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Lessons learned: Engaging culturally diverse families in neurodevelopmental disorders intervention research

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Abstract

Low-income and ethnic minority families continue to face critical disparities in access to diagnostic and treatment services for neurodevelopmental conditions, such as autism spectrum disorder and attention deficit hyperactivity disorder. Despite the growing cultural diversity of the United States, ethnic minority children and families continue to be substantially underrepresented across research on neurodevelopmental disorders, and there is a particularly concerning lack of research on the treatment of these conditions in low-income and ethnic minority communities. Of note, there are currently no published studies on adapting autism spectrum disorder treatment for low-income Latino communities and relatively few studies documenting adapted treatments for children with attention deficit hyperactivity disorder in these communities. This article describes methodological considerations and adaptations made to research procedures using a Diffusion of Innovation framework in order to effectively recruit and engage low-income, ethnic minority, particularly Latino, families of children with neurodevelopmental disorders, in a comparative effectiveness trial of two school-based interventions for executive dysfunction.

Keywords

attention deficit hyperactivity disorder; autism spectrum disorders; family functioning and support; interventions; psychosocial/behavioral

Efforts to systematically adapt established treatment programs for different contexts are growing (e.g. Dumas et al., 2010; Lochman et al., 2001). However, despite the growing ethnic and economic diversity of the United States, there is a paucity of research on the implementation of evidence-based behavioral treatments for low-income and ethnic minority children and families (Huey and Polo, 2008) with neurodevelopmental disorders (Norbury and Sparks, 2013; Rothe, 2005), impeding their dissemination to community providers (Dingfelder and Mandell, 2011). Indeed, there are currently no published studies on adapting autism spectrum disorder (ASD) treatment and only a few on adapting attention deficit hyperactivity disorder (ADHD) treatment for low-income Latino families (Gerdes and Schneider, 2009; Magaña et al., 2013). The handful of prior studies that have addressed this issue have indicated that cultural adaptations are likely needed for successful implementation (Huey and Polo, 2008; Lang et al., 2011). Research is needed to better understand how existing treatments can be adapted to engage and meet the needs of these underserved children and families. Using the well-established Diffusion of Innovation (DOI) framework (Rogers, 2003), this article describes strategies utilized and lessons learned in the process of adapting two executive function (EF) interventions implemented as part of a comparative effectiveness trial targeting health disparities, as well as related measures and research procedures, with ethnic minority families, with a particular focus on first-generation Latino families in the United States.

Latino¹ children, who currently represent approximately 17% of the US population and are among the fastest growing ethnic groups in the United States (Krogstad et al., 2015), have substantially reduced access to diagnostic and treatment services for neurodevelopmental disorders (Liptak et al., 2008; Magaña et al., 2013). They are also diagnosed with ASD and ADHD at a significantly lower rate than their White peers (Centers for Disease Control, 2014; Visser et al., 2010), despite evidence indicating that rates should be invariant across cultures (Dyches et al., 2004). In addition to the socioeconomic and cultural barriers faced by all low-income ethnic minority communities in the United States, first-generation Latino families face additional obstacles to receiving care, including lack of English language fluency (Denney et al., 2007; Magaña, 2000), reduced knowledge of the US healthcare system and public resources (Bronheim et al., 2015), deficits in knowledge of ASD (Ratto et al., 2015) and ADHD (Rothe, 2005), and concerns about deportation and interactions with the legal system (Garrison et al., 1999).

Mirroring disparities in access to diagnostic and treatment services for neurodevelopmental conditions (Begeer et al., 2009; Liptak et al., 2008), there is a concerning lack of ethnic and income diversity in neurodevelopmental research (Norbury and Sparks, 2013). Despite long-standing recognition that engaging members of ethnic minority groups in research is necessary for the development of culturally competent clinical and preventive interventions (National Institutes of Health, 2001), effective engagement strategies are rarely discussed in the literature (Amaro and De la Torre, 2002). Cultural differences in familiarity with research and medical systems, as well as historical experiences of discrimination, make recruitment and retention of low-income ethnic minority participants more complex (Yancey

¹The term Latino denotes all persons living in the United States whose origins can be traced to the Spanish-speaking regions of Latin America, including the Caribbean, Mexico, Central America, and South America (Flores, 2000).

et al., 2006). Latino families report less familiarity and comfort with clinical research than typical White, high socioeconomic status (SES) research participants (Skaff et al., 2002). Moreover, clinical research trials commonly require English language fluency of participants, due to the lack of treatment protocols (Gerdes and Schneider, 2009; Magaña et al., 2013) and measures available in Spanish (Huey and Polo, 2008; Soto et al., 2015).

