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Caregiver Strategies for Communication in Children with Autism in Spanish-Speaking, Developing Countries

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Abstract

The literature review provides current and relevant information for speech-language pathologists (SLPs) who service families with a child with autism (CWA) in Spanish-speaking, developing (SSD) countries. This review gives an overview of autism spectrum disorder (ASD) as it relates to language and language development and SLP scope of practice in the U.S. as it relates to ASD. Applicable evidenced-based strategies will be given to help SLPs provide family education to increase functional communication with their CWA. To be sensitive to cultural differences in SSD countries, interaction styles and customs will be defined and interviews from families and SLPs in SSD countries will be conducted. After synthesizing the current evidenced-based strategies and cultural norms for families in SSD, clinical implications will be outlined.

Introduction

Purpose of Project

The purpose of the project is to provide speech-language pathologists (SLPs) with information about engaging in culturally-sensitive education about communication with caregivers who have children with autism (CWA) in Spanish-speaking, developing (SSD) countries. This independent study is comprised of two separate parts. In Part One of this paper, autism spectrum disorder (ASD) and its impact on a child's/children's language will be defined. The SLPs' scope of practice as it relates to ASD and SSD will serve to provide implications for service outside of the United States. Programs commonly used to support the development of balanced communication skills in the 0-5 year-old population will be identified. Through research and interviews from people residing in SSD with connections to SLP services or CWA, we will synthesize the impact of culture on parent/child interactions in relation to strategies used in the identified programs in Part Two of this project.

Independent Study, Part One

Autism Overview

In order to support parents of CWA in using communication and various communication strategies with their child(ren), it is important to first understand the definition of autism and the possible characteristics that can present with the disorder. ASD is not easily defined because its characteristics present differently across people affected. SLPs are accountable for being vigilant in assessment to aid in a differential diagnosis and providing evidence-based intervention in assessment and treatment of language, speech, and social communication in CWA.

ASD has been defined in the Diagnostic and Statistical Manual of Mental Disorders as a neurodevelopmental disorder that presents with varying characteristics in two domains: repeated behaviors and/or limited interests and social communication (American Psychiatric Association, 2013). Perseverative and/or restricted patterned behaviors may include repeated motor movements or speech patterns, inflexibility with motor and verbal rituals and routines, fixation on a small range of topics or interests, or either strong or low reactions to sensory input (American Psychiatric Association, 2013). Social communication and pragmatic deficits may include decreased length and complexity of utterances length, topic maintenance, conversational turn taking, inferencing, detection of humor or sarcasm, and general lack of awareness of established social norms (Wahlberg, Obiakor, Burkhardt & Rotatori, 2001).

When CWA acquire language skills, they typically have expressive and receptive language development deficits when compared to their peers. Some CWA have less than five expressive words that they use daily, which classifies them as nonverbal (Rice, Warren, & Betz, 2005). In a 2004 study, 14-20% of nine-year-olds with ASD were classified as nonverbal (Lord, Risi, & Pickles, 2004). In verbal CWA, expressive and receptive language scores tend to fall behind their typically developing peers (Rice et al., 2005). In addition, characteristics of autism will present themselves in early stages of development and will cause impairment in daily activities of interaction and living. As CWA age, deficits may surface and further manifest as more demands are placed on them.

SLP Scope of Practice in the United States as it Relates to Autism and SSD Countries

The American Speech-Language-Hearing Association (ASHA) defines an SLP as a professional who cares for and treats anyone with a communication or swallowing disorder. The

concepts of communication and swallowing cover a variety of components: assessment and treatment of speech production, fluency, expressive and receptive language, cognition, voice, andresonance all fall within the term communication. In the United States (U.S.), ASHA is an organization that grants certification to SLPs after completing the required schooling and clinical hours (ASHA, 2019d). ASHA has a defined Code of Ethics and Scope of Practice for SLPs. Further, ASHA provides an Issues in Ethics revision which clarifies that ethical practice for SLP's also includes being culturally competent during practice (ASHA, 2019c). These documents provide guidance as to the roles SLP might fulfill professionally and how to practice ethically in all clinical contexts.

As indicated above, one of the primary impacts of ASD on a child's development is impaired communication. Because of this, SLPs in the U.S. are responsible for treating individuals with ASD by providing therapy for any aspect of their communication or swallowing that is not typically-developing. Common communication disorders that coexist with ASD and would be treated by an SLP can include: expressive and receptive language, speech production, social, prelinguistic, and paralinguistic communication, atypical eating (food selectivity, etc.), and more (ASHA, 2016).

While ASHA's Scope of Practice clearly defines the SLP's role in assessment and intervention of a CWA in the U.S., other countries around the world may have different (or no) expectations when it comes to SLPs treating individuals with ASD. This is not to suggest that other countries do not wish to care for CWA; however, a formal structure for doing so is lacking in most countries outside of the U.S.. As an example, according to the United Nations (2012), there are a total of eighteen developing countries in Latin America that are Spanish-speaking. Of these eighteen countries, only six have official audiology and speech-language pathology

associations that may provide resources for SLPs or have code of ethics for members listed on

the ASHA website. Countries with associations include Argentina, Colombia, Ecuador, Mexico,

Paraguay, and Venezuela (ASHA, 2019b). In an effort to support professional development

outside the U.S., ASHA has teamed up with the Pan American Health Organization to

collaborate and advance the education for individuals treating communication disorders in Latin

America. They first started with the three countries that thought of themselves as needing the

most assistance and have added more to include: Belize, El Salvador, Guayana, Ecuador,

Honduras, and Paraguay. ASHA teams up with different organizations or universities in these

countries to provide support in connecting the need of services with available supports in that

country (ASHA, 2019a). For SLPs practicing in SSD countries, providing service for individuals

with ASD may be more difficult without a national-level professional organization or clearly

defined scope of practice.

Aside from having accreditation organizations, laws guiding access to services such as

speech-language therapy and a free and appropriate education inform how CWA might access

support from an SLP. In the U.S., two laws have been put into place to ensure that education and

special services are being provided to individuals with special needs. The Individual with

Disabilities Education Act (IDEA) provides individuals who require special education with free

and appropriate education (U.S. Department of Education, 2019). The Americans with

Disabilities Act (ADA) is an act that protects the civil rights such as, employment, public

accommodations, transportation, state and local government services, and telecommunications

for individuals with disabilities (U.S. Department of Justice, 1990). These regulations allow for

the guarantee of a variety of services for individuals with special needs across the lifespan.

