommittee, for this opportunity to share with you Autism Speaks' global perspective on autism. I am Andrew Shih, vice president of scientific affairs at Autism Speaks, where I oversee the etiology portfolio, including research in genetics, environmental sciences, and epidemiology as well as lead our international scientific development efforts. I am a molecular biologist by training and have had the honor and pleasure of serving in the autism community for the past decade.

As Congressman Smith mentioned, ASD transcends geographic, economic, and cultural boundaries. Current scientific consensus is that 67 million people, or about 1 percent of the world's population, is affected with some form of ASD, a prevalence that is higher than AIDS, diabetes, and cancer combined. While there is currently no known medical cure for autism, behavioral treatment programs can be quite effective, particularly when diagnosis is made early and subsequent interventions are begun. This growing recognition around the need for better screening or treatment has led groups such as the American Academy of Pediatrics to mandated autism screening for all children between 18 and 24 months of age. The success in improving care in both North America and Europe also make it clear these approaches can be adapted and extended to countries around the world.

Unfortunately, today, in most of the world, early autism diagnosis and intervention remain more an aspiration than reality. A major barrier to improving the health and well-being of families and individuals is the lack of expertise and capacity to diagnose this disorder and deliver appropriate interventions. Without expertise and capacity, solutions that improve the quality of life for individuals with ASD and their families remain out of touch. In many countries, there is little awareness and simply no autism service providers. As a result, affected children and families do not receive proper care and support, and opportunities for a better outcome and improved quality of life for the families are lost.

To address this global public health challenge, in 2008 Autism Speaks launched the Global Autism Public Health Initiative, an ambitious international advocacy effort to provide support to other countries in order to enhance public and professional awareness of autism and to increase capacity to enable early detection and intervention as well as research.

Built around the core value, of sense of urgency, scientific excellence, and the benefits to individual and families touched by autism, Global Autism Public Health Initiative, or GAPH, provides technical expertise and support to our partners to help realize their vision of progress. We collaborate broadly and inclusively with stakeholders at all levels, such as health and education ministers, expert clinicians and scientists, as well as parents and families, because we recognize the development and implementation of meaningful and sustainable program solutions require local leadership and ownership.

GAPH's strategies and content are continually informed by the latest research in clinical and dissemination science. In addition, experience we gained and the data we collected from GAPH programs will help us advance and refine autism science and inform future policy and service development. Indeed, benefits from GAPH-related activities are expected to reciprocal—with greater international collaboration there will be new insights into causes, including environmental factors, sociocultural influences on diagnosis and treatment, education, and service development—answers that will help affected individuals and families the world over, including those in the United States.

Autism Speaks currently supports GAPH-related activities in 23 countries on six continents, and these collaborations are already

yielding impressive returns for our community both here and abroad. We have assisted countries like Brazil, Mexico, and Qatar in developing their own awareness campaigns and establishing recent collaboration with U.S. scientists. We are supporting governments like Albania and Ireland in their review and development of autism-related national health policies and programs. As an official NGO partner of the WHO, we are working with Geneva and a number of health ministries in Southeast Europe and Southeast Asia to develop and implement regional collaborative health networks focusing on awareness and training. In fact, Autism Speaks and the WHO are collaborating with the Bangladesh Prime Minister's office as well as the Ministries of Health, Education and Social Welfare to host an international conference this July in Dhaka to officially launch GAPH-Bangladesh and to bring together like-minded stakeholders from India, Thailand, Sri Lanka, Bhutan, and Maldives to explore regional coordination and collaboration.

Finally, the recently published first ever autism prevalence study in South Korea reported a stunning prevalence of 2.6 percent, with many previously unidentified cases found in the mainstream schools. In addition to the potential implications for environmental sciences research, the differences between the case-finding methodology used in the Korean study and the one deployed by the CDC to monitor prevalence in the U.S. raise important questions about the robustness of our statistics, and if we are actually underestimating autism prevalence in these United States.

It is important to note that prevalence and other public data on autism that can guide policy and services development is not available for most of the world. By one recent estimate, over 90 percent of autism research is conducted on about 10 percent of the global community. By supporting GAPH-related activities and research like the Korean study worldwide, Autism Speaks is helping to bridge that knowledge gap, to inform policies and development, enhance the evidence base and, as a result, narrow the service gap.

In South Africa, for example, we have funded a prevalence study in a region where AIDS is endemic to help establish basic public health statistics and explore the potential risk posed by a compromised immune system on brain development. Simultaneously, we are working with stakeholders from that country, including government officials, to develop consensus community priorities that will inform upcoming policy and program discussions with federal agencies. It is worth noting that one of the recurring themes we have encountered working with health officials in low resource countries like those in Africa is how best to prioritize autism and developmental disabilities when so many life-threatening diseases or conditions such as AIDS, malaria, and malnutrition compete for public health resources.

While we understand that perspective, we believe that such public health policymaking is overly simplistic. As child mortality decreases, simple math predicts an increase in the number of children with developmental disabilities. So instead of seeing mortality and developmental disorders like autism as two distinct public health challenges, they should be tackled as part of the same problem. Autism Speaks and our partners around the world believe that by addressing autism and related disorders now, South Africa

and other developing countries can get ahead of the curve, help maximize outcomes for affected individuals and families, and minimize long-term costs to society.

In conclusion, the unmet needs of the global autism community mirror the daily challenges that are familiar to any individuals or families in this country struggling with autism spectrum disorders. By sharing our experience, expertise, and translating and adapting current best practices into feasible and sustainable health solutions, we believe we can make a difference in communities with less know-how and resources. Just as important, we can also learn valuable lessons from these collaborations that can help improve the quality of life of our families here. But we need help. Our work with WHO and other international partners have confirmed the power of collaboration in accelerating progress and speedy deliver of answers to our families. We welcome suggestions and recommendations about how perhaps we can work with other U.S. Government agencies to further our global effort.

Thank you.

[The prepared statement of Mr. Shih follows:]

Andy Shih, PhD
VP Scientific Affairs
Autism Speaks

Hearing Date: May 31, 2011

House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights

Prepared Remarks

Thank you, Chairman Smith and members of the subcommittee for this opportunity to share with you Autism Speaks' global perspective on autism.

I am Andy Shih, VP of Scientific Affairs at Autism Speaks, where I oversee the etiology portfolio, including research in genetics, environmental sciences, and epidemiology, as well as lead our international scientific development efforts. I am a molecular biologist by training, and have had the honor and the pleasure of serving the autism community for the past decade.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social behavior and communication, and a restricted range of activities. Autism symptoms vary by person from mild to severe. Some individuals have strong intellectual and language abilities, whereas others are cognitively impaired and require life-long care.

ASD transcends geographic, economic and cultural boundaries. Current scientific consensus is that 67 million people, or about 1% of the world's population is affected with some form of ASD—a prevalence that is higher than AIDS, diabetes, and cancer combined.

While there is currently no known medical cure for autism, behavioral treatment programs can be quite effective, particularly when the diagnosis is made early and subsequent interventions are begun. This growing recognition around the need for better screening with treatment has lead groups, such as the American Academy of Pediatrics, to mandate autism screening for all children between 18 and 24 months of age. The success in improving care in both North America and Europe also makes it clear that these approaches can be adapted and extended to countries around the world.

Unfortunately, today, for most of the world, early autism diagnosis and intervention remains more an aspiration than reality. A major barrier to improving the health and wellbeing of individuals and families touched by autism is the lack of expertise and capacity to diagnose the disorder and deliver appropriate interventions. Without expertise and capacity, solutions that improve the quality of life for individuals with ASD and their families remain out of reach. In many countries, there is little awareness and simply no autism service providers. As a result, affected children and families do not receive proper

care and support, and opportunities for a better outcome and improved quality of life for the families are lost.

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Built around the core values of a sense of urgency, scientific excellence, and benefits to individuals and families touched by autism, GAPH provides technical expertise and support to our partners to help realize their vision of progress. We collaborate broadly and inclusively with stakeholders at all levels, such as health and education ministers, expert clinicians and scientists, as well as parents and families, because we recognize the development and implementation of meaningful and sustainable program solutions require local leadership and ownership. GAPH strategies and content are continually informed by the latest research in clinical and dissemination science. In addition, the experience we gained and the data we collected from GAPH programs will help us advance and refine autism science, and inform future policy and service development. Indeed, benefits from GAPH-related activities are expected to be reciprocal—with greater international collaboration there will be new insights into ASD causes, including environmental factors, socio-cultural influences on diagnosis and treatment, education, and service development, answers that will help affected individuals and families the world over, including those in the United States.

Autism Speaks currently supports GAPH-related activities in 23 countries on 6 continents, and these collaborations are already yielding impressive returns for our community both here and abroad. We have assisted countries like Brazil, Mexico, and Qatar in developing their own awareness campaigns and establishing research collaborations with US scientists. We are supporting governments like Albania and Ireland in their review and development of autism-related national health policies and programs. As an official NGO partner of the WHO, we are working with Geneva and a number of health ministries in Southeast Europe and Southeast Asia to develop and implement regional collaborative health networks focusing on awareness and training. In fact, Autism Speaks and the WHO are collaborating with the Bangladesh Prime Minister's office, as well as Ministries of Health, Education, and Social welfare, to host an international conference this July to officially launch GAPH-Bangladesh, and to bring together likeminded stakeholders from India, Thailand, Sri Lanka, Bhutan, and Maldives to explore regional coordination and collaboration. Finally, the recently published first ever autism prevalence study in South Korea reported a stunning prevalence of 2.6%, with many previously unidentified cases found in the mainstream schools. In addition to the potential implications for environmental sciences research, the differences between the case-finding methodology used in the Korean study and one deployed by the CDC to monitor prevalence in the US raise important questions about the robustness of our statistics, and if we are actually underestimating autism prevalence in these United States.

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While we understand that perspective, we believe such public health policy-making is overly simplistic. As child mortality decreases, simple math predicts an increase in number of children with developmental disabilities. So instead of seeing mortality and developmental disorders like autism as two distinct public health challenges, they should be tackled as parts of the same problem. Autism Speaks and our partners around the world believe that by addressing autism and related disorders now, South Africa and other developing countries can get ahead of the curve, help maximize outcomes for affected individuals and families, and minimize long term costs to society.

In conclusion, the unmet needs of the global autism community mirror the daily challenges that are familiar to any individual or family in this country struggling with autism spectrum disorders. By sharing our experience, expertise, and translating and adapting current best practices into feasible and sustainable health solutions, we believe we can make a difference in communities with less knowhow and resources. Just as important, we can also learn valuable lessons from these collaborations that can help improve the quality of life of our families here. But we need help. Our work with WHO and other international partners have confirmed the power of collaboration in accelerating progress and speeding the delivery of answers to our families. We welcome suggestions and recommendations about how perhaps we can work with other US government agencies to further our global efforts. Thank you.

Mr. SMITH. Dr. Shih, thank you very much for your testimony. Again, thank you for the fine work Autism Speaks does not just here in the U.S. but around the world.

I would like to now invite Arlene Cassidy, who is the

CEO of Autism Northern Ireland, if she could provide us with her testimony. I would note she is speaking to us from the U.S. consular office in Belfast, Northern Ireland.

Ms. Cassidy.

Ms. CASSIDY. Good evening.

Mr. SMITH. Thank you for being here.

STATEMENT OF MS. ARLENE CASSIDY, CHIEF EXECUTIVE OFFICER, AUTISM NI

[The following testimony was delivered via telephone.]

Ms. CASSIDY. Thank you. Please let me begin by thanking Chairman Smith, Ranking Member Payne, and the members of the subcommittee for the opportunity to appear before you this evening. I hope that by the end of this evidence the subcommittee will look beyond the relatively short history—20 years—of the autism movement in our small country and recognize the huge steps taken over the last 4 years to address the issue of inequality and the legacy of neglect regarding service planning and funding that is our experience.

In my written evidence, which was submitted last week, I referenced in some detail the impact that the troubles had in stunting the growth of social and economic development generally in Northern Ireland. Those decades of that particular civil conflict coincided with the birth and spread of the global autism movement, but that wave of autism awareness and knowledge passed us by.

The progress regarding post-conflict reconstruction of Northern Ireland therefore has been a barometer of the fortunes of autism. In the 1990s, knowledge about autism swept in and was absorbed by families in the nonprofit sector, but government ownership was absent. The subsequent decade has witnessed the fledgling efforts of various government departments to plan strategically for autism alongside the establishment of the devolved Northern Ireland Assembly.