For many Latino families, participating in treatment programs, particularly in research contexts, may be an unfamiliar strategy, contrary to usual methods of seeking help and to cultural beliefs and attitudes. Often, families turn to informal sources (Berkule-Silberman et al., 2010; Nichols et al., 2009), relying on sources they already use the most, such as family members, rather than professional advice and services (Halfon et al., 2002; Schuster et al., 2000). This tendency may be even stronger within lower SES and minority cultures (Colson et al., 2006; Cornwell and Cornwell, 2008; Fisher et al., 2004; Horvat et al., 2003). Enhancing participation in treatment research by families of children with neurodevelopmental problems, particularly those from minority communities, may require explicit strategies to support new behavior. Viewing such participation as an innovation can facilitate the development of such strategies. DOI theory (Rogers, 2003) provides a framework for understanding how individuals and groups adopt new beliefs, knowledge, and practices and how those who are presenting these innovations can maximize their adoption. Here, DOI is used to organize the issues faced in engaging Latino families in the present treatment study. DOI has been used to better understand the dissemination and implementation of interventions in diverse fields (Gotham, 2004; Glisson and Schoenwald, 2005), including autism intervention research (Dingfelder and Mandell, 2011). Here, however, it is applied to the process of engaging minority families in research evaluating new treatment approaches for children with neurodevelopmental disorders, focusing on executive functioning.

Within Rogers' DOI Model, awareness and adoption of an innovation are accomplished by a process in which the innovation is communicated through channels over time among members of a social network. Most research has focused on why certain innovations diffuse and how the process can be replicated. Increasingly, however, efforts are geared toward accelerating the pace of adoption to avoid an accumulating disadvantage for those who do not embrace the innovation (Dearing, 2008; DiPrete and Eirich, 2006). The question the research team faced at the start of this comparative effectiveness trial of EF interventions was whether specifically adapting the treatment protocols and research procedures early in the diffusion process would lead to quicker adoption in low-income Latino groups that are often lagging, thus reaching the "tipping point" (i.e. the threshold when an idea begins to spread rapidly) faster (Gladwell, 2002 [2000]).

Engaging low-income Latino families in testing the impact of EF interventions addresses an important health disparity. EF treatments are just emerging as empirically supported treatments in ASD (Kenworthy et al., 2014b) and ADHD (Abikoff et al., 2013), despite EF problems being common in both disorders and associated with significant impairment and exacerbation of symptoms (Kenworthy et al., 2009; Seidman, 2006). Prior studies have also found that living in poverty dramatically increases the risk for long-term executive dysfunction and related behavioral and emotional problems in children (Noble et al., 2007;

Raver et al., 2013). Therefore, low-income children with neurodevelopmental disorders are at even greater risk of developing behavioral problems (Flouri et al., 2015).

Larger study methodology

Participants for the comparative effectiveness trial were drawn from 3rd through 5th graders with ASD and ADHD attending Title 1 eligible schools (those with a high proportion of students from low-income families) in the Washington, DC metropolitan area. The schools involved in the present trial serve low-income children from ethnic minority backgrounds, predominantly of African American/Black and Hispanic/Latino ethnicity. The sample is reflective of these schools and includes families from a wide range of economic and cultural backgrounds (Table 1). Notably, approximately 31% of the total sample comprised first-generation Latino families, who reported significantly lower income ($t = 9.60$, $p < 0.0001$) and years of education ($t = 7.18$, $p < 0.0001$) on average than other families in the sample (Table 2). Latino families in the Washington, DC metropolitan area are predominantly first-generation immigrants from Central America (primarily El Salvador, Guatemala, and Honduras), Mexico, Bolivia, and Peru (Singer, 2007). The adaptations described below focus primarily on efforts required to reach this subset of families in the larger study but also include adaptations used more broadly throughout the trial to reach low-income families of all ethnic backgrounds. Of the 233 children referred by schools for participation in the study, 170 completed baseline evaluations for study inclusion, and 148 were included in the final study. Of those who were referred but not evaluated, approximately 25% ($n = 16$) identified Spanish as their preferred language ($\chi^2 = 0.39$, ns). Of those excluded at the baseline evaluation stage or who chose to withdraw, approximately 32% ($n = 7$) were Spanish-speaking ($\chi^2 = 1.30$, ns).

Intervention description

The present trial compares a cognitive-behavioral EF intervention, Unstuck and On Target (UOT), to the current standard of care, a contingency behavioral management program. The UOT intervention (Cannon et al., 2011; Kenworthy et al., 2014a) is designed to teach children flexibility, goal setting, and planning skills to regulate their behavior. Lessons are taught through concrete experiments, videos, visuals, and discussion of scenarios. The contingency-based behavior management intervention, Parents and Teachers Supporting Students (PATSS), is based on differential reinforcement strategies implemented by parents and teachers with specific goals and high rates of positive reinforcement that have been previously demonstrated to be highly effective for EF deficits (Abikoff et al., 2013). Children also learn skills in small-group settings for emotional/behavioral regulation, assertiveness, and accepting consequences. Both interventions were delivered in children's schools by trained school staff (e.g. school counselors, special educators) in an effort to overcome disparities in access to clinic-based services. These sessions are supported in the mainstream classroom and at home through consistent use of strategies across settings, visual supports, and vocabulary. Additionally, classroom teachers were provided with a brief training session and supportive materials, and families were invited to receive parent manuals and four group training sessions, delivered by the research team.