Without these in place, individuals with special needs across the country would possibly not

receive the appropriate services and education they have the right to. The U.S. is one of the few countries in the world with such laws.

In SSD countries, there have been worldwide efforts in creating laws and regulations for United Nationsproviding free and appropriate education and services to individuals with disabilities. Two such laws supporting individuals with disabilities are *Article 21 of the Universal Declaration of Human Rights* and *Article 24 of the United Nations Convention on the Rights of Persons with Disabilities* (Portland State University, 2019). According to the Universal Declaration of Human Rights by The United Nations (2005), free education is a human right for everyone, parents can choose the type of education they want for their children, and developing a respect for human rights should be part of the educational process. The United Nations Convention on the Rights of Persons with Disabilities (United Nations, n.d.) states that developing personality, talents, and different abilities to their fullest potential for individuals with special needs is a human right. They also state that appropriate accommodations for individuals should be made in order for them to perform and learn in the most accessible way. No person with a disability should be turned away from general education or free obligatory schooling. In order to provide the best possible academic and social development, focus on individual support with the goal of providing full inclusion is required (Portland State University, 2019).

Though these declarations are important in terms of providing a mandate ensuring that individuals with special needs have the right to education and/or services, they are not always adhered to. In fact, depending on the country, city, or region in question, there may be zero penalties for failing to preserve and provide protections to individuals with disabilities. According to the The Organisation for Economic Co-operation and Development (OECD), a

priority going forward is to work towards education being provided to all children including those with special needs around the world. In fact, OECD states that efforts to provide education for all persons are ongoing and have become a large part of the global plan for education (Organization for Economic Cooperation and Development, 2019).

Of all SSD countries, Mexico is the only country that has laws written for educational rights for individuals with special needs (Portland State University, 2019). Mexico's first federal law for individuals with special needs was implemented in 1993. It allows for accommodations for students who need special services and provides the option for receiving school services in a setting outside of the general education program, if necessary. Children with special needs in Mexico are put into five categories which include: auditory handicap, intellectual handicap, motor skills handicap, visual handicap, and others (disorders that do not fit into the other four categories). These five categories are used to describe the child's symptoms, rather than their specific disability (Portland State University, 2019). For example, if a child has ASD, they may be categorized as having intellectual handicap or any appropriate title that fits that child's characteristics, instead of being labeled as having ASD. There are two types of service delivery options in Mexico for CWA or other disabilities: the Regular Education Support Service Unit and Multiple Attention Centers. The first service type is how the children are evaluated in different subjects both with standardized and non-standardized assessments. This evaluation lets the professionals know who needs accommodations, allows for integration of kids with special needs in the classroom, and shows what that integration will look like. The second is the service that provides different education settings for individuals who were unable to successfully learn to their best ability in a general education classroom (Portland State University, 2019).

Education for all individuals is considered a human right worldwide. It is the belief that everyone deserves free and appropriate education. The U.S. has laws for implementing this right so it would be helpful to have regulations and rules in all countries, including SSDs. Rules and regulations can be implemented by SSDs by providing education and/or accommodations for individuals with special needs including ASD.

Caregiver-Child Interaction Style and Cultural Perspectives on Autism in SSD Countries

It is important to understand how individuals (including parents and caregivers of CWA) across different cultures perceive communication and ASD when navigating ways to provide therapy aimed at improving communication. In this section, typical family roles and perspectives on ASD in Hispanic/Latino cultures and households will be further examined for a better understanding of the differences between these cultures and the majority of Anglo mainstream culture. The term Anglo mainstream culture refers to the culture of individuals from the U.S. and Canada who speak English and derive from Europe (Encyclopedia Britannica, 2019).

Due to little research conducted in SSD countries on topics related to language development, assessment, or treatment, information based upon research from the Latino and Hispanic culture in the U.S. will be reviewed to explain differences in cultural perceptions of communication and ASD. According to Falicov (1998), the term Latino includes anyone coming from a Latin American country. He found that the majority of Latinos in the U.S. include individuals from Mexico, Puerto Rico, and Cuba. Of these three countries, Mexico and Cuba are both considered developing, which means that the majority of the Latinos in the U.S. come from an SSD country's culture and/or background (World Population Review, 2019). Someone who is

considered Hispanic, on the other hand, is anyone who has come from a Spanish-speaking area and may also speak Spanish. These two terms are often used interchangeably, although their meanings are quite different.

Communication differences across cultures

Communication interaction styles differ between SSD cultures and Anglo mainstream cultures in a variety of ways. It is important to note that these differences do not represent a right or a wrong way to interact. Rather, acknowledging these differences can help identify challenges when professionals from one culture provide services to individuals from another culture. Due to the fact that the majority of therapists come from and reflect Anglo cultures, being knowledgeable about the cultural differences can help professionals understand, acknowledge, and plan for differences that exist between cultures.

Two important distinctions exist between Anglo and Hispanic cultures with regard to communication amongst family members. These distinctions can impact how SLPs view clients and families. First, the Anglo mainstream culture encourages children to ask their elders questions. On the other hand, families from Hispanic backgrounds have been found to discourage children from asking questions (Westby & Rouse, 1985). When children are taught to not ask questions, they may initiate conversations less frequently than children from Anglo backgrounds. When a child from the Hispanic culture does not initiate conversations as frequently as his/her Anglo peers, an adult or SLP may see this as a characteristic of a communication disorder, rather than as a cultural difference. Secondly, extended family relationships play a key role in the lives of Latino families. The needs of the immediate, nuclear family are often overlooked in favor of the needs of the extended family (Skogrand, Hatch, &

Singh, 2005). Skogrand and colleagues (2004) state that although the nuclear family finds

importance in extended family connections, being involved in extended family members' lives

can cause a burden on the nuclear family at home. On one hand, this could be difficult for a

family who has a CWA because their priority might be focused on the members of the extended

family rather than on their CWA at home. That said, close familial ties also create a strong bond

and support system which would benefit any family with a CWA (Skogrand et al., 2005). In

order to understand familial roles and responsibilities across generations in Hispanic families,

healthcare providers should keep this cultural characteristic in mind, as family interactions are

typically spread across different people and generations. This could potentially cause further

stress to the caregivers of the CWA, as differing priorities for child rearing, attitudes toward

disability (see section below), or power structures within a family might impact how family

members communicate. As family-centered intervention is a typical focus of speech-language

therapy in the U.S., Anglo SLPs should be aware of important cultural differences when

providing service to Hispanic families.

