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**Ad Hoc Committee for Technical Support to
National Institutions (Ministry of Health and
National Secretariat for Human Rights of
Persons With Disabilities) in Paraguay**

December 2018

Final Report

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Submitted by T. Rosario Román, CCC-SLP, Chair

I. BACKGROUND

In February 2016, the first conference call was conducted among the following representatives:

- ASHA representatives;
- national counterpart representatives from (a) the MOH/Mental Health (MOH/MH), (b) the Ministry of Health/Institute of Social Welfare (MOH/ISW), and (c) the National Secretariat for Human Rights of Persons With Disabilities (SENADIS);
- the PAHO Regional Advisor on Disability and Rehabilitation; and
- the PAHO/Paraguay focal point.

During the conference call, the national counterpart authorities reviewed issues related to (a) the training of individuals who provide services in communication disorders and rehabilitation, (b) the number of allied health care professionals available in Paraguay, (c) the number of rehabilitation centers in Paraguay with a focus on communication disorders, and (d) general considerations about Generalized Disorders of Development (GDD) [also known as Developmentally Delayed (DD)] in the United States.

Following an initial conference call among representatives from ASHA and PAHO with country stakeholders, ASHA conducted a needs assessment trip to Paraguay in May 2016. The PAHO country office organized an agenda that included meetings with representatives from the Ministry of Health, the National Secretariat of Human Rights for Persons With Disabilities (SENADIS), university representatives, and representatives from parents' organizations of children with disabilities. Participants from these institutions jointly prioritized their identified needs and developed a work plan.

Ad hoc committee's charge: To provide technical assistance to the Ministry of Health and the SENADIS, enabling them to educate service providers and parents of individuals with communication disorders.

The goal of the joint collaboration between ASHA, PAHO, and national institutions (PAHO/Paraguay, Ministry of Health, SENADIS) is to create a sustainable service delivery model for Paraguay by developing a set of hands-on workshops to selected clinical agencies that are providing services for children with disabilities.

Short term:

- Based on guidance from the PAHO/Paraguay Office and national counterparts, the hands-on workshop will start with training to a select group of phon audiologists, including psychologists, developmental specialist counselors, psychiatrists, nurses, and physical therapists who will become the "trainers of trainers" in Paraguay. Phon audiologists are providers of speech, language, and hearing services in this country.

- A network of trained professionals will be created to ensure continuing exchanges and learning about communication disorders.

Long term:

- Universities and parents’ organizations will be included as key players within the network.
- Campaign awareness for the general public will be developed.

The ad hoc committee on Paraguay was created in August 2016.

Ad hoc committee members:

T. Rosario Román (chair), Henriette Langdon, Rosa Abreu, Maria Adelaida Restrepo, Lynette Austin (International Issues Board [IIB] liaison), and Lily Waterston (ex officio)

Summary of the Initial Meeting

The SENADIS representatives, MOH representatives, university representatives, and representatives from various organizations of parents who have children with disabilities (many of whom were present at the initial meeting) explicitly requested training of service providers for development of materials and strategies for providing direct clinical services.

The Paraguay work plan was composed of four phases:

- Phase 1: Conduct a needs assessment.
- Phase 2: Conduct train-the-trainer workshops on early detection and intervention of speech and language disorders. This included meetings with parents who have children with autism and with Paraguayan university professors in the field of phonoaudiology.
- Phase 3: Develop materials using augmentative and alternative communication (AAC), and visit participants’ institutions/clinics.
- Phase 4: Visit rural areas to design appropriate service delivery, and continue with development of materials.

To achieve the above, the **Ad Hoc Committee for Technical Support to National Institutions (Ministry of Health [MOH] and National Secretariat for Human Rights of Persons With Disabilities) in Paraguay** (hereafter, “the Committee”) was formed.

The next section of this document outlines the activities that were accomplished throughout the various phases.

II. 2016 ACTIVITIES

2016 activities consisted of Phase 1 (needs assessment) and Phase 2 (train-the-trainer workshops), both of which are detailed below.

Phase 1: Román Conducted a Needs Assessment

The Committee completed Phase 1, which consisted of a survey and needs assessment, in May 2016.

Objective: The purpose was to provide technical assistance to the Ministry of Health and the SENADIS, enabling them to educate service providers and parents of individuals with communication disorders.

