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## Autism in Brazil - perspectives from science and society

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### AUTISM SPECTRUM DISORDERS

Autism is a complex neurobiological, developmental disorder that is typically diagnosed in childhood with symptoms that often last throughout a person's lifetime. Autism is part of a group of disorders known as autism spectrum disorders (ASD), characterized by varying degrees of symptom severity and impact, ranging from mild to quite severe. The hallmark characteristics of autism include an impaired ability to communicate and relate to others socially. Autism is also associated with a restricted range of activities and repetitive behaviors, such as obsessively arranging objects or following very specific routines.

ASD can usually be reliably diagnosed behaviorally by 24 months of age although new and promising research aims to establish screening and diagnostic measures for children as young as 12-18 months<sup>1</sup>. While there is no known cure, research indicates that early intervention in an appropriate educational setting for at least two years during the preschool years can result in significant improvements in language, cognitive ability, and social skills for many young children with autism spectrum disorders<sup>2,3</sup>.

### ASD EPIDEMIOLOGY

The prevalence of ASD is not documented in many countries around the world, with most information coming from regions such as in Europe and the United States, where standardized diagnostic approaches are available. Despite some preliminary efforts<sup>4</sup> there is not a reliable population-based prevalence estimate published in Brazil, nor in any other Latin America country<sup>5</sup>. In the last two decades of epidemiological research, best-estimates of ASD prevalence ranged anywhere from 4/10,000 to 6/1,000<sup>6</sup>. The most recent estimates of ASD prevalence in the U.S.<sup>7,8</sup> and other Western nations<sup>9</sup> indicate that almost 1% of children are affected. Based on these international estimates, it is conceivable that as many as 1.5 million Brazilians are currently living with ASD.

While the apparent increase in ASD prevalence may be due in part to shifting diagnostic practices and increased awareness, these factors alone may not explain the entire

increase. Other risk factors that may be contributing to the increase in prevalence remain unknown and warrant further investigation<sup>10,11</sup>. What is known is that autism affects far more individuals than previously imagined and the cost of autism is staggering. The economic cost of this disorder in the U.S. is close to \$35 billion annually<sup>12</sup>. These numbers may be even higher in cases with co-morbid disorders and autism.

The neurodevelopmental deficits underlying ASD are believed to transcend racial, ethnic, sociocultural, and geographic boundaries, thus there is increasing momentum to examine autism internationally. Such investigation will begin to address the more perplexing epidemiologic questions surrounding autism including how prevalence varies between settings and what factors, either genetic or environmental, may influence the prevalence and phenotypic expression of ASD. However major barriers stand in the way of conducting research and providing services to those affected by autism around the world. Levels of awareness, research capacity, service availability, and local beliefs about behavioral differences differ markedly across countries. In addition, the burden autism presents on society is unknown due to the absence of reliable epidemiologic data on prevalence.

Well designed, robust epidemiological research is required to help professionals and governments identify autism as a public health priority, and to provide a platform for autism policy reform. This is the case for Brazil. The guidelines of the Brazilian Public Health System (SUS) suggest that actions of public policy must be based on scientific evidence<sup>13</sup>. From a public health perspective, research on ASD conducted in a particular country is very important to estimate the magnitude of ASD, its etiology, and how to plan strategies of intervention. The ultimate goal of autism research is to improve the care and the outcomes for individuals with ASD and their family.

### INTERNATIONAL LEADERSHIP

International organizations have played an important role in encouraging the recognition of autism and other

mental health issues worldwide, and in guiding local decision-makers on the development of necessary public health policies. An interesting example is the current Grand Challenges in Global Mental Health (GCGMH), involving NIMH, WHO, London School, among other internationally recognized organizations. This consortium of international researchers is seeking consensus on the major barriers to improving research and provision of services in autism and mental health around the globe.

