

Adapting an Education Program for Parents of Children with Autism from the United States to Colombia

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One of the lingering aspects of coloniality in the Americas is paternalism. In Latin America, this power structure plays out among people with autism spectrum disorder (ASD) through beliefs that people with disabilities need to be protected and guarded at home, and that they are unable to learn and function in society. We developed a program to empower parents of children with ASD through peer education to help their children realize their potential. This program was implemented in the United States (US) for Latino immigrant families and then adapted for use in Bogotá, Colombia. In this paper, we discuss some of the ways the manifestations of colonialism have influenced the adaptation of this program from North to South. For example, in Colombian society it is not common to use non-professionals or peers to deliver scientific information because within a paternalistic society there is ‘*respeto*’ (respect) for persons who are older, male and have credentials. Therefore, promoting the use of peer-mothers in this context was a challenge in the adaptation that warranted compromise. We explore and discuss similarities and differences in the adaptation and delivery between North and South and problematize the idea of Latinos in the US versus Colombia.

Keywords: decolonialism; autism; parent education; Latinos; Colombia

Introduction

This paper approaches decoloniality in two ways: first as an active and participatory research process; and second in analyzing how colonialism affects people with disabilities in a Latin American context. In the literature, decoloniality is usually juxtaposed with coloniality from the framework that the latter imposes Euro-centric social and political power upon lesser groups (Lugones, 2010). While decolonialization is a term used to recognize the ‘colonial matrix of power,’ it is grounded in historical coloniality and is ingrained in all aspects of the modern world (e.g. civic, economic) (Mignolo, 1991; Quijano, 2000). Decoloniality, then, urges groups in power to take a critical look at the hierarchies established by coloniality and

works to include the voices and values that coloniality has silenced (Bhambra, 2014). In the case of a parent education program, decoloniality is central to the adaptation of a program developed for Latino immigrants in North America to benefit residents in a South American community. As researchers, we hope to include the voices and values of parents in Colombia, and ensure that North American values, ideas, and methods do not dominate the parent education program.

Decolonizing the parent education program is important for many reasons. Firstly, scientific research has historically aligned with a colonizing agenda (Zavala, 2013). That means that even research aimed toward aiding oppressed populations has historically been used to maintain the status quo instead of fully liberating these populations- people of color, people with disabilities, and non-Western and non-Northern cultures- from oppression. Recognizing the ways in which scientific institutions uphold racism and ableism is a first step to breaking free from it. Researchers working in the social sciences must assist in the developing of an understanding of how theories used in disability studies have come from colonized discourses (Gómez-Bernal, 2014). As Munevar (2013:299) states, it is important that we understand:

...interactions between social critical studies before applying the expertise, in order to situate the representation and knowledge production from the perspective of social studies of science, technology and medicine, and from the experiences, to revive discussions opened by postcolonial and feminist studies. As a result, epistemic distancing questions the ways of doing research and thinking/understanding the sociopolitical reality experienced by women and men with disabilities.

Second, Latin America is at the heart of coloniality, and special care must be taken to ensure that Latin American people have agency in the research performed in this area (Asher, 2013). Colonization created many of the modern amenities that we take for granted in the US, and even some approaches that we promote in the parent education program. Researchers must recognize coloniality for what it is, but also to equally value the knowledge and experience of the Latino perspectives that also guide this work. Including mothers of children with autism as part of the parent education program is a way to recognize the value of their experience, and it creates a means to co-produce knowledge; thus moving away from traditional approaches based on ‘experts’ and ‘clinicians’.

Lastly, it is important to decolonize the parent education program in order to reexamine and recreate social hierarchies that are understood differently in different cultures. Most obviously, our work must challenge the idea that the North American perspective is superior (Taylor, 2012). Instead, as the parent education program is adapted for a South American culture, it must inherit the culture’s values and approaches and hybridize them with North American ones (Harding, 2016). With respect to healthcare and treatment, the idea that only

interventions based on evidence should be considered is one being imposed from North to South for example.

One of the lingering aspects of coloniality in the Americas that must be considered in this analysis is paternalism. Paternalism got a foothold in Latin America through colonization by Spain and the Catholic Church (de Kadt, 1967). In Latin America, this power structure plays out among people with disabilities through beliefs that individuals with disabilities need to be protected and guarded at home, and that they are unable to learn and function in society. In Colombia, mothers are often blamed for causing their child's disability and are sometimes abandoned by their father (Ortega, 2010).

