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# Cultural and Linguistic Adaptations: Equitable Accessibility to an Evidence-Based Intervention for Diverse Caregivers

## *Adaptaciones Culturales y Lingüísticas: Accesibilidad Equitativa a una Intervención Basada en Evidencia Para Cuidadores Diversos*

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**ABSTRACT**

Families from minoritized backgrounds experience healthcare disparities, including a lack of evidence-based interventions and services that are culturally relevant. The study at hand provides documentation of the adaptation processes conducted to provide equitable accessibility to a packaged intervention for Spanish-speaking Latino parents, Parents Effectively Addressing Challenging Behavior en Español (Project PEACE). The adaptation process follows the Cultural Adaptations Process Model (Domenech et al., 2011) and the Ecological Validity Model (Bernal et al., 1995), and details the initial phase in the process for developing a parent training intervention with cultural sensitivity. The present study also provides further evidence about how cultural adaptations can be implemented within an evidence-based intervention model for parent training. The study documents the processes and phases of the cultural adaptations for the purpose of future replication.

***Keywords***: parent training, cultural adaptations, cultural sensitivity, equitable accessibility, Spanish-speaking services

**RESUMEN**

Las familias de orígenes minoritarizados sufren disparidades en la atención médica, incluyendo la falta de intervenciones y servicios basados en evidencia y culturalmente relevantes. El siguiente estudio proporciona documentación de los procesos de adaptación llevados a cabo para brindar

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acceso equitativo a una intervención integral para padres latinos de habla hispana, Padres Manejando Efectivamente el Comportamiento Desafiante en Español (Proyecto PEACE, por sus siglas en inglés). El proceso de adaptación sigue el Modelo de Proceso de Adaptaciones Culturales y el Modelo de Validez Ecológica, y detalla la fase inicial en el proceso para desarrollar una intervención de capacitación para padres con sensibilidad cultural con el fin de replicarla en el futuro. El estudio también proporciona más evidencia sobre cómo implementar las adaptaciones culturales dentro de un modelo de intervención para la capacitación de padres..

***Palabras Claves***: entrenamiento de padres, adaptaciones culturales, sensibilidad cultural, accesibilidad equitativa, servicios en español

## CULTURAL AND LINGUISTIC ADAPTATIONS: EQUITABLE ACCESSIBILITY TO AN EVIDENCE-BASED INTERVENTION FOR DIVERSE CAREGIVERS

Researchers have found disparities in access to health care and mental health services for non-Hispanic Black families, Latino families, and individuals with lower incomes (SAHMSA, 2015; van Dyck et al., 2004). Families from minoritized backgrounds, therefore, experience a lack of evidence-based interventions and services that are culturally relevant, specifically language and/or cultural competency in service provision. In addition to this gap in services for families from marginalized backgrounds, there is another reality that compounds this need. Over the next several decades, the United States (U.S.) is projected to see its population of people of two or more races, Asians, and Latinos become the fastest growing racial and ethnic groups (Vespa et al., 2018). Moreover, two of every three children are expected to be of a race and/or ethnicity other than Non-Hispanic White. Simply put, the U.S. population is growing more racially and ethnically diverse.

Given the growing need for culturally responsive behavioral and mental health services for diverse communities, there is also a need for continued demonstrations of cultural adaptations of such interventions. Specifically, it is critical to provide examples of these adaptations in practice and beyond theory. The current paper presents an adaptation for Spanish-speaking Latino families in Puerto Rico with the Research Units in Behavioral Intervention (RUBI)'s Parent Training for Disruptive Behavior manualized program and Acceptance and Commitment Therapy (ACT) oriented supports. The resulting packaged intervention, Parents Effectively Addressing Challenging Behavior en Español (Project PEACE), was developed to address the behavioral and socioemotional needs of Spanish-speaking families of children with autism spectrum disorder (ASD).

