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Adapting parent-focused interventions for diverse caregivers of children with intellectual and developmental disabilities: Lessons learned during global crises

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Abstract

Parent-focused interventions have been designed to provide training and support to caregivers who are essential in achieving positive outcomes for children with intellectual and developmental disabilities (IDD). In 2020, significant crises, including the COVID-19 pandemic and continued racial tensions, profoundly impacted the livelihood of children with IDD and their families. Many ongoing efforts to address disparities among this population were halted temporarily and required further adaptations. Researchers adapted interventions and support to address the disparities impacting children with IDD and their families with limited guidance. We provide a descriptive case analysis of four parent-focused interventions that responded to the global crises to continue serving children with IDD and their families. The four distinct programs were based on applied behavior analysis and naturalistic, developmental-behavioral paradigms that were culturally adapted for families of young children with IDD from diverse cultural and socioeconomic backgrounds. We present the qualitative reports on the challenges and benefits that arose with adapting the four parent-focused interventions for telehealth implementation. We focused specifically on adaptations made in recruitment and retention, instrumentation and measurement, research staff training, and intervention delivery. We synthesize our experience with challenges and solutions in adapting parent-focused interventions for racially/ethnically and socioeconomically diverse children with IDD and their families. We conclude with

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CONFLICT OF INTEREST
The authors declare no conflicts of interest.

ETHICS STATEMENT
The projects described in the manuscript all received institutional IRB approval prior to research initiation, with each corresponding author overseeing the informed consent and confidentiality of research participants. All research participants provided informed consent.

recommendations for researchers and practitioners on methods for adapting parent-focused interventions to address the significant health disparities that impact racially, ethnically, and socioeconomically diverse children with IDD and their families.

Keywords

autism; COVID-19; intellectual disability; parent-focused interventions; practice; racial/ethnic diversity

INTRODUCTION

In March 2020, the spread of COVID-19 across the world limited in-person activities based on recommendations by the Centers for Disease Control and Prevention (US Department of Health and Human Services, 2020). These recommendations halted in-person scientific research and clinical services worldwide. With the closure of businesses and schools, additional labor and socioeconomic crises ensued, with increased unemployment and underemployment in the midst of growing racial tensions (Cheah et al., 2020; Ibrahimi et al., 2020). For children with intellectual and developmental disabilities (IDD) and their families, the shift to homeschooling or online delivery of health services and education, and the loss of services and support, resulted in increased stress (Asbury et al., 2021). The barrage of critical events in a short time intensified the inequalities affecting racial/ethnic minority and low-resource communities (Padilla & Thomson, 2021; Suarez-Balcazar et al., 2021). Researchers serving these communities were tasked with adapting programs and modifying research protocols to continue vital work addressing inequalities and disparities. Due to the unprecedented crises, little guidance was available to shape these adaptations with even fewer resources.

A widely used intervention model for children with IDD is parent-focused interventions (e.g., parent education, parent-mediated interventions; Rutherford et al., 2019) that empower and teach parents to be change agents supporting and improving their child’s developmental outcomes (Bearss, 2019). Most parent-focused interventions that target racially, ethnically, and socioeconomically diverse communities are delivered through face-to-face formats, increasing engagement, familiarity, and comfort between caregivers and providers. Parent-focused interventions are effective as parents have invaluable knowledge about their child’s development, have consistent access to their child, and implement parenting practices across contexts and settings to generalize skills (Burrell & Borrego, 2012). To date, an extensive body of research, as well as national and international policy initiatives, has highlighted the utility, practicality, and efficiency of parent-focused interventions in addressing the developmental and behavioral needs of children with IDD (National Research Council, 2001; Shalev et al., 2019; World Health Organization, 2019). Parent-focused interventions can address significant barriers that racially/ethnically and socioeconomically diverse children with IDD encounter in receiving evidence-based treatments. This article describes how parent-focused interventions were adapted in response to the global crises and highlights how specific features of parent-focused interventions can address the disparities experienced by children with IDD and their families.