For autism-specific activities, it is important to highlight the efforts of Autism Speaks. Autism Speaks (AS) is the world's largest autism science and advocacy organization in the world, dedicated to changing the lives for all who struggle with autism by enhancing and supporting autism awareness, research and services worldwide. In 2008, AS launched the Global Autism Public Health initiative (GAPH), an ambitious international advocacy effort designed to: (1) enhance public and professional awareness of autism; (2) increase clinical and scientific expertise/capacity and promote international research collaborations; and (3) enable service development and training in early detection and intervention around the world. The GAPH development process and content are informed by the latest findings in treatment research and by systematic knowledge translation. The aim is to accelerate the delivery of meaningful benefits to individuals and families by working collaboratively with all the stakeholders, including health, education, and other government officials, expert clinicians and scientists, as well as families in the community. In 2010, GAPH was introduced to the Brazilian autism community at the First Brazilian Meeting for Autism Research.

AS has worked collaboratively with partners in Central and South America, as well as the Middle East, Asia, and Africa on GAPH-related activities, including technical development, training, and awareness efforts. On the research side, more than 100 investigators from over 30 countries currently participate in the International Autism Epidemiology Network (IAEN). A component of GAPH, the network promotes collaborative research by providing a forum for communication and idea exchange between epidemiologists from around the globe. Among the investigators who participate to IAEN and other GAPH efforts are those from Brazil.

AS initiatives have facilitated meetings between Brazilian and international investigators, promoting collaboration and idea sharing on how to address the autism research priorities in Brazil and around the world. One such example is the partnership between AS and the International League Against Epilepsy (ILAE). As comorbid disorders are common among individuals with ASD, this has become an area of key concern and focus among the international autism research community. Epilepsy, for instance, has been estimated to affect 20%-40% of

autism cases<sup>14</sup>. The AS-ILAE partnership aims to establish a bridge of communication between professionals working in ASD and those working in epilepsy to address common clinical and research objectives, and Brazil is also represented in this initiative.

## AUTISM IN BRAZIL

A recent systematic review of the Brazilian scientific literature on ASD shed light on the current state of autism science in Brazil. On one hand, the review demonstrated a significant increase in the Brazilian autism scientific production in the last two years. On the other hand, it showed that most of these publications are not focused on matters that contribute significantly to improving public health surrounding autism in Brazil. Most publications refer to uncontrolled intervention studies with small convenience samples, while epidemiological studies (a prevalence study, as a first step) and validation of diagnostic and neuropsychological instruments are almost nonexistent. These efforts, as mentioned previously, are essential for guiding public policies around the magnitude of and response to the autism crisis. Another intriguing finding of this review was the extreme concentration of scientific production in only two Brazilian regions. Investigators from southeast (mainly São Paulo) and south (particularly Rio Grande do Sul) were first authors of almost 90% of all papers published between 2002-2009<sup>15</sup>.

The paucity of research utilizing more robust methodologies and the concentration of scientific production in a small number of regions throughout the country reflect the lack of specific funding for autism research in Brazil. An additional consequence of this situation is the lack of specialized human resources and a subsequent lack of services for affected individuals and their families. In this sense, the creation of centers of excellence, research consortiums, and unified community/family associations, at national and international levels, are vital to enhancing autism research and services in Brazil.

## BRAZILIAN MEETING FOR AUTISM RESEARCH - LEARNING FROM THE SCIENTIFIC AND AUTISM COMMUNITIES

In an effort to better understand the state of autism in Brazil, a first-of-its-kind event took place in April 2010: the 1<sup>st</sup> Brazilian Meeting for Autism Research ([www.ufrgs.br/ebpa2010](http://www.ufrgs.br/ebpa2010)). The meeting was a unique opportunity to disseminate results of Brazilian autism research to the scientific and parent communities as well as to promote networking and collaboration between international and Brazilian experts in clinical and basic sciences.

Over three days, speakers presented the latest results and new scientific knowledge about autism to an audience of over 400 participants. Brazilian Public Policy for autism was presented and discussed by government representatives from the Brazilian Ministries of Health and

Education. In addition, Autism Speaks participated in the event and presented the Global Autism Public Health Initiative as an approach to enhancing research, services, and awareness that Brazil could contribute to. While most attendees were autism investigators and professionals from the Health and Educational fields, there was also a strong presence from the autism advocacy community representing numerous Brazilian autism organizations as well as parents from across the country. These stakeholders had a special one day meeting to debate their needs and main barriers to achieve them, attended by over 100 parents.