Adaptation methodology

In alignment with the Patient-Centered Outcomes Research Institute (PCORI) funding mechanism (Hickam et al., 2013) and DOI principles, stakeholders were involved in all decision-making processes for this trial from its inception, including at the grant writing stage. Collaborators from the National Center for Cultural Competence at Georgetown University served as co-principal investigators and helped guide decisions about research design and implementation to address challenges frequently encountered in community-based intervention research. The DOI model proposes that adoption of an innovation is strongly increased by attention to its *compatibility* with the needs, existing values and past experiences of potential adopters (Wejnert, 2002), and its level of *complexity*. Stakeholders from or with extensive experience with target communities were involved throughout the process of adapting procedures and materials, building collaboration with schools and monitoring implementation to promote culturally and linguistically appropriate practice and encourage community participation in this intervention program.

Stakeholder team members

A stakeholder advisory board (SAB) was established at the beginning of the study (Figure 1). The SAB included community practitioners working with children with ASD and ADHD, families of children with ASD and ADHD (including families from ethnic minority groups), school professionals, community advocates, and clinical researchers. In the initial stages, the SAB reviewed the proposed research plan, proposed strategies for community engagement, and actively worked to overcome pragmatic barriers. The SAB also reviewed parent manuals and all of the proposed parent-report research measures to provide guidance on cultural appropriateness, family burden, and accessibility. As the trial shifted into the implementation phase, the SAB was continuously consulted about a range of issues, including recruitment of schools and families, supporting ongoing engagement and retention of families and schools in the trial, identifying accessible community locations for research appointments when schools were not available, and communication with families about research findings. Given the significant stress that low-income ethnic minority families of children with neurodevelopmental disorders face, the involvement of the SAB has been vital in helping the research team implement the intervention in ways that ease rather than increase burden.

In considering potential barriers to recruiting a Latino population specifically, a bilingual family navigator was hired—a first-generation immigrant Latina mother of a child with ASD—who was embedded within the targeted community. Consideration of the DOI framework led to the decision to include this professional throughout the trial, including the early development stages, as the endorsement of community members can support the awareness and adoption of new strategies within the community. The family navigator was an integral member of the team who participated in creating and translating materials, and she led the Latina parent review of all parent-directed materials. Throughout the trial, she focused on supporting family engagement in the interventions and helping families implement the interventions on their own at home. She was critical for reaching families whose work schedules did not allow them to participate in group-based parent training sessions, as she

was able to provide individualized support and training by phone. She also engaged in critical outreach during the recruitment and consenting phases to help build community trust with the research team.

Adaptation and translation of materials

Several adaptations were made to treatment materials to meet the needs of schools and families in these low-income communities, as part of the efforts to encourage awareness and adoption of our strategies, consistent with the DOI framework. This included reducing the number of sessions in the intervention and the cost of materials for the interventions. Additionally, for each intervention, a companion workbook-style parent manual was provided to support generalization of skills and family engagement. Both parent manuals were reviewed by focus groups of parents of children with neurodevelopmental disorders from ethnic minority communities in the area, and their feedback about relevant cultural and socioeconomic considerations resulted in many important changes. Cultural adaptations included using parent-friendly language, shortening manual length, minimizing text and making use of high-impact visuals, emphasizing cost-free reinforcement systems and activities, and utilizing culturally relevant themes. This included culturally diverse child names, culturally relevant family activities such as going to the grocery store, and images of culturally diverse families throughout parent manuals. Parent training sessions were also altered to be more accessible, engaging, and user-friendly for low-income families (e.g. offered in more transit-friendly locations, closer to where families live and in trusted community locations, snacks and childcare provided, offered to smaller groups of families to promote engagement and discussion of specific barriers for each family rather than didactic presentations).

As the research team adapted treatment content and delivery methods for low-income families, the translation team worked to translate parent materials into Spanish, as part of our efforts to reach Latino families. The core translation team consisted of bilingual project staff, who were either native English or Spanish speakers. Early involvement of the translation team in the adaptation/development of both interventions ensured deep understanding of the interventions and identification of concepts and vocabulary that might present translation challenges. Translations were performed individually and reviewed by two other members of the team. Following this process, a bilingual child psychiatrist (native English-speaker) and the Latina parent advocate reviewers (native Spanish speakers from South and Central America) conducted additional reviews for accuracy and cultural appropriateness. Changes were made as needed to these translations based on this feedback, prioritizing meaningful, accessible translations of key concepts, rather than literal or highly exact translations. The community advocates also provided important feedback about dialectical differences specific to the Latino communities in the region.

In addition, all parent-report measures were made available in Spanish. Members of the translation team consulted with the larger research team and the SAB on selection of measures with this consideration in mind. Previously published translations were reviewed and utilized where appropriate. Adaptations were made to published translations as needed for effectiveness within the targeted communities, in consideration of factors such as parent

literacy and education, as well as differences in dialect. Study-specific measures were translated using the process described above for the parent manuals. Inclusion of both linguistic and cultural considerations in translations was vital, given the strong influences of culture on parent perceptions of child behavior and parent responses to questionnaires about neurodevelopmental disorders (Rothe, 2005; Soto et al., 2015).