IMPACT OF THE COVID-19 PANDEMIC ON DIVERSE CHILDREN WITH IDD AND THEIR FAMILIES

The COVID-19 pandemic significantly impacted children and families worldwide as disruptions were observed across education, health, and other sectors (Kyeremateng et al., 2022; UNESCO, 2022; Wilke et al., 2020). In the midst of the pandemic, specific communities (e.g., racial/ethnic minority, disability, low-resource) experienced pronounced challenges and barriers to access services while experiencing heightened risks for illness, safety, prejudice, and discrimination (Cheah et al., 2020; D'souza et al., 2021; Egede & Walker, 2020; Ibrahimi et al., 2020). For children with IDD, the COVID-19 pandemic resulted in a significant loss of instruction and therapeutic services (Jesus et al., 2021; UNESCO, 2022). The loss of instruction and therapeutic services were more pronounced among children with IDD with greater support needs (e.g., self-contained class; Valicenti-McDermott et al., 2022). The requirements for remote learning required parents and children with IDD to connect with a device to an online platform to participate in synchronous instruction or to access asynchronous content; however, this requirement placed significant burdens on families who had little to no access to these devices. For example, Valicenti-McDermott et al. (2022) found that foreign-born parents, parents with lower levels of education, and parents who spoke limited English experienced greater challenges in setting up remote learning for their children with IDD. Parents that were not able to set up remote learning, either due to limited or lack of internet connectivity, lack of devices, or limited cellular data plans, were at greater risk of losing therapeutic services for their children. This cascade of challenges resulted in parents becoming responsible for their child's daily educational and therapeutic plans. Other studies have also found that caregivers of children with IDD had higher levels of anxiety and depression at the onset of the COVID-19 pandemic, and these caregivers were more likely to have increased levels of anxiety and depression 6 months later (Iovino et al., 2021). The challenges experienced by caregivers and children with IDD during the COVID-19 pandemic serve as a call for action for researchers and providers to identify and evaluate adaptations for greater inclusion and accessibility for racially/ethnically and socioeconomically diverse communities.

CULTURAL ADAPTATIONS OF PARENT-FOCUSED INTERVENTIONS

While there are systematic approaches to adapting evidence-based interventions for culturally diverse communities, "expert reviews" (Xu et al., 2018), surface/deep structure adaptations (Knight et al., 2009), or a broad scope of dimensions (Ecological Validity Framework; Bernal et al., 1995), these approaches have not been necessarily applied to contextual adaptation needs. The current crisis significantly altered family and public life in a way that required parent interventionists to adjust. Culturally adapted intervention programs are well equipped to respond to these challenges through their inherent flexibility. Specific features of parent-focused interventions that may be integral to their success include cultural adaptations to recruitment and retention methods and culturally responsive measurements.

Participant diversity in recruitment and retention

Recruitment and retention of racially/ethnically diverse populations is critical to ensure the generalizability and impact of parent-focused interventions (Ceballos et al., 2020). However, much of the existing intervention research does not adequately report demographic information (e.g., race, ethnicity, disability category, family characteristics), and researchers often recruit homogeneous, White majority samples (Pierce et al., 2014). By not including diverse samples, researchers fail to capture intersectional identities (e.g., racial/ethnic minority and autistic identity) that may impact the external validity of research findings (Cascio et al., 2021; West et al., 2016). Despite specific recruitment strategies to engage diverse communities in research (Zamora et al., 2016), widespread adoption of these strategies remains limited. Recruitment of diverse populations to telehealth research can be further complicated by relying on technology to identify and locate racially, ethnically, and socioeconomically diverse participants. To include and retain representative samples, researchers should consider the vital role of cultural adaptations in all aspects of intervention research (i.e., intervention technique/delivery, recruitment practices, and retention strategies). Specifically, for Latine families, informal interactions and personal stories (i.e., personalismo) support connections with service providers, but online communication may impact the quality of these interactions (Evans et al., 2007).

