

Developing Knowledge of Autism in Majority World Countries: Examples of Bolivia and Paraguay

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Abstract: Bolivia and Paraguay are Majority World countries, which are defined as areas within which most of the world's population live, natural resources and landmass are located, but are often economically poor. Minority world countries, such as, the United States, have a smaller percentage of the world's population, but often a greater share of the world's wealth. Many Majority World countries, such as Bolivia and Paraguay, have not collected prevalence data on autism and assessments and interventions for persons are quite limited, if they are available at all. Persons with autism in Bolivia and Paraguay are at most underserved and the majority are unserved. This article reviews topological, demographic, and economic/political factors affecting the identification and provisions of services for autistic children and the current health and educational status for autistic persons in Bolivia and Paraguay. Descriptions of the efforts of outside consultants to assist parents and professional within those countries to gain information and develop assessment and intervention programs for autistic children are described. Attention is given to methodologies employed by United States consultants to ensure the implementation of culturally responsive practices. Consultants employed skilled dialogue when interviewing parents and professionals in Bolivia and Paraguay to understand their perspectives so as to guide content of trainings. The PRECEDE-PROCEED framework was employed to develop a culturally-responsive approach to assessment and intervention.

Keywords: culture, autism, PRECEDE-PROCEED model, skilled dialogue, minority/majority counties

Introduction

There is agreement across the world that the prevalence (or total number) of persons with autism is increasing. The majority of information on autism, particularly its identification, intervention strategies, and attitudes about autism is based on research primarily in a few Western countries. To develop a better understanding of the international response to the increasing numbers of autistic children, the Autism Committee of the International Association of Communication Sciences and Disorders (IALP) organized a symposium for the 2023 IALP congress held in Auckland, New Zealand. This paper is one of several developed by committee members and colleagues that were presented at the congress and published in this journal issue. North American, European, mid-East, and several Asian countries have documented the increasing autism prevalence. Minimal autism prevalence data is available from South American countries. In this paper, the authors (a) describe factors affecting autism prevalence data from two South American countries, Bolivia and Paraguay; (b) describe the efforts of American professionals collaborating with professionals and families in these two countries to offer training opportunities that address the needs of autistic children and adults; and (c) describe culturally responsive approaches to the development and implementation of assessment and intervention programs that are based on the beliefs, desires, and needs of Bolivians and Paraguayans.

Although some websites, such as <https://wisevoter.com/>, <https://prevalence.spectrumnews.org/>, and <https://worldpopulationreview.com/> provide some autism prevalence data for Bolivia and Paraguay, it is unclear as to how this data were obtained. Several reviews of autism prevalence studies around the world report the extremely limited prevalence data from South America.¹⁻⁴ What is reported is questionable because there has been no documentation of how the

information was obtained. The reported data reflect a very low prevalence in South American countries, suggesting that many autistic persons are not being identified. Although both Bolivia and Paraguay have ministries/departments or committees at the national level that are to address the issues of persons with disabilities, neither have a system for collecting autism prevalence data, nor do they have any country-wide system for identifying children with any type of disability and providing intervention services. The majority of persons with autism in Bolivia and Paraguay are unserved.

Factors Affecting Autism Identification and Services

Both Bolivia and Paraguay have been considered to be developing countries.⁵ According to the United Nations, a developing country is a country with a relatively low standard of living, undeveloped industrial base, and moderate to low Human Development Index (HDI). This index is a comparative measure of poverty, literacy, education, life expectancy, and other factors for countries worldwide. The term, “developing country” has become controversial.⁶ The United Nations does not have an official definition of a developing country. Increasingly, the terms, “majority world” and “minority world” are being used. The term, Majority World, refers to areas within which most of the world’s population, natural resources, and landmass are located, but they are often economically poor. Bolivia and Paraguay are part of the Majority World. The United States is a Minority World country. Minority World countries have a smaller percentage of the world’s population, but often a greater share of the world’s wealth. In this article, the authors use the terms Majority and Minority countries. The topography, demographics, economy, and political situations in Bolivia and Paraguay present challenges to those countries in providing adequate healthcare and educational services for their populations.

Topography

The topography of Bolivia and Paraguay contribute to the difficulties in identifying and providing services for persons with disabilities. Transportation is problematic in these two landlocked countries in the middle of South America. The altitude in Bolivia ranges from 90 meters (300 feet) in the Amazonian region to 5000 meters (16,400 feet) above sea level in the Andes Mountains. The Bolivian mountainous region is one of the highest inhabited areas in the world. Road conditions outside of major cities and those roads connecting the major cities of La Paz, Santa Cruz, and Cochabamba are considered hazardous; 28% of the roads are paved.^{7,8} In the lowlands, during the rainy season, most roads have potholes and roads and bridges are washed out. Four-wheel drive is highly recommended in mountainous areas where the gravel or dirt roads are narrow with no fencing or barriers. Twenty nine percent of Bolivians live in rural areas.⁹

Paraguay’s topography in the eastern one-third of the country, where 95% of the population live, consists largely of farmlands and grasslands with an area of marshy lowlands prone to flooding. The two-thirds of Paraguay, which is in the western region, is arid.¹⁰ A lack of roads and navigable rivers in the western area makes the region inaccessible. Only 10% of the interurban roads in Paraguay are paved. Roads are heavily potholed and regularly flood, making travel throughout much of the country difficult and even impossible.¹¹ Thirty seven percent of Paraguayans live in rural areas.⁹ Consequently, the typology in both Bolivia and Paraguay makes accessing health and educational services challenging for a large percentage of the populations.