### Addressing Challenging Behavior and Mental Health

Significant stressors that impact the mental health of underserved families with children with ASD include cultural acceptance of the disability, language proficiency, misconceptions of ASD, and challenges navigating or accessing services, among others (Iadarola et al., 2019; Zuckerman et al., 2017). Further looking at these stressors, the findings of Magallón-Neri and colleagues (2018) introduced prevalence rates of mental health disorders and subsequent mental health service utilization for Puertorican parents and relatives of children with ASD. Strikingly, in comparison to Puertorican caregivers without children with ASD, Puertorican caregivers of children with ASD had higher rates of serious mental illness and other mental health psychiatric disorders (e.g., depression, anxiety). However, even with higher rates of mental health needs, this population did not utilize mental health services at a greater rate than the comparison group. Ultimately, these preliminary findings highlight the disparity in mental health treatment for Puertorican caregivers of children with ASD. Interventions for underserved communities should, therefore, address service and health disparities while being individualized to caregiver experiences and characteristics.

Rovane and colleagues (2020) found that regardless of the effectiveness or relevance of a treatment, parent stress negatively impacted parents' fidelity and adherence to the intervention. Further, when parenting stress is low and the intervention is not too burdensome (i.e., high cost,

time intensive), parents demonstrate high adherence to the intervention. For this reason, implementing interventions that focus on both parent psychological wellbeing and child behavioral needs is crucial, especially as parental stress is largely associated with child problem behavior (Benson, 2010; Lecavalier et al., 2006; Postorino et al., 2019; Zaidman-Zait et al., 2017). This may be done by incorporating specific coping strategies into parent behavior training (Singh et al., 2019; Zaidman-Zait et al., 2017). Researchers engaged in this line of study found there is a need to systematically address both parent management of child challenging behavior and parental stress (Singh et al., 2019; Whittingham et al., 2009; Zaidman-Zait et al., 2017).

**RUBI Parent Training for Disruptive Behavior**

The RUBI Parent Training program is a manualized program which has been studied through multiple randomized clinical trials (RCT; Bearss et al., 2018). RUBI has been empirically validated, proving to decrease parent stress while increasing child adaptive skills and significantly reducing disruptive behavior (Bearss et al., 2015; Postorino et.al, 2019; Scahill et al., 2016). Several of the RCTs which evaluated the RUBI parent training manual met What Works Clearinghouse (WWC) standards, a rigorous systematic review process.

Researchers have investigated whether parent training is a better intervention compared to parent education for improving disruptive behavior and daily living skills of children with ASD (Bearss et al., 2015; Scahill et al., 2016). The intervention, delivered over the course of 11 to 13 sessions, provided training to parents on strategies for managing their children's problem behavior utilizing the RUBI manual. By contrast, parent education, delivered across 12 sessions, consisted of basic information regarding ASD with no further strategies for managing problem behavior. Researchers found the RUBI parent training to be a more efficacious intervention in reducing challenging behavior in children with ASD, which in turn led to enhanced daily living skills, especially in children with higher cognitive abilities.

**Enhancing RUBI for Caregivers**

Although the RUBI parent training program has been shown to decrease parental stress, several studies have also explored interventions that systematically address parental stress in families with children with ASD (Gould et al., 2018; Sairanen et al., 2019). One-way psychological stress in parents has been addressed is through ACT-oriented interventions. One of the principal outcomes of ACT is psychological flexibility. Psychological flexibility refers to "how a person: (1) adapts to fluctuating situational demands, (2) reconfigures mental resources, (3) shifts perspective, and (4) balances competing desires, needs, and life domains" (Kashdan & Rottenberg, 2010, p. 866). Ultimately, ACT focuses on a values-driven approach to guide behavior and decision-making within the individual's past experiences and current environmental context (Bach & Moran, 2008). A values-based approach is a beneficial, feasible, and successful supplement to parent behavioral training. Further, as ACT highlights a flexible approach to finding solutions, by becoming more adaptable in their parenting approach, parents ideally also become more open to trying new methods of addressing child challenging behavior (Whittingham & Coyne, 2019). ACT can be used to guide parents to engage in flexible and compassionate parenting, even in the face of psychological stress.

Studies involving ACT-based interventions have found that parents of children with chronic conditions, including autism, can benefit from web-based ACT interventions and that these interventions can help increase caregivers' values-directed behavior (Gould et al., 2018; Sairanen et al., 2019). The results of these studies also indicated that ACT interventions for parents decrease symptoms of burnout and depression, improve mindfulness and cognitive defusion, and promote behavioral gains that are maintained well after the intervention. Results further suggested that "ACT may be a beneficial complement to community-based [applied behavior analysis (ABA)] service delivery models" (Gould et al., 2018, p. 87).

