



Autism Speaks Global Autism Public Health (GAPH) Initiative

The Challenge

Autism spectrum disorder (ASD) is a developmental neurological disorder characterized by deficits in social behavior and communication, and a restricted range of activities. ASD transcends social, cultural and geographic boundaries. At least 1 in 150 individuals are affected with ASD.

Autism symptoms range from mild to severe. Some individuals have strong intellectual and language abilities, whereas others require life-long care. Many suffer from medical problems along with autism. The American Academy of Pediatrics (composed of over 60,000 pediatricians) has recommended mandatory autism screening for all children between 18 and 24 months of age because there is compelling evidence that early intervention can result in significant gains in language and cognitive and impact long term outcome,

A major barrier to improving the health and wellbeing of children and families touched by autism is the lack of knowledge and expertise. This limits access to care and early intervention and impedes the development of appropriate public health programs that can improve the quality of life for individuals with ASD and their families. These challenges are further complicated by a shortage of experts and trained professionals.

Autism Speaks' international efforts seek to address these challenges. We have witnessed success in improving care in both North America and Europe, and are now beginning to replicate those successes elsewhere. Our efforts focus on awareness and building capacity for research and services. We achieve these goals by engaging governments, stake-holders, and grass-roots organizations to help bring about the necessary changes to benefit affected families and society.

Autism Speaks' mission to change the future for all who struggle with ASD is clear, Autism Speaks' international priorities are to **increase autism awareness** and recognition, **service delivery**, and **research collaboration** around the world. Forming strategic partnerships among countries with different cultures, levels of expertise, and existing service infrastructure is critical for achieving this goal. We firmly believe that, in addition to direct benefits to individual countries and territories, lessons learned from these partnerships will help the entire global autism community.

The Solution: Autism Speaks' Global Autism Public Health Initiative

The Autism Speaks Global Autism Public Health (GAPH) Initiative is an innovative, integrated approach that focuses on three goals:

- Increasing public and professional awareness of autism spectrum disorders (ASD)

- Increasing research expertise and international collaboration through training of autism researchers, with a focus on epidemiology, screening and early diagnosis, and treatment
- Enhancing service delivery by providing training and expertise to service providers in early diagnosis and intervention.

We are seeking partners worldwide who can work with us to foster collaborations among governments, communities, and scientists, who can help support a self-sustaining public health infrastructure to enhance awareness and capacity for autism services and research. We recognize that differences in resources, infrastructure, culture, and priorities require a customized plan of action for each territory. Interested stakeholders help determine the best approaches to delivering solutions to their unique region of the world.

How is this accomplished?

✓ Awareness

Autism Speaks' successful U.S. awareness campaign has **dramatically increased public and professional recognition** and understanding of ASD and **supported the passing of significant federal and state legislation** aimed at enhancing research and services. We are eager to share our campaign strategy, content, dissemination channels, and methods of impact evaluation so they can serve as a starting point for interested partners. This approach has been used in our Pan American Autism Awareness Training Initiative (*Please see folder insert*). Specifically, we can provide assistance in the development of a culturally-sensitive advertising campaign and/or educational material aimed at increasing the overall awareness of autism among both the general population as well as health and education professionals.

✓ Training and Scientific Collaboration

A necessary step toward building research capacity worldwide is the **adaptation of standardized screening and diagnostic instruments** for cultural relevance and sensitivity. Validated instruments ensure accurate diagnosis and facilitate early detection of ASD. While these instruments have been translated into some languages, there are still many territories that do not have access to them. To help address this need, Autism Speaks is collaborating with Western Psychological Services (WPS), the publisher and owners of copyrights on many of the key diagnostic assessments. With the help of WPS, we have devised a process that streamlines the translation process, ensuring best practices and timely approval.

Furthermore, Autism Speaks' International Autism Epidemiology Network (IAEN) (*Please see folder insert*) is designed to **promote collaborative research** through the exchange of epidemiologic ideas and practices between investigators and across countries. Nearly 80 investigators representing over 30 different countries have participated. In addition to fostering collaboration, scientific networks such as IAEN offer an ideal platform for **training the next generation of autism researchers**, where talented young scientists can learn by engaging in world-class, cutting edge efforts.

✓ Services Training and Delivery

Effective treatments involve close collaboration between professionals and families, and require sensitivity to cultural perspectives and values. Thus, while we are able to provide information and training regarding empirically-supported "best practices", the actual

practices employed and effects achieved will vary according to the specific needs, cultural preferences, and values of a given territory. Accordingly, efforts to provide international service training must be vetted and modified by local stakeholders to fit cultural norms and values at the point of delivery. Such stakeholders include parents, medical and mental health professionals, early education professionals, and special education professionals.

Our training model ***builds capacity for services*** by providing professional development, technical assistance, content development, and education. The model is comprised of three phases:

Phase 1: Identification of a national planning group of parents and professionals that will determine the national goals and needs, and make cultural adaptations, as required.

Phase 2: Development, training, and provision of on-going technical assistance for the national training team in the desired intervention practices

Phase 3: Support for the national training team while it transitions to become independent trainers of others in their territory.

The goal is to have a self-sustaining system for service delivery and training of service providers at the community level by the end of this three-phase process.

Summary

Autism Speaks' GAPH Initiative seeks to

- Form global partnerships and learn from one another
- Enhance awareness and understanding of autism worldwide
- Build capacity for research excellence across the globe
- Improve the quality of life for individuals with ASD and their families through training and education

We welcome your participation in the GAPH Initiative. If you are interested, please contact: Andy Shih, Ph.D., Vice President of Scientific Affairs (ashih@autismspeaks.org).