Outcome: Three train-the-trainer workshops for clinical services have been conducted with stakeholders: (a) Evaluation Methods, (b) Augmentative and Alternative Communication, and (c) Autism and Other Disorders. This last workshop included 1 week in two 4 towns in rural communities and a second week in Asuncion. The same participants, 29 service providers and 15 parents of children with disabilities, were trained in each workshop.

Phase 2: T. Rosario Román and Mary Ellen Ulibarri Conducted Train-the-Trainer Workshops

For Phase 2, the Committee conducted train-the-trainer workshops October 21–26, 2016, with the goal of training attendees on formal and informal evaluations and meeting with parents. This phase consisted of informal assessments, formal assessments, dynamic assessments and therapeutic strategies, and meetings with parents.

Meetings With Parents

Dr. Mendoza, Dr. Rodriguez, Román and Ulibarri met with parents from different Paraguayan’s association. This meeting revealed that parents were concerned about a number of issues, including the following:

- How to deal with members of their own family and the community at-large who do not understand autism.
- How to deal with schools in Paraguay. At this time (October 2018), schools are not accepting children with autism. Even though Paraguay has a law on providing special education for all children, it is so hard to enroll a child with autism in a school. One parent said that she went to eight different schools before her child was accepted.
- Lack of doctors’ knowledge to refer children at a young age for evaluation and therapeutic services.
- The difficulties that parents face in finding medical doctors and dentists who are willing to treat their children.

All parents present agreed on two important conclusions:

1. There is a need to educate the public through awareness campaigns so that children with autism can be accepted in the wider Paraguayan society. Parents will be working on the details of education and time line.
2. Parents of children with autism need to start sharing their experiences with one another regarding their difficulties in navigating Paraguay’s health and educational systems.

III. 2017 ACTIVITIES

2017 activities consisted of Phase 3, which is detailed below.

Phase 3: Román Developed Materials Using Low-Tech and High-Tech AAC, and Visit Participants’ Institutions/Clinics

For Phase 3, Rosario Román traveled to Paraguay June 5–9, 2017.

Develop Materials Using AAC

On June 5–9, 2017, Román conducted training on developing materials using low-tech and high-tech AAC and also visited the participants’ institutions/clinics. The training was 3 full days and 2 half days. The visit to centers were 2 half days.

Visit Participants' Institutions/Clinics in Asuncion

On June 8 and 9, 2017, the trainers visited participants' institutions/clinics in the town of Asuncion.

Institutions/clinics that the trainers visited were:

- **Vivir Jugando**, a center for children with autism
- **Instituto de Bienestar Social San Roque**, a school for children ages 2–5, who come from low-SES families and who have challenges and difficulties with getting adequate nutrition
- **EPA**, a private organization that serves children with autism
- **SENADIS**, a governmental agency

IV. 2018 ACTIVITIES

2018 activities consisted of Phase 4, which is detailed below.

Phase 4: Visit Rural Areas to Design Appropriate Service Delivery, and Continue With Development of Materials

For Phase 4, Committee member Román traveled to Paraguay April 30 to May 11, 2018. Dr. M.Mendoza (MoH), R. Román and a PAHO representative visited 2 small cities of Paraguay to design appropriate service delivery and to conduct training sessions that addressed the continued development of materials for children with autism and other disorders.

Villarrica del Espiritu Santo

The trainers first traveled to the city of Villarrica del Espiritu Santo, where they conducted workshops for paraprofessionals (the 15 attendees included pediatricians, nurses, and psychologists). The trainers also conducted meetings with three parents whose children have autism Dr. Mendoza and Roman listening to the parents' concerns and perspectives. These parents are teachers who are concerned about the lack of support in early intervention that they are witnessing with their own children. As teachers, they are concerned about the education that their 2-year-old children with autism will be receiving. Paraguay's educational policies support inclusion, but teachers lack the knowledge of curriculum adaptation for those students with different abilities.

Concepción

The trainers then traveled to the city of Concepción, where they met with leaders Hospital Regional de Concepcion. They also visited the clinic where one of the participants provides therapy. While in Concepción, Román conducted a workshop for parents, professionals, and medical students; the workshop attracted 80 attendees. Dr. Mendoza, E. Lobos and R. Román visited the SENADIS center where one of the workshop participants provides therapy.