Demographics

Cultural and language variations complicate assessment of disabilities. In Bolivia, after centuries of intermixing, it is difficult to determine the proportion of each ethnic group, but it is estimated that mestizos (those of mixed European and indigenous ancestry) form more than two-thirds of the total, indigenous make up about one-fifth, and people of European ancestry account for about one-twentieth of the population.¹² Bolivia has the highest percentage of indigenous people in Latin America – approximately 62% of the population identify as belonging to one of 37 recognized ethnic groups. Spanish, Quechua, Aymara, and Guarani are the most frequently spoken indigenous languages.¹³ Spanish is spoken by 70% of the population, but 63% of the population reported they had learned to speak a first language other than Spanish as their mother tongue.¹⁴ The 2009 Bolivian Constitution and the General Law of Linguistic Rights and Policies require that the Bolivian government must use at least two languages in operations, one being Spanish and the other being chosen based on the situation and needs of the area.

Almost all Paraguayans are mestizo. Paraguay is the most bilingual country in Latin America, as the majority of the population speak both Spanish and Guaraní (an indigenous language). About 70% of the population is bilingual, speaking Spanish and Guaraní at least to some degree.¹⁵ Guaraní is the only indigenous language of the Americas whose speakers include a large proportion of non-indigenous people. Spanish and Guaraní were established as Paraguay's official languages in the 1992 Constitution of Paraguay. Nearly 87% of the country's population speaks Spanish; Guaraní is spoken by over 90% of the people of Paraguay. Guaraní is the native or predominant language of people in rural areas; in some rural areas, 52% of the Guaraní speakers are monolingual. Spanish is the native or predominant language for a large part of the population born in large urban areas. The Languages Law of 2010 requires that all public officials learn Guaraní and that children start school in their first language, as opposed to forcing all students to speak Spanish.¹⁶ The relationship between Spanish and Guaraní has been viewed as a case of diglossia – the two languages are used in different contexts within the community often by the same speakers. Spanish is used largely in government affairs, education, mass media, and business; Guaraní is used primarily in the home context, family/social/cultural activities in the community, and correspondence with family and friends.¹⁷

The version of Guaraní spoken by most Paraguayans is actually a mixture of Spanish and Guaraní known as Jopara.¹⁸ Linguists claim that pure Guaraní is not spoken conversationally by Paraguayans.^{19,20} Most communicative interactions involve the simultaneous use of Guaraní and Spanish. When Guaraní is taught in schools, it has more likely been an academic variant of Guaraní than the Jopara used in the community. Students' families and teachers have complained that the academic Guaraní taught bears little relation to the Guaraní actually spoken and understood by both children and educators.²¹ Choi²² argues that it is essential to implement academic Guaraní language teaching, but also to balance it with Jopara, the spoken register, which is used daily in the country.

The multiple languages and the relationships between the languages in Bolivia and Paraguay contribute to challenges in assessing developmental differences and disorders.

Economics/Politics

Political unrest poses a threat to governance and stability across Latin America. Both Bolivia and Paraguay have had a long history characterized by political unrest, corruption, economic problems, and authoritarian rule.^{23,24} These countries rank 6th and 7th in corruption out of 30 Latin American and Caribbean countries in 2022.²⁵ The roots of political unrest can be partly traced to extreme inequality. In inequality metrics such as the World Bank's Gini coefficient, the region consistently underperforms the rest of the world. The poorest 50% of the population earns just 10% of total income, while the wealthiest 10% earns 55%, according to the World Inequality Report.²⁶ Inequality is one of the most distinctive characteristics of Latin American economies.²⁷ The region remains among the most unequal in the world. Latin America has significantly higher income inequality than would be expected based on its degree of development. In addition to the income inequality, there are wide differences in education quality, larger than in other regions of the world; and there are increasing levels of public-private school segregation.

According to the World Bank, Bolivia has recently moved from the lower income to lower middle income category. Although in the last 15 years, Bolivia is one of the South American countries that has made the greatest progress in poverty reduction, its income inequality remains the highest in Latin America and one of the highest in the world; 39% live below the poverty level, with 11% in extreme poverty.²⁸ Paraguay ranks as an upper middle income country with 24% of the population below the poverty level; 4–5% in extreme poverty.²⁹ Due to the extreme income inequality in both Bolivia and Paraguay and related high poverty rates, few families have the financial ability to access services for children with disabilities. As a consequence, many children with autism or other disabilities are unidentified.