Collaboration with schools

Both treatments were designed to be delivered in schools by school personnel to reduce barriers in access to care for all low-income families and to directly address generalization of treatment effects, which is a common and significant challenge in children with ASD (Cowan and Allen, 2007) and to a lesser extent in children with ADHD (Piffner et al., 2007). Within the DOI framework, close collaboration with trusted community agencies can accelerate the process of awareness and adoption of new strategies. In considering ways to reach low-income families, and Latino families specifically, schools are a powerful resource, as they are often trusted entities within the Latino community and are able to build relationships with families over time (Brannon et al., 2013), which enabled the research team to build community trust more quickly. Importantly, this choice involved not simply using schools as research or recruitment sites but rather working collaboratively with schools to provide them with the support, training, and resources needed to have school staff implement the intervention directly with their students. Latino families in particular often have limited access to clinic-based resources for behavioral health services, due to language and other barriers described above; thus, making intervention directly available within the school system allowed the research team to reach these underserved families (Garrison et al., 1999). Although students were required to be proficient in English, parents were able to participate if they had basic proficiency in either English or Spanish, broadening access to this treatment.

As the research team worked to evaluate children for the research trial, schools identified key personnel who would implement the intervention. School staff were invited to a training session to provide an overview of the project and guidance on how to support the intervention throughout the school day. School interventionists, usually special educators or school counselors/psychologists/social workers, received more intensive trainings in the implementation of the interventions. Throughout the trial, monthly meetings were conducted with school interventionists to provide ongoing consultation and support in intervention implementation. Decisions about logistical details (e.g. scheduling student intervention sessions) were left to schools to support ease of implementation and feasibility. Schools were also encouraged to make adaptations as needed to make the treatment effective for their students (e.g. incorporating school-specific vocabulary).

Lessons learned

This health disparities research included initial design components, outlined above, with the explicit aim of effectively engaging low-income, ethnic minority families. However, the research team was aware that successful implementation of community-based intervention research requires openness to making changes to the original plans and adopting new

strategies when needed. Although many of the strategies described above have been successful in engaging families, the team has also learned a number of lessons along the way, which are consistent with factors promoting adoption of innovations. In the DOI framework, acceptance and implementation of novel beliefs or practices occurs in a stage-ordered process with increasing awareness or knowledge of an innovation and the development of positive and persuasive perceptions of the innovation enhancing the likelihood of adoption (Greenhalgh et al., 2004; Rogers, 2003). Below, we discuss the lessons learned about engaging culturally diverse families in the research process, in terms of these key components of the diffusion process (see Table 3).

Knowledge

The innovation-decision process begins with increased awareness by individuals of the connection between the innovation and their needs. The information sought in this stage reduces uncertainty about the cause-effect relationships related to the innovation's capacity to solve an individual's problems. The research team found that families often lacked information about their children's problems and the types of interventions that may be helpful. This was particularly true in the case of Latino families, and several adaptations were made to meet these families' needs. Both interventions were designed to support children with ASD and ADHD. Although all families were referred for participation by school staff and completed forms authorizing the research team to contact them, the research team frequently encountered families who were unaware of how or why their child had been referred for the study. The first contact with these families was a screening call, to determine if children were likely to meet basic eligibility criteria. The calls required research staff to ask different questions of parents of children with a prior diagnosis of ADHD versus ASD and thus routinely began with research staff asking parents about their child's diagnosis. The research team quickly discovered that Latino families found this question uncomfortable and invasive. Many families simply lacked information about known or suspected diagnoses, results of any formal cognitive testing, and details about the school services their child was currently receiving. Some families shared that a diagnosis of ASD or ADHD had been suspected in their child but that they had not received any clinical confirmation of a diagnosis. The research team also found that many parents were reluctant to characterize their children as having a "problem" or needing "help," consistent with prior studies finding that ethnic minority parents often endorse lower feelings of burden related to their child's disability (Biel et al., 2015; Magaña and Ghosh, 2010). The use of informal sources for child-rearing help rather than professionals is stronger within working class, poor and minority cultures, in which perceptions of such sources are strongly related to trust (Berkule-Silberman et al., 2010; Horvat et al., 2003).

In response to these experiences, the research team altered the protocol to initiate the phone call by asking more general questions about the child and end by asking if the child had an existing clinical diagnosis. The team also worked with the Institutional Review Board and PCORI to modify the inclusion criteria such that participants still had to meet research criteria for a diagnosis of ASD or ADHD but were no longer required to have a preexisting clinical diagnosis. This allowed us to reach a real-world sample of children with critical

health needs, rather than be constrained by requiring a confirmed clinical diagnosis that many families may not have been able to afford or may not have wanted to pursue.

Even families who had received a clinical diagnosis for their child often had limited knowledge about their child's disability and about available community resources and organizations that could support and help their child. Unlike common medical disorders (e.g. allergies, asthma), neurodevelopmental disorders are a relatively specialized area of practice, which many pediatricians do not feel qualified to discuss with families (Boreman et al., 2007). Thus, the research team broadened parent sessions to include time for parents to discuss more general topics related to their child's disability and raising a child with special needs. Parents often had many questions about the basic features of their child's disability, access to public supports and services, and simple strategies that were not unique to either intervention (e.g. use of visual supports).