Asunción

R. Román completed her visit with a trip to Asuncion, in which they accomplished the following tasks:

- Review AAC and the Picture Exchange Communication System (PECS) with attendees.
- Introduce attendees to TEACCH®
- Introduce of *theory of mind* and teach them how to incorporate it into their work with children through the use of play and stories.
- Design a simple book to elicit language.

- Create “Social Stories”
- Continue developing therapy materials, taking into account assessment level in the areas of independence, cognition, language, motor skills, and the child’s environmental life.
- Introduce attendees to the concept of *sensory integration* as it relates to autism (on www.autism.com, Cindy Hatch-Rasmussen defines *sensory integration* as “the integration and interpretation of sensory stimulation from the environment by the brain”).
- Learn to use recycled materials to create therapy materials.
- Remind attendees that all materials used in the clinic or the classroom need to take into account the goals established by the clinic and the school, as well as those established by the parents for when the child is at home.
- Explain to attendees that all goals established for the child *must* lead to independence.
- Meet with parents of children who have autism, and provide participants with a 1-hour workshop (there were 18 participants—16 parents plus two teachers).

V. SUMMARY OF RESULTS AND CONTINUED AREAS OF NEED

After completion of Phase 4 (visit rural areas to design appropriate service delivery, and continue with development of materials), the following results are reported (see subsections that follow).

Feedback From Participants

Participants told trainers that they would like to continue receiving assistance in the following:

- Learning to work with all ages. (specifically seeking suggestions and ideas for working with teens and adults and for job coaching)
- Learning more about adapting AAC boards and tasks for people with physical disabilities (e.g., individuals with cerebral palsy, babies exposed to drug and alcohol, children who have been abused or neglected, individuals with traumatic brain injury)
- Learning about other types of clinical methods for providing language therapy
- Continuing to develop therapy materials
- Learning how to provide therapy services and how to modify curriculum in the schools

Parents’ Concerns and Needs

Parents told Román about their concerns and needs, which include the following:

- Parents are concerned about getting an appropriate education for their children. Paraguay’s official policy is that the country adheres to an inclusion model. Yet, according to parents, in the current Paraguayan educational climate, children with different abilities attend school *only* if their parents pay for an aide to go to school with their child. Once in school, the child mainly sits in the back of the classroom and does not do much learning. The trainer was told that the amount of learning that a child does is based on their behavior in class on a given day.
- Parents know that the teachers themselves are unprepared to teach children with different abilities. One parent commented, “We are teachers, and we have no idea how to teach these children.” (“These children” meaning “children with autism.”)
- Parents are concerned about economics and equity: For example, the children of parents who cannot afford an aide simply do not attend school.
- Parents worry about their children’s future: They wonder, “How can my youth/adult son/daughter with a disability contribute to society?”

Challenges

Attendees enumerated several challenges that exist in the current educational model in Paraguayan schools:

- Most attendees said that they are paraprofessionals and therefore lack extensive knowledge of language development.
- Attendees noted a widespread lack of resources and materials that could otherwise assist them in teaching and treating children with autism—specifically, they cited a lack of computers, printers, and laminators in the workplace.
- Attendees admitted that they lack knowledge of how to work with youth and adults with disabilities.
- Attendees stated that they do not have the knowledge required to work with people who have swallowing problems, need hearing rehabilitation, or need educational adaptation in daily classroom instruction.

Positive Changes

Attendees cited the following positive changes that came out of this partnership:

- Of the original 33 attendees, 29 attendees continue to be members of a team. Most of them are still regularly sharing information with one another and are training others in their place of work.
- Daniela Carreras (phonoaudiologist in Paraguay) has opened her house for the team to get together to create materials once a month. Carreras has a laminating machine and a printer that she is sharing with the group. The group is splitting the cost of the materials.
- Through the work of this partnership, the attendees and (now) other paraprofessionals in Paraguay are increasing their knowledge of language development.
- One attendee wrote, “I have learned that the participants’ background, professional knowledge, and therapeutic styles are different from the treatment style of the speech-language pathologist or phonoaudiologist—for example, the psychologist’s method is to change behavior without taking into account the cognitive level of the client. Does the client understand cause–effect?”
- Román stated, “I learned that
 - Guaraní does not use articles (*the, an, a*).
 - One word could be a complete sentence.
 - Verbs are conjugated using ‘je’ in front of the verb.”
- Some members of this team teach at the university level, in the area of psychology. These professors are teaching their students the use of icons to create low-tech communication boards (remember, 90% of these professionals are not phonoaudiologists).
- The “borders” disappear[ed] (i.e., working for the state or private, working in rural or city, working in schools or clinics), and also their professional titles disappear[ed] (psychologist, pedagogue, phonoaudiologist, nurse, special education teacher); instead, they were sharing knowledge and complementing one another.
- One of the participants told a trainer, “Plantaste una semilla que florecerá y crecerá!” (“You planted a seed that will flourish and grow!”) The Committee acknowledges that it is growing, but, as the trainer said, “All plants need consistent care, water, fertilizer, and pruning in order to grow to be strong and fruitful. This is called *sustainability*.”
- At the closing of the third workshop, participants were informed that this was the last trip sponsored by ASHA, as the 2 years (of the Committee) have come to an end. The participants were very upset; they commented that they are just starting to understand language development and early intervention, and that this program *must* continue.