Health and Education Services in Bolivia and Paraguay

Many countries address the needs of persons with disabilities through health departments or educational systems. Both Bolivia and Paraguay are struggling to improve their health care systems. In 2019, the Bolivian government implemented a Universal Health Insurance program for the 50% of the population not covered by insurance through their employer. Access to public healthcare services has increased, but medical staff and funding are insufficient, resulting in long waiting times and shortages in medicine.³⁰ Bolivia does have Law 1678 which created the CONALPEDIS (the National

Committee on Persons with Disabilities). CONALPEDIS developed a system for identification of persons with disabilities. Those who are identified as disabled are granted a disability card which provides them with some funding.³¹ In practice, this system has not been functional. Only neurologists are qualified to give a diagnosis of autism. There are few neurologists in Bolivia; those few are located only in the larger cities.

Paraguay is also considering ways to develop a more universal health care system. The Paraguayan health system is fragmented.³² It consists of three subsystems: the public subsystem, the social security subsystem, and the private subsystem. The three subsystems are largely vertically integrated, raising funds and delivering service independently. Only about a quarter of the population are covered by health insurance. There are strong inequities in access to health services related to geographic and socioeconomic differences, a severe shortage of healthcare providers, high out-of-pocket spending, low-quality health care (particularly compared with international standards), and inadequate coordination among providers. There are not enough health facilities to meet the needs of the population. Neither Bolivia nor Paraguay have provisions within the healthcare systems for regular screening of children for disabilities. The majority of assessment and intervention services for children with autism are provided in the private practice sector. Because of the high poverty rates in these countries, few parents have the financial resources to access services for their autistic children.

In Bolivia and Paraguay, most speech-language pathologists (SLPs), known as phono-audiologists, have been trained in other Latin American countries. It is only in recent years that Bolivia and Paraguay have established 4-year bachelor level programs to train entry-level phono-audiologists. Bolivia has four programs and Paraguay has two. In these programs, the courses during all four years are specific to the field of communication disorders. In contrast, in the United States the first two undergraduate years primarily involve liberal arts courses in a variety of disciplines; coursework specific to communication disorders is completed in the last two undergraduate years and a two-year graduate program. Graduates from these phono-audiology programs (as opposed to programs in communication disorders) in Bolivia and Paraguay are able to be employed as both speech-language pathologists and audiologists. Compared to US programs in communication disorders, the phono-audiology programs tend to have more coursework in medical aspects of hearing and speech impairments, and less coursework in language and a variety of communication disorders such as autism, dyslexia, and ADHD. Phono-audiologists are most likely to be employed in private practices or health services; they are rarely employed in schools.

Public educational opportunities are unevenly distributed in both Bolivia and Paraguay, with girls and indigenous and rural children less likely to be literate or to complete primary school. Overall, the school systems in both countries are rated as poor.³³ There is a lack of teacher training, limited resources, and poor school physical structure. Both countries have laws that are to promote inclusive educations for children with specific educational support needs, but in practice, public schools offer few, if any services, for children with special needs. In theory, there are integration policies that guarantee a quality education for all children, whatever their condition. In actuality, the reality is very different. When a child with a disability turns five, they should have access to a placement in public school. However, most schools deny these children a place, alleging the lack of training of educators and the scarcity of resources. Even when children with disabilities are permitted to attend school, the number of openings for children with disabilities in a school is limited. Furthermore, schools may select the types of disabilities they will accept. If the child needs support, parents may be required to attend school with the child or pay for an aid to assist the child. Often, however, having a disability can lead to exclusion from the education system: in Paraguay, only 36% of children with disabilities ages 6 to 18 years attend school³⁴ and in Bolivia, less than 40% of children with disabilities attend school.³⁵

In both Bolivia and Paraguay, data and research on autism have been nonexistent. A few articles have only recently begun to appear. Rod Jara et al³⁶ interviewed 46 parents or guardians of persons with autism in both urban and rural areas of Paraguay. Participants reported that support they received came from close relatives because there were no effective social, state, or educational policies to help them. They described that access to health services and therapies is minimal and focused only in main cities. The supports are not multidisciplinary and few professionals have specific knowledge about autism. Some participants reported having to give up leisure time and work extra hours to pay for therapies. Participants whose autistic children were in school reported there was a stigma and lack of knowledge about autism and their children received no systematic or structured teaching. In an effort to facilitate earlier diagnosis of autism in Paraguay, Terol, a Paraguayan phono-audiologist completing her doctoral degree in the US, recently conducted the first

study to investigate demographic factors that contribute to age of autism diagnosis in Paraguay.³⁷ She has also conducted focus groups and individual interviews with caregivers, professionals, and autistic adults to have them evaluate recommendations to culturally adapt the Parent Taking Action curriculum designed for Latinx families in the US for use in Paraguay.^{38,39}