The question is: Are we going in the right direction? And yes, this can be viewed as progress until one considers that planning has been limited to single government departments such as Health. Planning has not built upon the developments of the 1990s. Instead, the more proactive government role has resulted in existing services being deconstructed and innovative local research ignored, causing delay as new, untried models are set in place. Also, planning and liaison is more disconnected between the statutory sector and the nonprofit sector than ever before.

The funding priority overall is still very low. Funding allocations are based upon an outdated placement of ASD within the learning disability budget. The result: ASD services are funded by money taken from the learning disability budget feeding back into the lack of services for people with ASD with an IQ score of 70 plus.

The campaign for the Autism Act NI 2011 began in homes across Northern Ireland of families increasingly voicing their frustration about how the lack of dialogue and planning across government de-

partments was seriously impacting upon their lives as support across the various life transitions, so challenging for individuals with autism, failed and failed again.

The campaign for the Autism Act began in the hearts and minds of parent activists increasingly aware that at the core of all the flawed planning and absent funding was a fundamental inequality. ASD was not recognized or clearly defined in disability legislation in the United Kingdom, resulting in all decisions regarding service and benefit entitlement that are based upon disability legislation being open to interpretation, rejection, and inconsistency. This campaign united families and nonprofit sector and public representatives at a period in our political history when the art of lobbying political institutions was in its infancy and lobby agencies were nonexistent. A democratic lobby of the people has been created. So we made an impression—and we had to—because the status quo was against us. Few public servants understood the need for change and therefore they opposed it.

The campaign gained momentum in 2006, encouraged by developments in Wales, where the Welsh Assembly government invited Autism Cymru, the autism society of Wales, to unite the public and nonprofit sectors in planning for ASD across government departments. Within the U.K. and across the world the call for national strategies and/or legislative social change was getting stronger. The creation of the Celtic Nations Autism Partnership and the 2007 delegation to Washington, DC, to meet with the cochairs of the Autism Caucus was part of that movement.

It was no accident therefore that the Autism Act is rooted in the realities of our society. It is unique to our situation and encapsulates the aspirations of families here. Yet it is an example of one mechanism that is available to many societies and in addressing fundamental human rights and inequalities when the state is resistant. And that is legislation.

There is little doubt that the changes brought by the Northern Ireland Assembly regarding clarification of the definition of disability will reverberate across the other jurisdictions within the U.K. And the Republic of Ireland. As the Autism Act (Northern Ireland) initiates legislative change beyond its own jurisdiction, what a compliment to the journey we have traveled.

The next steps at home are crucial. As the Northern Ireland executive agrees the implementation phase for the Autism Act, we must ensure that the lessons of the past are well learned and that families living with autism are not disenfranchised again. There has never been a budget or cost center for autism across government departments because well, "Why budget for a condition that doesn't exist in Northern Ireland?" And when there is no data, there is no problem. This will be the greatest challenge—finding the budget, quantifying the need.

The Autism Act is our hope. Above all, it is evidence that we have citizens with autism who can no longer be ignored.

Thank you.

[The prepared statement of Ms. Cassidy follows:]

US Congressional Hearing:

31st May 2011

Subcommittee on Africa, Global Health, and Human Rights.

Subject:
Global Perspectives on Autism – A Growing Public Health Crisis

Submission witness:
Arlene Cassidy (CEO, AutismNI)

Evidence on the status of ASD in Northern Ireland.

Introduction:

The autism movement in Northern Ireland began in 1990 with the establishment of AutismNI, in the midst of a prolonged period of civil conflict known as 'The Troubles' which left a well documented legacy of under investment in social and economic infrastructure.

The global autism awareness movement and the establishment of the autism societies in mainland UK and the Republic of Ireland in the 1960's and 1970's had had no impact. Northern Ireland remained isolated. This reality combined with the general social impact of the Troubles resulted in a deficit in strategic service development and expertise in ASD that is still being addressed today.

AutismNI therefore became a magnet for concerned parents and committed professionals from across all sectors as a source of support, information and as a catalyst for change. Many of AutismNI's achievements since have therefore been the result of innovative partnerships, across health, social care and education which have been driven by committed pioneers.

AutismNI reached out to autism experts in North Carolina, New York and the UK and as a consequence significant progress was made in the specific areas of assessment, diagnosis and early intervention underpinned by an active research partnership with the University of Ulster. AutismNI assumed a training accreditation and family support function, developing a family support network of 30 branches (or chapters) across the region as well as international links across the globe.

There has been an absence of government ownership and leadership regarding autism until quite recently. The result has been a real lack of strategic planning and resourcing of autism services across Northern Ireland.

The opportunity to address this deficit came with the end of Direct Rule from London and the introduction of devolved government to Northern Ireland with the setting up of the Northern Ireland Assembly.

The Current Need:

In 2010, AutismNI produced two research reports ("The Hidden Community" and "Is Anyone Listening") into the pressures experienced by families 'living with autism'. The following statistics are taken from those reports:-

- 80% of mothers contacted were experiencing high levels of anxiety through to 50% who are on long term anti-depressant medication.

- 64% of adults with ASD live at home, 13% live on their own, and 25% are financially independent.
- 57% of adults with ASD had suffered depression, 65% anxiety and 34% mental health problems as a result of lack of support.

In 2010, in evidence submitted to the NI Assembly Health Committee, AutismNI noted that despite a 500% increase in the numbers of school age children between 2001 and 2009, financial investment within health and social care had increased by only 100%:-

- Department of Education figures estimate 5000 school age children with ASD in 2009. The figure was 900 in 2002.
- In addition, Department of Health figures indicate a prevalence rise from 1:100 to 1:60 within the past 3 yrs.

The Current Provision:

In 2002, as a result of recommendations made within the Task Group on Autism Report, the Department of Education established a regional team of advisors and educational psychologists as well as the Middletown Centre for autism to support pupils with ASD.

This report was designed to trigger comparable investment from and joint planning with the Department of Health but failed to do so. One impact has been the under utilisation of the Middletown Centre resulting in an extremely negative report from the NI Audit Office regarding value for money measures.

In 2008, the Department of Health and Social Care, began the implementation of an ASD Strategy that includes engagement across all sectors. At the same time, the Department of Education announced a separate ASD strategy would be undertaken within their department.

Other government sectors have engaged with 'the autism issue' on a project by project basis which is frequently initiated by the voluntary sector. Examples include partnerships with the Department of Employment and Lifelong Education regarding EU or Lottery funded social enterprise and supported employment schemes.

There are a growing number of supported living/residential services for adults with ASD but these are largely crisis rather than strategic developments. Yet again the voluntary (non profit) sector is the key initiator.

The private sector has failed to establish itself in the provision of ASD services in Northern Ireland. This is largely the result of the under investment in terms of recognition of ASD as well as lack of funding and strategic planning by the statutory (public) sector.

New Innovative Developments in Northern Ireland:

It can be argued that the above catalogue of activity fits neatly under this title. However there is a huge opportunity opening up before us that has the potential, if carefully managed, of putting the last 9years of government interest in ASD in the shade.
The Autism Act (NI) 2011 now commits the Northern Ireland government to the establishment of a cross department strategy for ASD and with this, the legislation also, registers autism under disability legislation protection for the first time. The equality and human rights issue addressed at last to ensure ASD is recognised and on the government agenda for change alongside other conditions. "Autism has come in from the cold"(Dominic Bradley MLA during the final Assembly debate on the then Autism Bill)

The Autism Act is truly significant for Northern Ireland in addressing the historic lack of strategic cohesion but is also a beacon for the wider global ASD community because it.....

- is the result of a 5 year lobby partnership led by Autism NI working with the All Party Group on Autism (APGA) at the NI Assembly and supported by the wider Autism community across NI.
- supersedes the English Autism Act (2010) as the most comprehensive and progressive legislation for Autism across the UK and Ireland.
- is equality and rights based, bringing entitlements for people with Autism into line with the rest of the disability sector.
- is the first legislation binding all government departments to plan, cooperate and implement an agreed strategy and services for individuals with a disability.
- sets in place a system of scrutiny and accountability that is overseen by the NI Assembly.

The impact for families can be significant because the Act will.....

- by implementing changes to DDA, impact with the removal of the IQ score of 70+ as a barrier to accessing services.
- by implementing changes to DDA, clarify the legal basis for discrimination cases regarding Autism in the areas of, for example, employment and benefit entitlement.
- by implementing changes to DDA and creating an Autism awareness campaign, improve public knowledge and understanding of the condition, potentially reducing isolation felt by families living with Autism in their local communities.
- bring a legal basis for the recognition of Autism and an end to the denial of the condition by certain professions.
- require all government departments to plan together for Autism for the first time ever. The government strategy will mean that some government departments will be contributing to Autism services for the first time.

Key Influencers:

In the introduction to this evidence there was an acknowledgment of the establishment of devolved government to Northern Ireland and across the United Kingdom.

Within the ASD voluntary (non profit) sector this has seen the emergence of a greater sense of national identity, common purpose and cooperation as is witnessed by the work of the Celtic Nations Autism Partnership (CNAP) www.celticnationsautism.eu.

In 2006, the achievement of Autism Cymru and the Welsh Assembly Government in working together to implement a national ASD strategy inspired AutismNI to campaign for similar cohesive cross sector planning for Northern Ireland.

In 2007, assisted by the NI Bureau and the Autism Society of America (ASA), a cross community delegation of NI Assembly political representatives (led by CNAP) met with Congressman Smith and Congressman Doyle (as Co-Chairs of the US Congressional Autism Caucus) and the final piece of the jigsaw fell into place as the role of legislation to effect social change for ASD impacted upon the Northern Ireland delegation.

With the signing of the ASD Memorandum of Understanding (MOU) between Congressional and NI Assembly Representatives, began an affinity which was made tangible by the immediate establishment of the All Party Group on Autism (APGA) at the NI Assembly and the ongoing desire to bring the full aspiration of the MOU to fruition.

AutismNI has maintained its liaison role between the ASD community, the APGA and CNAP to inform and empower the campaign for the recognition and establishment of equality and human rights for individuals with ASD in our community. This is now embodied in the aspirations attached to our fledgling legislation.....the Autism Act (NI) 2011.

It therefore is a great source of pride to us that the example of this achievement (set within the unique context of Northern Ireland's history) is beginning to influence discussion in Wales, Scotland and the Republic of Ireland over the precedent set by the NI Assembly to address inequalities within UK disability legislation.

Arlene Cassidy
CEO – AutismNI

www.autismni.org
27th May 2011

The Political Viewpoint re ASD:
Extracts from Party Manifestos - NI Assembly Election 2011

DUP:

- "Conduct a value for money review of the Autism Centre at Middletown.
- Overhaul the Regional Autistic Spectrum Disorders Network and speedup diagnosis and intervention for autism.
- Further improve the processing system to take greater account of, and show more sensitivity to, the difficulties experienced by people with conditions such as autism".

SDLP:

- "SDLP MLA Dominic Bradley brought an Autism Bill through the Assembly. This legislation will ensure government plans holistically and realistically for the future needs of people with autism, their families and carers. We made sure that all parties signed up to the SDLP's Autism Act. This groundbreaking piece of legislation will ensure that people with autism, their families and carers now have access to the full range of services they require throughout the course of their lives. We will support the new developments in safeguarding children and encourage Trusts to continue developing family support services for children in need. In particular, we will emphasise the continuing necessity for respite care for children with learning needs and children with autism".

Alliance:

- "The Alliance Party supports the Autism Act. The views of people with autism and their carers should influence policy across all departments. The full range of appropriate services and easy access to mainstream services should be available in a timely on-going manner. Awareness training for staff and the public in all settings and earlier detection, intervention and support would enhance the experience of people with autism and their carers. Agreed referral and care pathways are required including seamless transition between child and adolescent mental health and adult mental health services. Support systems for parents, families and other carers are crucial including resourcing for parent groups".