Persuasion

Adoption of innovations depends on the promotion of positive perceptions of the service. A great deal of evidence has shown that people are more likely to adopt an innovation if it offers them a better way to do something, is compatible with their values, beliefs and needs, is not too complex, can be tried out before adoption, and has observable benefits (Agarwal and Prasad, 1997; Dearing, 2009; Rogers, 2003). Below, we organize lessons related to four key characteristics of innovations that influence adoption.

Complexity—Complexity refers to the level of difficulty in understanding and using an innovation's requirements and procedures. Several lessons learned prompted adaptations to make participation easier for low-income Latino families, with limited English proficiency and low literacy. First, leader-driven format for parent sessions were less successful in involving Latino parents. Although PowerPoint slides were generated for use in parent training sessions with English-speaking families, less emphasis was placed on this format for Spanish-speaking families. PowerPoint slides were translated to serve as a handout and resource, but parent training sessions were structured as group discussions (*charlas*), rather than in a traditional lecture format. This decision was made based on the research team's past experience that Latino families tend to be more responsive to this more informal, personal style of interaction (Denney et al., 2007; Skaff et al., 2002) that emphasizes discussion, use of videos and graphics to illustrate key concepts and focus on solving specific problems parents are having with their children. Even with English-speaking families, the research team quickly learned that the traditional lecture format, which had previously been successful with middle to upper-middle class families (Kenworthy et al., 2014b), was not a useful strategy for engaging the lower income families in this study. These trainings required more interactive, small-group, solution-focused sessions and less emphasis on pre-prepared presentations.

Additionally, logistical aspects of the program increased the complexity of involvement. As expected, scheduling times for families to come to research appointments for eligibility determination and parent training sessions was challenging, across all low-income families but particularly for our low-income Latino families who often had intense work schedules.

Consistent with prior studies of successful research strategies with low-income ethnic minority families, all research appointments and parent training sessions were scheduled outside of normal business hours (or at parent convenience during business hours), in locations with access to public transportation, and food and childcare were provided (Brannon et al., 2013; Miranda et al., 1996). The research team built upon these recommendations by purchasing cell phones for research assistants and the family navigator to enable them to communicate with families outside of business hours and while working in the community. This proved to be a crucial strategy, given the constantly changing nature of families' schedules and need for alternate forms of communication. In addition, texting in Spanish helped the team to efficiently communicate with families who were not always easily accessible by email or phone.

Initially, the research team scheduled appointments and parent training sessions 1–2 weeks in advance and then followed up with email reminders. Although this approach was helpful for some families, many had limited or no access to email. Families also frequently had last minute changes in schedule, often due to work demands, leading to cancellations and no-shows for appointments and parent sessions. In response, research assistants contacted families to schedule appointments closer to the appointment date and followed up with phone call and text message reminders. For Latino families in particular, many of whom utilized prepaid phones and/or worked in jobs that penalized them for accepting phone calls during the day, text messages became the primary form of communication with the research team. Consultation with the SAB about these challenges also led to the decision to change the structure of compensation offered to families throughout the trial to shift the majority of the compensation to the post-treatment appointments, which were often the least motivating for parents (as their children had already completed the intervention phase of the trial by that point).

Finally, language barriers magnified the complexity of involvement by Latino families. In conducting baseline evaluations, the research team found that many first-generation Latino families struggled to understand and complete study forms independently, despite the fact that all forms were available in Spanish. As a group, first-generation Latino parents had significantly fewer years of education than other parents in the study ($t = 7.04$, $p < 0.0001$), which may have contributed to this pattern. The research team quickly responded to this need by asking all families (regardless of ethnicity) at the beginning of the appointment if they preferred to complete questionnaires independently or jointly with a member of the research team, consistent with how other researchers have handled this challenge (Magaña, 2000; Skaff et al., 2002). Latino families in particular also benefited from a general orientation to the questionnaires and from guidance in understanding the questions asked, as the concept of rating behaviors was less familiar to these families (Canino and Guarnaccia, 1997). Many families also sought clarification on translated forms regarding terms and concepts that are less frequently used in these communities (e.g. flexibility/*flexibilidad*). These families were also less familiar with the language used in translated consent forms and with the research process and thus needed additional time to review forms (as described further below).

Relative advantage—Many first-generation Latino families reported limited knowledge of their child's diagnoses and school services, even in comparison to other families within the study. Many felt that lack of English language fluency prevented them from effectively communicating with the school and medical professionals, and thus many received information about their child primarily from a less expert member of the staff, such as a receptionist or school secretary. Parents frequently shared that they had tried to seek services for their child but had found that specialty clinics for children with neurodevelopmental disabilities did not have the necessary resources to serve Spanish-speaking children and families, consistent with what other researchers have found (Welterlin and LaRue, 2007). The research team responded to this by providing families with contact information for local providers and clinics that accepted the family's insurance to allow them to seek care, as well as information about public organizations with additional resources for information.