In a literature search, only two articles were found that made specific reference to autism in Bolivia. Because of the lack of research on autism in Bolivia, Bravo-Clouzet, a Bolivian-American pediatrician, surveyed pediatricians and primary care physicians in Santa Cruz, Bolivia on their knowledge of autism.⁴⁰ Of 255 responses, 74% of physicians felt “poorly prepared” or “not prepared at all” to diagnose autism; and only 4% felt “prepared” to diagnose autism. Calle Sanchez interviewed seven parents of autistic children to discover the coping strategies they used to manage the stress of dealing with their children.⁴¹ With this type of information, it was believed psychologists could offer caregivers more specific programs that would benefit the autistic child and all family members. Buell and Chadwick⁴² explored the experiences of Bolivian people with communication disabilities (not specific to autism) and their families, professionals, service providers, educators, and policymakers. Participants reported that speech-language services were a barrier rather than a facilitator to improving communication. Parents reported a poor quality of services. They explained that the treatments were repetitive and expensive and the SLPs did not talk to them about what they were doing or how their children were improving.

Developing Services in Majority Countries

Developing Services in Paraguay: The ASHA-PAHO Collaborative

From 2016 to 2018, an Ad Hoc committee of the American Speech-Language-Hearing Association (ASHA) in collaboration with the PanAmerican Health Organization (PAHO) provided technical assistance to Paraguay’s Ministry of Health (MOH) and the National Secretariat for Human Rights of Persons with Disabilities (SENADIS) to enable them to educate service providers and parents of individuals with communication disorders.⁴³ Rosario Roman, Bolivian-American SLP and co-author of this article, was the ASHA coordinator for the project. In February 2016, a conference call was conducted among the following representatives: ASHA representatives; Paraguay national counterpart representatives from the MOH/Mental Health (MOH/MH), the Ministry of Health/Institute of Social Welfare (MOH/ISW), and the National Secretariat for Human Rights of Persons With Disabilities (SENADIS); and the PAHO Regional Advisor on Disability and Rehabilitation. 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].

In May 2016, Roman and an ASHA representative conducted a needs assessment trip to Paraguay. The PAHO country office organized an agenda that included meetings with representatives from the MOH, SENADIS, university representatives, private practice representatives, representatives from MOH therapeutic preschools, and representatives from parents’ organizations of children with disabilities in the area of language. Participants from these institutions were asked to list the five most important things they would like to learn regarding working with children with disabilities in the area of language. From this data, participants jointly prioritized their identified needs and developed a work plan. Paraguayan representatives explicitly requested training of service providers on how to conduct assessment for a variety of developmental disabilities, tools to use for assessment and intervention, and how to develop materials and strategies for providing direct clinical services. In preparation for the second visit, Roman asked staff from the MOH to identify 30 professionals from throughout Paraguay who would commit to intensive training to become trainer-of-trainers with the intent to return to their home communities to train others.

On the second visit, the 30 identified professionals participated in five full-day trainings in the capital city, Asunción. The majority of workshop participants were psychologists, along with a few teachers, nurses, social workers, and one phono-audiologist. To prepare workshops that considered the participant’s background knowledge and would be applicable to the ways they practiced, Roman requested information on participants’ academic training. Workshops were conducted by Roman and Ulibarri, a Spanish-speaking American SLP colleague, on evaluation methods and tools,

strategies to facilitate communication development, augmentative and alternative communication, hearing loss, Down syndrome, and autism and other disorders. The workshop presentations included examination of standardized assessments with norms and informal observational evaluations including language sampling. American standardized tests in Spanish were shown so that participants understood the nature of standardized tests but the presenters explained that the tests could not be used in Paraguay because their content and standardization was specific to the United State. Particular attention was given to demonstrating to professionals how to model for parents ways to implement therapeutic interactions with their children. The concept of differentiated instruction was also explained and modeled. Using lessons from the *Systematic and Engaging Early Literacy* program,⁴⁴ participants were shown how to take a thematic activity and modify it for children at different levels of language development.

In the evenings, presenters met with parents who raised many questions, such as how can I help my child, how is therapy done in the United States, when will my child be like other children, how long before my child is cured of autism, will my child be able to have a job/marry, what will happen with my child after I die. The questions are ones that are asked around the world by parents of children with disabilities. Parents expressed concerns about the way phono-audiologists provided services, suggesting that training programs for phono-audiologists be modified to include parent mentoring strategies. They described the marked difficulties they experienced in attempting to find a doctor or dentist who would see their children or a teacher who would admit their children into school. Parents asked how parents in the United States dealt with these issues. In response to these questions regarding obtaining services for their children, Ulibarri described the development and function of the Individual with Disabilities Education Act (IDEA). With this as background information, parents began to collaborate to develop a law that would ensure their children's access to medical services, therapeutic services, and schooling. As a result of their efforts, a law has recently been passed that requires professionals in a variety of disciplines to have training about autism and enables autistic children to receive medical and therapeutic services and to attend public school. The law requires additional governmental approvals before it can be implemented.