Historic Commitment:
Final Assembly Debate on the Autism Bill (March 2011)

DUP:

- "We are proud that the DUP have supported the Autism Bill (NI) from the outset and are delighted that all major parties saw how morally right this was." Jonathan Craig MLA, Ian McCrea MLA and Alex Easton MLA

Sinn Fein:

- "Sinn Fein welcomes this Bill reaching the final stage of the process. It will create a legislative framework to develop a strategy for those on the Autism spectrum who have previously fallen between two stools. " Michelle O'Neill MLA

SDLP:

- "The Autism Act (NI) 2011 now supersedes the 'adult services only' focus of the Autism Act (England) 2010 and becomes the most comprehensive and equality based law for Autism across the UK and Ireland. The NI Assembly has truly come of age in having the vision to identify and address a longstanding gap in our disability sector." Dominic Bradley MLA

Alliance:

- "This is a vital first step but families need to know their new rights under the law and the real impact this will have. This battle was not won overnight and it was waged against massive ignorance and reluctance to recognise Autism. The work to activate the potential of this new law will be just as vital and I have no doubt that Autism NI, once more, will be at the forefront in ensuring that people with Autism in Northern Ireland and their families no longer get second rate consideration. They are to be congratulated for their selfless work on this new law." Kieran McCarthy MLA

Mr. SMITH. Ms. Cassidy, thank you so much. If you could hang on for a few moments perhaps to answer some questions. I want to again thank you for the work that you have done with the All-Party Caucus, which works so closely with our own caucus here. The more we collaborate, share best practices, and learn from your new Autism Act of Northern Ireland 2011, the better. We can all borrow best practices and hopefully put them into law and policies. So thank you so very much.

I would like to now ask Ms. Kobenan if you would proceed.

STATEMENT OF MS. BRIGITTE KOBENAN, FOUNDER, AUTISM COMMUNITY OF AFRICA

Ms. KOBENAN. Thank you, Congressman Smith and members of the subcommittee, for the opportunity to share with you my experience in dealing with autism in Africa.

My name is Brigitte Kobenan, founder of the Autism Community of Africa and a mother of a child with autism. In 2007, after being invited on the Voice of America television to talk about autism in Africa, I was contacted by a young lady from Nigeria. She was asking for help because she recognized the symptoms of autism that I had talked about on the show and she was convinced that her brother has autism. But she was more alarmed by the treatment that he was receiving. He was tied on a tree and beaten with a stick to "chase the evil out of him."

A lady from Cote d'Ivoire contacted me because her sister was on the verge of depression. Her niece had a severe case of autism, but had no help. With the cultural stigma labeling her daughter as a bad omen and the constant challenge and lack of sleep in raising her daughter, the mother ended up in a mental institution.

Another concerned sister from Atlanta, Georgia, contacted me because her sister in Ethiopia was exhausted. Her sister was looking for something, anything, that could help her deal with her daughter's autism condition. We can say with caution that through the years, the awareness for diseases like HIV/AIDS, malaria, and malnutrition has reached a great deal of maturity in Africa and around the world compared to autism.

A Minister of Health in an African country, which I will not name for privacy, once told me, "What is autism anyway? Why don't you do malaria? Everybody knows malaria." My point exactly. Everybody knows malaria.

Not to minimize these issues in any way, but what do we do after children are feeling better from malaria, malnutrition, or receive treatment for AIDS, but still have autism?

In Africa, children with autism are a burden for most families in society due to the lack of awareness, education, and proper treatment. They need to be given the necessary tools to care for themselves. Autism can be treated. My son is living proof. Vinny was nonverbal until the age of four. After receiving his diagnosis, my husband and I, as the Congressman said earlier, began an uphill battle. We moved to Phoenix and we began an uphill battle that every family with autism faces. It was hard, frustrating, and sometimes brutal. But we had to stay calm and keep going because we knew that our failure as parents was not an option. Vinny was lucky enough to be born in the United States of America, where he

was able to get the treatment that he needs. The infrastructures are there, so we as his parents had no excuse to fail him.

Today, at 11 years old, even though he is a little different from his peers, Vinny is self-sufficient and he is in mainstream school. He is doing well, according to his IEP, Individual Education Plan. Sometimes during our conversations he gives me the magic phrase, "Mom, you just don't understand," complete with the attitude to go with it. I smile and give thanks to God for living in this great country. But my joy is bittersweet because I think about all the children and families with autism in Africa, and I shed a tear.

These children in Africa are not so lucky. There are no infrastructures to help them. Doctors don't have the equipment necessary to diagnose the problem and there is no follow-up program. As of now, a few NGOs in countries like Nigeria, Cameroon, South Africa, and Ghana, are struggling to take on the challenge. These NGOs were created mostly by parents who were frustrated by the lack of infrastructure to help their children. But they are faced with a variety of challenges—lack of funds, lack of support from the government, fear from families to show their evil child with autism, et cetera. A mother told me once, "If I show my son to you, what are you going to do for him?"

And this is the reality on the field. These kids are hidden. Parents are afraid to show their children with autism because they know that there is nothing that can be done for them. They think that they will just expose the child for nothing. They do not have any hope. They do not feel protected. And I think that the local government, by collaborating with NGOs and families, will help bring them a sense of security.

Throughout my work and experience with ACA, I had the opportunity to meet many families with children with autism as well as decision-makers in the United States and around the world. One of the main obstacles I observed with regards to the Africa continent is the lack of political will. For any program to be successful, leadership and ownership is required, among other things. But the majority of the leaders and stakeholders on the local level in Africa are either misinformed or just not interested in the subject. Again, to think that a Minister of Health asked me the question, "What is autism anyway?" Just imagine the level of knowledge among the population.

One other great challenge is poverty. Many families do not have the means to see a doctor, let alone care for a child with special needs. And for those who can afford it, well, there are no resources. Hence, the importance of autism awareness campaigns in Africa, as well as care.

Thank you.

[The prepared statement of Ms. Kobenan follows:]

Brigitte Kobenan
Founder
Autism Community of Africa

Hearing Date: May 31, 2011

House Committee on Foreign Affairs, Subcommittee on Africa, Global Health, and Human Rights.

Prepared Remarks

Thank you, Chairman Smith and members of the subcommittee for the opportunity to share with you my experience in dealing with Autism in Africa.

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My point exactly! Everybody knows Malaria!

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In Africa, Children with autism are a burden for most families and societies due to the lack of awareness, education and proper treatment. They need to be given the necessary tools to care for themselves. Autism can be treated. My son Vinny is a living proof. Vinny was non-verbal until

the age of four. After receiving his diagnosis, my husband and I began the uphill battle that every family with autism faces. It was hard, frustrating and sometimes brutal. But we had to stay calm and keep going because we knew that our failure as parents was not an option. Vinny was lucky enough to be born in the United States of America where he is able to get the treatment that he needs. The infrastructures are there so we, as his parents, had no excuse to fail him.

Today, at eleven years-old, even though he is a little "different" from his peers, Vinny is self sufficient and in mainstream school. He is doing well according to his IEP-Individual Education Plan. Sometimes during our conversations, he gives me the magic phrase "mom you just don't understand" complete with the attitude to go with it! I smile and give thanks to God for living in this great country. But my joy is bitter sweet because I think about all the children and families with autism in Africa and I shed a tear.

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This is the reality on the field. These kids are hidden. Parents are afraid to show their children with autism because they know that there's nothing that can be done for them. They think that they would just "expose" themselves and the child for "nothing"! They do not have any hope and do not feel "protected". And I think that local governments by collaborating with NGOs and families could help bring them a sense of security.

Throughout my work and experience with ACA, I had the opportunity to meet families and children with Autism as well as decision-makers in the United States and around the world. One of the main obstacles I observed with regards to the African continent is the lack of political will. For any program to be successful, leadership and ownership is required among other things. But the majority of the leaders and stakeholders on the local level in Africa are either misinformed or just not interested in the subject. Again, to think that a Minister of Health asked me the question:"what is Autism Anyway?" Just imagine the level of knowledge among the population…

One other great challenge is poverty. Many families do not have the means to see a doctor let alone care for a child with special needs. And for those who can afford it, well, there are no resources. Hence the importance of Autism awareness campaigns in Africa as well as care. Thank you.

Mr. SMITH. Thank you so very much.

We are joined by the distinguished gentlelady from New York, Ms. Buerkle.

Ms. BUERKLE. Thank you, Mr. Chairman, and thank you for holding this hearing on an issue that has significant global health implications.

Autism can be difficult to diagnose, but even harder to understand, especially for those who have no personal acquaintance with the disease and the disorder. Autism is no respecter of persons. It reflects all racial, ethnic, religious, and socioeconomic groups. Regardless of whom it affects, autism is a heavy burden for families who have a child with autism.

But there is hope. Modern medicine has seen the development of new treatments for autistic children. Early intervention is key. Autism no longer has to be a barrier to the future successes and fulfillment of those affected by autism.

With the increasing prevalence of reported cases of autism, this hearing is indeed timely. And I am glad we will have additional hearings on this topic.

Thank you, Mr. Chairman. I yield back.

Mr. SMITH. Thank you very much.

I would like to now yield such time as he may consume to Mr. McCool.

STATEMENT OF MR. TOM MCCOOL, PRESIDENT AND CEO, EDEN AUTISM SERVICES

Mr. MCCOOL. Congressman Smith, thank you for inviting me to participate in this dialogue on the global aspects of autism.

As you mentioned, Eden Autism Services started in Princeton, New Jersey, 36 years ago. During that time, our organization has gained a great deal of knowledge and experience in addressing the needs of children, adults, and families impacted by autism. All of us in the autism community recognize that there is a lot to be done and each of us has a role to play. In its short history, Autism Speaks has been able to significantly increase awareness of autism and its impact on families. They have also been extremely successful in raising funds to support its awareness activities and also support autism research projects.

In recent months, Autism Speaks has begun to focus on the plight of adults with autism, particularly looking at the broad range of residential and employment programs needed to support this growing population. The Autism Society, another one of our partners, has a long history of bringing family members and professionals together nationally and through their local chapters. They annually present successful program models that can benefit a broad range of needs for children and adults with autism. The Autism Society financially supports training programs for teachers and direct care professionals working in the field of autism.

Eden has not yet had the opportunity to work with the Autism Community of Africa. However, several Eden professionals have visited Africa to work with families dealing with autism. Eden provided family and staff training and the Eden curriculum.

The role Eden Autism Services plays in this arena is the direct service delivery component—that interaction between a person

with autism and those teachers, family members, and other professionals that follow a prescribed scientifically based treatment methodology. Eden does this in its schools and adult residential and employment programs and works with other direct service providers across the country to duplicate this treatment wherever needed.

There are two basic components to this process. The first component is the treatment model. In 2009, the National Autism Center issued its national standards report that emphasized the importance of evidence-based practices and the need to ensure that research-based treatments are given the priority over those that have not yet been proven effective or those that research has shown to be ineffective or worse.

The second component is the autism-specific curriculum, the teaching content that promotes the acquisition of knowledge and skills that support the person with autism's ability to function in society. Eden has developed an autism-specific curriculum that is used in both public and private schools across the United States and several other countries.

Eden Autism Services and the thousands of direct service providers across the country provide that intensely personal interaction between teacher and student, using treatment models and lesson plans to decrease and eliminate inappropriate behaviors and increase the capacity for children and adults with autism to live as productive citizens in society. Eden has acquired expertise in teacher training, family training, and direct care training, using applied behavior analysis in addressing problem behaviors exhibited by children and adults with autism. We have developed a curriculum that contains hundreds of specific lessons that can be used effectively by teachers, families members, and direct care staff.

Our goal is to share the knowledge and experience Eden Autism Services and many other direct services providers have developed to improve the quality of life of children, adults, and families impacted by autism, wherever they are. The information is available. The technology is available. And our hope is that we will be able to find a way to share this knowledge and bring help to those children, adults and families impacted by autism in other countries where such help does not exist.

One thing I wanted to mention that we have gotten involved in most recently that has significantly enabled us to directly impact more children with autism, and it is a social networking network called edWeb. EdWeb builds communities where different types of educators or different categories of educators are able to directly connect with one another. So Eden has hosted the autism community on edWeb, and it is a way for teachers who are working directly in classrooms with children with autism to connect with one another and deal with very specific issues. An e-mail e-blast goes out to everyone on the network and a question is asked how to deal with a specific issue, and an immediate response is taken. EdWeb is available. It is on the Internet. It is something that could be very valuable beyond the borders of our country. So we are looking forward to working with our partners and to take the knowledge that we already have and find ways to get that knowledge and experience to those who really need it.

Thank you.
[The prepared statement of Mr. McCool follows:]

Action In Autism

Thomas P. McCool, Ed.D.

President/CEO Eden Autism Services

Princeton, New Jersey

May 31, 2011

House Committee on Foreign Affairs

Subcommittee on Africa, Global Health, and Human Rights

Testimony

Eden Background Information

The mission of Eden Autism Services is to improve the lives of children and adults with autism and their families by providing a range of community-based services to meet specific needs throughout the lifespan.

Eden was founded as a private school in Princeton in 1975 by Dr. David Holmes and 14 families, and opened adult services programs in the early 1980's. Eden Outreach was established to provide consultation and support to families who needed services but could not be accommodated in Eden education and adult programs.