**Diverse Communities**

Van Dyck and colleagues (2004) investigated the number of children with special healthcare needs across the nation, describing their characteristics as well as how well their needs were being addressed and their families supported. Researchers found disparities in access to health care services for non-Hispanic Black families, Hispanic families, those without health care insurance, those with lower incomes, and those with a child severely affected by their disability. Hispanic and non-Hispanic Black families were more likely to be dissatisfied with their child's health care and, the lower the income of the family, the more likely they also were to report dissatisfaction. In addition to disparities in access to health care services, families from marginalized backgrounds often also experience a lack of evidence-based interventions and services that are culturally relevant, including service providers who lack language or cultural competency (López et al., 2019). When minoritized families receive culturally relevant information which addresses their specific needs, there are significant improvements in their confidence in using evidence-based approaches, the frequency with which they use them, and their knowledge about their child's rights (López et al., 2019).

**Current Literature on Cultural Adaptations**

The need for cultural adaptations to behavioral and mental health interventions is highly warranted as historically marginalized populations are overrepresented in these systems yet supports rendered to these communities are typically normed around White-ethnocentism (Baumann et al., 2015). Utilization of resources that do not culturally meet the needs of clients leads to an ineffective provision of mental and behavioral health services. There is a current emphasis amongst researchers and practitioners to adapt pre-existing evidence-based programs (EBPs) to address cultural-specific needs of diverse populations.

Weeks (2022) completed a systematic review to examine the effectiveness of theory-based strategies currently being used in the process of cultural-adaptation to EBPs. Two frameworks to consider when making cultural adaptations include the Cultural Adaptation of Evidence-based Interventions Model (Barrera & Castro, 2006) and the Ecological Validity Model (Bernal et al., 1995). These frameworks name specific areas of focus for adaptations, which include information gathering, preliminary adaptation design, preliminary adaptation tests, adaptation refinement, language, persons, metaphors, content, concepts, goals, methods, and context. Beyond these areas, Aarons and colleagues (2012) add that those adapting pre-existing interventions should be mindful of changes made to core components of intervention models, as this may negatively impact the

effectiveness of the program. In addition to framework-driven guidelines, Weeks (2022) identified current adaptation themes that involved either system level changes (e.g., organizational implementation changes) or changes at the individual intervention level. Specifically, themes included adaptations to content, language, concepts, level of family involvement, service delivery modality, and therapeutic norms between clients and practitioners.

Clinicians and researchers have seen success as current EBPs have been adapted to become more culturally relevant. Specifically, adaptations to program content, language, and service delivery modality have yielded clinically significant effects with culturally and linguistically diverse populations with various mental and behavioral health needs (Burrow-Sánchez and Hops, 2019; Muroff et al., 2017). However, there is still much work to be done in advancing diversified EBPs. Those working on program adaptations might benefit from taking time to focus on the needs, normative practices, and preferences of families and communities while building sustained capacity for local clinics (Valdez et al., 2017).

## ADAPTATION MODELS USED IN CURRENT STUDY

In addition to general recommendations in Weeks (2022), the adaptations described for the current study followed those described in the Cultural Adaptation Process Model (CAP; Domenech-Rodríguez and Wieling, 2004) and the Ecological Validity Model (EVM; Bernal et al., 1995). These were jointly conceptualized as a means to adapt the content of each component presented through the packaged intervention. The cultural adaptation model described in the current paper includes both (1) a broader model for the adaptation process (i.e., system level) and (2) specific adaptations made to the content of the intervention (i.e., intervention level).

### Cultural Adaptation Process Model (CAP)

The CAP emphasizes process-informed, system-level adaptations to make interventions more culturally relevant and linguistically sound. The CAP is broken down into three phases: setting the stage, which outlines steps to take prior to the intervention; initial adaptation, which notes the importance of engaging the target community; and adaptation iterations, including activities that aid in the iterative process of the adaptation (Domenech-Rodríguez and Wieling, 2004). Each phase also has individual steps to help guide the process of cultural adaptations. The CAP was utilized to help guide the general process of cultural adaptation of Project PEACE.

