

**House Foreign Affairs Committee**

**Subcommittee on Global Health, Global Human Rights and International Organizations**

*Subcommittee Hearing – November 20, 2024 at 2 PM*

**Hearing title: “Meeting the Challenges of Global Brain Health: Diagnosis and Treatment for the 21st Century”**

Testimony of Dr. Andy Shih – Chief Science Officer, Autism Speaks

Thank you, Chairman Smith, Ranking Member Wild and all distinguished members of the Subcommittee for inviting me to testify and for holding this important hearing.

I am Dr. Andy Shih, Chief Science Officer for Autism Speaks, a national, non-profit organization dedicated to creating an inclusive world for people with autism throughout their lifespan. We do this through advocacy, services, supports, research and innovation, and advances in care.

In addition to the work we are engaged in domestically, Autism Speaks has been committed for many years to developing and implementing strategies and programs that positively impact the lives of people with autism and other developmental disabilities around the world. The primary vehicle for this has been our Global Autism Public Health initiative (also known as GAPH). GAPH is a community participatory research and advocacy program where, in addition to facilitating high impact science to inform program and policy development, we serve as technical advisors to governments and NGOs committed to enhancing support for our community. We help source expertise, support community-based knowledge co-production, and facilitate dissemination and implementation of sustainable solutions.

What we’ve learned from our many years of work in this space and through our Autism Leadership Network, a distinguished group of leading international autism advocates that Autism Speaks has supported for over a decade, is that there are some absolutely incredible individuals and organizations working in countries across the globe to raise awareness of autism and increase access to services. These are truly some of the most remarkable, caring people you will ever meet, who often work with extremely limited resources and in difficult political climates. What we’ve also learned is that while these advocates have made a significant impact, we have only scratched the surface in terms of building the awareness and acceptance of autism, and infrastructure for services that is needed around the globe to meet the needs of autistic people.

While much of the work that we engage in internationally involves working directly with community organizations, last year, we had the opportunity to collaborate with the World Health Organization and UNICEF on a first-of-its-kind report, *The Global Report on Children with Developmental Disabilities*. This report provides a comprehensive perspective on the prevalence and characteristics of children with developmental disabilities globally and serves as a call to action for all nations.

I’d like to focus on a few of the findings and recommendations from this report, as I think they are helpful in informing our conversation today. First, the report notes that there are an estimated 317

million children and adolescents worldwide that have health conditions that contribute to developmental disabilities and 95% have no access to appropriate care. Children and adolescents with developmental disabilities are at increased risk of mental health conditions and premature death due to illnesses such as obesity, diabetes, heart and respiratory diseases. Their needs are largely neglected and they “continue to experience stigmatization, prejudice, institutionalization and barriers to participation, as well as social, economic, educational and other forms of exclusion,” and “barriers in accessing health care [along with] poorer quality of care when compared with their peers.”<sup>1</sup> This results in widespread inequity in terms of health outcomes, and tragically, premature mortality for many people with developmental disabilities.

Despite the depth of these challenges, this report provides hope and a path forward. The overarching objective of this report is to **take action for change**. Children with developmental delays and their families have long been neglected to the margins, and that has to change. That has to change now. The report maps out 10 action areas to accelerate changes in policies and care systems for children and young people with developmental disabilities. I encourage all of the members of the subcommittee to read through them.

One key takeaway from the report is that improving health outcomes for these children must involve a holistic approach. To truly make progress, institutional barriers to care must be addressed and, at the same time, more personalized approaches must be utilized to address each child's individual needs.

To accomplish this, one approach known as the “stepped-care” model is being increasingly recognized as an efficient and effective way to build tiered systems of care for children with developmental disabilities. This approach involves making available care options of varying levels of intensity, linked through defined care systems.

Recently, Autism Speaks implemented the stepped-care approach by supporting a UNICEF pilot that focuses on early identification and intervention for children with developmental delays in three countries (Bulgaria, Peru and Uganda) as part of the Care for Child Development Initiative. The work being done in these countries is already having a substantial impact, and *The Global Report on Children with Developmental Disabilities* will continue to serve as a rallying point, as well as a roadmap, to make progress around the world.

Lastly, while millions of people with developmental disabilities around the world still struggle to access appropriate health care, I would like to acknowledge the progress that has been made in the development of tools to improve autism diagnosis. Autism Speaks supported the development of two freely available tools, the Open Source Screening and Diagnostic (OSSDx) tool for autism spectrum disorder and the Nigerian Autism Screening Questionnaire. The ability to reliably screen and diagnose autism is critical in determining the most appropriate level of care for autistic children. High-quality screening tools like these are necessary to address the challenges of improving diagnosis and intervention.

Chairman Smith, throughout your career, you have been an incredible champion for autistic people not just here in the United States, but around the world. If passed, the Global Autism Act that you have previously proposed would be a tremendous step in the right direction in helping to address some of the challenges I've mentioned today. I'm grateful to you for inviting me to testify at this

particular hearing where we are focused on neglected aspects of public health. People with autism and other developmental disabilities around the world have tragically been neglected for many years and across every system of care. As I said earlier, the time for change is now and I look forward to working with you and all members of the subcommittee in making that change. Thank you again and I look forward to your questions.

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<sup>1</sup> World Health Organization, & United Nations Children's Fund. (2023). Global report on children with developmental disabilities: from the margins to the mainstream. World Health Organization. <https://www.who.int/publications/i/item/9789240080232>