Currently Eden serves 60 children in the New Jersey School; 43 children in two Southwest Florida schools; 100 adults in three New Jersey adult employment centers; 75 adults in New Jersey residential programs (group homes and apartments) 10 adults in residential and employment services in Southwest Florida; and more than 2000 individuals and organizations across the country and beyond through Eden Outreach. Recently Eden has expanded its direct impact on autism classroom teachers via edWeb.

International Activities

In November 2006, Eden Autism Services participated in the World Congress Autism Conference held in Cape Town, South Africa and launched its web-based autism training program for teachers and families, and highlighted the Eden Curriculum as an essential element of a comprehensive autism education program.

From time to time Eden Autism Services sponsors internship programs at the request of organizations around the world including: an 18 month internship program in adult services for 8 interns from the Philippines; other intern programs have been provided to students from Singapore and Canada.

Eden Outreach Services has conducted evaluations of individuals with autism from Bahrain and Abu Dhabi, and the Eden Curriculum is being used in Singapore, Philippines, Canada, Israel (and is in the process of being translated to Hebrew) and South Africa.

Eden Autism Services Partnerships

- National Association of Private Special Education Centers – association of schools serving children with disabilities
- Autism Society of America – advocacy and information sharing; presentations at annual conferences held across the US.
- Autism Speaks – advocacy and information sharing; awareness. Eden is working with AS on its Advancing the Future of Adults With Autism
- National Association of Residential Providers for Adults with Autism – shared expertise among providers of direct care services nationally and internationally. Fall conference in England is being planned.
- Autism Europe Member – information sharing

- Eden Innovative Learning – partnership with Innovative Learning, a technology company that has developed competency based testing protocols for web based learning.
- Florida Gulf Coast University – cosponsor of annual autism conference "Promising Pathways" since 2008.
- CARF (Commission on Accreditation of Rehabilitation Facilities) – assisted in developing autism specific standards for this international accreditation organization.
- Princeton University - Since 1995 Eden and Princeton University have sponsored an annual lecture series on autism research. Since its inception, the Series has featured globally recognized scientists, researchers, educators and administrators. Attached is a listing of the autism experts who have participated in the Eden-Princeton University Lecture Series. Summary

Summary:

Our goal is to share the knowledge and experience Eden Autism Services has gained over the past 36 years to improve the quality of life of children, adults, and families impacted by autism. The information is available; the technology is available. Only with a united and focused effort will we be able to achieve this goal.

edWeb

Eden Autism Services is working with edWeb.net to create online communities of practice to support educators serving students with special needs, particularly autism and engage educators who are working within an organization, across organizations, or anywhere in the world. edWeb.net is a professional social network for the education community that makes it easy to connect with peers, share information and best practices, spread innovative ideas, and create professional learning communities.

The U. S. Department of Education recently issued a draft report – ***Connect and Inspire: Online Communities of Practice in Education*** – that makes the case for "broadening educators' access to and participation in online communities of practice, which show strong potential to support professional learning and collaboration." See http://edcocp.org.
Eden Autism Services has two online communities of practice for educators on edWeb.net:
Teaching Students with Autism: Effective Strategies for Grades preK-5
Teaching Students with Autism: Effective Strategies for Grades 6 - 12

The program uses a combination of interactive live webinars and online discussion forums so that educators can connect on an ongoing basis to receive support from the Eden staff and from each other. The online community is used to archive all of the webinars and supporting resources. Tools like a blog, discussion forum, shared calendar, documents library, wiki, polling tool, and shared links – support the creation of an active and engaged collaborative community of educators.

Webinars are held weekly, and each week, members of the community receive a free lesson plan from Eden. The structured, ongoing activity is the key to active engagement. Community

members also receive a CEU certificate for attending the webinar, or watching a recording and taking a quiz.

The webinar topics are:

- Understanding the Unique Needs of Students with Autism
- Effective Strategies for Paraprofessionals
- Goal Selection for Students with Autism
- Positive Behavior Support Strategies
- Effective Transition from the Classroom to Adulthood
- Establishing Play and Leisure Skills for Students with Autism
- Toilet Training Students with Autism
- Generalization: Why Is It So Critical?
- Facilitating Language and Communication in the Classroom Environment
- Troubleshooting: What is it, and How do you do it?
- Utilizing the Principles of Reinforcement in a Classroom Environment
- Meeting the Needs of Students with Asperger's in the Classroom Environment

The program launched in March 2011 and already has over 900 educators participating.

Mr. SMITH. Thank you very much for your testimony and for the great work Eden has done for all these decades. At least for this member, and I know for many other lawmakers, including our Governor, Eden has been transformational for us in helping us to understand this devastating disability. So thank you so much for the great work you have done.

Let me just begin the questioning. I will start with Mr. Shih, if I could.

You spoke of the Global Autism Public Health Initiative which you began in 2008. I know that WHO began a six-country pilot program in 2008 as well. I am wondering what kind of collaboration your organization is having with the World Health Organization, and if you could, what are the biggest challenges? We just heard from Ms. Kobenan that when she and others speak to health ministers—and I raise this myself every chance I get in Africa and elsewhere—the knowledge base is so rudimentary and so lacking as compared to other pandemics, including HIV/AIDS, malaria, tuberculosis, which need proper resourcing, but it seems as if you—and I think you offered a very clear way forward—that we need to see this as the other side of the coin in mitigating child mortality. As that improves, obviously this will exacerbate and get worse unless we address it.

So if you could speak to the Global Autism Public Health Initiative, maybe elaborate for us on that. Also, if you might speak to where we are now in terms of getting to the root cause of what is triggering autism. I know it is always controversial. I will never forget in 1998 when I first proposed the Brick study and introduced the ASSURE Act. Some very well-meaning person from the Centers for Disease Control got up in my face literally and put her finger in front of my face and said, when I mentioned vaccinations as a possible—maybe multi-vaccinations; thimerosal was also something people were concerned about and perhaps still are—but it was like, "Don't go there."

I would say for the record that I am a very strong advocate of vaccinations. I was the sponsor of the amendment that doubled the amount for the Child Survival Fund from $25–50 million in the early 1980s. I was in El Salvador when they immunized upwards of 2,000 kids against polio, diphtheria, pertussis, and other leading killers of children. So vaccinations are very, very important in combating disease, and especially preventing it. But there should not be an acceptable collateral damage, if there is, particularly with multi-dosing, perhaps five or six at a time, where a little body cannot metabolize that.

So if you can perhaps speak to that as well.

Mr. SHIH. Thank you, Mr. Chairman. First, to address your question about the Global Autism Public Health Initiative. We are an official partner with the WHO. Their mandate is a little broader than Autism Speaks. Their focus is on child mental health and disability, including autism. We saw our relationship as one where the AIDS community has come together with the international AIDS agencies and health agencies to address the tremendous public health challenge with HIV infection. As a result, even though the focus is on HIV or AIDS by these groups, I think it can be argued that they have benefited by the research overall globally. And we

see a similar kind of relationship with WHO relative to autism and their child mental health priorities.

So the six pilot programs that you mentioned recently launched, we are in discussion about where we can be most helpful. We are part of a discussion ongoing at the Institute of Medicine, the Neuroscience Board, talking about how do we address mental health and developmental disability needs in the sub-Saharan Africa. So that is still in discussion. My expectation is that activities with these pilot projects will be launched in the next 6–9 months and our expectation is to be at least part of some of those efforts.

Indeed, the bigger challenge, I think, in addition to capacity and expertise, really is awareness. As Ms. Kobenan mentioned, at the country leadership level often you run into individual ministers and more highly-placed officials who know next to nothing about autism. That makes the challenge of helping the families even more difficult.

What Autism Speaks does on a yearly basis now is that around the time of the United Nation's General Assembly we organize an awareness event for the first spouses of the world's leaders. We bring them in, show them a little bit what we know about what is happening in autism worldwide, and we ask for their help. This year actually we are going to be working with WHO. So that in addition to engaging the first spouses from around the world, we are also able to bring in the Ministers of Health in these countries so that there will be a more immediate connection from the good will generated by the country leadership and the public health official of that country. So we are optimistic that going forward we will be able to bring a higher level of awareness to public health officials, education officials, as well as leadership from around the world.

It is actually a very exciting time for autism. I think over the past 4 or 5 years there has been a tremendous amount of advancement made in terms of the understanding of the causes of autism. I think it also has been and remains the case that autism is like diabetes, cardiovascular diseases. It is a complex disorder that involves genetic predisposition as well as potentially environmental factors. In recent years, we have learned a lot more about the genetic architecture of autism. We understand where the problems are, where in the biological system that goes wrong that results in autism. And that has given us a foundation in which we can explore both development and interventions as well as environmental factors, interactions.

So we have now started to partner with industry as well as other Federal agencies, including NIH, to delve more deeply into the causes of autism and what can we do to turn this knowledge into meaningful applications and solutions for individuals and families affected by the disorder. We are also working with industry as well as public agencies to take best practices and to disseminate them broadly because we do know things like behavior intervention as a result of the diagnosis do work and do help many individuals and families affected by autism. But the challenge has been to disseminate these best practices in every corner of this country as well as the world.

Mr. SMITH. You mentioned working with NIH. I have met with Dr. Shah twice, the head of U.S. Agency for International Develop-

ment, and stressed with him the importance I think of USAID, with its multiple missions overseas, especially in Africa, to initiate an autism initiative within the department. I am wondering, have you had collaborations with them? Same way with Dr. Frieden internationally with CDC. Are they also looking to dedicate and prioritize autism at those two agencies?

Mr. SHIH. Sure. I think global health is a priority at NIH, and we are fortunate to be able to work with the National Institute of Mental Health and CHHD, Child Health and Human Development, for instance, in this area. CDC similarly has an interest, often globally, in an international research network that Autism Speaks developed called International Autism and Epidemiology Network, which was actually codeveloped with the CDC and right now includes over a hundred researchers from 30-plus countries.

I think USAID and other agencies, certainly we will welcome an opportunity to work with them. We have approached USAID previously. Understandably, at that point autism was not one of their priorities. But we certainly look forward to revisiting that opportunity and to work with the agency.

Our sense is that from our travels and conversation with stakeholders around the world is that it is a highly respected agency and their work has had tremendous impact on the population around the world. And we would love to be a part of that.

Mr. SMITH. You were diplomatic in saying it is not among their priorities at USAID. Is it even on their agenda?

Mr. SHIH. I believe so, but I think it is a matter of prioritization; yes.

Mr. SMITH. I appreciate that.

Finally, you mentioned South Korea, at 2.6 percent, which seems extremely high. Is it better prevalence studies or is there something that may be triggering autism among South Korean children?

Mr. SHIH. Right. I don't think we have a simple answer at the moment. I think this study has set the stage for more elaborate investigation looking into the possibility of environmental factors. But what is clear is that the Korean study employed a methodology that is more comprehensive than is being used here in the CDC. Specifically, the Korean investigators actually went into the general schools, the mainstream schools, trying to identify the children who might have been missed. Shockingly, stunningly, if they look at just the special schools, as we do here, the prevalence is about the same—8.9 percent. But the mainstream schools they found almost 2 percent—almost 2 percent of kids not previously detected and served by the community.

So I think the lessons here from our perspective is that we should think about using perhaps more robust methodology so we can get a more accurate reflection of what is going on in the United States.

Mr. SMITH. I yield to Ms. Buerkle.

Ms. BUERKLE. Thank you, Mr. Chairman. I just wanted to follow up on the question on methodology. It sounds like our method just goes into special schools, not into the general population of children in schools. Is there anything else that is different between how we conduct our research?

Mr. SHIH. I think that is the main difference. I think what we are encouraging people to do now is to try to do case finding in a more comprehensive manner, the way we have done in South Korea, because what I think about when I think about the Korean study is not necessarily the high prevalence in South Korea, even though that is very important; I think about the individuals and families who have not been officially diagnosed who may be struggling through schools, dealing with all the issues that they are dealing with, with little assistance at this point. I think we as a society, as a community, are in a position to do something about that. We have the resources, we have the means.

Ms. BUERKLE. Thank you.

Mr. SMITH. I will return to our distinguished gentlelady from New York.

Just a few more questions.

Ms. Kobenan, you mentioned the cultural stigma labeling that daughter as a bad omen. I would note parenthetically I was recently in Nairobi and met with some neurosurgeons who were working on treating Africa children with hydrocephalic conditions. In one case, I was told how in Uganda, children who develop water on the brain, which is terrible and lethal, unless there is an intervention, hydrocephalic condition, are often seen as a bad omen or something along those lines.