During the first week of the third visit, Roman and a representative of the MoH visited several of the rural communities where project participants lived and worked. The intent was to obtain a better understanding of the Guarani language and increased awareness of the culture and communication patterns of speakers in the communities so as to better design appropriate service delivery strategies and materials. Participating professionals showed Roman and the MoH where they worked and the materials they used and described how they provided services. Meetings were sometimes held with other professionals, such as hospital staff, who might be providing services to persons with disabilities. In the evenings in each village, a meeting was held for parents. These meetings provided parents with short informational workshops on disabilities and language development and the opportunity to ask questions. In one village, over 100 people attended, including students from a local university.

During the second week of the third visit, the original 30 participants attended five full-day trainings. Roman provided recyclables to show service providers they did not need to purchase therapy materials; they had the supplies in the community to construct effective materials. Participants had the opportunity to make therapy materials and discuss clients they were seeing in their practices. Workshop content addressed strategies for working with children focusing on autism, Down Syndrome, deaf and hard of hearing, cerebral palsy and a variety of neurological issues; developmental levels of receptive and expressive communication; sensory issues; and environmental considerations and modifications, including positioning and seating.

The ASHA-PAHO Paraguayan collaborative was a three-year project. This third visit was the final official activity of the collaboration. Roman has continued to maintain contact with some Paraguayans associated with the project. She learned that before the COVID epidemic, a number of project participants maintained contact with one another, getting together to share and make materials. The phono-audiologist brought her own printer and laminator and participants contributed funds to purchase ink. The intent of the ASHA-PAHO Paraguay collaborative had been that participants in the trainer-of-trainer workshops would train school personnel. Because funding for the program ended, this step did not occur. Governmental elections in 2023 resulted in some changes in personnel originally involved in the collaborative. Efforts are being made to re-establish relationships with participants and governmental officials to consider future training activities.

Developing Services in Bolivia

In Paraguay, representatives from PAHO and national offices are collaborating with US consultants to coordinate strategies to address the issues of an increasing prevalence of autism. In Bolivia, there has been no collaboration with or among governmental agencies, service providers, or outside consultants. In this article, the information about autism services in Bolivia is based on the experiences of volunteers from the United States who have been involved in providing training and consulting services to professionals and parents.

Since the early 2000s, Rosario Roman, a Bolivian-American SLP, has frequently returned to Bolivia, initially providing intensive clinical training for staff at the Instituto Psicopedagógico Ciudad Joven in Sucre, a residential program for children with a variety of disabilities. As internet and phone access increased in Bolivia, parents with autistic children began seeking Roman's assistance with their children, and she began to provide consultation and trainings for staff working in some of the private programs in Sucre, Santa Cruz, Cochabamba, La Paz, and Tarija.

Around 2010, members of Partners of the Americas (POA) began to work with Bolivians to identify the needs of persons with autism in the country and to provide training for professionals and parents dealing with autism. Partners of the Americas is a volunteer organization with more than 100 chapters in over 30 countries in the Western hemisphere. A chapter in one country is paired with a chapter in another. The goal is to bring together people in communities to solve local and global challenges. The Utah and North Carolina chapters are linked with the Bolivian La Paz and Cochabamba chapters, respectively. POA members in La Paz and Cochabamba specifically requested assistance in addressing the increasing needs of autistic persons. The majority of US POA consultants responding to this request were SLPs. In 2012, US POA consultants presented 2-day conferences on autism in La Paz, Cochabamba, and Santa Cruz. Roman joined the POA members in these activities and has continued her POA involvement as well as her personal activities in addressing needs of persons with disabilities in Bolivia. Between 2012 and the emergence of COVID, POA collaborators conducted workshops on a variety of topics related to autism assessment, intervention, behavior management, and health conditions for parents and professionals around Bolivia. During this timeframe, POA volunteers established extensive connections with professionals associated with hospitals, private practices, educational programs for persons with disabilities, and parent organizations. Roman and other POA members arranged meetings with the Bolivian PAHO representative and officials in the Ministries of Health and Education. In Roman's first meeting with the Bolivian PAHO representative, the representative stated he had no interest in any project related to disabilities. In a later meeting between POA members and a new PAHO representative, the PAHO representative indicated a willingness to collaborate. However, the collaboration required participation by Bolivian governmental officials. Staff from the Bolivian Ministries of Health and Education indicated they had no interest in any collaboration with PAHO or the POA activities. This lack of collaboration with government officials has made it difficult to develop any coordinated system of services for autistic persons across the country.

In August 2016, the POA autism specialists from the United States held a variety of extensive autism trainings in La Paz, Cochabamba, and Tarija. Nearly 700 persons attended the presentations. Information flyers on the trainings were widely distributed throughout the communities. The POA autism specialists did television interviews and, in addition to the presentations, visited with staff at university programs, educational service centers, medical centers, and local municipality offices. In all three cities, US POA members met with Bolivian POA and Rotary members to discuss possible future activities. Because travel expenses prohibited frequent visits for ongoing training with autism experts, local Bolivian committees suggested the use of technology to help meet these training needs.

