

PRESS RELEASE Success of Phase I and Phase II of the Bolivia Autism Project**DATE:** October 16, 2012

The Autism Conferences are over in Bolivia. From all reports, the Conferences went very well. There were over 200 in attendance at both Santa Cruz and La Paz and about 100 attending in Cochabamba. From feedback and testimonials, this project was a great success.

The team who presented at the Bolivian Conferences were UNC faculty: Linda Watson, Betsy Crais, and TC Bethea. A consultant and lecturer on the project was Rosario Roman, an autism expert from New Mexico. Recent UNC graduate Maggie Fitch served as the Project Coordinator.

The Bolivian Partnerships provided many services to the project with local logistical help. The American Embassy in La Paz was very helpful with their \$4,200 donation. The 4 American Airline tickets donated were quite significant to the overall project. NC Partners raised over \$3500, plus had \$2000 more that could be used, if needed. The UNC Chapel Hill School of Medicine contributed \$3930 to the cost of the faculty and staff participating in the project.

A comprehensive report is available that both summarizes the "birth" of the project and also gives guidance to move the project beyond Phase I and Phase II, now completed.

EXECUTIVE SUMMARY

The Partners of the Americas chapters in North Carolina (NC) and Cochabamba initiated a discussion in 2007 regarding the lack of services for individual with autism spectrum disorders (ASD). Further conversations with people active in Partners of the Americas chapters in Santa Cruz and La Paz confirmed a widespread recognition of the need for more services and programs to serve people with ASD in Bolivia. Formal planning for a collaborative project began in 2008, with the identification of faculty with expertise in autism at the University of North Carolina at Chapel Hill (UNC-CH) who would be willing to travel to Bolivia. A plan for a multi-phase project evolved. In Phase One, Ms. Lucía I. Méndez, a bilingual speech-language pathologist and Ph.D. student in Speech and Hearing Sciences at UNC-CH, traveled to Bolivia in late 2009 to conduct an assessment related to the needs for information about ASD. This was accomplished through a series of 10 focus groups in three different cities as well as conversations with parents and professionals concerned about ASD, and visits to programs serving children with ASD and other disabilities.

The plan for Phase Two of the project was to hold conferences on ASD in multiple locations in Bolivia. Bolivian Coordinating Committees were formed in Santa Cruz, Cochabamba, and La Paz, consisting of members of the Partners of the Americas chapters in those Bolivian departments and other interested individuals or organization leaders with a stake in improving services for individuals with ASD in Bolivia. Mr. Hank Graden, Executive Director of the NC Chapter of the Partners of the Americas, provided overall coordination for the project and secured funding as well as gifts-in-kind. The UNC faculty proposed conferences included content information based on the needs identified during Ms. Mendez' visit. The Bolivian Coordinating Committees gave input on the conference agendas, and handled all local arrangements in Bolivia. The NC team traveled to Bolivia during the second half of June, 2012, presented

at conferences in each of the cities listed above, and interacted with Partners of the Americas members, parents of children with ASD, and various higher education students and professionals concerned with AS. Conference participants in each location participated in discussion groups to identify: (a) the major challenges related to ASD in Bolivia; (b) strengths in Bolivia and/or the local community; (c) priorities for addressing the needs related to ASD in Bolivia; (d) short-term steps; and (e) resources needed.

The NC team also visited local programs for children with ASD or other disabilities. In La Paz, Bolivian representatives and the NC team met with the Director of Special Education in the Ministry of Education, the Minister of Health and Sport, and the Director of the Bolivian office of the Pan American Health Organization (PAHO). In each visit, multiple challenges related to ASD in Bolivia were acknowledged, and the officials indicated they were open to formal proposals related to improving awareness and/or services related to ASD.

The NC team was impressed with the energy and commitment to advocating for people with ASD in Bolivia, and the valuable, if insufficient, resources available in Bolivia such as strong parent organizations and well-trained, knowledgeable professionals. The NC team recommends that the stakeholders in Bolivia move immediately to form a national organization for ASD in Bolivia, a step recommended by a number of the Bolivian conference participants.

RECOMMENDED NEXT STEPS

The reflections are offered by the NC team for consideration by the leaders in Bolivia who are moving ahead with efforts related to ASD. Originally, the overall plan for this project included a separate phase of data collection on the prevalence of ASD in Bolivia and the current services for individuals with ASD and their families that would help clarify the need for building capacity in meeting the needs related to ASD. However, discussions with Bolivian university faculty and other autism experts, the conference participants, and Dr. Thieren of PAHO during Phase Two of the project made clear that accurate data on the prevalence of ASD in Bolivia is a longer-range project that will require a strong epidemiology research plan and the financial resources to support it.

Factors making accurate data collection from existing resources difficult include: (a) no current national data collection on disabilities in Bolivia that includes the category of ASD; (b) a lack of autism awareness among the general population in Bolivia; (c) lack of cultural acceptance of disabilities, including those that accompany ASD, such that many families hide their family members with disabilities; (d) limited numbers of professionals with the expertise to accurately diagnose ASD; and (e) lack of access of families to affordable diagnostic services and ones provided in appropriate languages. Bolivians we spoke with also indicated that a good response rate to censuses related to disabilities in their country is greatly enhanced by financial incentives contingent upon the identification of a family member with a disability.