I am wondering what can be done to dispel that very dangerous myth which leads to these children being ostracized. When I was in Lagos on that trip when I met with Chiti, he said that some of these children in Nigeria are just put aside and they are allowed to die because they are thought to be contaminated or possessed or some terrible condition rather than have a physical developmental disorder that with the right interventions could be greatly helped.

If you could.

Ms. KOBENAN. On this issue, that is what ACA is doing. We are trying our level best to take on the awareness. The most important part is letting people know what is going on, that the children are not bad omens. So communication is the key. And the way to communicate in Africa—most countries in Africa—is using the media—TV, radio, and even having social workers going from school to school or villages to villages and having forum. What we call forum is they know that this person is coming from this government health department talking to the village and they will come to a public place and the person will talk to them.

So it is organizing a small group of leaders that can go to these places, families and villages, and talk to them and say it is okay to come out. You do not need to hide your child. Your child is not a bad omen.

In my case, just to wrap up, the lady went to see my mom when I was on TV and I was talking about it. She was so touched she went to see my mom. She had a 19-year-old daughter that she has been hiding all along. And she said that because of your daughter I can bring her out and I am not ashamed to show my daughter.

So communication is the key. TV, radio, and everything like that.

Mr. SMITH. Mr. McCool, you were at a World Congress Autism Conference in South Africa in 2006. Was that issue addressed particularly for the sub-Saharan African context, and could you just

elaborate on the buy-in? Were there health ministers there? Was it a robust participation? Was it what you expected?

Mr. MCCOOL. No, it was not. Actually, it was a little disappointing. We did have—it was part of the World Autism Conference. There were people from about 53 countries represented. One of the things that we tried to look at was what was available in that part of South Africa. We didn't go through the entire country. And we found that many of the children were leaving home or being taken from the home to get the proper educational programming because they couldn't get served and the families were resistant to recognizing that autism was something that could be treated in a positive way. We actually visited a school, a nearby school, that had about 100–150 children who were basically educated out of the home because of this issue.

Mr. SMITH. I know that Eden is involved in Singapore, developing curriculum, Philippines, Canada, Israel, South Africa. Could you, you know, tell us, what is Eden doing vis-à-vis these countries.

Mr. MCCOOL. Yeah, these are very specific, focused activities where we are contacted by someone. Often, we have groups that travel through the U.S. to look at model autism programs and will visit Eden among the programs that they look at.

What we found is that they really look at behavioral interventions as the priority for autism. And so, applied behavior analysis is something that has demonstrated effectiveness in people, want to learn how to be trained, and to train direct care workers and families in how to apply applied behavior analysis.

What we find is, they are so focused on the behavior that they fail to bring content into the equation. And so, in many cases, they are not teaching specific skills. And so what we have tried to do is to pair the curriculum with the behavioral training.

And Anne Holmes, who runs Eden outreach services, through technology now can observe classrooms and teacher interactions anywhere in the world and has done so. And so she can actually watch the behavior, consult with the teacher or the family and, sitting in Princeton, New Jersey, really provide that kind of support to anyone anywhere in the world.

The only other obstacle we have is language. You know, our curriculum is in English. We have made several attempts to have it translated into other languages. Right now it is in the process of being translated into Hebrew. But all of the people we have worked with thus far have been able to navigate with English.

Mr. SMITH. Ms. Cassidy, you mentioned the 500 percent increase in diagnosed autism cases in Northern Ireland since 2002. Can you tell us to what you attribute this increase?

And, secondly, you note the 2011 Autism Act for Northern Ireland is among the most progressive and, I think, enlightened pieces of legislation anywhere in the world. Are there recommendations that you might have for us on how we could improve our efforts? And, of course, that might be replicated elsewhere.

And, finally, you also point out that the troubles in Northern Ireland—and I would note parenthetically that we actually had 11 hearings in this subcommittee on the troubles in Northern Ireland, so we are very well-acquainted with what turmoil you have been through—but we hear it all over the world, especially in some of

the places in Africa, Cote d'Ivoire is obviously going through its own problems right now, and we are told that the autism resource organization in Cote d'Ivoire has shut down during the crisis. So, again, kids are put on hold while political problems deteriorate into violence.

So if you could speak to some of those setbacks. And, you know, there needs to be almost like a separate focus on, what do we do in conflict areas. You know, there needs to be some awareness that the needs, and special needs at that, of an autistic child do not go away with political turmoil.

Ms. CASSIDY. Thank you.

Well, starting with the 500 percent increase, I think that—yeah, all the queries just tie in together—I think that reflected a catch-up. You know, no data collection had taken place, and then all of a sudden one of our Government departments decided to do some data collection with school-age children, so there was a captive audience in the local school population. And then, a number of years later, they kept on that data collection. So that is really all we have to go on.

And I really know that, in 2002, even when the original report was done, they talked about an autism wave traveling through the school system in Northern Ireland, so they knew there was a tip of the iceberg going on here. But I think I would attribute it to just really the way it has happened worldwide. It is exactly the same issues as you are picking up on. It is about increasing awareness, increasing expertise in identifying and diagnosing the condition.

You know, I do believe that there are a lot of questions to be asked about environmental factors. So we are just in the mix with everyone. I don't think there was anything particular to Northern Ireland except for the fact that there was, until 2002, no baseline information gathered. Then there was the baseline information that 900 children were identified in Northern Ireland, school-age children, with autism. And then, a number of years later, when the same exercise was carried out, the figure they come up with was 4,000 children, almost 5,000 children.

So, data collection, you know, has been a huge issue in Northern Ireland. Various services are starting to collect some data, but the data is non-transferrable. The information is usually particular to that service, to child health or to education, and the departments haven't been exchanging the information. And that is one of the really, you know, good things about the legislation that has come about, because within that legislation there is a requirement for all government departments to agree to communicate over data that they are collecting and to develop a common language so that they can plan within single departments and across departments.

I would be extremely humble with regard to our legislation. We are tremendously excited about it because we come from such a low baseline. And we believe that we have addressed a core difficulty, and that is the whole inequality issue. It was one of those, you know, "eureka" moments that we had when we looked at our own disability legislation and realized that it was out of date. I know that in England they updated their disability legislation and created the English Equality Act, but some of the other devolved jurisdictions within the U.K. did not.

And, in Northern Ireland, I think we looked at it, you know, initially, probably first, discovered that the legislation was out of date, that it didn't make allowances for the interpretation of autism within the definition of "disability," and, therefore, that needed to be changed. So that is one of the things that is really exciting about the new legislation, as well.

So, in short, the new legislation, for us it really recognizes autism for the first time within disability discrimination legislation and protects citizens with autism and gives them a voice and gives them a possession.

The other thing that came up with the legislation was the need for a cross-departmental approach to autism, a government approach to autism. And with our particular—we have, as you know, particular challenges with the mandated coalition system in the Northern Ireland Assembly, where various government ministers are in place from various specific political parties. And their policies may or may not agree, so policies and individuals bump into each other from time to time. So it was quite something to get uniform agreement.

So I think this legislation, to my knowledge, is the first Northern Ireland legislation that requires our Government ministers to work together on an issue, and that issue being autism. So that is another first, if I am correct, that is another first for this legislation.

As I say, in the legislation it requires data, but it also requires the government to fund the first autism awareness campaign. And I agree absolutely with your previous speakers. I think one of the greatest challenges for autism throughout the world is knowledge. Ignorance is the greatest enemy; arrogance, too.

And, you know, I think with the situation in Northern Ireland, I think it comes back to your third point, the particular—in conflict situations, I think parents are paramount. This legislation would never have come about in Northern Ireland if it hadn't been for the nonprofit sector working with parents on the issue of parent empowerment, to make their voices known. Because they were basically disenfranchised citizens, and they now have developed a voice. And they were able to lobby their local public representatives and get their voices heard in the Northern Ireland Assembly.

And there was uniform support for this legislation across the parties, so that was very encouraging to see. But I think, you know, given the troubles that we have had in Northern Ireland, it was fantastic to see the final debate when the bill became law. You know, the members were congratulating other members across the aisle for their role in bringing this legislation about.

So I think I would end by saying that parents are paramount. I do take the point—you know, we had—about the autism society in part of Africa, you know, having to disband at a time of extreme conflict. That actually happened in Northern Ireland, because in the 1970s there was an autism charity and they fractured, as well. And it wasn't until 20 years later, 1990, that the charity that I worked for was formed by parents again. And that time, the timing was right. And, you know, that was 1990, and, you know, people's minds were turning to, "Can this go on forever?" and looking maybe toward, you know, the ceasefires, which came a few years later.

But, certainly, in the legislation in Northern Ireland, the parents and the links they had with local politicians—they brought local politicians to family days and events so that the politicians could see what it was and what they were coping with and the home situation, some very challenging children and adults. And gradually over—this took 10 years, I think, this legislation. A lot happened in the last 4 years, but we have been working on this with local parents and politicians for the last 10 years.

I hope that helps in addressing——

Mr. SMITH. Ms. Cassidy, thank you very much.

And I remind my colleagues and our audience that Ms. Cassidy is actually in our consular general's office in Belfast, Northern Ireland. And we are most appreciative of her leadership but also of her time in joining us today.

Congresswoman Buerkle?

Ms. BUERKLE. Thank you, Mr. Chairman.

Dr. Shih, I would like to go back to your previous testimony with regards to the research that CDC is doing. And you mentioned that we should be more comprehensive. So we talked about what venues we go into and what we—can you just expand on that? In a perfect world, what would you consider comprehensive research?

Mr. SHIH. I think, in an ideal world, the data that we use to estimate prevalence of autism in the United States should come from multiple sources, in addition to special schools and physician records. There probably should be some effort to screen the general school population, not all of them, of course, but do it in a representative fashion, just so that we can be sure that we are not missing any children that, because of perhaps their milder condition, are actually in the mainstream school, and try to deal with all the challenges that they are facing with little or no assistance at this point.

Ms. BUERKLE. Thank you.

And then in a previous statement, as well, you mentioned USAID and that you did feel this was a priority and that they had other priorities. As we see the incidence of child mortality decreasing, obviously, it would seem like we are going to begin to see an increase in disabilities. Do those two pieces have to be separate from each other? Can we address mortality and then look at disabilities, including autism, jointly?

Mr. SHIH. Yes, I think that would be an ideal situation. I mean, I think our perspective is that they are not distinct issues; they are interrelated. And we have heard from some of our advocate friends is that they would like to have survivalist ability without disability, and that is their ultimate aim.

I think that makes a lot of sense, you know. It is not just about being able to survive a terrible disorder and diseases as a child, but being able to go on and realize your full potential as an individual. And that is much more difficult, obviously, when you have to deal with disabilities.

So I think we can get ahead of the curve and think about and highlight public health policies that not only address the mortality issue but plan for the future. What are we going to do with children that are going to emerge with disability as time goes on? I think it would really help us in terms of thinking not only in the

context of public health but also development in general for the country and our ability to address, you know, global public health issues, such as autism and other noncommunicable diseases.

Ms. BUERKLE. Thank you, Dr. Shih.

Ms. Kobenan, you mentioned in your testimony about Voice of America and being able to go onto that radio and talk about autism. Have you been back with Voice of America speaking?

And, beyond that, how have you found the media? Have they been a good partner in getting the word out? You mentioned communications earlier, how important that is. Has the media been helpful? And, if not, could you maybe talk to us about how that would look if they were going to become a partner in this?

Ms. KOBENAN. Voice of America have become a friend. They invited me—as a matter of fact, last April I was there, April 2nd, World Autism Awareness Day, I was there. And they have been very helpful in passing the information around, because the audience, the target audience, is in Africa. So I get a lot of feedback from people from Africa seeing me on Voice of America. Yes, I have been back on Voice of America, and I hope that in the future they will keep inviting me and we can have a close partnership.

As far as Cote d'Ivoire, for example, where I have been on TV, they are so—I am going to use the word "ignorant" about the subject, that they don't even know how to handle it. And I think that when you address these type of issues, when it comes to health, it is always important in Africa when you have the approval of the Minister of Health or somebody in that department. So when you go on TV and the journalist or whoever is inviting you knows that you are working with the Department of Health, they give you enough time and a platform and everything you need to talk about your subject. But when you come as an organization, there are so many small organizations talking about so many things, that sometimes they don't give you enough time, and the communication part is not very strong.

So I think that, by talking to the stakeholder and the responsible parties, that we will have enough time and a platform with the TV and the radio, and they will be more, you know, acceptable to receive us.

Ms. BUERKLE. Thank you.