In this paper, we will first define autism spectrum disorder (ASD), discuss the conception of autism in Latin America, and provide a description of the context in Colombia for children with ASD and other developmental disabilities and their families. We will then describe the parent education program called Parents Taking Action (PTA), and describe the process of adaptation to families in Colombia including perceptions of the program. Lastly, we will provide an analysis of the process we experienced in adapting the program to the Colombian context.

Autism definition in the US and conceptualization in Latin America and Colombia

One might say that the definition of ASD and the development of the concept of autism have originated in the US and Western Europe and are being imposed on countries that are outside of these geographic, political and cultural spheres, therefore, creating a colonial context in itself. However, communities around the world do turn to the West to learn about ASD, and then adapt the established diagnostic systems and treatments to their individual context by incorporating culturally specific instruments and systems (Elsabbagh, 2012; Sarrett, 2015). Although aspects of ASD may not be easily translated to different cultural environments, there is little research available on how aspects of ASD may be affected by culture (Daley, 2002). Thus, for now, we will first provide the definition that is currently being used in the North as defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013), and then explore how people in some Latin American cultures have considered autism. The DSM-5 describes ASD as a lifelong neurological disorder which interferes with an individual's ability to communicate and develop socialization skills. It primarily consists of two domains of impairment 1) social communication and social interaction across contexts; and 2) restrictive and repetitive patterns of behavior, interests or activities (American Psychiatric Association, 2013). While it is considered to be a spectrum disorder, the spectrum is considered to be from needing support to needing substantial support. In contrast, the previous definition based on the DSM-IV included specific categories within the spectrum such as Asperger's Syndrome, Autistic

Disorder and Pervasive Developmental Disabilities Not Otherwise Specified (American Psychiatric Association, 1994). These categories may still be widely used in Colombia among professionals perhaps more than in the US (Colombian Minister of Health, 2015).

Very little scholarship has been devoted to how people in different Latin American countries conceptualize and respond to ASD. For example, in Brazil there has been a longstanding debate between mental health professionals and parents about how to respond to ASD (Block and Cavalcante, 2012; Rios and Costa Andrada, 2015). Mental health professionals coming from a psychoanalytic tradition, believe that it is best not to label people with their specific disabilities including autism, but to understand the psychosocial origins and context of their challenges. In contrast, parents have argued that it is important to diagnose ASD early and provide evidence-based treatments, believing that the mental health professionals do not understand how to treat their children. Interestingly, both of these groups would agree that rights and social justice are at issue (versus a quest for a cure) and their arguments somewhat align with a social model of disability approach. However, their approaches to perhaps the same goal, differ (Block and Cavalcante, 2012; Rios and Costa Andrada, 2015). Other countries in South America may have a similar conflict between a psychoanalytical approach and current evidence-based approaches used in the global North. Argentina, for example, has a long tradition of the common use of psychoanalysis and linking this to understanding the cause of autism (Bleger, 1967).

Although there has been an increasing awareness of ASD in Latin America, most Latin American countries do not have the infrastructure and capacity to meet many of the needs of individuals with ASD and their families (Mercadante et al., 2009). Thus, parents of children with ASD either need to advocate for services their child need, or provide the interventions themselves (Brezis et al., 2015). In 2014, due to parent organizing, discussions began in Colombia about formal diagnostic services for children with ASD in the Colombian Health System. There is a lack of research, diagnostic tests, trained professionals and appropriate services for children with disabilities, especially for ASD according to the Task force for Autism. In 2015, for the first time, the Colombian Ministry of Health announced the dissemination of clinical guidelines for diagnosis and treatment of children with ASD. These clinical guidelines were created as a response to the pressure from families of children with ASD who were looking for diagnostic services when they suspected developmental problems and the option of receiving applied behavior analysis and other services when their children were diagnosed with ASD (Colombian Minister of Health, 2015). Similar to the recommendations by parent movements in Brazil, these guidelines introduce a focus on early detection and comprehensive services to children and families.

Despite these efforts, in Colombia, the health care system is based on insurance and one's ability to pay, which makes attention to the needs of a person with ASD difficult by fragmenting, diluting and increasing the costs of services. In addition, ASD is

underdiagnosed because the system's capacity for early diagnosis is very poor. Complicating the diagnostic process, is the fact that there are very few pediatric neurologists in the country, and they are the only professionals authorized to diagnose ASD. Furthermore, it is recognized that there are great disparities and inequalities in access to diagnostic and treatment services (Moreno, 2011). Some families are receiving services such as speech, occupational and physical therapies, but this is uneven, depending on socio-economic status, transportation and proximity to these services. Furthermore, the quality of these services is uneven too. For families who are on public insurance, they may receive these therapies, but are likely to have a different therapist at each visit (Moreno, 2011).