When racially/ethnically diverse participants are recruited, additional considerations are necessary for retention. A few commonly documented issues include decreased motivation to participate due to perceived insufficient benefit; lack of resources to enable participation (e.g., transportation, childcare vouchers, monetary incentives); and competing obligations and stressors acting as barriers to prioritization of research participation (Carr et al., 2016; Pellecchia et al., 2018).

Instrumentation and measurement

Many parent-focused interventions use validated and reliable screening and assessment tools to characterize the children included in the study. These protocols often collect developmental and medical history, assessment of child skills and abilities, and observations of child behavior and social interaction (Prelock et al., 2003). However, many screening and assessment tools have not been adequately adapted for racially/ethnically and linguistically diverse children and families (Vanegas et al., 2016; Harrison et al., 2017). Many of these tools require direct observation of the child and caregiver and the administration of specific tasks or activities to elicit behaviors, language, and social skills. These procedures require physical proximity between the clinician/researcher or the parent and the child to capture and note the specific observations accurately.

Furthermore, when assessments are conducted remotely with children and families from racially/ethnically and socioeconomically diverse backgrounds, researchers may often assume that families will have the necessary materials or resources to complete the assessment. This includes developmentally appropriate toys, books, webcams, and dedicated spaces for play (Shah et al., 2019). Significant efforts are needed to incorporate culturally responsive tools and procedures into screening and assessment practices. Adaptations and alternative methods are critical for evaluating specific behaviors to inform the outcomes of parent-focused interventions.

The purpose of this article is to present a descriptive case analysis of four parent-focused interventions addressing disparities impacting children with IDD and their families. We provide an overview of each intervention and describe the implementation adaptations and challenges in response to the global crises. We present lessons learned in adapting parent-focused interventions and provide recommendations on clinical and research practice to guide others who may need to adapt programs for challenging circumstances.

OVERVIEW OF PROGRAMS

In this next section, we briefly describe four parent-focused interventions. We describe the populations and communities, implementation of the parent-focused interventions, and delivery mechanisms. We then describe the adaptations made and outline challenges experienced and how they were resolved.

The following interventions have been included in this manuscript as examples of parent-focused interventions for young children with, and at-risk for, Autism Spectrum Disorder (ASD) and developmental delays. A unique link between these programs is the implementation timeframe in early 2020 (see Table 1 for detailed study characteristics). While the COVID-19 pandemic-initiated shut-down varied between parent-focused interventions, each intervention was in the early stages of implementation, (i.e., recruitment, the start of the intervention, baseline), thus allowing for additional adaptations to occur without compromising the integrity of the project.

Parents Taking Action Chinese was culturally adapted from Parents Taking Action (PTA; Magaña et al., 2017), targeting Chinese immigrant families of children with ASD under 10 years of age to address the disparities faced by this population. We used single arm, pre-, and post-design to evaluate the preliminary efficacy of *PTA Chinese*. Children with ASD from Chinese families face multiple layers of barriers such as language barriers, lack of culturally tailored intervention, and services (Chiang, 2014; Lo, 2008; Son et al., 2017). To the best of our knowledge, *PTA Chinese* is the first culturally tailored intervention adapted with Chinese immigrant parents of children with ASD. In the intervention, parents received a 10-week intervention on stress management, advocacy, child development, autism, and naturalistic, developmental behavioral intervention (NDBI) strategies that encourage communication and reduce problem behaviors (Schreibman et al., 2015). Parents watched an hour-long pre-recorded video lecture each week and joined an hour-long online group learning session and discussion. The pre-recorded lectures were delivered by a social worker, two special education teachers, one father of an adult son with ASD, and two behavioral therapists (i.e., a board-certified behavior analyst, a graduate student specializing in applied behavior analysis). The online group learning sessions were led by four parent peer advocates (Chinese mothers of youth with ASD) in groups of 5–9 participants via zoom. The study was in its pilot phase during the COVID-19 pandemic with 28 families from Chicago and New York.