Current perspectives on autism in Hispanic/Latino culture/households

There is little research with a focus on understanding ASD in SSD cultures. That said, a

few exemplar studies provide useful information for understanding potential differences in how

ASD is perceived and treated between Anglo and Latino cultures. Non-Latino children receive a

diagnosis of ASD two and a half years sooner than Latino children (Mandell, Listerud, Levy &

Pinto-Martin, 2002). Zuckerman and colleagues (2014) interviewed 33 Latino parents of a CWA.

Overall, the researchers found three themes that could contribute to a late diagnosis of autism

which include: latino community knowledge, parental and family factors, and the health care

system (Zuckerman et al., 2014). The parents interviewed in this study were also asked to

explain what it was like having a CWA, share experiences they have had, and identify barriers they have experienced connected to ASD. The majority of the parents in this study reported that they felt that education and knowledge about ASD was lacking which, in turn, resulted in a late diagnosis of ASD for their child. They believed that both they and the communities they lived in did not fully understand what autism was, let alone seek out a diagnosis of it. Furthermore, when considering parental and family factors, respondents stated that limited English proficiency, poor awareness of available services, and poverty played a part in the late diagnosis as well (Zuckerman et al., 2014). Communicating in different languages and being unaware of the services their children were entitled to were shown to have affected whether parents sought help for their child. Poverty also made seeking help more difficult due to the cost of transportation, diagnostic testing, insurance, etc.

Additionally, respondents reported that healthcare system factors contributed to a late diagnosis of ASD, including the amount of help provided by the primary care doctor, the complexity and inconvenience of the diagnostic process, and the discomfort of the ASD diagnosis itself (Zuckerman et al., 2014). The amount of support and help the caregivers reported to have received varied between respondents. Some stated the primary care doctor supported them in finding a diagnosis, but others disagreed. Those who disagreed felt the language barrier made it more difficult for them to communicate with the doctor. Caregivers stated that several inconveniences also made for a late ASD diagnosis. For instance, they expressed that finding child care, arranging time off work, and finding transportation to appointments was very difficult. Parents also reported that when their child with ASD was overstimulated or out of their daily routine by going to these diagnostic evaluations, the experience turned into a negative one, therefore making the parents not willing to come back for subsequent appointments.

Issues regarding attitudes toward ASD impacted respondents' likelihood to pursue treatment for their child's disorder (Zuckerman et al., 2014). For instance, when the participants learned about the diagnosis of ASD, almost all reported no knowledge about the disorder. Some parents perceived this disability was a sign of weakness, was embarrassing, or was something to be ashamed of. Some parents stated that in the Mexican culture, if the child was acting differently because of their ASD, the family would hide them in fear of others thinking the child not disciplined correctly or had a different type of developmental disability (Zuckerman et al., 2014). One parent reported that when she was younger, she asked about someone she saw in public with ASD and was told that the person with ASD was an "idiot" (Zuckerman et al., 2014, p. 304).

Additionally, mothers of CWA stated that *machismo* affected how they thought the father felt about their child's diagnosis (Skogrand et al., 2005). Machismo is a term to describe the male gender roles in the Latino culture. The mothers reported that the fathers might feel less of a man because of their "weak" or "disabled" boy. Typically in Hispanic culture, the mother is the caretaker and nurturer, while the father is seen as the provider and decision maker for the family (Skogrand et al., 2005). The dynamic of the family could shift if the father considers himself less of a man because of his child's diagnosis. The father's identity as the provider or decision maker of the family may shift and he and others may perceive this as a lack of machismo.

Knowing the potential perceptions that caregivers have toward a CWA from this culture is important for SLPs and healthcare providers to keep in mind. Anglo perceptions of ASD likely differ from those observed within the Hispanic culture. A lack of understanding of these differences could cause a disconnect between the goals that professionals and caregivers have for

a CWA. With counseling, empathy, and understanding across cultures, working toward the same goals for a child and family understanding an ASD diagnosis is possible.

Evidence-Based Strategies for Increasing Communication in Children with Autism

The National Research Council Committee on Educational Interventions for Children with Autism (2001) recommended the following for communication growth in CWA: a child should receive early and intense intervention, caregivers should be considered the primary communication partners, play and functional communication should be targeted, and communication should be individualized for each child. In order to provide culturally-sensitive education on communication strategies to caregivers in SSD countries, an SLP should first be aware of evidence-based strategies commonly used among CWA or language delays and be able to identify where and how these practices might be impacted by cultural differences between therapists, clients, and families. To this end, a variety of programs and approaches for supporting the development of functional communication in important daily settings (e.g., home) have been developed by professionals of multiple disciplines. Three of these widely-used programs are summarized below, with a subsequent discussion of considerations related to the use of these programs with families and clients from non-Anglo cultures.

The Greenspan Developmental-Individual Differences-Relationship Floortime Approach

Dr. Stanley Greenspan and his colleagues first developed the Greenspan Floortime Approach in 1979 with CWA in mind (The Greenspan Floortime Approach, 2019). Dr. Greenspan found that one-on-one interaction that built upon skills a child already possessed was beneficial for growth toward achieving social-emotional milestones, such as expanding

emotional thinking and improving social communication. (Ohio Center for Autism and Low Incidence, 2015).

In the Floortime program, strategies for increasing communication involve setting up a one-on-one interactions between a child and caregiver (Mercer, 2017). As the title of the program states, the caregiver sits on the floor with the child and interacts with the child, who is leading the playtime activities. Caregivers follow the interest of the child, showing reciprocal interest and not placing communication demands on the child (ie: asking them to label objects or answer questions). The overarching goal for the caregiver during the Greenspan Floortime Approach is to expand upon the play ideas of the child or the utterances the child makes. Expansions help further semantic growth by giving the child alternative ways to communicate about and interact with the stimuli (Mercer, 2017).