Across ethnic groups, the research team found that family engagement was highest when parents had developed connections with individual members of the research team, consistent with findings from prior studies with low-income and ethnic minority families (Magaña, 2000; Skaff et al., 2002; Yancey et al., 2006). Interactions with parents were most successful when team members engaged in more general conversation and showed interest in families' lives. Families began to build relationships with the research team, including sharing about the ongoing stresses of their daily lives that interfered with their ability to participate in evaluations or parent training sessions. This included updates on children's extracurricular activities and changing work schedules, as well as more dramatic events, such as deaths in the family and marital separations. Ongoing contact with families, as well as frequent check-ins and reminders, resulted in families feeling more personally connected to the experts on the research team, consistent with the Latino cultural value of *personalismo* (personalism), and thus being more motivated to participate in parent sessions and post-intervention evaluations. Because of the importance of a strong partnership between research staff and families, the project now provides targeted training for all staff focusing on the key aspects of engagement: understanding beliefs and attitudes, empowering families, supporting resiliency, and communicating effectively.

Compatibility—Adoption is strongly determined by its compatibility with the needs, existing values, and past experiences of potential adopters (Wejnert, 2002). In consideration of meeting families' most important needs, the research team was aware that financial strain and resulting pressures on daily life created barriers to accessing care and participating in research. The resulting daily pressures interfered with families' involvement in the program, even though they felt that their family would benefit, particularly from the parent sessions. They found sessions difficult to attend, due to long work hours, inadequate transportation, and limited access to help with household responsibilities. The challenges that low-income families already face were compounded for the families in this study by the added complexity and expense of caring for a child with a neurodevelopmental disability. As the research team began to observe low attendance rates at parent training sessions, particularly for Latino families, new procedures were implemented through consultation with the SAB. The research team offered more phone check-ins to support families who could not attend

parent sessions in applying strategies at home. Additionally, compensation was offered for attending parent sessions, to help mitigate transportation expenses.

The research team was also mindful of different beliefs, value systems, and expectations around developmental and behavioral issues of Latino families that impact participation. Latinos often place a strong emphasis on family as the major source of one's identity and protection against the hardships of life (Magaña and Ghosh, 2010). Commonly, decisions are not to be made by the individual without consulting the family. In this study, screening phone calls and baseline evaluation appointments were often lengthy in part because of parents' desire to discuss research participation with spouses or other family members. This was particularly true among first-generation Latino families, who sometimes attended baseline evaluation appointments and after reviewing the consent form with the research team, chose to postpone the evaluation to another date in order to discuss the study with family members. This required the team to be flexible and keep in mind that families might need to schedule more than one baseline appointment to complete all procedures.

Consistent with the Latino value of *familismo* (familism), healthcare decisions can be strongly influenced by family beliefs and expectations (Rothe, 2005). Through family sessions, the research team learned that, among Latino families who had been able to obtain medical diagnoses for their children, many reported that their child was the first in their extended families to have received a developmental/behavioral diagnosis. These families had often received negative feedback from extended family members who believed that they were unnecessarily stigmatizing the child. The issue of stigma and being perceived negatively by community members due to their child's behavior was particularly salient for these families, as neurodevelopmental disorders like ASD and ADHD have direct effects on children's social behaviors, often leading to embarrassing situations for families (dosReis et al., 2010; Gray, 2002). Many mothers also shared that children's fathers were uncomfortable with or resistant to the diagnosis, consistent with what other researchers have described, related to the Latino concept of *machismo* or masculinity, in which a child's difficulties may be seen as threatening to a father's identity or self-worth (Wilgosh and Scorgie, 2006). These mothers sometimes noted that they had chosen to seek services for their child, including participation in the research trial, against the wishes of the child's father. For these families, communicating directly with the family navigator, who is herself a first-generation Latina mother of a child with ASD, was a powerful experience. Mothers were encouraged to continue seeking support for their children and inviting their child's father to participate in seeking services. As other researchers have noted, the willingness of a research team member to engage in some self-disclosure about personal experiences seeking services and utilizing the interventions, including both successes and failures, was deeply beneficial to engaging families in the intervention (Skaff et al., 2002).

The compatibility of innovation is hampered without validation from trusted sources, preferably from the same community and cultural/linguistic background. As described in the methodology, the research team was aware of the critical importance of building community relationships in designing this trial, and schools and community were involved as stakeholders in the process from the beginning. Yet, even with these pieces in place, the team found that community-based intervention with low-income, ethnic minority families

simply cannot be rushed. Extra time is needed in order for the research team themselves to build a reputation in the community, form relationships, and develop trust with the community. As numerous other researchers have shared, personal contact between the research team and participants (*personalismo*) is critical to recruitment and retention of participants (Brannon et al., 2013; Cabral, 2003; Skaff et al., 2002). As a new entity in these communities, the research team had some difficulty in recruiting the targeted number of families for participation during the first year of the study. With community outreach and engagement, word of mouth generated greater interest in the study (Rodríguez et al., 2006) and the number of referrals for participation tripled in the second year.