And as a—not really a follow-up but another question, as a mother of a child with autism, can you tell us what tools have been most helpful to you in dealing with his disability?

Ms. KOBENAN. It has been very hard, and we tried it all. We tried supplemental vitamins and everything. But what has worked with us, which is a little bit controversial, is homeopathy.

Each child has his own situation, and whatever works with one child might not work with the other. In the case of Vinny, it was so hard that sometimes we were putting him down, wrestling our child to take his medication. And I was crying all the time, and I said, "There has to be a better way." The doctor said, "Put it in applesauce." After a while, applesauce tastes like medication, and the child knows it and he doesn't want to take it. So, eventually, we came across the homeopathy lady who really helped him, and that worked for us.

As a matter of fact, this lady is working with some children in Africa. What we did is we found a way to bring these children with her, and she deals with them through CD, she watches the children through a CD, videotape, and then she has a questionnaire. There is a way for her to work with these children, because it is cheaper and it is more affordable. Well, in Africa, everything cheap is good, right? So that is what she is doing right now.

We started with a couple of children, just to see how it goes, among other treatment that we are doing. We have our challenges, like, for example, the war, so we had to take a break and things like that. But it is working, and eventually the parents said that the children are more calm, quiet.

So homeopathic is one way, and then, of course, you have your treatment and regular pediatrician medication and everything that we have over there. We have a pharmacy in Cote d'Ivoire, for example, where they can get their medication to help them cope with it, yes.

Ms. BUERKLE. Thank you.

Mr. McCool, in your testimony, you talked about the edWeb program. You talked about 900 educators being involved in it. Is this just for educators and those involved in education, or is it more comprehensive than that?

Mr. MCCOOL. EdWeb itself is more comprehensive. It has communities for different segments. Eden established the autism community as part of edWeb. And so the people I was referring to, I think we have about 1,200 teachers who have signed up, public and private school teachers around the country, who network with each other, dealing with specific autism-related educational issues.

Ms. BUERKLE. Are you aware of any other programs similar to this, similar to edWeb?

Mr. MCCOOL. No. I think Facebook and Twitter and all those have been used by various people around the country, but we have found that this is so focused that it really helps people make a direct connection, rather than having to go through a lot of, you know, other systems that you have to sort of navigate through with Facebook and Twitter and LinkedIn.

This is very specific. There was a community of librarians, for example, who really deal with school library issues. There is a community for special education administrators. So you are communicating on very specific, meaningful topics. And it is one-to-one once you sign up.

Ms. BUERKLE. Thank you very much.

I yield back, Mr. Chairman. Thank you.

Mr. SMITH. Thank you very much.

Mr. Marino?

Mr. MARINO. Thank you, Chairman Smith. First of all, I apologize for being late. Some constituents kept me a little longer than I anticipated. But thank you for calling this hearing, because it is critical.

I have two children with special needs, and I am going to just pose a little scenario to the panel and ask if each one of you could respond to my question. We will start with Mr. McCool.

My son has been—it has been suggested by a couple of physicians that he has a very mild form of autism, Asperger. But then

there have been other physicians that say, no, they are off the mark.

How well-defined are we and how in tune are we with diagnosis today of autism, and particularly the breakdown elements of autism? Do you understand my questions?

Mr. MCCOOL. Yes.

Mr. MARINO. Please.

Mr. MCCOOL. Well, autism is one of those diagnoses, that there is no medical test, no blood test for, so it is done by observation and by sort of looking at the different categories. Obviously, autism impacts that part of the brain that impacts speech and other communication behavior, those kind of things. It doesn't impact IQ. So I think, obviously, the expansion of the definition to include Asperger's has impacted the numbers.

I think what we see is, if someone is diagnosed or suspected of having Asperger's, the thing to do is to really look at their communication and find out, you know, is their communication system intact, is it appropriate? That seems to be the most singular indicator. Because children, especially young children, have different levels of development, and so you don't really want to characterize someone or give them a label until you are pretty sure that they are going to have it.

So I guess the big question is, if someone is suspected of having Asperger's at an early age, would you treat them any differently now, suspecting that, or not saying that they actually have autism? And so we basically say, let's treat the person normally, let's see what happens. Generally, when we get to the point where it starts impacting their behavior or socialization skills, then that is a bigger indicator than just language development.

Mr. MARINO. Please.

Ms. KOBENAN. I think there is a lot more that needs to be done as far as diagnosis is concerned. The experience that I had with my child, up to 4 years old he wasn't speaking, and his pediatrician kept telling me it is because I speak French, not to worry. And this is here in America, not to say anything bad with that. But he lives here, and up to 4 years old he couldn't tell me.

And the test that I had, he went to Canada on vacation, and the doctor there saw him because he was accompanying his cousin who just had a cold. The doctor just gave the cold medication to his cousin and spent 45 minutes on my son and diagnosed him and faxed me the prognosis.

So I want to say there is a lot more that needs to be done. Even though in the United States we are so far ahead, compared to, you know, Africa, but there is a whole lot that needs to be done. In my case, they had do a brain map to know exactly what Vinny's problem is. And when we did the brain map, the doctor told me that he was smart, he has a high IQ, that I shouldn't worry about the intelligence part but worry about the society part, how to help him live in society with everybody. So, spend your effort on that department, and that is what we did. Because if you don't know that, you are all over the place trying to help him, when it is expensive, you waste money to treat him on the wrong direction. So that kind of helped us, the brain map helped us a lot to find out exactly where to put our effort.

So, as far as diagnosis is concerned, I think, you know, the United States, I am very grateful for what we have, but of course in Africa there is nothing.

Mr. MARINO. Doctor?

Mr. SHIH. So, as Mr. McCool mentioned, you know, autism is diagnosed largely behaviorally these days. And there is a tremendous amount of heterogeneity among the population. I think a well-regarded researcher from the Albert Einstein School of Medicine, Dr. Isabelle Rapin, said that when you have met one child with autism, you have met one child with autism. So it is very difficult to generalize beyond the social communication deficits.

Having said that, there are these diagnostic instruments, psychological instruments, that have been used and been standardized. And so the ability to discriminate an individual on the spectrum from an individuals who are not is fairly robust at this point.

I think the question you asked about Asperger's and all these subcategories of autism, I think historically we have used them to differentiate people who are perhaps verbal or nonverbal, who have intellectual disability versus those who are not. But I think those definitions are falling away as we learn more about autism.

I think, at this point, the new edition of DSM–5, which is the bible for psychiatric diagnoses, they are going to do away with all these subcategories; there is just going to be one autism spectrum disorder. So all the things that we previously talked about—high-functioning, low-functioning, Asperger's, and so on—will be actually part of one broad spectrum disorder diagnosis.

And this is consistent with the evidence we have so far. You know, we certainly have individual—we are now appreciating that individuals who are nonverbal actually have very rich inner life, very robust intelligence; they just don't have the faculty to be able to express themselves well. Whereas there are people who have, you know, average or above-average verbal faculties but have a tremendous amount of issues, you know, intellectual disabilities as well as social interactions.

And, certainly, these categories, these labels that you put on these children doesn't always predict in terms of the outcome. And there are many individuals who seem to be very challenged in early parts of life who actually went on to have very productive lives, whereas others who didn't seem to make as much improvement.

So I think, as we learn more about autism, I think the more we appreciate really it is a very broad spectrum of disorders. So, often, what we say now instead of autism as one disorder, you talk about "autisms." Just like the way we talk about cancer, even though it is a big collection of disorders but there are individual types of cancer that require different types of treatment approaches.

Mr. MARINO. Thank you.

I yield my time.

Mr. SMITH. Mr. Marino, thank you.

Let me just ask a couple of final questions.

Mr. McCool, in your testimony, you talked about teaching students with autism, effective strategies for grades K through 5 and effective strategies for 6 through 12. And I am wondering, you know, one of the things that we have all come to a better understanding of is that, unlike other disabilities—mental, emotional,

whatever it be—that autism is in a league of its own. It is a category. It is a type of teaching where, unless the teachers are very specifically trained, it is very difficult to meet the challenges.

And I am wondering, you know, in her testimony, Ms. Kobenan said that there are three primary problems: Lack of awareness, lack of education, and lack of availability of proper treatments. In the United States, where we have been grappling with this for several years, we have still not trained the teachers in a way that is commensurate with the problem and the challenge that we face.

And I am wondering if the teaching you espouse can increasingly be exported to Africa and exported either via the Web or training seminars or bringing people to Princeton, to Eden Institute or similar institutions, so that there can be a teach-the-teachers initiative to meet this challenge.

Mr. MCCOOL. Absolutely. And that certainly is the model that we are advocating. With webinars, the great thing about webinars is that they can be live so they can be interactive. They can be rebroadcast later so that people can look at them.

I think one of the biggest issues with autism training is back to the certification. Most teacher education programs do not have a specific autism certification track. California has passed legislation that has defined specific certification in autism that requires both instruction and coursework and a practicum, so that a person can get a level 1 or level 2 certificate as an autism teacher. And that process has begun. A lot of those courses are available online so that people can get them.

The motivation for this is, obviously, to be a better teacher, but also there are incentives built in to pay increases for people who achieve higher levels of certification. I am not aware of any other states right now that have that same process in place. We are working with Neumann University in Pennsylvania, who is looking to establish a similar process in Pennsylvania even though there is no state law that defines it, but building on what California has done, looking at the same coursework, the same kinds of things.

What people look at in terms of autism certification is a national certification, board-certified behavior analysts. And this is a very rigorous training program. The majority of people believe that if you get the BCBA certification that you have skills, you have acquired skills that make you proficient in dealing and teaching children and adults with autism. And, again, it is very rigorous. You have to take coursework, and have to do about 1,500 hours in a year of practicum under the supervision of another BCBA.

And so we use that model. We have BCBAs at Eden. We look at them to train the ABA therapists. There is no real certification for an ABA therapist, people who work in residential or employment programs. But the teacher certification for autism right now is just something that is emerging. More and more colleges and universities recognize the need for it. And there are, you know, several proposals out there. Kean University in New Jersey has just established one, as well.

So I think it is not a normal—it is so behaviorally intensive that regular college coursework doesn't really equip people to be effective ABA therapists.

Mr. SMITH. Thank you.

Mr. Shih?

Mr. SHIH. I would like to just add to that.

I think that has been one of the major challenges, is to train our professionals to really meet the needs. And I think, in less optimistic moments, you wonder if you will ever train enough people to might all the needs out there.

Fortunately, I think in recent years there has been research done now where people have now started to train nonspecialists as co-therapists in taking care of their children, and that includes parents. And there has actually been, over the past couple of years, several really well-designed studies that have been published that demonstrate that nonspecialists, as well as parents, when working with an expert, can actually faithfully deliver intervention at home for their children.

And we see this as a possibility, in terms of our international development, because, number one, it empowers the parents, because every parent knows their child the best and knows their needs need. And you are giving them the toolset to better manage behavior, to help them learn in the way that they need to learn.

And the second thing is that you can even do this kind of training via the Internet, this learning technology. Again, there have been recent publications that have demonstrated that there is practically no difference when you train professionals via the Internet versus an in-person setting. You get the same kind of expertise coming out of your class in providing services for the families.

So there is reason for hope.

Mr. SMITH. Thank you.

Again, Dr. Shih, you had mentioned in your testimony, and it is worth quoting again: "The current scientific consensus is that 67 million people, or about 1 percent of the world's population, is affected with some form of ASD, a prevalence that is higher than AIDS, diabetes, and cancer combined."

In his testimony that was submitted for the record from WHO, Dr. Shekhar Saxena, director of the Department of Mental Health and Substance Abuse of the World Health Organization, in his—this will be part of the record—it says that tens of millions of people are estimated to be affected in Africa only.

And I am wondering, you talked about the numbers in South Korea being higher. It seems, when we study it, it is like a tip-of-the-iceberg phenomenon, where it is worse than we thought.

And I am wondering, again—and I asked this earlier, but I ask it with emphasis now, because I have raised it with Dr. Shah at the U.S. Agency for International Development. This needs to be made a priority, and I hope it becomes one in the Global Health Initiative, because we have a—you know, pandemics are usually reserved, by definition, for infectious diseases, but I think, you know, with quotes around it, we can say this is a pandemic that is going largely unrecognized. And it is about time; our hope is with this hearing, to begin with vigor and a fresh set of impetus and eyes to make this a global effort with our tax dollar, which heretofore has not been the case internationally. Domestically, I think we are making progress.