Greenspan and other Floortime developers have accessed more than 50 years of research in the fields of psychology, medicine, and education to develop and refine the Greenspan Floortime Approach. This research was primarily focused on the domains of "language, attention, mental health, attachment, infant development, sensory processing, and motor development" (Cullinane, n.d.). To review the effectiveness of the Greenspan Floortime Approach, Mercer (2017) found that, across 10 empirical studies designed to research the Greenspan Floortime Approach, all articles showed communication improvement in participants with autism. Research on the efficacy of the Greenspan Floortime Approach has various limitations between different studies, such as the frequency or duration of Floortime services versus control groups; however, no adverse effects were found across literature. Mercer (2017) determined The Greenspan Floortime Approach can be considered evidence-based practice

because of the multiple positive outcomes of the studies; however it cannot be considered evidence-based treatment due to the weak-designs of literature about the approach.

The Hanen Approach - More Than Words

Another approach for increasing effective parent-child interaction is The Hanen Approach. Designed by SLPs, The Hanen Approach is founded on the idea that children benefit from daily, meaningful interactions with caregivers (The Hanen Centre, 2016a). One program within The Hanen Approach, called More Than Words (MTW), is made specifically for caregivers of CWA (The Hanen Centre, 2016b). The program educates caregivers on finding their child's communication style and motivation, provides strategies to facilitate language, and provides additional resources and guides on communication.

Caregivers complete training programs in the MTW curriculum to receive comprehensive education about communication and their CWA. This curriculum focuses on three specific strategies to support high-quality caregiver interactions: child oriented strategies, interaction-promoting strategies, and language modeling strategies. Each is described below: Child-oriented strategies are similar to the Greenspan Floortime Approach (The Hanen Centre, 2016b). MTW promotes following the child's lead in communication using an "observe, wait, and listen" approach (The Hanen Centre, 2016b, p. 3). By giving the child space to respond, either verbally or nonverbally, will inadvertently promote interaction. The caregiver should physically be on the child's level and let the child navigate the interaction through his or her own interests.

- Interaction promoting strategies are focused on the caregiver facilitating a communication exchange during daily routines (The Hanen Centre, 2016b). The

child can be prompted a child to make a conversational exchange through turn-taking, but must allow the child to lead the interaction after the initial prompt.

- Language modeling strategies focus on teaching caregivers to develop appropriate language use in the daily environment to encourage a child to communicate (The Hanen Centre, 2016b). For example, caregivers learn to simplify their message and slow down their rate of speed when talking with the child. Caregivers may also narrate their own actions or narrate the child's actions during a routine or a play-based interaction. In addition to narration, repeating a child's verbalization or expanding upon a verbalization can be used by parents to facilitate language learning. Using intonation to indicate word importance, and using visuals to help connect verbal concepts are two other strategies that can help expand a child's language.

Three studies have investigated the effectiveness of the MTW program (McConachie, Randle, Hammal & Le Couteur, 2005; Girolametto, Sussman, & Weizman, 2007; Carter et al., 2011). Overall, the three studies found that parents who participated in the MTW program reported increased vocabulary size in their children and an increase in effective parent-child interaction. In two of the studies (McConachie et al., 2005; Carter et al., 2011), the MTW program did not show an increase in the child's social interaction skills. However, one study discovered that turn-taking and initiation behavior in participants increased (Girolametto et al., 2007). The findings suggest that when children consistently interact with caregivers as communication partners a child's vocabulary can expand and they may have increased social communicative behaviors.

Enhanced Milieu Teaching

Enhanced Milieu Teaching (EMT) is a type of evidenced-based intervention that caregivers can use to facilitate communication with their CWA (Kaiser & Stanton-Chapman, 2013). EMT is based on the belief that caregivers are the child's best communication partners and that naturalistic environments are the best places to learn and generalize communication. EMT comes from "milieu teaching" which is when a child's natural environment is altered to allow for an increase in specific behavior (U.S. Department of Education, 2012). EMT uses the same principles but the targeted behavior is specifically communication. EMT supports strategies mentioned previously in the Greenspan Floortime and MTW approaches, such as letting the child initiate and lead the interactions, waiting for and listening to communication attempts, using simple language as a model, expanding upon the child's verbalizations, and using less toys. Specifically, there are four general components to EMT which allow for communication growth through a multitude of strategies (Kaiser & Stanton-Chapman, 2013):

- Setting the foundation for communication allows caregivers to build towards communication interactions. First, when children and their caregivers participate in a joint attention activity like playing, children can learn better. When playing, EMT strategies suggest that the adult communication partner should avoid directing or questioning the child. If interaction is initiated by the child, the adult should "notice and respond" (p. 10) to each communication attempt. They should only respond to the interaction and wait for another interaction to be made to promote conversational turn-taking. If the child is not initiating communication, a "mirror and mapping" technique can be used (p. 12). An adult can copy or "mirror" the child's actions and then "map" by use simple phrases to describe the actions.

- Once the foundation is in place for communication, caregivers can begin the next step of "Modeling and Expanding Play and Communication" (p. 8). During a simple routine in play, adults can use various short phrases to describe the actions and the objects of play. Routines in play are important because children can learn from predictable, repeated actions. Parents can also model simple language which allows for more imitation opportunities for the child. Modeling language can be especially effective when parents are responding to the child's action or communication attempt.

- The step of "Environmental Arrangement to Promote Communication" (p. 16) allows for nonverbal cues to be given by the adult communication partner. These cues may be "offering choices, pausing within a routine, waiting for a cue" (p. 16) for example. If these nonverbal prompts are ineffective, the adult caregiver can begin using "Prompt Language" (p. 7) to elicit verbalizations from the child: using open-ended questions, questions that provide a choice, and modeling the intended phrase.

Few studies have been conducted to determine whether EMT impacts caregiver or child communication behaviors. Hancock and Kaiser (2002) studied EMT's effectiveness in improving communication in four preschool CWA. The results showed after 24 EMT sessions, targeted communication increased in all participants and was generalized in the home setting with three of the four participants. Kaiser and Hester (1994) found that after 20-minute EMT sessions four days a week among six participants, utterance length increased and vocabulary became more diverse.