The University of North Carolina Chapel Hill (UNC) received grant funding for the Program for Early Autism Research, Leadership, and Service (PEARLS). As part of PEARLS projects, faculty members and graduate students from UNC developed Spanish-language videos designed to provide informational support for family members and professionals who care for and serve persons with autism. The project includes twenty-five pre-recorded Spanish-language presentations made available to family members and professionals at no cost. These video presentations, which were made specifically for the population of Bolivia, offer information and education on autism regarding evaluation, treatments, and medical management. The developers recommend use of the videos as a career curriculum or as professional training for doctors, teachers,

therapists, or other professionals. The videos can be viewed at: <https://www.med.unc.edu/healthsciences/pearls/service/en-espanol/>.

In 2023, Michaela DuBay, a faculty member at the University of Virginia (who had been involved in the Bolivian POA project as a doctoral student) obtained funding for an ECHO project. ECHO is an acronym for Extension for Community Healthcare Outcomes. ECHO is a model for medical education and information exchange developed at the University of New Mexico. It uses tele-mentoring to share knowledge between specialists and primary care providers.⁴⁵ Since its original development, the ECHO model has been implemented to mentor parents and professionals in a variety of medical and educational areas, including autism.⁴⁶

The aim of the 2023 ECHO project was to create a network of 1) highly trained diagnosticians who could provide ASD evaluations and differential diagnoses and 2) frontline workers who could recognize early symptoms of ASD and refer families to these highly trained diagnosticians. A two-session virtual seminar was conducted with front-line workers such as pediatricians, early childhood educators, and speech-language pathologists to a) recognize early signs of ASD and b) provide families with appropriate referrals to ASD diagnosticians. Then 93 professionals participated in an average of 6 ECHO trainings - once per month 90-minute sessions over a 10-month period - to gain knowledge and skills to diagnose autism. Participants from various sites throughout Bolivia attended teleconference meetings hosted by a central “hub” team to present individual cases, consult with a multidisciplinary team of specialists, and learn from the cases presented by other providers. Over the course of the program, participants learned new clinical skills in ASD evaluation procedures and differential diagnosis through guided practice and collaborative case-based learning. At the end of the ECHO mentoring, clinicians connected with the frontline workers who participated in the first phase through a final joint meeting and virtual community forum. Because the Bolivian government only recognizes autism diagnosis given by a neurologist who works in a public hospital, not all persons who attended the training will be able to provide a disability card to their patients. Despite this, professional service providers and parents felt that even having an “unofficial” diagnosis of autism is still extremely valuable because it provides them with guidance in how to develop interventions for the children.

In 2024, DuBay received funding to implement a parent-mediated autism intervention modeled after a program employed in other low-resource settings.⁴⁷ Parent leaders, identified through engagement in an ECHO virtual learning series for families, have been trained in a cultural adaptation of Caregivers of Autism Support and Training (CAST), a parent-mediated autism intervention. Parent leaders have received 40 hours of in-person training sessions across 5–6 days and in 7.5 hours of virtual training. Parent leaders will implement the intervention in in-person sessions with their assigned groups of family participants for a 10-week intervention. These sessions are designed to be 2 hours each. The parent leaders will also attend ECHO sessions for support during the same 10 weeks they are implementing the intervention. The ECHO sessions are all virtual, and will be about 1–1.5 hours each.

Strategies for Developing Culturally Responsive Services in Majority World Countries

Many majority countries around the world have no data on the prevalence of autism, and without such data, there is no urgency to seek assessments and provide interventions. Professionals from minority world countries frequently serve as consultants to majority world countries. Providing appropriate, equitable assessments and interventions for people experiencing communication disability globally is a challenge for the speech–language therapy profession. Minority world professionals must be cautious that they not simply export their training with few modifications to the majority world.⁴⁸ Such attempts to duplicate professional practices in different cultural, economic, and linguistic contexts may result in services that are neither relevant nor culturally responsive.⁴⁹ Not only do governmental and educational systems differ from those in minority world cultures, such as the United States, but also beliefs about disabilities, child development, and child rearing practices differ in Bolivia and Paraguay. Strategies such as skilled dialogue and the PRECEDE-PROCEED model for program development can facilitate the design and implementation of trainings and services that reflect beliefs and desires of persons in the community. Programs that meet the desires and expectations of the persons for whom they are developed are more likely to be sustainable.