Padres de Niños con Autismo Como Técnicos en el Análisis Conductual (*PACTO*) or *Partnering with Parents of Children with Autism in Early Behavior Intervention* used a concurrent multiple probe design across parent and child dyads to assess Latine caregiver fidelity of NDBI strategies and child social communication outcomes. Underserved Latine children with autism are at risk for long-term disparities associated with prognosis (Casillas et al., 2017), hence, customized early intervention is a grave concern for this population that requires further investigation. The overarching goal of *PACTO* was to improve the adoption and implementation of NDBIs for Latine caregivers with their young children aged 2–5. *PACTO* incorporates an adapted version of PTA and parent synchronous and asynchronous coaching (see Akemoglu et al., 2020) based on NDBI. *PACTO* has three main components: (a) psychoeducational training (adapted from PTA); (b) 40 hours of parent-adapted synchronous instruction in applied behavior analysis; and (c) and 3 months of weekly synchronous coaching from a Spanish-speaking board-certified behavior analyst. The total intervention duration was approximately 6 months.

Tick-Tock: Caregiver-mediated Intervention for Children on a Wait-list for an Autism Diagnosis used a single-case, concurrent multiple baseline design to target autism symptomatology and higher-order restrictive and repetitive behaviors and interests in toddlers (21–35 months) waiting for an autism diagnostic appointment. Years can elapse between parental suspicion of a developmental delay and a diagnostic assessment, ultimately delaying access to medically necessary, autism-specific intervention, with even longer wait times for families of color (Martinez et al., 2018). In this study, parents were coached via telehealth to decrease interfering, inflexible behaviors during play using four evidence-based applied behavior analytic strategies: modeling, prompting, differential reinforcement of appropriate behaviors, and response interruption and redirection. Six mother–child dyads were recruited from pediatrician offices and early intervention service districts in the United States and were considered underserved, underresourced, or living in rural locations (see Kunze et al., 2021).

The *ASD Screening and Parent ENgagement* (*ASPEN*) intervention program used a randomized controlled trial to measure the efficacy of parent education combined with parent coaching on improving child and parent outcomes. For racially/ethnically diverse families of children with ASD or developmental delays with low resources, intervention recommendations, and costs may not be feasible, practical, or sustainable given the required investment of time, money, and effort (Pickard & Ingersoll, 2016). To address this issue, the *ASPEN* intervention was adapted from PTA (Magaña et al., 2017) and Project ImPACT (Ingersoll & Dvortcsak, 2010) to create a culturally informed intervention available in English and Spanish and tailored for racially/ethnically diverse families in low-resource households (e.g., public insurance, low-income, low education). In this ongoing study, parents (n = 160) are recruited to receive parent education about stress, social support networks, and child development, and receive coaching on NDBI strategies to influence the child's (age range = 18 months–6 years, n = 160) communication, language, play skills, and behavior. The *ASPEN* program is delivered by a graduate student clinician (intervention and control group) and a peer leader (i.e., parent, sibling, or family member of an individual with a disability; intervention group only) across 12 weekly sessions for parents in the intervention group or 4 tri-weekly phone sessions for parents in the control group. Families were recruited from pediatric clinics, Head Start schools, and parent support groups throughout Texas.

DESCRIPTION OF ADAPTATIONS, CHALLENGES, AND PROBLEM-SOLVING

Participant recruitment and retention

Traditional recruitment methods (e.g., disseminating flyers, community outreach) were no longer feasible at the onset of the COVID-19 pandemic. We found recruitment challenging as typical venues (i.e., parent support group meetings, resource fairs, conferences) were no longer available, and connections developed previously had been through in-person engagement. Before the COVID-19 pandemic, projects had slowly begun building an online presence. More robust web pages and social media accounts (e.g., Facebook, Twitter, and Instagram) were needed during the transition to virtual recruitment. Active online recruitment strategies take time, as accounts require an active online presence (e.g., weekly tips for families and webinars for parents) to assist with recruitment and facilitate online engagement. Organizations, centers, agencies, and clinics that adhere to face-to-face support may have a less established online presence, limiting the dissemination of recruitment materials. In addition, knowledge and access to technology directly impacted outreach to families with fewer resources.