Kaiser and Roberts (2013) investigated the impact of parent training in communication strategies through EMT. In this study, parents and therapists used EMT with 38 children with

intellectual disabilities. When compared to untrained parents who enrolled their children in EMT

sessions only, parents who used EMT were able to generalize and maintain the strategies at

home. After a year of parent-facilitated EMT strategies, the participants had increased utterance

length, vocabulary diversity, and targeted communication skills that were determined

individually. Overall, EMT provides effective strategies that caregivers can use at home to

promote communication growth.

Table 1: A Summary of Evidence-Based Parent Strategies to Encourage Communication in the

Home Environment

		Supported By Program		
Communication Strategy	**Description of Strategies**	**GFA**	**MTW**	**EMT**
Setting the Environment	Create an optimal communication environment of one-on-one interactions between child and caregiver.	**X**	**X**	**X**
	Limit the number of toys during caregiver-child reciprocal play.	**X**		**X**
	Participate in short, simple routines to allow for language learning to occur through a predictable sequence.			**X**
Interaction Strategies - Demeanor/ Behavior of	Allow the child to lead the interaction and expand upon the play or verbalizations of the child.	**X**	**X**	**X**

Communication Partner	Observe, wait, and listen to the child during one-on-one interactions.		X	X
	When communication is attempted, always "notice and respond."			X
Interaction Strategies - Verbal Behavior of Communication Partner	Do not place communication demands on the child (ie: demanding a child to label an item).	X		
	Use intonation and stress to indicate important words.		X	
	Model by narrating actions of self and child during routines and play.		X	
	Shorten, slow, and simplify sentences.		X	X
	Repeat and expand upon the verbalizations of the child.		X	X
	Imitate or "mirror" the child's nonverbal action and use language or "map" to expand upon those actions.			X
	Limit directing actions and asking questions during play-based interactions.			X

Additional Prompts	Use visual aids to help the child make connections.		X	
	Use a hierarchical prompting strategy to elicit targeted communication by starting with nonverbal encouragements, open-ended questions, questions that elicit a choice, and verbally modelling the targeted communication behavior.			X

Note: The abbreviations in this table represent the titles of the approaches reviewed. GFA stands for the Greenspan Floortime Approach. MTW stands for More Than Words. EMT stands for Enhanced Milieu Teaching.

Recommendations for Culturally Responsive Practice

Two main purposes of this paper are to understand cultural implications on ASD from SSD countries and to address the fact that the majority of SLPs treating these individuals are white, monolingual SLPs. The summaries above are meant to identify ways in which SLPs can bridge the gap between their perceptions of ASD and perceptions of a culture different than their own. To this end, it is important for SLPs to keep in mind a number of factors based on cultural differences when working with families of CWA from Hispanic cultures:

1. Instead of providing information about the diagnosis or current treatment plan to only the child's caregivers, the entire family should be included as a whole when educating them about the diagnosis or different techniques being used in therapy. When considering a therapy plan, an SLP should remember that the extended family typically plays a major

role in the child's life. When thinking about home programs or what goals they should focus on, the whole family and not just the parent's ideas should be prioritized.

2. When it comes to educating the family or members of the community, SLPs should be sensitive to typical familial roles (e.g., mother as caretaker, father as provider) (Skogrand et al., 2005). In the Hispanic culture, these roles are typically important and this piece of cultural information would be helpful to know during any interactions the SLP has with the family regarding the CWA.

3. When providing therapy or interacting with the children, an SLP should not expect a child from an SSD culture will routinely initiate conversation. While in the Anglo culture this may be indicative of an expressive language delay or disorder, that may not be the case in SSD cultures. Because elders discourage children from speaking first, children being quiet until asked to speak is typical for those cultures.

4. Due to the cultural differences between the SSD and mainstream Anglo cultures, some of the highlighted interventions for increasing communication in a CWA may be different between cultures:.

   a. Allowing the child to lead interactions and initiate conversation may be problematic because children in a Hispanic household are not encouraged to ask questions or initiate communication with older generations (Mercer, 2017; The Hanen Centre, 2016b; Kaiser & Stanton-Chapman, 2013; Westby & Rouse, 1985). The child may be hesitant to lead or the caregivers may consider the child initiating communication as disrespectful.

   b. One-on-one interactions may be limited in some families due to the emphasis of prioritizing the needs of the extended family over those of the nuclear family

(Mercer, 2017; The Hanen Centre, 2016b; Kaiser & Stanton-Chapman, 2013; Skogrand et al., 2005). Caregivers may not be able to attend directly to the CWA in a full household.

Independent Study, Part Two

Interviews

In an effort to better understand how families of CWA from SSDs have experienced ASDs within their culture and how SSDs perceive ASD, several individuals were interviewed to determine their lived experiences. We will examine interview responses, with a focus on respondents' experiences, perceptions, and knowledge of the treatment of individuals who have ASD in their communities and/or homes. By reviewing this information, we will have a better sense of what types of services or treatment the people of these communities currently have, and what could potentially benefit them in the future. By learning more about what the current status of speech-language pathology in SSD countries, we will have a better understanding of what education, resources, or outreach programs might be developed.

Study Design

In this study, interviews were conducted via email between individuals from the Dominican Republic, Costa Rica, Panama and the U.S. (Honduras). These four countries have all been defined as developing countries by The World Population Review (2019) and are Spanish-speaking countries. Interview questions and answers are included in Appendix A. Note that interviews were completed in Spanish, then later translated to English for reporting and analysis.

Participants

Participants in this study were contacted via e-mail by the authors of this paper. Pseudonyms have been assigned to each participant to protect their confidentiality. One interviewee provides first-hand insights on the perceptions and experiences of having a relative with ASD in a SSD (Ambar). Other interviewees share perceptions and experiences of their general cultures related to the treatment of individuals with disabilities such as ASD in their communities (Roberto and Sylvia). In the fourth interview, an SLP from the U.S. who practiced in Honduras, provides information about her experiences and cultural differences she noticed from a professional perspective (Nicole). Table 2 summarizes interviewees along with demographic information for each.