#### *Phase 1: Setting the Stage*

In following the first phase of the CAP, and in preparation for the cultural adaptation's development of Project PEACE, a literature review on EBPs was conducted to address challenging behavior in children with ASD and support the mental wellbeing of their caregivers. Further, the literature was also perused to determine best ways to address the cultural adaptation of the selected interventions (i.e., RUBI parent training manualized program and ACT-oriented supports). As part of this phase, multiple collaborations with stakeholders were developed.

First, a partnership was developed with local faculty and mental health providers in the community of interest who helped inform the process as members of the target community (i.e., Puertoricans). These stakeholders assisted in determining a subset of the target community who would benefit from the intervention and who could serve as participants in the iterative trials of

the intervention. Second, a partnership was also developed with faculty in Kansas City, Missouri who were already implementing the intervention with Spanish-speaking Latino families. This collaboration enabled further discussions about how to adapt the intervention given their experiences and with Latino families from a broader spectrum of communities (e.g., other countries of origin). Third, discussions and meetings were also scheduled with the first author of the RUBI manualized program (i.e., treatment developer) to maintain the general integrity and concepts of the adapted videos. All three partnerships assisted in guiding the general adaptations that were adopted for Project PEACE. Finally, development of a needs assessment was initiated to determine community needs. Researchers conducted a literature review of past needs assessments administered to the target community (i.e., Spanish-speaking Latino families and Puertorican families of children with ASD). The literature review guided the development of the needs assessment to inform component adaptations.

***Phase 2: Initial Adaptation***

For the second phase of the CAP, researchers selected measures to be used for Project PEACE. Measures were selected based on those previously used in the manualized RUBI intervention as well as through determining those measures available in Spanish and normed for the Latino community. Through Project PEACE, multiple methods of data collection were proposed including the use of rating scales, direct observation, and caregiver interviews. This is a similar approach as used by Domenech-Rodríguez and colleagues (2011). The intervention itself was further adapted following the specifications of the EVM and as guided by information collected during the CAP's phase 1. General adaptations included translation of content for components of the packaged intervention and cultural adaptations of the intervention.

***Phase 3: Adaptation Iterations***

Through the third phase of the CAP, changes were made to the content of the packaged intervention in an iterative fashion during discussions with collaborators. These changes included increasing cultural relevance of content as well as increasing feasibility of methodological components. Regarding the linguistic adaptations, after the content of the RUBI videos were translated into Spanish and adapted by the principal investigator, who is also a native speaker, stakeholder discussions led to further changes. Specifically, some of the terminology being utilized in the videos was adapted (e.g., *resfriado* versus *gripe*) to be made more inclusive of various Spanish-speaking communities. Intervention schedules were also discussed with local stakeholders to determine best time frames to provide the intervention to the target community. The intervention was initially set to be delivered during the middle and end of the summer. As families usually go on vacation at the end of the summer (as discussed with community experts), researchers adjusted the timeline to begin later in the spring and end mid-summer.

**Ecological Validity Model (EVM)**

The framework used to provide a structure for the cultural adaptations of the individual components was chosen to strengthen the ecological validity of the packaged intervention. In other words, it was important that there be a direct correspondence between the intervention (i.e., Project PEACE) as experienced by the participants (i.e., Spanish-speaking Latino families) and the

intervention as proposed by the investigators. For this reason, the question at hand was whether the intervention would work in the real world for people with different cultural contexts. The EVM (Bernal et al., 1995) was therefore utilized as a method to adapt the content of the evidence-based intervention components. Researchers within the current study followed Bernal and colleagues' 8 dimensions of ecological validity through adaptation development:

***Language***

The dimension of Language ensures that the intervention is available in the language of the participant, with "special efforts…directed toward ensuring the use of cultural syntonic language" (Bernal et al., 1995). This involves the understanding of regional and subcultural terminology used by the target community. Within Project PEACE, the RUBI component includes not only the manualized content but also the use of video examples which were originally developed and tested in English. Researchers translated the manualized content for participants and created videos in Spanish to replace the original English versions. They further placed special emphasis to ensure the terminology matched the needs of the target community. The RUBI content is currently being implemented in Spanish in Kansas City, Missouri, by psychologists in the community. Language adaptations to the content and videos were discussed in meetings with the Kansas City group as well as with the first author of the RUBI manual.