As *Autism Speaks* notes in its Epidemiology Information Guide:

It is often the case, particularly in low-resource countries with limited public health infrastructure and research capacity, that these expansive data sources are not available. In situations such as these, epidemiologic techniques for collecting data often involve special data collection approaches. In order to do this feasibly with available resources these approaches often will rely on screening. Screening is a first step in identifying individuals with a disorder, intended to sort out those likely to have the disorder from those unlikely to have it using affordable, easy-to-implement approaches. After a positive screen,

individuals will then be seen by the research team to determine if they meet criteria for a formal diagnosis.

(http://www.autismspeaks.org/docs/sciencedocs/epidemiology_faq.pdf, retrieved 14 July 2012).

The risks of collecting prevalence data prematurely or with insufficient rigor are considerable; such data almost surely would underestimate the actual numbers of individuals with ASD in the country and thus could lead to the conclusion that an expansion of capacity for meeting the needs associated with ASD should not be a priority. An epidemiological survey study is underway in Mexico that relies on screening and follow-up assessments as suggested in the Autism Speaks guide, and this epidemiological study might serve as a model for such research in Bolivia. A link to one screening study in Mexico is <http://onlinelibrary.wiley.com/doi/10.1002/aur.1235/pdf>

Looking to other low- and middle-resource countries for examples, efforts in Aruba, Mexico, and Brazil supported by the Autism Speaks Global Autism Public Health Initiative all began with an emphasis on autism awareness and building networks of parents and professionals to advocate for and implement new initiatives related to ASD (<http://www.autismspeaks.org/science/science-news/autism-awareness-month-highlighted-progress-mexico-brazil-and-aruba>, retrieved 14 July 2012).

During Phase Two, the enthusiasm and commitment of many people in Bolivia to working for further changes in Bolivia was apparent. Issues related to ASD in Bolivia are national ones, and especially in obtaining government support for systems changes, and therefore it is important to develop broad-based national advocacy and plans to address the needs of individuals with ASD and their families. There are several important next steps to be accomplished in order to be able to sustain and coordinate efforts in the future. In particular, by the end of 2012, the following steps should be accomplished in order to continue the momentum that has been generated thus far. The NC team recommends that the various groups and individuals committed to advocating for individuals with ASD in Bolivia immediately move to form a national association devoted to this purpose. Such an association could become the central organization coordinating efforts, developing a consensus related to priorities, developing a strategic plan, advocating, and raising funds to support advocacy, training, and services. A national organization would be in a position to establish credibility with government agencies and funders as the organization able to represent the interests of individuals with ASD, their family members, and professionals and others seeking to meet needs created by ASD in the society. Establishing an enduring national organizational structure is crucial to sustaining the efforts of so many in Bolivia and ensuring that the efforts will be effective in promoting positive changes. This overall recommendation of the NC team for a national organization raises several questions for consideration by the leaders in Bolivia.

- (1) What will be the leadership for a national effort? For example, are the existing Conference Coordinating Committees in each city willing to continue to provide leadership? If not, which group(s) will provide the overall leadership and coordination? The existing associations of parents of children with ASD are valuable assets in Bolivia; how can their strengths best be used in the future? How can representatives from the other six Departments in Bolivia be identified and recruited to help lead these efforts?

- (2) How could an organization be most effectively structured? An organization such as this would need overall leadership to provide direction and coordination. However, there are many people in Bolivia with ideas, skills, and energy to address different priorities that were mentioned related to ASD. Would it be possible to develop teams within a larger organization to work on different issues such as (a) an autism awareness campaign in Bolivia; (b) ASD training for health care providers and other professionals; (c) ASD training for educators; (d) ASD training for parents/family members; (e) gathering data on ASD in Bolivia; (f) advocacy with the Ministries; and (g) fundraising?
- (3) Clarify the desired role, if any, to be played by the NC team in future ASD efforts in Bolivia. Among many possibilities are: (a) one or more of the faculty could return to Bolivia to assist with more focused and intensive training, such as training in ASD diagnosis or training for teachers or therapists working with children with ASD, or training for parents; (b) Bolivians and some of the UNC-CH faculty could collaborate in ASD research in Bolivia; (c) the UNC-CH faculty could assist Bolivians in identifying other ASD experts who might be best suited to collaborate in research or training related to a particular aspect of ASD (e.g., working with adolescents and young adults, a particular treatment approach); (d) the UNC-CH faculty could host professionals who wanted to spend some time studying ASD in North Carolina.
- (4) A strategic plan or long-range action plan should be developed to guide the efforts related to ASD for the next five to seven years. Once the leadership structure in Bolivia is clarified, this plan should be generated by Bolivians, using the priorities identified by the Phase Two discussion groups and the information obtained in meetings with PAHO and the Ministries of Health and Sport and of Education to guide the development of the plan. The NC team is willing to provide support in the development of the plan as requested by the leaders in Bolivia.

Hank Graden, NC Partners of the Americas