Table 2. Interviewee Demographic Information

Interviewee:	**Ambar**	**Roberto**	**Sylvia**	**Nicole (SLP)**
Country:	Dominican Republic	Panama	Costa Rica	United States
City:	San Juan de la Maguana	Panama City	San Jose	Chicago, IL
Relationship to Individual with ASD	Sister	N/A	N/A	SLP- few clients with ASD

Interview Process

Interview questions were sent to each interviewee via email. Interviewees answered each question, then returned their responses in the same manner. Answers from each interviewee were examined using a categorical approach to data analysis, wherein themes across respondents were

derived. Using this process, we identified four different categories that were evident across all

interviews: school/therapy services available, communication abilities/styles, opinions and

community acceptance, and community groups/support systems. Each is discussed in depth

below.

School and Service Availability

First, we found trends in different schooling opportunities and service resources provided

for individuals with autism in SSD countries. Ambar stated that her brother, Mateo, who has

ASD, has never been to school. The special school there did not accept Mateo because of his age,

as students are only accepted who are below the age of 10. He received one year of speech

therapy at a facility three hours away from home, which was too difficult for the family to

sustain. Ambar stated that her family wished they had the resources to help Mateo pronounce

some words and learn sign language, but despite this, they continue to try to understand him

better.

Roberto stated that he had never heard of speech-language pathology. He also stated that

there are no places in his community that he knew of that provided this type of service. It is

important to note that this statement could be due to lack of knowledge about the profession, and

therefore not realizing his community has it. Conversely, Sylvia stated that there were SLPs who

worked to help individuals learn to communicate through signs or other ways. She explained that

the social security system of Costa Rica (which helps provide these services) is strong, therefore

making these services accessible to those who need them.

Nicole, the SLP from the U.S. who volunteered in Honduras, reported that speech-

language pathology was not an actual field in Honduras until recently. She stated, "I did not meet

any Honduran SLPs during my time there. But, I am hopeful this will change soon!" She recalled

that she met developmental therapists who had some speech and language knowledge, but "not

extensive enough to diagnose or treat according to best practice." Additionally, Nicole noted that

a big difference between her service provision when in the U.S. versus when she worked in

Honduras was the amount of caregiver/teacher education she provided. She explained that

educating others on what an SLP is and does within their scope of practice was a large part of

what she does in the U.S., but even more so in Honduras. Lastly, Nicole made a comment

regarding the services provided in Honduras:

> "I think this goes back to understanding Honduras as a developing country and
>
> the political and economic situation that the country is in. I think it's easy to scoff
>
> and wonder how families aren't getting the services they need, but I continue to
>
> work on my worldview and understanding of Honduras as a country and culture.
>
> The safety alone is so concerning that it truly may not be safe for a typically
>
> developing child, never mind a child with communication needs, to regularly
>
> attend school. Once at school, the schools are often understaffed and exceptional
>
> learners cannot receive the accommodations they need."

Communication

Ambar shared about some of Mateo's (her brother with ASD) most frequent forms of

communication. She reported that

> "he sometimes makes eye contact with me, and if I speak or try to play with him,
>
> sometimes he smiles and sometimes he pushes me. If he wants water, he looks for a cup

and gives it to me, so I know he wants water or juice--same with food. With my family,

he allows hugs (sometimes), kisses, and we can hold his hand."

When asked if he has been able to interact with anyone outside of his house and in public,

Ambar stated that he has no communication with people in the community. She explains that he

doesn't leave his house, but rather spends some time on the porch but does not go much further

than that.

Interviewees from the Dominican Republic, Panama, and Costa Rica were asked general

questions regarding their culture's communication style and whether children were encouraged

to ask adults questions. All three participants responded that questions by the children were

encouraged by families. Roberto explained that parents who have a child with disabilities are

typically more aware or attached to their children. Sylvia shared that more recently, parents and

children have been encouraged to communicate openly so that parents are the first to know if

something is wrong with their child. She also explained that in the past, while the mother was

typically the caretaker and the father went to work, that has changed. She went on to say that it's

now common for both parents to "care for and guide their children…[and] spend more time

together and that has led them to create very close ties and very good communication." She

noted that this is the same for children with or without disabilities.

Opinions and Community Acceptance

Again, Ambar, Roberto, and Sylvia each reported that individuals with disabilities in

their communities are sometimes "teased" or "excluded," though sometimes people try to

include them. Ambar says that many people try to help integrate individuals with disabilities into

everyday activities. Both Ambar and Sylvia noted that both of their communities are not

"educated" enough or have sufficient information when it comes to interacting with individuals

with disabilities. Sylvia states that this lack of knowledge leads to fear due to the unexpected

behaviors a person with autism may exhibit.

Ambar says that the people in her community ask her and her family about many topics

related to Mateo, including: why they don't take Mateo in public or why they don't take pictures

of him. She said that when Mateo does go out in public, he "fusses as if he is afraid" if there are

a lot of people or noise. Otherwise, she says, he is "normal."

Community Groups and Support Systems

Lastly, Ambar spoke on the community support they receive as well as what it's like

being a caregiver of someone with ASD. She reported that there are no other families or support

groups that they can talk with for support in their community. When it comes to being a

caretaker, she stated that they have a "devoted and dedicated" mother. They sometimes struggle

when trying to understand if something is wrong with Mateo or if they need to figure out his

personal needs. She wrote that:

> "As the sister, to be a sister of someone with autism, it is often a challenge, because I try
>
> to be there for him all the time so that he knows no one is going to hurt him. I want to be
>
> present so that he knows that we love him. But without any doubt, he is our greatest
>
> blessing as a family and has taught us how to show our love and receive it without the
>
> need to say 'I love you!'"

Clinical Implications Emerging from this Project

Upon reviewing current literature regarding communication strategies and cultural characteristics and conducting targeted interviews, we created a list of strategies for use by SLPs working with families of CWA in SSD countries. Overall, most communication strategies suggested in Table 1 (which summarizes strategies commonly used in the US to treat CWA) are recommended strategies cross-culturally, though some strategies would be suggested over others, as they were considered as culturally similar or different to those in an SSD culture.

One strategy that aligns well with SSD country characteristics would be narrating routines, as supported by EMT (Kaiser & Stanton-Chapman, 2013). Exposing the child to language during simple and predictable routines is beneficial for increasing communication in a CWA. It also allows for daily communication opportunities. Based on the themes found in the interviews, this strategy of narrating actions would be easily implemented in a home environment. For example, Ambar in her interview stated that, during mealtimes, nonverbal communication is frequently occurring. If this strategy were to be implemented, she and her parents might narrate the actions they make during mealtimes to promote communication.