***Persons***

The Persons dimension of the EVM centers around the match between the therapist and the client. The therapeutic relationship should include whether the intervention is flexible in considering ethnic and racial differences and similarities and its role in shaping the relationship. In the Project PEACE intervention, the practitioners' education is flexible. Practitioners can deliver the intervention regardless of education level if they are familiar with and trained in the individual components of the intervention (i.e., RUBI and ACT). The pilot version of this intervention will be tested by the principal investigator, a graduate doctoral student with three years of clinical experience, who is a Board-Certified Behavior Analyst, a native speaker, and a first-generation Latina (i.e., Puertorican). These therapist characteristics further emphasize the correspondence between the therapist and the participants in the intervention.

***Metaphors***

The Metaphors dimension of the EVM refers to the symbols and concepts that are shared by the target community. These are those embedded aspects of the intervention that promote understanding, comfort, and familiarity. As part of the Project PEACE intervention, there are two aspects of the Metaphors components that were considered when developing the cultural adaptations. Within the video adaptation developed for the RUBI component, various objects were changed to match the culture and location of the participants. For example, in one of the videos, the concept of controlling the environment as a prevention strategy was presented by having a child actor request a cereal the parent did not want the child to eat. Several cereal boxes were displayed on the kitchen counter in this scene. As most Latino families have different breakfast options, an additional option was made available on the Spanish adaptation (i.e., *huevitos* or eggs). Another example included the clothing the child was asked to put on during various scenes;

specifically, the use of a coat. As in some Latino countries winter gear is not often used, the researchers changed this clothing item for shoes; where the parent asked the child to put on his shoes as part of the video example. Within the ACT component of Project PEACE, several metaphors and analogies are used. Researchers ensured the use of metaphors that were familiar to the target community, including metaphors centered around parenthood.

***Content***

The fourth dimension of the EVM refers to the Content of the intervention as seen through a cultural lens. Within this dimension, it is important to reflect appreciation and understanding of the values, traditions, and customs of the target community. Some values important to Latinos which may become evident through a parent training intervention include familialism, the importance of close family relationships; *respeto*, an emphasis on child obedience and deference to adult authority; and *personalismo*, a genuine emphasis on interpersonal trust and respect. Within the current packaged intervention, family values are directly discussed early in the ACT protocol (i.e., Session 1.b; see Table 1). This allows the practitioner to be aware of and acknowledge the values of the target community early in the intervention. In relation to these specific values, although the primary target participants are the caregivers, additional family members interested in participating and who may be generally involved in the day-to-day of the child's life (e.g., grandparent, older siblings) are also welcome.

**Table 1**

*Project PEACE Content Outline*

| Session | RUBI manualized intervention | ACT protocol |
|---|---|---|
| 0 | Initial intake and introduction to the PEACE intervention | |
| 1 | Behavioral Principles | Values |
| 2 | Prevention Strategies + Daily Schedules | Acceptance |
| 3 | Reinforcement 1 & 2 | Thought Disconnection |
| 4 | Compliance Training + Planned Ignoring | Engagement with Present Moment |
| 5 | Teaching Skills 1 & 2 | The Observing Self |
| 6 | Functional Communication + Generalization/Maintenance | Committed Action |

***Concepts***

The Concepts dimension of the EVM refers to the reason for treatment (or the problem) as conceptualized within the treatment model and whether the client understands and agrees with this conceptualization. Concepts in the intervention should be carefully evaluated for cultural sensitivity because the therapist's credibility and the treatment efficacy could be compromised should these concepts be inconsistent with the client's belief system and values (Bernal et al.,

1995). In Project PEACE, the initial ACT session provides an opportunity for caregivers to provide their informed consent for allowing the therapist to guide and coach them through intervention activities. Obtaining 'permission' from the participant to engage in didactic sessions and feedback, provides the therapist an opportunity to explain the intervention, let the participant know what to expect, and evoke agreement.

***Goals***

Within the Goals dimension, it is important that there be agreement between the therapist and the client about the goals of the intervention. For there to be effective consistency between the two parties, the therapist should frame the goals of the intervention through the lens of the values and traditions of the target community. Through the intervention at hand, as previously described, the values of the client are openly discussed as part of the intervention model. This provides the practitioner an opportunity to explore these values and set the intention for the rest of the intervention. Collaborating on goals and engaging in values-directed discussions, will enable the therapist to elicit agreement regarding the intervention's objectives.