In our mixed experiences, participant recruitment via social media groups varied. For example, several groups and organizations had a vetting process for advertising on their social media accounts (e.g., Facebook, Instagram, Twitter), while some groups with inactive or low activity had limited reach. In other cases, recruitment was more accessible due to existing social media groups and platforms with high activity (e.g., WhatsApp). Accessing participants solely online had limitations, including dependence on established partnerships or *new* partnerships with organizations with an active social media presence (e.g., holding frequent webinars, presentations, group support via teleconferencing).

In other instances, online recruitment made reaching families outside of specific regions more accessible. For example, *PTA Chinese* recruited families through a Chinese social media platform from two metropolitan areas. Snowball sampling worked well on this platform since it utilizes group chat rooms where parents can forward the flyer to specialized group rooms for parents of children with autism. The *ASPEN* program expanded beyond the central Texas region (i.e., Austin, San Marcos) to the entire state of Texas. This allowed for researchers to reach and serve families in areas with low resources and decreased availability of support systems.

Retention

Beyond recruitment, additional challenges surfaced with the retention of research participants. Although several studies have previously outlined recommendations for retaining minoritized communities (Zamora et al., 2016), the COVID-19 pandemic created additional challenges yet to be investigated. Many uncertainties and constant fluctuations with work, school, and therapy schedules made it difficult to plan for consistent sessions and engagement with families. This led to cancelations and rescheduled sessions becoming the norm, especially when families encountered challenges with childcare. Despite liberal cancelation policies and flexibilities in the hours and days of participation, retention of families continues to be a challenge in research. Specific to the COVID-19 pandemic, families in underserved communities were at a greater risk of job loss, reduced childcare, and limited community support (Padilla & Thomson, 2021). This resulted in a double disadvantage for families in these communities; they were experiencing significant stressors that called for support, however, these same stressors limited their availability to engage with those supports.

Retention also became a factor in engagement with community organizations and support groups. Successful initial contacts would result in the sharing of the recruitment materials and engagement with families who were more immediately connected. However, due to the sheer volume of content posted on social media and online platforms, continued sharing of recruitment materials was necessary, thus requiring continued contact and collaboration with the initial contacts.

Research staff training

The four distinct parent-focused interventions presented here faced initial challenges of transitioning from in-person to online training methods. All four projects pivoted to either synchronous or asynchronous formats of staff instruction. This required additional materials than were previously included, such as supplementing in vivo modeling and instruction with existing online modules or videos (e.g., Help is in your hands, Centers for Disease Control, Autism Navigator, and Project ImPACT), using virtual breakout rooms for role-playing, wireless headphones for synchronous coaching, and adopting best practices and tips on navigating telehealth delivery (e.g., Council of Autism Service Providers, 2020). Further, staff training was especially difficult for community health workers unfamiliar with software and programs (e.g., PowerPoint, Word, and Zoom) and often required that the research team assist with technology when working with families. When consulting the telehealth ethics research literature around implementation, we found little instruction on coaching interventionists for this specific modality. While telehealth-related ethics and guidelines for practitioners were available (Pollard et al., 2017; Reed et al., 2000), how they were adopted and implemented across disciplines varied based on policies mandated by specific universities, professional organizations, and local jurisdictions.

Instrumentation and measurement

Data collection—Across all four projects, data collection was achieved using teleconferencing–albeit with some challenges. Some exceptions included removing child outcome measures that required administration by a trained professional (e.g., Mullen Scales of Early Learning) and extensive measures that were not feasible via telehealth due to resource and time constraints. Recent studies have demonstrated that it is possible to conduct assessments with validity using parents as a proxy (Corona et al., 2021); however, when these studies were launched, these methods were emerging and focused on efficacy rather than effectiveness.

For self-report measures, screen-sharing capabilities allowed researchers to share questions with participants and address items that required clarification. For direct observation measures, teleconferencing tools facilitated data collection by automatically recording sessions and uploading them to a secure cloud. However, obtaining consistency across video observations was a challenge. Variability was due to limited optimal camera angles, extraneous variables in natural settings (e.g., toys used for parent–child interactions, and other family members in the background), and accidental muting of video recordings.