I would note parenthetically that in the late 1990s, when I introduced the ASSURE Act, CDC was spending $287,000 per year for

5 successive years, straight line. That doesn't buy a desk. That doesn't buy anything of value. And then they got into it, obviously, as a result of the legislation. We are now spending $22.1 million. In regards to NIH, we were spending $10.5 million. Now we are spending, in 2010, $160 million. So, you know, when we chronicle, when we prioritize, the money will follow. And, hopefully, the good work that that money buys will make a difference in the lives of people.

And I do have one final question. I read a book recently called "Dancing with Max" by Emily Colson. I invited her up. She talked to the members of our Autism Caucus. Mr. McCool, you might want to speak to this, as well.

Obviously, we are still focused on early intervention and what do we do about all these young people, how do we help them have a more productive life and to help the suffering, frankly, of so many of these heroic parents who are faced with, particularly with severely autistic children, a very, very challenging life.

And I am wondering, with the aging-out issue, in "Dancing with Max," Emily Colson tells the story of how her husband left. By the time Max was 9, she had had it. But then, through the grace of God—and it really was through prayer—and a lot of help from people around her, she got through it. And now Max is approaching adulthood, and the important regimentation that goes along with formal schooling will go away.

And she made an appeal to Congress, and I know Autism Speaks has been making this appeal very robustly—Autism Society, Mr. McCool, which you are a part of, is making that, as well—what do we do now with these young adults to ensure that their lives and the quality of life does not diminish?

And I am wondering if you could speak to that, because it obviously has international implications, as well as domestic ones, for those children. Does anybody want to touch on that?

Mr. SHIH. Sure. So one thing I have learned from talking to all the stakeholders around the world is that the concerns of the parents, what they want for their children, is all the same. They want the best possible life for them, and so on. So the idea of being able to help them to achieve those objectives I think is very worthwhile.

You know, the idea that the individuals and families could benefit from awareness and research and delivery is really not a very ambitious goal. I think it is actually within the reach of most societies. I think, as I think it has been talked about in this particular committee meeting, you know, I think it takes political will. It takes understanding and knowledge and awareness of the issues. And it also takes understanding that you don't really need to invest a tremendous amount of money to make a difference. So, oftentimes, a quality-of-life issue can be robustly addressed with the right investment, strategic investment, of resources and expert assistance.

So I think it is really important for this committee to help the global autism community to think about, what are the possible solutions, what can we do? We are not looking for charity per se. We are looking for empowerment and the ability to help them to help themselves.

Ms. KOBENAN. I just want to say something about the training, you know, tied up with this. What I want to say is, I hear these numbers that you are talking about, millions and millions, and I just go, "Oh, my." In Africa, it doesn't take much to do a lot. Just an example, in 2009 I sent—I mean, ACA sent $1,000 to Autism Cote d'Ivoire. With that $1,000, they were able to have two volunteers, French ABA professionals, that gave their time. They weren't paid for what they were doing, but we were able to put them in a hotel and buy them—you know, little things like that. And within a week, they trained a few teachers and a few caregivers.

Now, this is not a lot, but it is a small step, and it adds up. You know, little by little, every so often, 6 months or a year, you can have a good team of people, you know, with some tools and help. It is always hard when you want to have something on the bigger level and, you know, come with all these big grants. But we can start small, create these centers, you know, small centers. They don't need to be very sophisticated, but where they can go and get the information and where the communication can come from.

I just wanted to add that.

Mr. MCCOOL. I think we have to remember that, until 1975, children with disabilities weren't entitled to a free appropriate public education. And so, a lot of the strides that we see with early intervention services and with education are because of that legislation. It has put some teeth into the law.

So when children graduate from that educational system and become adults with disabilities, particularly adults with autism, that same level of support is not available. In fact, many times, the huge investment that has been made with behavorial therapies, speech therapy, occupational therapy disappears, the effectiveness of that disappears if the child becomes an adult and cannot be sustained.

So we recognize that all of the children diagnosed with autism now will be adults with autism in the future. And we have to look at housing, we have to look at support for them, we have to look at employment for them. And, right now, I think a lot of strides are being made to sort of look at the kinds of employment, the kind of jobs that align skills that people with autism have.

I know, years ago, when Bittersweet Farms was started as a model program, it fell out of favor because it was seen as an isolationist program or a segregated program putting people on the farm. What I see today is a growing number of farm programs. And, obviously, it is the model in Ireland, which has an agricultural culture. But even in our country, small farms are coming back, and they are employing people with autism, who enjoy that kind of work. It is very repetitive. It is the kind of work that aligns skills of certain people with autism and the duties and responsibilities of the employment.

So I think our challenge is to look at how, with the resources that we have, children age out of school, so there is a population constantly leaving childhood and entering childhood, but the adult program—adults with autism are living normal lifespans.

And so, right at Eden, at this point, we have group homes and apartment programs, residential programs, and some of those guys

have gotten up to their 60s, and we are looking at you know, what is that next step? What kind of support can we provide them?

So I think the model that we had with the Education for All Handicapped Children Act of 1975 really set an example of what can be done to help adults with disabilities, and particularly autism, as we go forward. The numbers are big, and we have to look at various streams of funding that can help provide that support and enable them to be productive in working to help support themselves.

Mr. SMITH. The chair recognizes Mr. Payne, the ranking member of the subcommittee.

Mr. PAYNE. Thank you very much. And thank you for prolonging the hearing so I could at least get here in time. I think he thought he was in the Senate, filibustering. But I appreciate that, having the opportunity to be here. I had a longstanding engagement which I was unable to alter.

But let me take the indulgence of the committee for a brief opening statement. It might be past tense now since you have testified, but we looked at your testimony and I am aware of what each of you had to say.

But I certainly begin my statement by thanking Chairman Smith. And, certainly, let me recognize his longstanding leadership on this issue, both domestically and globally.

I would also welcome our esteemed witnesses today and look forward as the testimony that you have given and that my staff heard and that we looked at earlier on autism globally and how proposed interventions would coexist and complement our efforts to combat Africa's leading killer diseases, namely HIV/AIDS, malaria, and neglected tropical diseases, where they have the emphasis, as has already been mentioned by the chairman, but issues like this, which impact on so many others, are left unattended to.

Autism, often identified by impairments in communication and social interaction, is usually recognized in early childhood, around the age of 3. Imagine the news that one's child, and as you must have experienced, faces the challenges of autism, and the devastation of hearing that this has beset your young child.

Fortunately, here in the United States and in other developed countries, progress has been made in our efforts to detect and treat those with the disorders. However, we still have a long way to go, as you mentioned in your testimony, Mrs.—say it?

Ms. KOBENAN. Kobenan.

Mr. PAYNE. Kobenan. I never would have said it so nicely.

But as you have testified and as I read in your remarks about how you had to leave this region of the country, where you would think that in Washington, DC, and in this environment of Maryland and Virginia we would have the most appropriate attention, given the resources, but you chose to move to Arizona because you knew that, there, there were better services.

And so we can just imagine how in a developing country, where many, many, many needs are, that autism certainly is an issue that seems to be, and mental health even in general, tends to be on the back burner, rather than diseases that we hear so much about.

In the U.S., there are public and private resources available for impacted families to better cope with the disease. Sadly, the same support structures provided in the developing world often do not exist in low- and middle-income countries, due to inadequate funding and a lack of understanding or diagnosis of the disorder. There are often neglected populations battling a wide range of physical, mental, and neurological disabilities in developing countries, further compounding the burden of poverty and weak health systems on families, communities, and governments.

The United Nations has taken some important steps to ensure equal rights for those with disabilities, including the 1981 declaration by the United Nations for the International Year of Disabled Persons. Then it established the United Nations Decade for Disabled Persons in 1983 to 1992. The U.N. then expanded the Universal Declaration of Human Rights to include people with disabilities some 35 years after the Declaration was adopted. And the United Nations reaffirmed equal rights for people with disabilities through several fora, particularly the Convention on the Rights of Persons with Disabilities in 2006, and declared April 2nd World Autism Awareness Day.

And so many times there is—and, actually, UNESCO has really moved forward in addressing the problems with the Framework for Action to Meet Basic Learning Needs, which calls on governments to pay special attention to the learning needs of the disabled and take steps to provide equal access for education for every category of disabled persons as an integral part of the educational system. This concept of equal education for mentally and physically disabled people has been endorsed by several countries through the ratification of numerous international and regional agreements.

And so, although we do hear criticism of the United Nations, I think that many issues would have gone unspoken throughout the world if it were not for the United Nations, going back 40 years ago, recognizing that countries, especially in low- and middle-income countries, would not raise the issue of the disabled when they had so many other basic issues, like clean water or malaria. So I do commend them for that.

There are certainly, as I mentioned, a lot of private resources available for impacted families to better cope—that is here in the United States—with the disease. Sadly, though, the same support structure provided in the developed world often does not exist in low- and middle-income countries due to inadequate funding and a lack of understanding or diagnosis of the disorder.

There is an often neglected population battling a wide range of physical, mental, and neurological disabilities in developing countries, further compounding the burden of poverty and weak health systems on families, communities, and governments. The United Nations has taken these important steps, as I mentioned before.

However, the right to education remains unattained for many autistic children in the developing world. While the United Nations' actions are commendable, many developing countries are failing to address the special needs of their autistic population. The World Health Organization found that, in middle- and low-income countries, there is only one child psychiatrist for every 4 million people. That is unbelievable.

I look forward to what you have said and has been recorded, looking at low-cost interventions, given their limited state budgets and over burdened public health systems, which developing countries can apply, and to better deal with the issues of autism within their borders.

We know that there have been several—the Journal of the International Association of Special Education found that children with autism in Africa do not share the same behavioral signs as their Western counterparts—it was very interesting—such as rocking back and forth. It seems that geographic and environmental differences impact the way that the disorder manifests itself, which makes it even more difficult because there is not going to be one kind of a treatment that covers all. And I look forward to how we might be able to work along with the fact that there are different signs.

Furthermore, we know that, from the Haiti earthquake and other examples, that in crisis situation those with disabilities are often inadequately cared for. We know that this a big problem.

And so I once again would like to join with the chairman in certainly thanking you for your appearance here and also for your interest. And I just have a quick question or two, since I have almost exhausted my 5 minutes. I don't know how to tell time.

But there appears to be limited information about the prevalence of autism worldwide, especially in Africa. What do you know about it, in a nutshell, about how widespread this disorder is in the world, particularly in Africa? And what are the greatest challenges in conducting autism prevalence studies abroad?

If any of you would like to try to take a stab at that.

Mr. SHIH. Sure.

So, the challenges of conducting prevalence studies in Africa is actually similar to elsewhere. It is about informing the community, informing the stakeholders, so they understand what you are trying to do and to work with you. And we found that when you have community buy-in, you are actually able to generate the highest-quality data.

And the greater challenge, I think, for working with territory in Africa is actually the second act. To do a study in a community is one thing, but trying to figure out what you are going to do with all the individuals and families who are affected by autism that you identified through the study is something completely different. And that requires a commitment not only to the individuals and families, but also a commitment to change community, society, and governments. And that kind of work takes a long time, it takes a lot of resources, it takes a lot of focus.

But, at the same time, that kind of policy change will be meaningful only if you have real solutions on the ground. The idea is that you want to nurture and support and grow things that are already working for individuals and families on the ground. So, going to any low and developing country, you need to really approach it from a top-down as well as a bottom-up perspective. You need the top-down so that the solution you develop from the bottom-up is sustainable and can be integrated as a meaningful solution for the national public health system in the longer term.

Ms. KOBENAN. I said it a minute ago, and I will say it again. One of the basic, basic challenges that we have are the lack of centers. You know, you can have a program to teach teachers, to educate stakeholders, and all that, but once the whole team is gone, whether you come from the United States, you teach these people, and then you leave, where do the parents go for more information? They need to have a center. Everybody has a house. They need to have a house that they call "autism center." It doesn't have to be sophisticated. But that is a major challenge.

Once they have those little centers, they can go there, get information. And if anybody has any question, they can go there. They can have a small staff member that can go part-time with no benefits and just work there to educate people, and they have a place to go. That is the first step.

Mr. PAYNE. Would you think that the church community in Africa or other developing countries could be a center, if there could be an educational campaign to educate the religious community and simply ask if their parsonage or some part of their building could be used for that?

Ms. KOBENAN. Yeah, that is a good point, because, indeed, that could be a solution. And when I say "center," it doesn't have to be a building; it can be those things, too.

Because, for example, the ex-wife of the Ambassador of Liberia—because at ACA we try to work with the wives of ambassadors and get them to be involved, and she got involved. Her solution was to talk to one of her church pastors and see if he could give her part of a building. And, indeed, within a year, she was able to do that. And she told me that the center actually was created.