Whereas impersonal channels (e.g. flyers) may create awareness of an innovation, interpersonal influence through social networks is the dominant mechanism for diffusion (Valente, 1996). In Latino culture, people who are not family or close friends are often slow to be given trust. Endorsement of the research trial and of the effectiveness of the intervention by trusted community members—including school staff, the family navigator, and other parents—helped families to feel more comfortable engaging with the research team, to the extent that some Latino families began bringing friends who were not involved in the study to parent sessions. The research team also found that parent engagement was highest at schools where the intervention became a valued part of the child's education and where the entire school staff participated in training and information sessions. These schools supported research team outreach to families by following up with families themselves, answering families' questions about the trial, and encouraging families to participate. These schools were also set apart by school staff's engagement in parent training sessions with the research team, illustrating the importance of these sessions to families by their presence.

Issues of trust were also involved in the increased time spent reviewing and signing consent forms for participation. Families of all ethnic backgrounds, but particularly Latino families, often had several questions about confidentiality and the use of their data, the safety of video recording data, as well as the ways in which information could be shared between the research team and the school and other public agencies. Families were often unfamiliar with terms used throughout consent forms as required by institutional policy and benefited from additional explanations of these terms. For example, many families were unclear as to what constituted a “de-identified database.” Visually illustrating this on a laptop computer or by sketching a diagram helped families to understand this concept and feel more comfortable with sharing data and information. First-generation Latino families in particular often had questions about whether or not governmental systems would have access to the data, which may have stemmed from concerns about immigration status (Garrison et al., 1999), although these questions were not asked in the study.

Observability—Innovations tend to be viewed as more positive if their benefits are clearly apparent or *observable*. Such observability is often boosted by experiences, which showcase an intervention in a convincing manner. Exemplary demonstrations increase the likelihood of diffusion partly by making novel and possibly intimidating activities more understandable and evidence of effectiveness more visible (Dearing, 2009). Messages from those who have successfully used an intervention in the targeted community/population may be a particularly salient way to jump-start the diffusion process (Castro et al., 1995; Puska et al.,

1986). Parents often described experiences of isolation and stigma related to parenting children with ASD and ADHD (dosReis et al., 2010; Gray, 2002). For many of the families in this study, this research trial represented the first time that they had met other families of children with ASD or ADHD. The ability to share and discuss their experiences as parents of children with neurodevelopmental disorders was deeply impactful for these families. In addition, the family navigator's willingness to disclose her own experiences helped to promote an atmosphere of sharing and discussion among parents.

Future directions

Attention to the particular needs of potential participants and their preferred communication channels increased the involvement of low-income Latino families in this neurodevelopmental disorders treatment research project. Elements of the original methodology designed to enhance engagement, as well as adaptations to procedures and materials made during implementation were consistent with key factors identified as contributing to successful DOIs, in this case defined as participation in treatment research. Changes were made to increase families' *knowledge* of the nature of neurodevelopmental problems and service needs and to promote positive perceptions of the project through emphasizing the *relative advantage* over other ways to get help. Changes were also made to address *compatibility* between the characteristics of participation and the needs, existing values and past experiences of families (Wejnert, 2002), to minimize the *complexity* of requirements and procedures of the project, and to enhance *observability* or knowing other families in their social networks who have used and liked the services. It is vital that future research include all children and families affected by neurodevelopmental disorders, particularly those who are currently underserved. For researchers to be able to effectively reach out to these families, however, adaptations must be made to the research process, as described here.

The strategies utilized in this study and pragmatic adaptations made over the course of the trial highlight the need for a thoughtful and flexible approach to working with low-income and ethnic minority families in community-based clinical research. Researchers need to take additional steps to build community trust and relationships in order to successfully recruit and retain participants in their studies. Doing so effectively takes additional time, beyond what is often given in standard, grant-funded research trials. Researchers must be willing and able to invest more time at the beginning of their studies to involve community stakeholders in the process, establish trust within communities, and make changes to usual procedures in order to meet the needs of underserved families. Successful conduct of research in low-income, ethnic minority communities requires funding mechanisms that provide the necessary time and financial support to allow researchers to effectively engage families and communities in the research process. The PCORI funding mechanism in particular aims to do this, by providing researchers with early stage funding for building stakeholder involvement and family engagement in order to apply for a larger patient-centered trial. This pragmatic approach also requires researchers to develop strong working relationships with local institutional review boards to communicate the aims of the trial and the high probability of the need to make rapid changes in methodology in order to successfully work within the local community.

This work also requires a focus on translating and adapting assessment and treatment outcome measures for use with children and families from a range of cultural backgrounds. Currently, measures of neurodevelopmental disorders, particularly those for the assessment of treatment outcome, are highly limited in languages other than English, and published adaptations do not always meet established standards (Soto et al., 2015). Minimal research has been performed assessing the validity of these measures across ethnic, linguistic, and economic lines, despite prior research indicating that these cultural factors have significant impacts on parent and other informant perceptions of symptoms (Daley, 2004; Harvey et al., 2013; Miner and Alison, 2008). Reliable, valid, and culturally appropriate measures are required for researchers to successfully conduct intervention trials and evaluate adapted interventions.