Validity of data—Collecting outcome data during unprecedented times can impact the validity of self-report measures used across the four projects. The COVID-19 pandemic has had a tremendous impact on the lives of families in ways we have yet to understand. For that reason, some projects dropped less proximal measures and relied on direct-child observation data. Less proximal measures, such as standardized testing, yield information about clinically significant changes in participants' behavior that were missed in these adapted parent-focused interventions.

Intervention delivery

Most programs had been planned for in-person, one-to-one, or group implementation within community organizations, homes, and university-based clinics. Refer to Table 1 for summaries of these changes. Given the safety restrictions of the COVID-19 pandemic, all programs were implemented via telehealth. Data were not collected on parents' pre-COVID experiences with telehealth. Yet, anecdotally, parents reported increased virtual intervention and education for their child (e.g., early intervention services, asynchronous, or synchronous schooling for another child in the household). Several procedural changes were made given the intensity of intervention components (e.g., psychoeducation, parent coaching) and increased overall virtual exposure. For example, programs had to reduce session duration and break up the delivery of planned content to families. Interventions were delivered through asynchronous and synchronous modalities. Technology challenges associated with telehealth intervention research (e.g., unstable internet connection) echoed past literature (Lerman et al., 2020). Some interventions had to provide specialized hardware and software (e.g., Wi-Fi hotspots, recording devices, headphones, and tablets). The challenges of variable participant knowledge and ease of technology use were addressed by providing additional training and support.

Our projects all had to pivot quickly, and this made it difficult to ensure quality. We used the best means possible to achieve some standard of quality. For example, *PTA Chinese* converted content into animated sketches and used existing video models to introduce concepts (e.g., autism characteristics, intervention strategies). An additional challenge with asynchronous instruction was the limited capacity to assess parent feedback on engagement, comprehension, and receptiveness to the content.

Components that required synchronous coaching also required substantial problem-solving. Although synchronous, virtual parent coaching strategies have been demonstrated to be effective (Unholz-Bowden et al., 2020), they are not without challenges (Lerman et al., 2020). Intervention components were split into shorter sessions, requiring multiple sessions with families to increase the feasibility of synchronous instruction. This also created scheduling challenges as families now needed to schedule sessions when other adults were in the home to watch the other children who were not the focus of the intervention. We experienced a high rate of cancelations due to the unprecedented challenges of the pandemic (e.g., COVID-19 infections, childcare needs, and homeschooling). It sometimes meant families participated during daily routines or while other children were in the home, resulting in divided attention. To address these limitations, wireless headphones were sent to families so that they could move around their homes freely, minimizing surrounding distractions.

DISCUSSION

This article describes how four distinct parent-focused interventions, designed for underserved communities, were adapted in response to the crises in the US. We outline important components of culturally adapted interventions that are flexible to modifications and present recommendations for researchers, clinicians, educators, and providers of children with IDD and their families. Although these adaptations arose during the COVID-19 pandemic, we acknowledge that these challenges are not new. The global pandemic, financial instability, and the digital divide are challenges that underserved families of children with IDD have faced even before the COVID-19 pandemic. These challenges have become exacerbated within the context of a global pandemic and more frequent states of emergency. Researchers, particularly those working with marginalized populations, need to rethink the norms of community engagement, recruitment, and retention. Although the strategies we describe in this article are not new, they may help inform and improve the inclusivity and accessibility of services. For example, implementing the strategies outlined in this article can build on principles of universal design to increase accessibility for all, but especially for under-served communities of children with IDD (Eisenbaum et al., 2022). Perhaps, the mere frequency of such events and their impacts (Smith, 2020) should shape the planning of future intervention research with low-resource and underserved families. How we problem-solve these challenges may inform future parent-focused intervention research with diverse populations.