One of the members of the Task Force (4th author of this paper) learned about PTA, an intervention developed for Spanish speaking families in the US, and began a collaboration between the Task Force in Colombia and the researchers who developed PTA in the US.

Description of the Parent Education Program: Parents Taking Action (PTA)

PTA is a parent educational program that is focused on empowering immigrant Latino parents of children with ASD in the US to take action by advocating for services for their children, and in using evidenced-based strategies to enhance their children's skills. A pilot study using this model found the program to be both feasible to implement and acceptable to families (Magaña et al., 2017a). We also found significant increases in empowerment oriented outcomes for Latino parents in their use of evidenced based strategies, and in child communication between pre and post-test. PTA has been conducted with Latino immigrant families in Wisconsin, Chicago, California, North and South Carolina, Washington and Indiana. The majority of families served by PTA have been of Mexican descent; however, parents from other Latin American countries have also been served. PTA is designed so that it is carried out by a *promotora de salud* (health worker) who is also a parent of a child with ASD. The promotoras receive 32 hours of training on the educational information discussed in the program. They then engage other parents in the educational program through 14 weekly home visits that last about 2 hours each. The topics of each session are: 1) Introduction to the program; 2) Understanding child development; 3) Understanding the autism spectrum and your child's needs; 4) What works to address symptoms of autism; 5) How to be an effective advocate; 6) Advocacy in the school system; 7) Play together, learn together; 8) Creating everyday opportunities to encourage communication; 9) Helping your child make friends and interact with others; 10) Challenging behavior is communication; 11) How to reduce challenging behaviors and respond appropriately when they occur; 12) Reducing stress and recognizing signs of depression; 13) Talking about autism to others and social support; and 14) Looking ahead.

The content of the program is grounded in evidence-based strategies such as the use of

visuals, social narratives and naturalistic applied behavioral analysis (ABA) strategies. While there is controversy in Disability Studies and among autistic self-advocates in the United States about the use of ABA, we found that the Task Force in Colombia identified ABA as one of the evidence-based strategies they wanted to make more available to people with autism and their families (Colombian Minister of Health, 2015). There is not yet a movement of autistic self-advocates in Colombia. Many of the critiques about ABA are centered around very structured yet discrete trial training methods used in the past that sometimes used aversive reinforcement methods in addition to positive ones. The ABA strategies we teach to parents are only based on positive reinforcement in naturalistic settings, with the understanding that we are not trying to make the child ‘normal’ or something that he or she is not. Therefore, consistent with decolonizing approaches, we felt it was best to listen to the voices of stakeholders in Colombia rather than introduce a dialogue from the North that may not be seen as relevant. Parents participating in the program receive a manual with all of the session content and a resource folder of programs and services in their area. Promotoras have a similar manual that includes the content and instructions to the promotora.

Using the *promotoras de salud* model is a shift from typical paternalist values that are often seen in the US healthcare system. This model, instead of imposing top-down professional knowledge onto families, encourages knowledge to be produced through dialogue, experiential learning and the sharing of narratives, which is consistent with the work of Freire (2000) whose work on decoloniality originated in Latin America. The *promotoras de salud* model offers a decolonizing approach to knowledge about ASD and its related systems and theories. This model has especially shown success within minority groups including Latino communities in the US (Magaña et al., 2015).

Adapting PTA to Colombia

It was critical that we engaged directly with our Colombian partners to adapt PTA to the lived realities of families of children with disabilities in Colombia thus recognizing and affirming their experiences (Greensmith, 2012). Our lead Colombian partner reviewed the PTA manuals and protocols with her team in Bogotá and suggested a few changes. She recommended removing the chapters on advocacy (these were written specifically for the US service system context) and suggested that service and advocacy information be provided orally by the promotoras and not in writing. This is because there may be a legal expectation of any service information that is put in writing that would be beyond the scope of what the program could provide. The adapted manual included 12 sessions rather than the original 14. Other changes that were made to the manuals involved vocabulary. The original manual was written primarily for Mexican Spanish speakers and some words from this dialect are less common in Colombia. For example, in Mexican Spanish the word ‘platicar’ is commonly used to refer to discussions or conversations, whereas in Colombia, the more formal word, ‘conversar’ is

used.