- Two weeks later, three members of this group began providing training to their coworkers and parents.

Present:

- The first network of professionals on communication disorders in the country was created using WhatsApp. They have named this network “The ASHA–PAHO Collaboration.”
- Since the last train-the-trainers workshop in May 2018, two participants have conducted their own train-the-trainer workshop, reaching out to more professionals in the country.
- The PAHO/Paraguay Office and the MOH would like to continue this collaboration. The director of PAHO/Paraguay sent a letter to ASHA requesting the continuation of the ASHA–PAHO collaboration in Paraguay.
- Dr. Mirtha Mendoza, director of the MOH, is going to meet with the Ministry of Education (MOE) so that the MOE can join the MOH in becoming part of this change. She will propose providing training to personnel in schools.
- The ad hoc committee has ended in October 2018.

VI. CONCLUSIONS

The work of the ad hoc committee for technical support to National Institutions in Paraguay concluded on October 31, 2018. Conclusions are reported, in boldface, for each of the desired goals stated below.

1. Training of paraprofessionals and other professionals in language development. Provided by Paraguay’s Universities. **Addressed (not in depth) by T. Rosario Román (ASHA) in 2016, 2017, and 2018.**
2. Teaching of professionals about differential diagnosis by their learning a variety of tests (e.g., ADOS and other Spanish-language tests; ICF).
 - a. ADOS and other Spanish-language tests. **Completed at the introductory level in October 2016 by ASHA.**
 - b. ICF. **Completed at the introductory level by ASHA**
3. Training of professionals in low-tech and high-tech AAC use for children with autism in Paraguay schools. **Completed at the introductory level in 2017 and 2018 by ASHA.**
4. Teaching of professionals in Paraguay about therapy methods and materials development for use in classrooms with children who have autism. **Completed at the introductory level in 2017 and 2018 by ASHA.**
5. Teaching professionals in Paraguay about autism and other disorders. **Completed at the introductory level in 2017 and 2018 by ASHA.**
6. Training of paraprofessionals and other professionals to address the evaluation and rehabilitation of individuals with hearing impairment. **Not addressed.**
7. Universities and parents’ organizations will be included as key players within the network. **Partially achieved**
8. Creation of campaign awareness for general public. **Not addressed.**

VII. RECOMMENDATION FOR FUTURE ACTIVITIES

The ad hoc committee recommends that ASHA and PAHO consider implementing the following future activities:

- Continue to support the growth of teachers and professionals in Paraguay regarding knowledge of language and speech therapy delivery models and learning environments (these environments include home, schools, and communities)
- Train teachers who work with children with different abilities to modify curriculum.
- Recruit volunteers to (a) assist the Paraguayan train-the-trainer team with their large caseloads and (b) provide continuation of mentoring to the local clinician. Consider recruiting volunteers from ASHA to provide training for professionals and families of people with disabilities. **NOTE:** We want to help phonoaudiologists in Paraguay create a model that fits their community and serves their population in Paraguay. Therefore, if this recommendation is enacted, ASHA volunteers must
 - be aware of the distinct linguistic structure, development, and speech sounds of both Spanish and Guarani (the two official languages of Paraguay);
 - be willing to learn the differences between Spanish and Guarani;
 - possess a meta-awareness of phonological characteristics and the linguistic structure of English and Spanish;
 - support clinicians at the clinic, schools, and rehabilitation centers in evaluating and treating clients/students in the cities and in rural areas; and
 - help develop appropriate materials that are relevant to the culture, age, and beliefs of the clients.