The first of the two culturally-different strategies that might be avoided focuses on the need for the child to initiate communication. This strategy was recommended by all evidence-based programs: Greenspan Floortime Approach, MTW and EMT (Mercer, 2017; The Hanen Centre, 2016b; Kaiser & Stanton-Chapman, 2013). The importance of child-initiated communication is to allow the child to learn and communicate about things that are most interesting to them. When the play activity is interesting to the child, the more attention it receives. As mentioned by Kaiser & Stanton-Chapman (2013) EMT promotes joint attention because it is a precursor for learning language. According to Westby and Rouse (1985), children in a hispanic culture are not encouraged to initiate conversation with their elders, therefore,

child-initiated communication might be culturally different strategy. However, based on the interviews, this cultural interaction-style Westby and Rouse discovered might not be as applicable to Hispanic families who have a CWA. Roberto stated relationships between a CWA and caregiver are "attentive" and "attached."

A one-on-one interaction style may also be difficult to implement in some families in SSD cultures. One-on-one communication settings are beneficial for CWA and are supported by all programs (Mercer, 2017; The Hanen Centre, 2016b; Kaiser & Stanton-Chapman, 2013). These types of interaction allow for uninterrupted, joint attention, and communication can be increased between fewer communication partners. In Hispanic cultures, extended family are prioritized (Skogrand et al., 2005). Due to the nature of big families, one-on-one interactions may be less easy to facilitate. However, in Sylvia's interview, she states that caregivers may be spending more time with their children than in years past. Due to increased time spent together, there are more chances for one-on-one interactions.

Overall, as an SLP, supporting parents who have a CWA is an ongoing process, especially when there is an added layer of being aware of differences between Anglo and SSD cultures. To provide culturally competent services for ASD, an SLP would need to be knowledgeable of cultural communication differences and considerations. When presenting families with evidence-based practice informed treatment strategies, SLPs can model the strategies and ask what would ultimately work best for individual clients and families, relative to cultural practices and preferences. Parents, too, experience their own ongoing process to deciding which communication strategies work best for them and their child. We recommend SLPs working with a clientele from SSD cultures individualize their professional recommendations across individual families in a way that honors their cultural norms.

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Appendices

Interview 1

Dominican Republic-Ambar

1. **How old is Mateo?** 24 years
2. **Has Mateo been formally diagnosed by a professional?** Yes
3. **If he has been diagnosed, what is his diagnosis?** Autism
   a. **What type of professional diagnosed him?** Neurologist and Psychologist
   b. **At what age was he diagnosed?** 7 years old
   c. **How long did it take for a diagnosis?** 5 years
4. **Has Mateo ever gone to school?** Never
5. **What type of school did Mateo go to?** N/A
6. **Did Mateo ever receive Speech-Language Therapy or feeding therapy?** Yes, for one year. The economic situation was not very good we would take him to Santo Domingo each month.
7. **How does Mateo communicate with you/your family?** He sometimes makes eye contact with me, and if I speak or try to play with him, sometimes he smiles and sometimes he pushes me. If he wants water, he looks for a cup and gives it to me, so I know he wants water or juice- same with food. With my family, he allows hugs (sometimes), kisses, and we can hold his hand.
8. **How does Mateo communicate with others/strangers in the community?** He has no communication with people in the community. Usually he goes to the porch and does not go further than that.
9. **Do you and your family have other families you can talk with that have similar experience in raising a child with autism?** No
10. **What is it like being the mother/father/sister/brother of Mateo.**
    We have a special mother- devoted and dedicated. There are some challenges like trying to understand if something is going on with him, and being aware and attentive of his personal needs….
    As the sister: to be a sister of someone with autism, it is often a challenge, because I try to be there for him all the time so that he knows no one is going to hurt him. I want to be present so that he knows that we love him. But without any doubt, he is our greatest blessing as a family and has taught us how to show our love and receive it without the need to say "I love you"!
11. **What opinions do others have in your community about Mateo?** They ask us many questions. They ask why we don't take him out in the public or why we don't take pictures of him.
12. **What is it like going in public with Mateo?** If there are many people or a lot of noise, he fusses as if he is afraid. But otherwise, he is normal (of course,being extra careful).
13. **Have you ever interacted with or communicated with someone other than Mateo who has a disorder in which communication is difficult?** Yes

14. **Are you aware of any speech services that can be provided for individuals who have a disorder that makes communication difficult?** Speech Therapy

15. **Have you ever heard of Speech-Language Pathology or Speech-Language therapy or know if your community has these services?** Yes, Speech therapy. There is a center care center for kids with autism but they only accept kids younger than 10 years old. There is also a special school, but neither accepted Mateo.

16. **How are individuals with disabilities or autism treated in your community?** Sometimes they are excluded or tease them. But there are also people who help them and integrate them into everyday activities. This specific community is not educated to deal with people with special needs.integrate them into everyday activities. This specific community is not educated to deal with people with special needs.

17. **What do people in your community/culture think of individuals who have disabilities?** There's been much progress in terms of treatment toward people with disabilities, we are currently working to include them in work and daily activities. But unfortunately there always appears to be people who scoff, mistreat, and offend people with special needs.

18. **For someone who has never met Mateo, how would you explain his diagnosis or behaviors?** That he has autism (many people do not understand this word), so we explain that normally he is jumping or moving a lot, he can not speak, he does not study, he can bathe himself, or find water or food, he is not aggressive, he likes music and likes to eat a lot, we try to soothe and show him how much we love him.

19. **Do you wish you had received any education or resources on your family member's disability or any ways to increase communication if you have not already?** Of course! Our biggest wish is that he can pronounce some words or have signs that help us understand him better and continue to help.

20. **In your culture, how do parents and children (with or without a disability) typically interact? Are children encouraged to talk to their parents**? Yes, Normally we always have communication with our parents.