An important change that was made to the intervention protocol was to add pre-professional speech and language students as promotoras. While the US partners were confident in the use of parent promotoras based on the experience of their studies, the Colombian partner was not convinced that parent promotoras could conduct the parent educational program. Furthermore, she also felt that parents would value the input of pre-professionals more than input from peers. From her perspective, in Colombian society it is not common to use non-professionals or peers to deliver scientific information because within a paternalistic society there is ‘respeto’ for persons who are older, more educated, male and/or have credentials. In contrast, the US authors found that immigrant parents in the US valued the shared experiences that peers had to offer in addition to the information and knowledge they conveyed about ASD, advocacy and evidence-based treatments. This may be a phenomenon of being immigrant in which the familiarity that peers from their country of origin provides is welcome. We decided to compromise and implement the program where half of the parents would be randomized to the parent-led promotora group and half to the student-led promotora group. Another adaptation to the intervention protocol was to extend the age eligibility. In the US, the program included children between 2 and 8 years old, but because of later diagnosis in Colombia, parents of children up to 10 years old were included. Overall, the Colombian team considered PTA to be a pioneering program in Colombia, because these types of programs are not available to families there.

Implementing the PTA program in Colombia

Training promotoras

Promotora training took place in a large, urban, public university in Bogotá, Colombia. The training was performed by the first, third and fourth authors and a research assistant who worked on the US study (and who was originally from Bogotá). All training staff were bilingual in Spanish and English, and the training was performed in Spanish. This is an important aspect of the training, as conducting the training in English and using an interpreter might have a colonizing effect. The training was done over a six-day period for four to five hours of training per day. In addition, our Colombian partners provided the remaining training sessions once the US team left. The four promotoras (two parents and two pre-professionals) attended every training session. Training sessions were also attended by other professionals in the community that were members of the task force, including speech therapists, psychologists, and teaching staff from a local grade school for children with disabilities and disability service professionals from a neighboring rural town. Our Colombian partners felt it was important to include these professionals as they could be community partners who would help us recruit families and add community credibility to the

program implementation.

The inclusion of professionals during the training was a new and interesting addition to the training process. Professionals were able to ask questions about specific information provided in the program and offer tips and feedback to the promotoras on how to implement specific strategies for children with ASD. Many times, however, the professionals' comments were not closely linked to the program training or the provision of the research study itself. The training team had to balance the training needs of the promotoras with the questions and comments from the community professionals in order to be inclusive of everyone's contributions.

There were many similarities and differences that the training team noted between the pre-professional promotoras and the parent promotoras. Both groups of promotoras arrived eager to learn and with a passion for teaching others. This motivation was appreciated by the training team, because it helped the promotoras focus throughout the long days of training. Another similarity between the two promotora groups was their affinity for sharing stories and experiences. Parents enjoyed telling stories about their parenting experiences, and pre-professionals shared stories about their work with other children with disabilities. This made the training highly interactive and personalized.

There were some differences between the two promotora groups. When learning about different strategies or therapies for children with ASD, the pre-professional promotoras often cited approaches that they learned in their coursework. Parents, on the other hand, connected what they learned to either their own experience with therapists their child worked with, their experiences helping their children learn, or the experiences of other parents they knew. It should be noted that one of the pre-professional promotoras was a mother of a nondisabled child, which may have given her more confidence in working with other mothers. Also, one of the parent promotoras was a nurse and a strong advocate while the other mother had less experience talking to other parents and exposure to information about autism.

The feedback received during and after the training from the promotoras, the Colombian partners, and the community professionals was overwhelmingly positive. Generally, those who attended the training enjoyed it and reported that they learned a lot and found the information from the training to be helpful. Some particularly positive feedback received during the training was in response to the different strategies for reducing problem behaviors in children with ASD. Parents, pre-professionals, and professionals all remarked that they never knew the strategies could be so simply implemented in the home. They thought that behavioral interventions could only be administered by a behavioral therapist or another professional. They were surprised at how easily parents could perform these strategies to improve their child's problem behaviors. An unexpected outcome of the training is that two of the teachers who attended were from a remote rural community and decided to implement

the program for families there who had no access to services.

