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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.

I am Brigitte Kobenan, founder of the Autism Community of Africa and a mother with a child with autism. In 2007, after being invited on the Voice of America Television-VOA- 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 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 Côte 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 GA 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 anyway, 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 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.

These children in Africa are not as 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 programs. As of now, a few NGOs in countries like Nigeria, Cameroun, 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 infrastructures 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 etc. A mother told me once: “If I show you my son, what are you going to do for him?”

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.