Our experiences in adapting parent-focused interventions highlighted the need for culturally adapted and tailored recruitment, retention, and implementation approaches. These issues have long been identified; however, widespread actions were limited before the COVID-19 pandemic (Lund & Gabrielli, 2021; Thompson & Nygren, 2020). In terms of recruitment and retention of families, culturally tailored engagement efforts, and liberal cancelation policies that are responsive to the needs and circumstances of families are critical. This calls for immersing oneself in the community that researchers want to engage with and creating relationships with key stakeholders. This is a focal point of community-based participatory research frame-works (McDonald & Stack, 2016; Tyler & Werner, 2014) and is vital for intervention research. Prior to the pandemic, many intervention studies had strict attendance and participation policies that required families to fully commit to intervention sessions, with few allowable cancelations or strict timelines for completing the intervention (Carr & Lord, 2016). These policies may disproportionately impact families from minoritized communities, thus impacting the representativeness of intervention research. Our experiences with training research staff highlight several considerations for IDD intervention researchers. This includes identifying the skills necessary to make the intervention content and delivery accessible to various levels of education, literacy, and language and creating a training curriculum or plan for adult learners.

In the transition to a complete telehealth approach to parent-focused interventions, the screening and assessment procedures were quickly modified to fit within the parameters of virtual engagement. However, the field has not yet caught up with validated assessment instruments for virtual implementation (cf., Telehealth Evaluation of Development for Infants, Talbott et al., 2020). While there are several benefits to telehealth for intervention delivery (e.g., decrease in travel (Child Mind Institute, n.d.)), this intervention mode is not without difficulties. For example, parents report problems with internet access or building trust during virtual meetings (Lerman et al., 2020; Tsami et al., 2019). Despite the increased adoption of telehealth, barriers remain (e.g., implicit bias of clinicians, cost of services, and rapport), and unsurprisingly, families who were underserved and underresourced continue to experience challenges in accessing services (Anakwe et al., 2021; Valicenti-McDermott et al., 2022).

Recommendations for research and clinical practice

The implementation experiences of parent-focused interventions during global crises have further enhanced our understanding of the critical issues that children with IDD and their families face. Based on our experience and lessons learned, we outline several recommendations that can inform parent-focused interventions when delivered to culturally diverse communities.

Community engagement is critical before, during, and after interventions— Community engagement is a critical first step in working with culturally diverse children with IDD and their families. This entails building and maintaining intentional relationships with community organizations to build trust with the community. Building trust is essential when working with racially/ethnically diverse communities to address disparities (Wieland et al., 2021). By being present (even virtually), researchers and providers can convey to organizations and families that they are committed to serving the community. Researchers and providers must also recognize that these relationships take time and effort to accomplish and do not end when the project or scope of work is complete. Community engagement should be carried into the process of implementation.

Embrace flexibility throughout the process—In delivering parent-focused interventions to families of children with IDD, researchers and providers should recognize the importance of flexible practices. This requires purposeful planning that addresses potential issues that may arise. Recruitment strategies may not work for the desired communities, families may delay participation due to other responsibilities or commitments, and families may not be able to complete all expected tasks, activities, assessments, or follow-up appointments. Furthermore, upon implementation of parent-focused interventions, researchers and providers may realize that certain procedures, tasks, or plans may not work as expected. Continuous check-ins with families to ensure the feasibility of these practices are essential. Contingency plans that allow for flexibility in participation (e.g., allowing for cancelations) while maintaining the integrity and rigor of the research or practice can help ensure the success of the project.

Adopt a holistic approach to working with children and families—During the COVID-19 pandemic, significant disruptions to the family system further contributed to disparities. Researchers and providers must recognize that the child and family do not function in isolation, but rather are embedded within complex interactional systems. Many children and families in racially/ethnically and socioeconomically diverse communities face pervasive, systemic issues that contribute to significant inequities in access to and receipt of services. Researchers and providers have an ethical responsibility to acknowledge and address the needs of children and families, especially when working with underserved communities. This includes providing referrals and resources to services and supports in the community or even incorporating case management within the scope of the project. This may require researchers to step outside the boundaries of academic research to support the communities that we work with. This is a necessity if our research and practice intends to promote equitable access and improve outcomes for all.