We received additional feedback on some things to change within the program that arose from the training sessions, some of which came from other professionals and staff from the school who were invited to the training. Unsurprisingly, some of the technical language in the training manuals needed to be personalized for a Colombian context. For example, the Spanish translation for ‘Applied Behavior Analysis’ is ‘Análisis de la Conducta Aplicada’. However, most Colombian professionals refer to ABA as ‘el Aba,’ a Spanish way of saying the English abbreviation. Similarly, some colloquial phrases in Spanish needed to be changed in order to make them more customized for a Colombian-specific audience. In particular, the word ‘rabietas’ which in the general Spanish word ‘tantrums’ was changed to the word ‘pataletas’ which is more common in Colombia. While these word changes appear trivial to the reader, they were important to the Colombia participants who wished to maintain a Colombian versus a Mexican identity. Linguistic studies on Spanish dialects have shown that shared dialects and shared regional vocabulary and syntax can create a shared bond within a group; in the case on PTA, this shared dialect strengthens the bond between parent and promotora (Toribio, 2000).

Furthermore, the training team received some feedback on the format of the program manual and its accompanying videos. Promotoras remarked that they preferred program activities that included a social component such as storytelling or interacting with others rather than reading a passage or filling out a form. They also preferred to edit the program videos, making them more visual with animations and changing the background music to be more culturally-appropriate. They emphasized that videos are very valuable in this context in order to show real experiences and modeling some of the content in the manual. Because the program was so new in Colombia, and there was a general lack of knowledge about information related to ASD, all of the promotoras were pleased with the value of materials and that they were presented in a familiar and friendly way.

Recruitment and implementing the program

Our Colombian partners were very well-connected to community organizations that served children with disabilities in Bogotá and had an established relationship with a public school that had an inclusive policy towards children with disabilities. This was the only public school in the city that allowed children with ASD to attend, given that there is no formal special education in public schools in Colombia. It should be noted that while public schools generally serve low-income children (middle and high-income families typically send their children to private schools), many children with disabilities who attended this school were from middle income households, because there were no other reasonable options for their children with ASD. Some of the professionals that attended our promotora training worked at

this school and helped the Colombian partner recruit families to participate in the program. They arranged with our Colombia partner to have a recruitment day to enroll interested families. Twenty-six parents from the school enrolled over the course of three days, which is quite remarkable. In the US, our experience has been that it can take up to a year to recruit this many eligible families. The original goal was to recruit 20 families, thus we exceeded our expectations. This may be due to an extreme lack of resources available in Bogotá, which highlights the differences in healthcare resource between North and South. Upon enrollment, the Colombia partners conducted the baseline assessment, which included measures of family empowerment outcomes, maternal depressive symptoms, engagement with evidenced-based strategies, services received by children, and child outcomes (ASD symptoms, maladaptive behaviors). These measures were included in a follow-up evaluation after parents complete the program. Results from the baseline and follow-up will be reported in a forthcoming paper, with preliminary findings presented at the International Meeting for Autism Research (Magaña et al., 2017b). After completing baseline assessments, families were randomized to receive the intervention by parent promotoras or pre-professional promotoras. The promotoras scheduled weekly home visits with the participating mothers. It was not necessary that the child be present, as the program is designed as a *parent* education program. There were challenges to implementation including cancellations and problems with transportation. Cancellations were also a normal part of the US implementation; however these were overcome because there is flexibility in the total time to complete the program. If a parent had to cancel, the promotora could reschedule for the following week, thus extending the number of weeks it took to complete the program. This flexibility enabled US parents to receive all of the content eventually. While the Colombia project was also flexible on cancellations, they had less time to complete the program due to funding constraints. Therefore, cancellations felt more stressful to them. Transportation was a unique challenge faced by the Colombia collaborators. Traffic is very heavy in Bogotá, and our promotoras did not drive. They relied on public transportation which is not as extensive as the public transportation system in Chicago and other places in the US. This highlights the lack of infrastructure and resources available in a setting that was previously colonized versus one that benefited from coloniality. Another difference between the two venues is that in the US, we had a larger number of parent promotoras and they only worked with one or two families at a time. Because of the time constraints of the project in Colombia, each promotora was assigned five families to visit each week. This was especially challenging to parent promotoras who were balancing their own family's needs. While there were challenges to implementation, twenty families finished the 12-session program.

