

## **Autism Speaks in Latin America: The Pan American Autism Awareness and Training Initiative**

Autism Speaks' [Global Autism Public Health Initiative \(GAPH\)](#) was not born over night. Designed to bring sustained solutions autism communities around the world, GAPH evolved over time as part of an ongoing process in understanding the important but complex relationship between autism advocacy, service provision, and research. By funding scientific grants internationally, we learned that while research can help answer important questions about autism science, in low resource settings research alone does not address the need for autism awareness and services. In fact research often *increases* the demand for services and information about the diagnosis and treatment of autism.

GAPH is tailor-fit to address the specific challenges faced by various autism communities around the globe and Autism Speaks is helping to develop programs on nearly every continent. Naturally, GAPH began close to home in a partnership between the United States and our closest neighbors in the [Pan American Autism Awareness and Training Initiative \(PAAATI\)](#). Today, Autism Speaks is exploring GAPH partnerships with more than a half dozen countries in Latin America.

[Pan American Autism Awareness and Training Initiative \(PAAATI\)](#)

[http://www.autismspeaks.org/press/multinational\\_initiative\\_to\\_raise\\_awareness.php](http://www.autismspeaks.org/press/multinational_initiative_to_raise_awareness.php)

The objectives of PAAATI are the same as those of our Global Autism Public Health Initiative (GAPH), as GAPH essentially evolved from this initiative. The purpose of this multinational initiative is to: (1) increase public and professional awareness of autism spectrum disorders, (2) increase research expertise and international collaboration among countries in North, South, and Central America by providing training to interdisciplinary autism researchers, with a focus on epidemiology and screening/early diagnosis, and (3) enhance service delivery across the Americas by providing training to professional service providers that focuses on screening, diagnosis and educational intervention.

PAAATI was designed in response to the recommendations developed following an Autism Speaks-sponsored meeting of the International Congress for Autism Research in Mexico City, in June of 2007. PAAATI features a collaboration between Autism Speaks and: CARSO Health Institute, Canadian Institutes for Health Research (CIHR), Clinica Mexicana de Autismo (CLIMA), National Institutes of Child Health Development (NICHD), and The American Academy of Pediatrics (AAP).

The first PAAATI workshop took place in NYC in June of 2008 and focused on designing a Spanish-language autism awareness campaign for Central and South America. Participants included representatives from the above-mentioned collaborators, as well as individuals from the CDC, Ad-Council, Mexican Council on Mental Health, the Mexican Academy of Pediatrics and The Ann Sullivan Center of Peru. The outcome of this meeting was a report outlining the recommendations for designing a Spanish-language awareness campaign. This report has since been submitted to CARSO for consideration; CARSO is anticipated to be the primary funding agency for GAPH activities in Mexico. (CARSO is already funding an early detection campaign operated through CLIMA and Dr. Carlos Marcin, Clinical Director of CLIMA). The second workshop will focus on research training will take place at U Miami in 2009 and will be

hosted by the NIH. The third workshop will focus on services development and will take place in Mexico City in late 2009. The 2nd PAAATI workshop was held at the University Miami in June of 2009 and focused on capacity building through the training of autism research and service professionals.

PAAATI held its 3<sup>rd</sup> and most recent workgroup meeting on April 15-17 in Mexico City, Mexico, at the Centro de Rehabilitación Infantil Teletón. Organized by [Clínica Mexicana de Autismo](#), and partnership between [Programa Autismo Teletón](#), [Instituto Carlos Slim de la Salud](#), and Autism Speaks, the meeting focused on community-based training programs for autism services with particular attention on parent-delivered intervention. Community-based training and parent-delivered intervention are strategies to overcome some of the challenges faced by low resource countries with insufficient numbers of trained service professionals and thus limited access for families to necessary autism services. The idea is to train additional service providers which can include both non-autism healthcare professionals as well as parents as co-therapists. This is a strategy that is gaining support among underserved populations in the United States and around the world and has demonstrated success in increasing capacity for autism services in areas of need.

Presentations from international experts in autism services delivered two days worth of presentations on topics including screening and diagnosis, early detection, behavioral intervention strategies, and examples of community-based service training of parents and professionals in the United States. Presenters included Dr. Deborah Fein from the University of Connecticut, Dr. Wendy Stone from Vanderbilt University and the University of Washington, and Dr. Lynn Brennan of the Nashoba Learning Group. The third day was dedicated to interactive discussion among the nearly 100 participants, autism service providers from all corners of Mexico, to design and adapt the practices they learned about into programs sensitive to the needs of their local Mexican autism communities. The meeting program also featured testimonial from mothers and siblings of children and adults with autism, some traveling from distant regions of Mexico to share their stories of promise and hope. While each story highlighted their own unique experiences with autism, the common theme was the overwhelming importance of family in Mexican culture and the increased importance of family involvement in the care for their loved ones with autism.

Not only are the countries of Central and South America some of our closest neighbors geographically, there is a growing Latino population in the United States among which is a growing autism community. The latest [CDC estimates](#) of autism prevalence in the US showed that about 1 in every 170 children of Hispanic ethnicity has an autism spectrum disorder. Compared to the national estimate of 1 in 110, investigators are unsure whether Hispanic children are truly less affected by autism or if lower access among Hispanic families to autism services in the US is to blame. However, research in Mexico and other countries of Latin America can help shed light on autism in Hispanic populations both abroad and in the US. Furthermore, the design of culturally sensitive and relevant awareness and service programs in Latin America can directly benefit Latin Americans living in the US as well.