Limitations and future directions

A few limitations to this qualitative case study are worth noting. Although the interventions were focused on under-served and under-resourced communities in the US, general parallels (e.g., the importance of community engagement) may be drawn with similar communities in high-income countries and in low-and-middle-income countries. Researchers and practitioners working with under-resourced families in other countries should take these recommendations with caution. In addition, the case study consisted of a convenience sample of researchers that are part of an informal collaborative research group focused on serving racially/ethnically and socioeconomically diverse communities of children with IDD. Although the present authors represent four regions of the US (i.e., Pacific Northwest, Midwest, East Coast, and the South), the experiences of researchers conducting parent-focused research in other parts of the country and larger projects are not represented here. Future case studies may sample from a broader range of the US population and minoritized groups not represented herein. Additional studies will be needed to identify and characterize how the COVID-19 pandemic has affected children with IDD and their families (e.g., language and communication development, parent–child interactions, and peer interactions), many effects that may not yet be realized. Furthermore, service providers and researchers should incorporate mechanisms for feedback (e.g., surveys, evaluations, and comments) from children with IDD and their caregivers to determine if changes made during the COVID-19 pandemic have been effective and responsive to their needs, as this can support the continuation of effective engagement methods.

CONCLUSIONS

We highlight several considerations that can have significant, long-term impacts on the cultural responsiveness of parent-focused interventions and research with children with IDD and their families from diverse racial/ethnic and socioeconomic backgrounds. To broaden the scope of practice and address the research-to-practice pipeline issues, we must continue to study the factors that lead to the successful dissemination and implementation of parent-focused interventions for racially, ethnically, and socioeconomically diverse children with IDD and their families.

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TABLE 1

Characteristics of the parent-focused interventions pre-COVID and adaptations made after the onset of the COVID-19 pandemic

Study name	Timepoint with phase	Delivery mode	Recruitment location/ mode	Session length	Participant time	Unique content
Parents Taking Action: Chinese	Pre-COVID	IP[a]	Region of 1 state	1 per week @ 2 h	10 weeks	Manual adaptations made with stakeholder feedback
	At COVID: adaptation	VT[a]: (S; AS)	Added 1 state, added social media groups	VT[a], AS: VT[a], S: 1 h	VT[a] AS: unlimited VT[a] S: 10 weeks	Additional pre-/post-measure on COVID-19 stress, added virtual session questions to focus group
Padres de Niños con Autismo Como Técnicos en el Análisis Conductual (PACTO)	Pre-COVID	IP[a]	Regional Community agencies: university-based clinic wait-lists	2 per week @ 45 min	6 months	Manual adaptations made with stakeholder feedback
	At COVID: Recruitment	VT[a]: (S)	Added social media groups, zoom presentations	1 per week @ 30 min	NC	Replaced psychoeducation with virtual synchronous coaching; delivery adapted (Rogers & Stahmer, 2021)
Tick-Tock	Pre-COVID	VT[b]: (S; AS) Ph[b]	2 states	1 per week @ 50 min	4 months	Individualized interventions
	At COVID: baseline	VT platform change	Expand to 4 states Added website	1 per week @ 20–30 min	6 months	Individualized scheduling with various make-up sessions per family; additional post-measure on COVID-19 stress, exposure, and impact on quality of life
ASD Screening and Parent ENgagement (ASPEN)	Pre-COVID	IP[b] (int); Ph[b] (cnt)	Regional of 1 state	1.5–2 h per week (int); 1 h every 3 weeks (cnt)	12 weeks	Manual and resources informed by stakeholders' feedback through an iterative adaptation process
	At COVID: recruitment/ intervention	VT[b] (Int); NC (cnt)	Entire state	NC	NC	NC

Note: COVID timepoint/phase: Pre = before COVID; at COVID = approximately March 2020; phase = study phase implemented at time of COVID impact.

Abbreviations: cnt, control group; int, intervention group; IP, in person; NC, no change; Ph, phone conference/call; VT, virtual telehealth (S, synchronous; AS, asynchronous).

[a] Group.

[b] Individual.