Perceptions of the program after implementation

After the program was implemented, all parents and promotoras were invited to attend focus group interviews at the university to discuss their experiences and perceptions of the

program. Focus group interviews are commonly used as a means of empowering culturally diverse groups and can offer some preliminary explorations about their attitudes on a specific topic (Huer and Saenz, 2003; Rabbie, 2004). The focus groups interviews also allow for the exploration of individuals' experiences and viewpoints about the program while interacting with others (Bragg, 2000; Dishald and Latif, 2013). Both parents and promotoras were actively engaged in lively conversations throughout a series of interviews that were conducted by the second author and her team who were not involved in the training and/or implementation of the program.

Overall, parents were overwhelmingly positive about their experience with PTA regardless of which promotora (parent or pre-professional) was providing the program, and they talked about how much of an impact the program had made on their lives. As this parent stated:

The program Parents Taking Action has been excellent and has been a strength for me. I was on zero...I had no idea what a special needs child was, much less one with autism. I had not even heard of autism. The tips and strategies have benefitted me, and I have taken these strengths to face the situation. So the program has given me strength, and my family and children have been exceptionally supportive.

We heard many stories similar to this one, and how the strategies and information provided by the program gave them strength to face daily situations and support their children, as this parent said:

...this program has taught me how to respond to other people when they ask, 'Hey, why is your child so ill mannered?' 'Hey, is it because you haven't taught your child how to behave?'...Yes, in this way (the program) has helped me. This is a strength of the program. It has helped me in my environment and it has helped me to control more, to insist.

Other parents also highlighted the unique aspects of the program, particularly that it provided support to families directly, rather than solely to the child. Many parents expressed comments similar to this parent's:

For me, (the program) was innovative, because usually they are with the child, and it's about the child, and this was different. It was with the parents. It seemed really, really cool, really special, because they work with you. They sat with you. It wasn't speech and language therapy or occupational therapy with the child, but it was for the parents. Parents are truthfully more in need of reinforcements. So for me, this program was excellent.

While parents in the US also appreciated the program, the emphasis by Colombian parents on

a program that was ‘for the parents’ instead of for the children exclusively was not something we heard from the US immigrant parents. The Colombian medical and school system in particular, cater toward the medical and diagnostic needs of children; families are generally not the focus of these programs (Moreno-Angarita and Gabel, 2008). In the US, this medicalization and individualization of disability also exists, but the prevalence of this perspective is challenged by self-advocacy groups and more socially-based familial perspectives. Colombia and other Latin American countries do not have many organizations focusing on self-advocacy as there are in the US. There is very little research on why this development has not occurred, but some neurodiversity scholars believe that the lack of ASD self-advocates in Latin America is directly related to the experience of colonialism in these countries (Acevedo, 2017).

As we examined what parents were saying in these focus group interviews, we noticed that the parent comments were very positive and similar in nature whether they were provided the program by student promotoras or parent promotoras. We did note a few differences in that parents who worked with the parent promotoras had more comments about the program content and advocacy compared to the parents working with pre-professional promotoras. In comparison, those parents who worked with the pre-professional promotoras appeared to discuss more the changes that the parents saw in their child over the course of the program. Overall, all parents had a great deal to say about the program, and its positive impact in their lives. However, it appeared that families were more comfortable talking to the pre-professional promotoras about the logistics of the program, but shared more personal information with the parent promotoras. Since pre-professionals were not used in the US settings, it is difficult to make a comparison of the two contexts.

Similar to the parents, the promotoras spoke highly about the program and its content, and they often made comments similar to this one:

All the information the families received was very important. It helped the families feel empowered. And that was one of the ideas (of the program), for families to feel empowered.

The promotoras also highlighted the impact they noticed on the families they were working with. As this promotora noted:

...there were gains made, especially in the area of communication. Many of the children were non-verbal, so the families liked the session on *el Aba*. They also implemented the pictograms (visual schedules). Also, the learning transferred to the teachers that served the children and the family and relatives closest to the child. There was also a noticeable change in the independence of the children. The mothers had more hope and a more positive outlook on their child’s development. They valued

their attempts more, and provided more support. There were visible positive changes.

Additionally, pre-professional promotoras also talked about how participating in PTA was a learning experience for them, as this promotora stated:

It's a process of learning to see, to put yourself in their shoes, which isn't easy...getting to know these different families, working with them, entering their world, one gets to thinking, like, well, we can adapt this and here are some things we can change. And this enriched our professional experience because we had that contact with all these families and their children as well.