During the meeting, data was collected from speakers and stakeholders to identify current challenges and barriers to autism research and services. This was an effort to define the consensus priorities around improving research, awareness and services for autism in Brazil. It is envisioned that the following valuable information can be used by research and service professionals, policymakers, and/or community advocates to take more suitable decisions for autism in Brazil.

The **main challenges and barriers** identified included:

- Lack of specific funding support for autism research
- Lack of well-trained investigators and clinicians in several disciplines
- Lack of multicenter national and international projects
- Lack of robust scientific studies, relying on large sample sizes
- Scientific evidence originates mostly from only two Brazilian States
- Lack of awareness campaigns to enhance understanding among the general public and professionals in the health and education systems

The **priority areas** identified in response to these challenges were as follows:

#### 1. Research

- Build capacity for research in diverse disciplines (e.g. epidemiology, psychology, genetics, etc.) through research training programs around the country
- Promote clinical training, including training in diagnostic instruments, early detection and evidence based interventions
- Determine the prevalence of autism in Brazil to be used for public health policy planning
- Investigate the impact and success of national education inclusion program in regular schools settings
- Implement strategies to achieve financial support from main Brazilian funding agencies (FAPESP, CAPES and CNPQ)
- Encourage collaboration between Brazilian investigators, and between Brazilian investigators and international experts.

#### 2. Awareness

- Raise public understanding and improve public per-

ception of autism by making information more accessible to the public

- Address detection of children through the public systems, principally in primary care and school settings;
- Address the needs for information on adolescent/adult care and services
- Disseminate the latest key scientific findings to the Brazilian community

#### 3. Services

- Enhance understanding of current approaches and best practices in service provision among Brazilian providers
- Build capacity for services in Brazil among professionals and in community-based settings
- Establish training program for screening early detection and intervention strategies, such as instruction to pediatricians and primary care clinicians.

## CONCLUSIONS

As demonstrated by the success of the Brazilian Meeting for Autism Research as well as previous and ongoing research activities, there is much potential for Brazil to enhance its presence in the world of ASD research. In addition, Brazil can continue to be a leader in Latin America, producing high-quality and impactful ASD research. There is much research that remains to be completed in ASD research, and Brazil is in the unique position to address unanswered questions in autism epidemiology and etiology. For example, the Brazilian population is highly diverse: 43% of the population is composed of persons of mixed race. Within this context, we would be able to explore associations between race and specific manifestations of the ASD. No studies are currently known which examine ASD in a mixed race population.

Our first recommendation is that future Brazilian autism research should be focused on understanding and improving issues related to public health. This includes developing guidelines to inform the SUS. In addition, the first population-based Brazilian prevalence study of ASD is crucial to inform public health policy. We expect that results from these activities will provide a solid foundation on which Brazilians can work together to address the challenges and barriers previously identified by experts and stakeholders in the Brazilian autism community.

Another key element to be addressed in the next few years is to increase clinical and scientific expertise, encompassing the various disciplines involved in the field of autism research and services. The creation of centers of excellence with the aim of training professionals in the areas of health and education is a demonstrated approach to enhancing professional capacity. Additionally, the establishment of national networks and unified associations would help accelerate the pace of scientific production by

galvanizing the Brazilian autism expert community. Together, these activities can improve the understanding of autism in Brazil, Latin America, and around the world by contributing meaningful scientific knowledge to the field. At the same time, the Brazilian autism community will benefit from the added expertise and capacity to provide much needed autism diagnostic and intervention services to those affected individuals and their families.

ASD cannot be considered a rare disorder anymore and over a million Brazilians are likely to be affected. The health and educational public systems must be prepared to assist this population in dire need of support. The above recommendations will start to address these challenges as well as begin to develop a sustainable system of service and research specialists in Brazil. Recent activities among Brazilian autism professionals including the 1<sup>st</sup> Brazilian Meeting for Autism Research should be seen as positive and forward movement in the effort to address autism in Brazil, however it is only scratching the surface of the efforts still needing. It is important for the Brazilian community to build on these efforts by supporting and investing in future autism research.

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