Interview 2

<u>**Costa Rica: Sylvia**</u>

1. **Do you have any experience with individuals who have disabilities?** yes
2. **Have you ever interacted with or communicated with someone who has a disorder that makes it difficult for them to understand you or for them to express their thoughts/wants/or needs?** Yes
3. **Have you ever heard of speech therapy or speech pathology? If so, what do you know about these?** Yes

There are therapies that help people who have communication problems that are either taught to manage or they learn to communicate through signs or other ways.

4. **Are there places in your community where people go to see a speech pathologist or receive speech therapy?** Yes
   a. **If so, how accessible are these services to people in your community? Please expand on the location or cost of these types of services.** They are very accessible because the social security of Costa Rica is strong.

5. How are individuals with disabilities like autism treated in your community?
There is not sufficient information for how these people should be treated. Because of that, it turns out that people fear them and they do not go near them because of the unexpected behaviors that they present.

6. In your culture, how do parents and children (with or without a disability) typically interact? Are children encouraged to talk to their parents?
Yes, they have very good interaction. In the past years, the communication has been promoted between both parents and children so that children have the confidence to tell their parents about whatever situation that happens to them, so that the parents are the first to know that they are uncomfortable. Currently the relationships are very good including between the father and the children. Now that time has passed, the task of caring for the children used to be covered by the mother while the father was at work because he thought the mother should take care of the children. Now, both parents equally care for and guide their children and young people, they spend more time together and that has led them to create very close ties and very good communication. It would be the same for children with or without disabilities.

Interview 3

Panama- Roberto

1. **Do you have any experience with individuals who have disabilities?** yes
2. **Have you ever interacted with or communicated with someone who has a disorder that makes it difficult for them to understand you or for them to express their thoughts/wants/or needs?** Yes
3. **Have you ever heard of speech therapy or speech pathology? If so, what do you know about these?** No
   a. **If so, what do you know about these?** N/A
4. **Are there places in your community where people go to see a speech pathologist or receive speech therapy?** NO
   a. **If so, how accessible are these services to people in your community? Please expand on the location or cost of these types of services.** N/A
5. **How are individuals with disabilities like autism treated in your community?** With a little more attention and calmly, they are given time to assimilate to things and receive a special treatment that is less strict, if not, more comprehensive.

6. **In your culture, how do parents and children (with or without a disability) typically interact? Are children encouraged to talk to their parents?** Yes, in fact, the relationship of parents to a child with disabilities may be more attentive and parents are more attached to their children, there tends to be more father and son relationship than with children who do not have a disability, in this case they are a little more free but in the same loving environment.

Interview 4

United States / Honduras- Nicole

1. **Please describe your background and schooling in the United States compared to speech-language pathologists in Honduras.** I received my Bachelor of Arts Degree in Communication Sciences and Disorders from Augustana College. I then started graduate school and earned my Masters of Science in CSD from Illinois State University. After graduating from ISU I went to Honduras to volunteer, so I actually didn't start my CF until returning to the US. Until recently, speech-language pathology was not an established program or field in Honduras. I met some developmental therapists that had some basic knowledge, but not extensive enough to diagnose or treat according to best practice. (That is just my clinical opinion!) BUT there is some exciting news. ASHA has teamed up with the Pan American Health Organization (PAHO) to start a program at a University in Tegucigalpa. I included the link for you here: https://www.asha.org/Members/international/Honduras/

2. **How long did you volunteer as a speech-language pathologist in Honduras?** I volunteered in Honduras through Nuestros Pequeños Hermanos (NPH) for 18 months. However, there were weeks or periods of time I wasn't working as a SLP for various holidays or events. So I more or less followed a school-based SLP schedule.

3. **What are some major cultural differences you noted there between parent/child interactions compared to the United States?** First of all, all of the children I worked with are on the home because they cannot be with their biological family for various reasons. So the adult interactions that they have are with caregivers, volunteers, and home employees. The children live in a larger home or *hogar*, and have caregivers. NPH as an organization strives to make the home resemble a family as much as possible, but the bottom line is that these children are not in a traditional nuclear family home. It's also so important to understand that each child has significant trauma and emotional baggage. That's not to say that kids don't have trauma in the US because they absolutely do. But the trauma and poverty and political situation that Honduras is in adds challenges that can be really hard to understand but absolutely impact a child's development and response to therapy. I handled my role as a [sic] SLP in Honduras very differently than I do here in the States. In Honduras I was a SLP, but I was also a volunteer and caregiver. I put children in my lap and gave them their therapy but also the adult attention and affection they need, whereas in the States the formality of my role and professional boundaries are much more defined. Another big difference is the amount of time I spent explaining the field and scope of practice. I educate parents and teachers here in the States too, but not nearly as extensively as I did in Honduras.

4. **What resources, that you knew of, did families of individuals with Autism receive in order to communicate more effectively?**

Because I only worked on the NPH home, I don't think I have a true sense of services and programs. I did find an article that may be interesting to you: https://www.wbur.org/hereandnow/2018/07/23/mental-health-rural-honduras

5. **What is the perspective on individuals with autism/communication disorders in the community?** Again, I was just on the NPH home so I don't have a wide national vision. I can share that the view on individuals with disabilities can be difficult simply because there isn't as much education available. I found this on the Autism Speaks page https://www.autismspeaks.org/international-autism-organizations: HONDURAS Asociación Hondureña de Apoyo al Autista - (APO-AUTIS) E-mail: "Administrativo/Docente" apoautis1997@yahoo.com"Junta Directiva" apoautis.ong.hn@gmail.com Teléfono/Fax: 2234-8045 Facebook page

6. **How available were speech-language pathologists in the area you were volunteering?** I did not meet any Honduran SLPs during my time. But I am hopeful this will change soon! (See the ASHA article I shared above.)

7. **Is there anything you wished people in Honduras/families of people with autism knew about speech-language therapy services, autism, or increasing communication?** This is a hard question, and I don't really know where to start! Of course, I wish there were so many more resources available. But I think this goes back to understanding Honduras as a developing country and the political and economic situation that the country is in. I think it's easy to scoff and wonder how families aren't getting the services they need, but I continue to work on my worldview and understanding of Honduras as a country and culture. The safety alone is so concerning that it truly may not be safe for a typically developing child, never mind a child with communication needs, to regularly attend school. Once at school, the schools are often understaffed and exceptional learners cannot receive the accommodations they need.