So that is a very good suggestion, too.

Mr. PAYNE. And we might even go further and ask our U.S. Department of State and USAID, as they move forward on this, that we might prod them on this issue and suggest to them that their ambassadors—and they all have projects that they can fund a little stipend that they could do, and they don't even need that. But if the ambassadors' wives could have the women, perhaps, of the countries and encourage them to have a meeting and then encourage the African community to therefore approach the hierarchy of the church, I think that we could—as you mention, you don't need a lot of money, you just need to use the resources. And everyone needs a home, you are absolutely right.

Because I was late and I have taken enough time, I will yield back and will ask no other questions. Thank you very much.

Mr. SMITH. I understand Ms. Buerkle has an additional question.

Ms. BUERKLE. Thank you, Mr. Chairman. Just as a brief follow-up, Ms. Kobenan, you mentioned regarding your son and the brain mapping that was done. It seemed to really shed light on what he was going to have difficulties with. Can you expand upon that? Is that an MRI of sorts?

Ms. KOBENAN. It is an EKG that you do. They put a lot of electrodes on his head and then he has to stay still and they do a map. They kind of read the activity on his brain for a period of time. It is very expensive. We had it in Arizona. But it is so helpful. So I wouldn't suggest that for every family if they have to come up with the money out of their own pocket because ours cost us $3,500. If

they can have the insurance, some kind of help, that would be very helpful because it really tells you right from the start whether you should plan on putting your child in the facility where he will be 24/7 taken care of by people or he can take care of himself when he grows up. So you can start investing money to find a good facility for him or you can invest your money into developing activities for him to help himself. So that kind of gives you a roadmap right from the start. We were lucky enough to have come across this doctor that did that.

Ms. BUERKLE. Does anyone have anything to add to that?

Is it not covered by insurance, does anyone know?

Ms. KOBENAN. Not at all, trust me.

Ms. BUERKLE. Is it an EEG?

Ms. KOBENAN. EKG.

Mr. SHIH. I think it is the EEG.

Ms. BUERKLE. So it is what they do somewhere for seizures and other types of brain function?

Ms. KOBENAN. Right.

Ms. BUERKLE. Thank you very much. I yield back, Mr. Chairman.

Mr. SMITH. Would the witnesses like to add anything further? Ms. Cassidy, thank you for your testimony from Belfast, Northern Ireland.

I would just like to close with the statement that Dr. Shih made and I think it again encapsulizes why we are so concerned. He noted in his testimony: As child mortality decreases, simple math predicts an increase in the number of children with developmental disabilities. So instead of seeing mortality and developmental disorders like autism as two distinct public health challenges, they should be tackled as parts of the same problem.

To continue his statement, he said, you said just a few moments ago, Autism Speaks and our partners around the world believe that by addressing autism and related disorders now, South Africa and other developing countries can get ahead of the curve, help maximize outcomes for affected individuals and families, and minimize long-term costs to society.

We have a pandemic with autism. Hopefully, we can launch and do much more with the Global Health Initiative and all the other related efforts at the U.N. at the country specific level to mitigate this devastating developmental disorder.

I thank you.

The hearing is adjourned.

[Whereupon, at 4:05 p.m., the subcommittee was adjourned.]

APPENDIX

Material Submitted for the Hearing Record

SUBCOMMITTEE HEARING NOTICE
COMMITTEE ON FOREIGN AFFAIRS
U.S. HOUSE OF REPRESENTATIVES
WASHINGTON, D.C. 20515-0128

SUBCOMMITTEE ON AFRICA, GLOBAL HEALTH, AND HUMAN RIGHTS
Christopher H. Smith (R-NJ), Chairman

May 31, 2011

You are respectfully requested to attend an OPEN hearing of the Subcommittee on Africa, Global Health, and Human Rights, to be held in **Room 2172 of the Rayburn House Office Building (and available live, via the WEBCAST link on the Committee website at http://www.hcfa.house.gov):**

DATE: Tuesday, May 31, 2011

TIME: 2:00 p.m.

SUBJECT: Global Perspectives on Autism - A Growing Public Health Crisis

WITNESSES:

Ms. Arlene Cassidy
Chief Executive Officer
Autism NI

Mr. Andy Shih
Vice President of Scientific Affairs
Autism Speaks

Ms. Brigitte Kobenan
Founder
Autism Community of Africa

Mr. Tom McCool
President and CEO
Eden Autism Services

By Direction of the Chairman

The Committee on Foreign Affairs seeks to make its facilities accessible to persons with disabilities. If you are in need of special accommodations, please call 202/225-5021 at least four business days in advance of the event, whenever practicable. Questions with regard to special accommodations in general (including availability of Committee materials in alternative formats and assistive listening devices) may be directed to the Committee.

COMMITTEE ON FOREIGN AFFAIRS

MINUTES OF SUBCOMMITTEE ON *Africa, Global Health, and, Human Rights* HEARING

Day *Tuesday* Date *May 31, 2011* Room *2172 Rayburn*

Starting Time *2:00 p.m.* Ending Time *4:05 p.m.*

Recesses *0* (____to ____) (____to ____) (____to ____) (____to ____) (____to ____) (____to ____)

Presiding Member(s)

Rep. Chris Smith

Check all of the following that apply:

Open Session [✓]
Executive (closed) Session [ ]
Televised [✓]
Electronically Recorded (taped) [✓]
Stenographic Record [✓]

TITLE OF HEARING:

Global Perspectives on Autism - A Growing Public Health Crisis

SUBCOMMITTEE MEMBERS PRESENT:

Rep. Chris Smith, Rep. Ann Marie Buerkle, Rep. Tom Marino, Rep. Donald Payne

NON-SUBCOMMITTEE MEMBERS PRESENT: *(Mark with an * if they are not members of full committee.)*

HEARING WITNESSES: Same as meeting notice attached? Yes [✓] **No** [ ]
(If "no", please list below and include title, agency, department, or organization.)

STATEMENTS FOR THE RECORD: *(List any statements submitted for the record.)*

Prepared statement of Dr. Shekhar Saxena of the World Health Organization

TIME SCHEDULED TO RECONVENE _____
or
TIME ADJOURNED *4:05 p.m.*

Sheri Rickert
Subcommittee Staff Director

MATERIAL SUBMITTED FOR THE RECORD BY THE HONORABLE CHRISTOPHER H. SMITH, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW JERSEY, AND CHAIRMAN, SUBCOMMITTEE ON AFRICA, GLOBAL HEALTH, AND HUMAN RIGHTS

Written submission for the Hearing on Autism as a Global Disability for Subcommittee on Africa, Global Health, and Human Rights in the Foreign Affairs Committee; 31st May 2011; Chair: Congressman Christopher Smith (New Jersey).

Submission by-
Dr Shekhar Saxena
Director
Department of Mental Health and Substance Abuse
World Health Organization
CH-1211, Geneva, Switzerland
e-mail saxenas@who.int

We appreciate the invitation to submit written testimony and we would like to thank the Subcommittee for taking the time to focus on autism and developmental disabilities and for your sustained commitment to robust U.S. investment in global health and development.

We are grateful for the opportunity to share the evidence on the global burden of autism and other developmental disorders and efforts undertaken by WHO towards improved awareness and access to care. WHO views development disorders within the overall priority of childhood mental disorders and disabilities.

Global burden of autism and other developmental disorders.

Developmental disorders, including autism, are disabling conditions characterized by impairment in functions related to the central nervous system maturation. Their prevalence is considerable across countries: tens of millions of people are estimated to be affected in Africa only. These disorders have childhood onset but tend to persist into adolescence and adulthood. Available scientific evidence suggests that a variety of both genetic and environmental factors contribute to their onset.

People affected by autism have severe impairment in social interaction, communication and language, and a narrow and repetitive range of behaviors, interests and activities.
They often have additional problems, including epilepsy, learning and intellectual disabilities. These neuro-developmental impairments seriously influence everyday functioning of affected children and severely interfere with their developmental, educational and social attainments.

Caring for children with developmental disorders is very demanding, especially in contexts where services and support are not provided: it may cause massive disruption in the lives of caregivers and bring significant economic hardship to families.
Children with developmental disorders and their families face major challenges associated with stigma, isolation and discrimination, as well as a lack of access to health care and education facilities, in violation of their fundamental human rights.

In spite of the complex and chronic nature of developmental disorders, early interventions have proved to be effective in improving the overall functioning of the child and long term outcomes. Multidisciplinary and intersectoral approaches are recommended which include provision of educational and occupational opportunities and support to caregivers.

WHO is concerned that despite the high burden of developmental disorders in children and adolescents, these conditions have received little attention in low and middle income countries including in Africa and have been widely neglected by policy makers and public health experts,

particularly in low- and middle-income countries. In fact, few countries in Africa have child and adolescent mental health policies. Efforts made by international development agencies to reduce stigma and improve access to care and support for children with developmental disorders and their families have also been inadequate. As a consequence, children and families in need have often poor access to services and do not receive adequate treatment and care. Even the basic human rights of children and adults with developmental disorders are often abused, in many cases in fragrant violation of existing UN declarations and treaties.

WHO contribution towards improved public awareness and access to quality care.

WHO recognizes the public health importance to address mental and developmental disorders in children, based on their prevalence, disability burden, long term health consequences and the associated human rights violations.

WHO is committed to provide technical assistance to Member States to deliver integrated health care services to children with mental and developmental disorders including autism.

The Organization's efforts in the field have focused on (a) generating data and evidence to inform service planning , advocacy, and further research; (b) development of technical materials and provision of technical guidance to support scaling up of health services in low-resource settings; (c) raising awareness on developmental disorders.

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(a) Generating data and evidence to inform service planning , advocacy, and further research

- The organization contributed to identify gaps in the way child mental health and the needs of children with mental and developmental disorders are captured in national policies and addressed in the delivery of services, by conducting a global survey on resources for child and adolescent mental health (WHO Atlas for Child and Adolescent Mental Disorders, 2005).

- In addition, systematic reviews on prevalence and correlates of autistic spectrum disorder and on effective interventions for identification and management of developmental disorders were conducted by WHO in collaboration with international experts.

- A research agenda on developmental disorders was developed following an experts' consultative exercise.

(b) Development of technical materials and provision of technical guidance to support scaling up of health services in low-resource settings

- In October 2008, a program aiming at scaling up services for priority mental disorders (the Mental Health Gap Action Programme -mhGAP) was launched by the Director General of WHO, Dr Margaret Chan. Developmental disorders, including autism, were identified among the priority conditions to be addressed. The program provides policy makers and stakeholders a clear set of activities which need to be implemented in order to improve access to mental health services and reduce the treatment gap for priority mental and neurological conditions, including autism. The program is currently being implemented in 6 pilot countries.

- Following an international consultative and participatory process an evidence-based clinical guideline (mhGAP Intervention Guide) was developed and was launched in October 2010 by the WHO DG. The Intervention Guide includes a full range of recommendations to facilitate early identification and quality care for autism and other developmental disorders at first- and second-

level facilities by the non-specialist health-care providers in resource-poor settings. The guidelines are widely used and have been translated in several languages.

(c) Raising awareness on developmental disorders.
WHO provides continued support to initiatives aiming to increase awareness on the public health relevance of developmental disorders, including the UN World Autism Awareness Day. Partnerships were recently established with other organizations committed to improve services and increase public awareness about autism, like Autism Speaks.

Critical unmet global needs.

WHO reaffirms its commitment to sustained efforts towards increased awareness on child mental and developmental disorders, and towards improved health services worldwide.

WHO recognize that, despite progress made in recent years and increased international public concerns for children with mental and developmental disorders, concerted actions are required to tackle global challenges and address unmet needs.

There is need for stronger efforts for:

1. Increased public awareness on the needs and right to care for children with mental and developmental disorders, at international and national levels, including in low- and middle-income countries.

2. Improved advocacy for inclusion of child mental health concerns into health policies and strategies, and for allocation of adequate resources by Governments and other stakeholders, including international development organizations.

3. Improved scientific knowledge, including evidence on effective interventions and models to deliver and scale up care for mental and developmental disorders in children in poor resource settings.

4. Increased coverage of quality care services for children with mental and developmental disorders, especially in low-and middle-income countries, and better access to a continuum of care, from community support, psychoeducation and rehabilitation interventions to specialized health services.

5. Increased multilateral partnership at the global level to enable implementation of the aforementioned proposed actions at the global level and also in Africa. Continued support of the United States of America including its federal agencies like USAID to this process will be helpful.

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