Parent promotoras talked about the personal impact the program had on them:

I gained courage to keep going, more strength. I feel stronger, more hopeful that I can do this, that it is not a disability, but a different way of learning. It's like every day I want to learn more so I can help, because it's not just the child, but also the family.

As we looked at what the promotoras discussed with us during the interviews, we noted many more similarities than differences regarding their comments about the program and working with parents. In particular, both groups talked about how motivated parents were to learn the strategies and try them out, but they also noted that it was difficult for parents to complete some aspects of the program (i.e. parents having a hard time finishing the homework). However, we did see that parent promotoras provided more examples of things that made the implementation of the program at times difficult: time, attendance, distance, and the program setup. Yet, the parent promotoras also reported on ways they overcame program implementation difficulties they experienced such as assisting families, setting boundaries, and solving issues that come up. In addition, parent promotoras, unlike the pre-professional promotoras, reported on how they were able to relate to the families, their ability to connect to their own experiences, and how parents' confidence in them grew during the program. In contrast to the parent promotoras, pre-professional promotoras talked more of their own increase of knowledge about working with families and the changes in parent perceptions they noted over the course of the program. One of the things we learned from this project is the value of using pre-professionals in interventions. Because we have not explored this with Latino immigrant families in the US, we do not know if this would also be valuable in this context. Perhaps a decolonizing strategy should include translating effective approaches from South to North. This counters the idea that the North American perspective is superior (Taylor, 2012).

Discussion of program adaptation from the US to Colombia

The adaptation of the PTA program from North to South was a collaborative process that involved Colombian parents, Colombian professionals and US professionals sharing their perspectives and ideas. The end result of this collaboration was that overwhelmingly the Colombian parents had positive experiences with the PTA program, and similar to parents in other parent programs in the Southern context (e.g. Brezis et al., 2015), appeared to gain a greater understanding of their child and were more confident about going out in public with them. A major reason for the successful implementation of the program was that from the very beginning, we tried to ensure that the process was decolonizing, and discussion of cultural values was front and center. Some themes in these discussions on coloniality and adaptation are paternalism, the Latin American cultural value of *respeto*, and transculturalism.

One example of a cultural value that was observed during the adaptation, was paternalism. As described, paternalistic values penetrate Latin American culture in many ways. The role of women and the role of people with disabilities are particularly affected by widespread paternalism in the Colombian cultural context. Many caregivers of people with disabilities in Latin America tend to be single mothers, since in some cases, men abandon their wives and families. Some studies reported that many men have trouble facing this situation, because it affects their notion of masculinity in that having a child with a disability is sometimes understood by society as a lack of virility (Ortega, 2010).

To combat paternalism, training mothers and giving them agency to make positive change in their lives and the lives of their children with ASD, was particularly empowering for them. Many of the mothers in the program commented on how important it was for them to feel empowered, and many reported changes in their children because of the strategies they were able to implement. Additionally, people with disabilities are viewed as needing guidance and protection under paternalistic cultural values. Parents in this program, however, reported that their children had more independence and opportunities, and they believed that this was a positive outcome of the program. While paternalism may also be considered a value imposed from North to South, and has become ingrained in Colombian culture, combatting this type of coloniality appeared to empower the Colombian parents.

A related cultural value from the South that played an important role in the adaptation of the program was *respeto*. *Respeto* is a cultural value that was likely imposed on the indigenous populations of Latin America by Catholicism and Spanish colonization (Gross, 2015). It emphasizes power hierarchies and encourages people to respect others in power (Zea et al., 1994). Thus, ironically, while *respeto* may have come from the North originally through colonization, this value is not as salient in the North today as it is in Latin America. Subsequently, it is important that we honor this value so as not to impose our own notions of

relationships and power. We see this value play out between parents and professionals; parents are encouraged to respect and not question or critique a professional's opinions on treatments and approaches for their children with disabilities. This may help explain the parents' unique relationship with the pre-professional promotoras that emphasized therapeutic strategies compared to the relationship with the parent promotoras that emphasized interpersonal relationships and shared experiences. The role of *respeto* encouraged us to use pre-professional promotoras instead of only parent promotoras in our adaptation of this program from North to South. The success of using pre-professional promotoras was surprising to the research team, especially considering the de-colonial history of using parent promotoras in the US. However, using both parent and pre-professional promotoras was one way to compromise Northern and Southern values and truly de-colonize the intervention.