Skilled Dialogue

In both the Bolivian and Paraguayan projects, American consultants have employed skilled dialogue, a conversational pattern that brings one's intellectual knowledge to face-to-face interactions. By using skilled dialogue, interviewers develop an anchored understanding of the persons they are interviewing. The interviewer comes to understand and value the beliefs and desires of the persons they are interviewing and the reasons for these values and beliefs. With this information, they are in a better position to develop programs that will be acceptable and useful to families and community professionals. Skilled dialogue has three aspects: respect, reciprocity, and responsiveness.⁵⁰ First, the interviewer shows respect by honoring the beliefs and behaviors of the person they are interviewing as a legitimate expression of their identity. The interviewer is alert to potential cultural differences between themselves and the person they are interviewing and they acknowledge and give explicit respect to any cultural differences that they identify between themselves and the interviewee. For example, compared to minority world professionals, majority world professionals and parents may have different expectations regarding child development – what a child should learn, how they learn, and when they learn. These differences in beliefs about child development will influence assessments and interventions.

The second aspect of skilled dialogue is reciprocity. One exhibits reciprocity by showing interest in the professionals' or families' stories. The interviewer recognizes their positive ideas and explanations. Their explanations might be behaviors the interviewer had never done and never would do, but they try to see how the behavior serves a positive function for that professional or family. The interviewer acts as a learner, not as an expert consultant. An aspect of reciprocity is being aware of one's communication style and sensitive to the communication style of the people with whom you are speaking. Mainstream English speakers from the United States typically use a direct, explicit style when conveying information. Persons from some collective cultures (such as Bolivia and Paraguay) may perceive this style as intrusive, challenging, or rude. In contrast, the minority world service provider may perceive the indirect, discursive style of persons from some cultures as a signal that the interviewees are intentionally evasive or that they lack comprehension or knowledge.

The third aspect of skill dialogue is responsiveness. This is the interviewer's willingness to understand what the professionals or family members are saying. The interviewer releases preconceptions of what they think they do not know or need to know. They think about the preconceptions they might have and attempt to put those aside. While they are engaged in the interview, they identify the cultural values that are identified in their interpretations of an individual's difficulties or in the recommendations for service. The interviewer should seek to determine whether the family recognizes and values those assumptions, and if not, how their views differ from the views of the interviewer. There's always a third space.⁵¹ A third space is an "in-between" space in the clash between cultures where meaning and representation are negotiated and cultural identity can be reconceptualized.⁵² Through discussion and collaboration, the interviewer determines the most effective ways of adapting their professional interpretations and recommendations to the value system of the client and family. Many families operate in a third space. They take some of the ideas from those who are providing professional services, but they integrate that with their cultural values and beliefs.

Precede-Proceed

PRECEDE-PROCEED is a logic model⁵³ that provides a procedural structure for assessing health needs of a community and for designing, implementing, and evaluating programs to meet those needs. It is a participatory model assuring community involvement. In this case, the framework can facilitate consultants' development of culturally relevant trainings in assessment and intervention for autistic individuals. PRECEDE provides the structure for planning a program; PROCEED provides the structure for implementing and evaluating the program. PRECEDE and PROCEED are acronyms. The PRECEDE phase involves exploring factors that could positively or negatively influence the development and implementation of a program (Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation). The PRECEDE phase outlines a process to assist in the development of a health or educational program. It represents the process that precedes, or leads up to, an intervention. PROCEED (Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development) guides the implementation and evaluation of the program designed using PRECEDE; it describes how to proceed with the intervention

itself. Roman's work in Paraguay represents PRECEDE elements. The activities of POA consultants in Bolivia reflect most components of the PRECEDE-PROCEED model. There are typically eight phases in the PRECEDE-PROCEED model, but not all phases are employed in every program. The following describes the purpose of each PRECEDE-PROCEED phase and the nature of each phase in the Bolivian autism activities carried out by the POA consultants from the United States Utah and North Carolina POA organizations.

PRECEDE phases:

- Phase 1: Identify the ultimate desired result. Consider what outcomes are desired by the parents of autistic children and professionals involved in assessment and intervention of autistic children. Ultimately, parents want a diagnosis to understand their children and interventions to support their children's development.
- Phase 2: Identify issues and factors that might stand in the way of achieving the outcome identified in Phase 1. Children cannot receive a diagnosis if there are not trained professionals to conduct assessments and if parents cannot access evaluation due to transportation or financial difficulties. US POA consultants worked closely with Bolivian PAO members, parents, and health and education providers to identify who would be trained, the types of training needed, and where and how the trainings could be provided. The professionals and parents receiving training had widely differing levels of knowledge regarding autism, thus requiring trainings with differing content at varying levels. Trainings were free and provided at several locations throughout Bolivia.
- Phase 3: Identify the factors that will create the desired behavior and environmental changes necessary. US POA consultants have a wide range of experience with autistic children to effectively address the needs of Bolivian participants. Bolivian POA members have many connections with parent organizations, professionals, and educational programs for children with disabilities throughout the country. This has facilitated recruiting participants and sites for training, and has enabled US POA consultants to visit many medical and therapeutic programs serving autistic children. These visits facilitate consultants' understanding of the values and intervention strategies employed so as to offer training that better meet the needs of training participants.
- Phase 4: Identify the administrative and policy factors that influence what can be implemented. Ultimately, PAO consultants and Bolivian parents and professionals would like to see national health and education policies that would support identification and education of autistic children. The lack of governmental collaboration with the US POA consultants, the lack of interest in a Bolivian ASHA-PAHO collaboration, and the lack of Bolivian government laws and policies to support screening and services for autistic persons make it difficult to bring about nationwide programs. Some municipalities and departments at a local level have negative relationships with the national government. Consequently, POA consultants are cautious about who they work with and how at local levels so as not to cause conflicts. Although governmental officials have exhibited no interest in collaboration, POA consultants will continue to seek ways to influence MOH and MOE administrators' ideas on serving persons with disabilities.