***Methods***

The Methods of the intervention, or the procedures for achieving the objectives of the intervention, is another essential dimension of the EVM. Within this dimension, incorporating cultural knowledge and relevance within the intervention procedures is critical. This requires the intervention methods and tasks to be compatible with and acceptable to the target community. Project PEACE provided parents the opportunity to determine whether in-person versus telehealth delivery would be most feasible for them. When families noted a desire for either modality, researchers secured devices for the families to use during the virtual delivery of information. By providing the necessary equipment and inquiring about the caregivers' preferences, researchers ensure further buy-in into the intervention. Moreover, the packaged intervention allows for and encourages the engagement of other family members in the intervention which is compatible with the known Latino value of *familismo*.

***Context***

The final dimension of the EVM considers processes that may be linked to the reason for needing the intervention. This may include such processes as economic conditions, availability of social or familial support, and any political context related to the community of interest. Our intervention considered contextual issues that could get in the way of caregivers accessing the intervention. The treatment barriers were addressed in several ways. First, economic conditions were undertaken by securing funds for participant compensation. Specifically, participants are to be compensated with a Visa gift card of $40-$60 for each weekly session they attend, for a total of up to $260 for their participation. Economic conditions are further addressed, as previously noted, with the provision of access to a device for the length of the intervention. This alleviates any disadvantages related to lack of technology for accessing the virtual intervention.

## IMPLICATIONS

Creating culturally and linguistically sensitive behavioral and mental health supports creates greater accessibility to evidence-based interventions for Spanish-speaking families.

Research has demonstrated that cultural and linguistic adaptations are essential to increasing engagement with interventions and increasing treatment efficacy (Bernal & Adames, 2017; Domenech Rodríguez et al., 2011). By providing research-sound examples of cultural adaptations in practice, access to effective services that are representative of people's lived experiences and engagement with EBPs is facilitated for underserved communities. Considering adaptations to be made beyond the content and materials of the intervention can also facilitate equity of accessibility. For instance, facilitating the delivery of interventions in different formats can make EBPs more easily accessible to minoritized communities. Providing an option for telehealth services, for example, and facilitating technological support when providing these services, can maximize accessibility to interventions otherwise difficult to deliver in person.

The individual components of Project PEACE have shown to be efficacious in increasing effective caregiver management of challenging behavior and use of evidence-based strategies, as well as decreasing child disruptive behavior and levels of parental stress. Selecting EBPs is the first step in ensuring that the needs of underserved communities are being successfully addressed. It is critical to note that beyond the system-level and intervention-level adaptations implemented, an intervention is only as good as the evidence it is based on.

Given the labor-intensive tasks often associated with these types of adaptations, and the costs incurred, this line of research and adaptation examples are critical and play a significant role in behavioral and mental health interventions. For this reason, a cost analysis was conducted for one of the tasks involved in this packaged intervention: the development of the Spanish videos. The development of the Spanish videos involved creating animated videos to adapt the language and physical aspect of the characters, and in this way, match the intervention participants. The videos took approximately 300 hours to create across 4 research assistants, 3 voice actors, and the principal investigator. The cost of development was approximately $4,800, including compensated time for those involved and the price of the annual subscription to the video animation platform.

## FUTURE DIRECTIONS

It is important to test the adaptations discussed in this study through additional research implemented in communities in which they have yet to be tested. For this reason, conducting the adapted intervention with a Spanish-speaking community and documenting the processes is critical for this line of research. Further, as suggested by the CAP, Project PEACE should be implemented as a pilot study to test the feasibility and acceptability of its intervention components, including specific adaptations. This implementation may be evaluated with a subset of participants from the target community (i.e., Spanish-speaking Latinos). Further, given past success of implementing similar lines of research using single subject designs (Gould et al., 2018), as well as the nature of the components being evaluated, a single subject research design may be considered during implementation.

Prior to implementing Project PEACE, and similar interventions, consideration of the specific needs of the community where the intervention is to be implemented is crucial. A needs assessment can provide additional information regarding delivery methods, current services being

accessed, as well as other variables of the intervention that could make the intervention more equitably accessible to the target community. Therefore, future research should consider developing and implementing a needs assessment prior to implementing Project PEACE as this information may be critical in modifying the individual intervention components, the delivery methods, and the cultural and linguistic adaptations.

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