Above all, making progress toward bringing evidence-based interventions to a broad range of children and families requires a commitment on the part of researchers to focus on treatment dissemination. We must be willing to move out of the “ivory tower” of research and embed ourselves in local communities to involve all children and families in neurodevelopmental disorders research. This includes greater representation of these families in every type of research, from basic science to treatment implementation. As our understanding of ASD and ADHD advances and new measures and treatments are developed, researchers should consider the needs of culturally diverse families from the beginning, to make our tools accessible to all families. In order for our research to have a lasting and meaningful impact, including broad adoption by the people who will benefit the most, we must actively work to involve children and families of all cultures in every stage of the research process.

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Figure 1.
Stakeholder team members.

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Table 1

Demographics of children and families by participation status.

Characteristics	Evaluated (n = 170) Mean (SD)/n (%)	Included in study (n = 148) Mean (SD)/n (%)
Child age	9.63 (0.95)	9.68 (0.89)
Child gender (% male)	n = 135 (79%) ^a	n = 120 (81.1%) ^a
Diagnosis		
Autism spectrum disorder	n = 50 (29.4%)	n = 47 (31.8%)
Attention deficit hyperactivity disorder	n = 105 (61.8%)	n = 101 (68.2%)
Excluded—diagnosis not determined	n = 15 (8.8%)	N/A
Ethnicity		
Caucasian/White	n = 45 (26.5%)	n = 44 (29.7%)
African American/Black	n = 36 (21.2%)	n = 29 (19.6%)
Asian American/Arab American	n = 10 (5.9%)	n = 9 (6.1%)
Hispanic/Latino	n = 53 (31.2%)	n = 47 (31.8%)
Biracial	n = 9 (5.3%)	n = 8 (5.4%)
Other/unreported	n = 17 (10%)	n = 11 (7.4%)
Wechsler Abbreviated Scales of Intelligence-2	n = 164	
Full Scale IQ	96.59 (14.46)	98.17 (14.16)
Verbal IQ	95.76 (14.62)	97.29 (14.28)
Performance IQ	98.10 (15.59)	99.49 (15.36)
Yearly net income	US\$88,425.13 Range: US\$9200–US\$400,000 (n = 128)	US\$94,794.78 Range: US\$9200–US\$400,000 (n = 115)
Highest reported parent years of education	14.97 (4.10) Range: 3–25 years (n = 126)	15.14 (4.02) Range: 3–25 years (n = 118)
Number of adults in home	2.25 (0.99) Range 1–7, (n = 154)	2.27 (0.99) Range 1–7, (n = 138)

SD: standard deviation.

^aOne participant identified as female to male transgender.

Table 2Demographics by preferred household language for study purposes^a (completing participants).

	English-speaking (n = 116) Mean (SD)	Spanish-speaking (n = 30) Mean (SD)	Significance test
Yearly net income	US\$110,342.55 (US\$82,075.58) (n = 94)	US\$25,200.00 (US\$12,112.97) (n = 25)	t = 9.60 (p < 0.0001)
Parent years of education (highest reported)	16.36 (2.96) (n = 95)	10.09 (3.93) (n = 23)	t = 7.18 (p < 0.0001)
Number of adults in home	2.11 (0.93) (n = 111)	2.93 (.96) (n = 27)	t = -4.08 (p < 0.0001)
Number of children in home	2.06 (1.09) (n = 110)	2.52 (1.01) (n = 27)	t = -1.96 (p < 0.05)

SD: standard deviation.

^aFamilies were asked to choose whether they preferred to speak English or Spanish with research study staff. In addition to English and Spanish, 12 other languages were reported as being spoken in the home by participating families. However, all of these families spoke English with sufficient fluency for research participation.

Table 3

Application of DOI components.

Adoption process component	Study-specific issue	Lessons learned
Knowledge		
Awareness	Families not aware why they were referred Families not aware of child's diagnosis or difficulty Families not wanting to identify child as a "problem" Many children without previous diagnosis	Don't require previous diagnosis, use "behaviors consistent with ____" Provide diagnostic and/or behavioral information only if requested
Persuasion		
Complexity	Financial strain and resulting pressures make participation in research and interventions difficult Difficulty engaging in parent training sessions Difficulty understanding study forms/language barriers	Flexible schedule (including Saturdays and Sundays, early morning and late evening) Flexible training modalities, <i>charla</i> model More frequent contact via text and phone Study staff available to go through the forms with families
Relative Advantage	Many had tried to seek care but end up receiving information through less expert staff who happen to speak Spanish Parents wanted to form relationships with study staff before trusting their "expertise"	Bilingual staff connected families with services, which resulted in families being more willing to engage in study interventions Study staff respected the importance of <i>personalismo</i>
Compatibility	Families needed consent from all important family members before signing consent forms Mental health/neurodevelopmental issues often stigmatized Community building takes time Issues of trust in consent process Families hesitant to include child's data in a database	Schedule multiple sessions with families Allow extra time for consent process Appropriate self-disclosure by family navigator to address stigma Plan to slowly build up recruitment over time Use trusted messengers Don't require video taping Show families what databases look like and explain the de-identification process
Observability	Many families thought they had never met anyone who had a child with ASD or ADHD	Use of family navigator's self-disclosure Use of parent videos in trainings Parent sharing opportunities Word of mouth