PROCEED phases:

- Phase 5: Implementation – the design and actual conducting of the intervention. Until recently, the work in Bolivia and Paraguay has been to gather information about what people wanted and felt they needed, and in response, to provide general information about autism to parents and professionals. It has not been to make changes at the systems level in terms of how assessment and intervention ultimately happen. The ECHO and Parent-Mediated Autism Project being carried out by Dr. DuBay specifically address the ultimate desired outcomes to implement a program of assessment leading to diagnosis and for children to actually receive interventions.
- Phase 6: Process evaluation. Is the project/program being done as planned? The 2023 ECHO mentoring project was carried out as designed. A two-session virtual seminar was conducted with front-line workers such as pediatricians, early childhood educators, and speech-language pathologists to a) recognize early signs of ASD and b) provide families with appropriate referrals to ASD diagnosticians. Ninety three professionals participated in the ECHO mentoring training - once per month 90-minutes sessions over a 10-month period – to gain knowledge and skills to

diagnose autism. In the 2024 ECHO project, five family leaders have received in-person and virtual training and are scheduled to begin working with their assigned families.

- Phase 7: Impact evaluation. Is the intervention having the desired impact on the target population? Data for an impact evaluation of ECHO have been collected and will be analyzed. This includes pre and post participation questionnaire data on the knowledge and skills of front-line workers in the area of recognizing early signs of ASD, how referrals are made, and the knowledge and skills of diagnosticians in the area of ASD evaluation and ASD diagnostic criteria. The proposal for the Parent-Mediated Autism Project describes plans for an impact evaluation. Two surveys assessing knowledge in ASD and self-efficacy in supporting individuals with ASD will be administered as pre-and post-tests to both parents who implement the intervention and families who participate in it. Qualitative interviews will be conducted with both sets of parent participants to assess the feasibility and acceptance of the intervention.
- Phase 8: Outcome evaluation. Is the intervention leading to the outcome (the desired result) that was envisioned in Phase 1? Ultimately, with respect to the ECHO project, the intent is to evaluate if there is an expansion of the professional network of front-line workers with diagnosticians who receive referrals, if there is a significant increase in the number of referrals made by front-line workers and received by diagnosticians, and if there is an increase in the number of children evaluated for autism. Outcome evaluation will require tracking of data over several years.

Concluding Thoughts

Nearly all that we know about autism comes from minority world WEIRD (Western, Educated, Industrialized, Rich, and Democratic) countries; minimal data and research is available from majority countries.⁵⁴ A large number of majority world countries, such as those in South America and Africa, have limited prevalence data on autism. Of three recent reviews of global prevalence data, two reviews had no data from any South American country^{2,4} and one review had data from only a single study in Venezuela.³ Lack of such data is an indication of the very limited services available for autistic individuals. This report on the collaborative autism projects conducted by American POA and ASHA volunteers with Bolivian and Paraguayan families and professionals reflects the complex challenges of gathering data on autism prevalence and response to the needs of autistic individuals and their families in these majority world countries. In Bolivia and Paraguay, country topography, language diversity, high poverty rates, and political instability/corruption affect the availability and quality of assessment and intervention opportunities for autistic persons. Programs such as the ASHA-PAHO Paraguay collaboration and the POA activities in Bolivia are making inroads into the autism training needs for parents and professionals. American collaborators seek to provide culturally responsive trainings by engaging in skilled conversational dialogue to ensure they understand the needs and desires of professionals and families with the countries. Ultimately, by employing the steps of the PRECEDE-PROCEED model, their intent is to build sustainable assessment and intervention programs.

To date, the number of people reached in these projects is relatively small in comparison to the need. Technology, such as that employed in the ECHO autism program described in this article, has the potential to provide access to trainings for assessments and interventions. The World Health Organization developed the Caregiver Skills Training Program (CST) for families of children with developmental disorders or delay, including autism to address treatment gap in low-resource settings.⁵⁵ The CST program was specifically designed to be implemented by non-specialist providers, but recently, the program has gone on-line and can be directly accessed by parents. This course is for caregivers of children ages 2 to 9 years with developmental delays or disabilities, especially in the domains of communication and social interaction. The program is intended for a global audience and was designed to be adapted to the cultural, socioeconomic, geographic, and resource context in which it is used. It is undergoing field-testing in more than 30 countries across the world and is being translated into multiple languages.⁵⁵⁻⁵⁷

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