At times, the program was difficult to implement because of *respeto*; we had to convince parents that using positive behavioral strategies such as rewarding with their child was not outside of their 'parental' role. Many Latin American parents use discipline with their children as a way of maintaining *respeto*, and see more positive-focused western strategies as being soft (Calzada et al., 2010). We also encountered some skepticism from the parent promotoras about their own ability to implement the program, because it was not their area of 'professional' expertise. Professionals, who also shared this skepticism, did not believe parents were capable of being interventionists. Furthermore, we had to change our approach to advocacy entirely for the Colombian program; we could not teach advocacy skills the same way we had in the US program because of the differing cultural context. However, keeping this value in mind during training and implementation, we were able to adapt the program to fit the Colombian cultural context. Parents and promotoras felt empowered themselves, but not disrespectful toward the power hierarchies of the disability service system. *Respeto* has a positive connotation to many of Latin American descent, and can mean having respect for others by maintaining dignity of those one relates to (Calzada et al., 2010). We were able to honor and reinforce the salience of this definition of *respeto* by offering the PTA program free for families and offering the program in their homes. The Colombian families who participated in the program were surprised that they were able to receive such a quality program at no charge. This made them feel respected and valued for their time. Offering the program in their home, blurred the lines of practitioner and caregiver in some ways, and this allowed our promotoras to bridge the hierarchical limits that *respeto* often places between practitioners and people with disabilities. By means of this cultural value, we were able to create an effective and successful program in the Colombian cultural context.

Transculturalism encompasses the ways in which we compromised cultural values from the North and South in order to bridge together the two cultures (Taylor, 2012). Transculturalism was an important approach to our adaptation so that we did not reinforce typical North to South power hierarchies, but rather we created an entirely new intervention approach that hybridized North and South. We saw this play out in countless ways throughout the program

adaptation, its implementation, and through our research activities. The former two paragraphs highlighted some of the ways we collectively shaped our approach to the program adaptation. In terms of program implementation, our parent and pre-professional promotoras helped us combine the important information about ASD education and behavioral strategies into a more culturally relevant delivery format. While our Colombian team found the information in the program manual and videos valuable, they suggested we alter the format of them. The pre-professional promotoras worked on creating more visually-appealing videos to transmit the information, and the parent promotoras helped modify our parent activities to make them more pragmatic and informal. This was a compromise that all parties were happy to take on. Finally, the US team had to adjust their research activities in order to accommodate the unique recruitment and evaluation challenges of the Colombian team. We adapted the recruitment approaches and focus group schedule in order to accommodate the travel challenges that Colombian families face. This way, we were able to gather important data without interfering with the daily life of our families. Clearly, this project has taught all of us the importance of applying multiple cultural perspectives to our adaptation work.

Implementing de-colonial research strategies into disability research is important in order to challenge the status quo and liberate people with disabilities from cultures that disempower them. Combining disabilities studies research approaches such as the social model of disability with de-colonizing research approaches, can help engage these two disciplines together to better understand the complex interlacing identities that disabled people have while also actively working to resist the hegemonies that affect both disabled people and ethnic minorities (Greensmith, 2012). We believe it is important to include more social science and empirical studies to decolonial approaches to disability. These kinds of studies can bridge the theoretical approaches with more applied approaches that can benefit the populations we write about. A decolonizing research strategy implemented in the current study was plurality of methodologies. The PTA researchers used both quantitative and qualitative research methods to measure program success. Researchers also put particular value on qualitative narratives by parents. This strategy has been used in similar research on parent education for children with ASD in India (Skinner and Weisner, 2007). Incorporating narratives into cross-cultural intervention research can ensure that the intervention is adapted in a relevant and effective way. Giving voice to oppressed groups is also a strategy for de-colonial resistance.

Typically, knowledge about disability programs and services is implemented from North to South, and follows the colonial trend of imposing knowledge and ideas. While this program is no exception to that tendency, we hope that our adaptation of a parent education program for families in Colombia highlights the importance of using decolonial strategies to guide the adaptation process. No matter how well-designed the parent program may be, what we know is that it will not work unless it finds a place in the cultural models and practices of the families it is intended for (Skinner and Weisner, 2007). PTA empowered professionals and

parents by making scientific knowledge available at the grassroots level and highlighted some ideas coming from the North that promoted concepts about dignity, equality, human rights and empowerment. While there were several challenges associated with adapting and implementing this program, there were also many benefits to using multiple cultural perspectives to guide our work. We hope this paper can be a guide to navigating cultural divergences in program implementation from North to South America.

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