

SPECIAL ISSUE ARTICLE

Parents taking action adapted to parents of Black autistic children: Pilot results

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Funding information

School of Social Work, University of Maryland, Competitive Innovative Research Award

Abstract

There is a dearth of culturally relevant, family-centered programs for parents raising Black autistic children, despite significant racial disparities in autism diagnoses and service access. Using a mixed-methods convergent study design, we report qualitative and quantitative findings from a pilot trial of a peer-to-peer program, *Parents Taking Action (PTA)*, adapted to primary family caregivers of Black autistic children with or at increased likelihood for autism. We aimed to understand the feasibility of delivering *PTA* with fidelity to the manual; participants' acceptability of program strategies; and pre-post changes in child, parent, and family outcomes. Three peer mentors ("Parent Leaders") delivered the 14-session intervention to seven participants. All Parent Leaders and participants were mothers of Black autistic children. We interviewed participants and Parent Leaders regarding program content and outcomes. We also collected fidelity checklists and pre-post, parent-report measures on autism knowledge, family outcomes (e.g., advocacy), stress, depression, and child behavior. Parents reported on program acceptability at post-intervention only. We found the Parent Leaders delivered the program with overall high levels of fidelity, based on our observations and Parent Leaders' self-reported checklists. Participants reported high acceptability of the intervention strategies and provided feedback on methods to improve application of the content. We found statistically significant pre-post quantitative improvements in parent-reported knowledge of their rights and child advocacy, autism knowledge, and child social competence. Participants and Parent Leaders expanded on these changes in interviews, and identified improvements in autism knowledge, parent stress and depression, family outcomes, and child behavior related to program participation. We conclude *PTA* is a promising, culturally and contextually relevant intervention for parents of Black autistic children. A randomized controlled trial is needed to rigorously evaluate changes in child, parent, and family outcomes.

KEYWORDS

autism, Black or African American, intellectual and developmental disabilities, parenting, practice

INTRODUCTION

Approximately 1 in every 44 US children has autism, a complex neurodevelopmental disability associated with social communication challenges and repetitive or restricted behaviors (Maenner et al., 2021). Parents of autistic children often experience elevated levels of stress (Hayes & Watson, 2013; McStay et al., 2014) and depression (Weitlauf et al., 2014), which are associated with increased internalizing (e.g., social withdrawal) and externalizing (e.g., aggression) child behaviors (Clauser et al., 2021; Falk et al., 2014). While most studies emphasize that there are a complex array of factors influencing parent stress and depression (e.g., see Falk et al., 2014), extensive research has found parenting stress and depression can be mitigated by addressing challenging child behaviors, obtaining social support, and building effective coping strategies (e.g., see Boyd, 2002; Hastings et al., 2005; Zaidman-Zait et al., 2014). One study of underserved families also highlighted that limited knowledge of the autism service system was stressful for parents (Iadarola et al., 2019). While less research has focused specifically on parents of color, one study found Black parents of autistic children also aimed to increase their knowledge of autism to counteract perceived discrimination from clinicians (Dababnah et al., 2018). Yet, these parents cautioned against information overload and advocated for individualized approaches to increase autism knowledge.

The bulk of autism research has focused on deficits and challenges in families of autistic children, yet research has also demonstrated the benefits of raising an autistic child. Studies have found that some parents flourish in their caregiving role, such as engaging in positive social experiences in the autism community, gaining patience, and appreciating their children's success (Kim & Dababnah, 2020; Markoulakis et al., 2012). Additionally, while research has found that advocacy skills can help parents cope with stress (Ewles et al., 2014), another study found that Black parents of autistic children temper their advocacy efforts due to fears of appearing aggressive (Lewis et al., [in press](#)). In total, the literature suggests the need for multifaceted, culturally relevant intervention approaches which address both child and parent outcomes and acknowledge family strengths along with challenges.

Recent studies have documented improved child outcomes in parent-implemented interventions (Bearss et al., 2015; Wetherby et al., 2014). Yet, most autism intervention studies have not been culturally or socioeconomically diverse (West et al., 2016). In response to the significant racial, ethnic, and socioeconomic disparities in accessing autism services (Nguyen et al., 2016), a growing field of research has tested methods to serve low-income families (Carr & Lord, 2016; Jamison et al., 2017).

Nonetheless, few interventions address cultural adaptations to meet the needs of historically underserved families.

Black American children typically experience a 3-year delay between parent's first child developmental concerns and an autism diagnosis, which significantly affects access to early interventions (Constantino et al., 2020). Some studies have identified factors such as autism stigma and poor parent-provider relationships may contribute to delayed diagnoses and reduced service access for Black autistic children (Burkett et al., 2015; Dababnah et al., 2018; Lovelace et al., 2018; Pearson & Meadan, 2018). Apart from a small body of research focused on culturally relevant autism interventions (e.g., see Jamison et al., 2017; Pearson & Meadan, 2021), which have found improvements in various outcomes including parenting stress, empowerment, advocacy, and autism knowledge, little is known about how to meet the needs of Black children and families.

Parents Taking Action (PTA) was first developed to serve autistic children and their families in low-income Latinx communities, with the goal of increasing service access and knowledge (Magaña et al., 2017). *PTA* utilizes community-based interventionists, in which Latinx parents of older autistic children deliver *PTA* to parents of younger autistic children. The peer-to-peer approach has been effective in the larger disability field to improve parent coping and well-being (Bray et al., 2017). *PTA* covers several topics, including child development, services for families with autistic children and related developmental disabilities, prevention and management of challenging child behaviors, stress reduction, and social support for parents. *PTA* aims to provide participants with more flexibility around scheduling and meeting location, thus reducing the financial and time constraints to participate. Furthermore, the parents who deliver the program are important role models and social supports for participants (Magaña et al., 2017). A multisite randomized controlled trial with Latinx parents found participants in the treatment condition were more confident in using evidence-based parenting strategies and reported using them more frequently compared with participants in the control condition (Magaña et al., 2020). Additionally, the trial showed that parents reported fewer social communication challenges and increased use of evidence-based services post-intervention.

Given *PTA*'s potential as an intervention for other underserved communities, we adapted the program for families of Black autistic children living in low-income urban neighborhoods. We described the adaptation processes, along with key barriers and facilitators to participation, in (Dababnah et al., 2021). In this article, we explored the following research questions: (1) Can the adapted program be implemented as intended? (2) Is the adapted version acceptable to participants? and (3) Are there changes in participants' autism knowledge, parent

stress and depression, family outcomes (e.g., advocacy), and child behavior related to *PTA* participation? We hypothesized *PTA* would be implemented with fidelity, would be acceptable to participants, and would result in improvements in all measured outcome variables.

METHOD

The first author's Institutional Review Board approved our research protocol. We used a mixed-methods convergent study design (Creswell & Clark, 2017), which allowed us to analyze various types of qualitative and quantitative data (i.e., standardized measures, fidelity checklists and observations, interviews) from different reporters (i.e., parents, peer mentors, research team members).

Participants

Our research team worked alongside a program team, which included a licensed clinical social worker and three Master of Social Work students, to recruit participants and deliver the 14-session intervention. After conducting a detailed intake on autism-related and material needs, the program team provided participants with support for various areas of concern (e.g., housing instability; health service access) throughout the program. We describe our recruitment processes and challenges in detail in (Dababnah et al., 2021) and summarize them below.

Parents and other primary caregivers of Black children ages eight and younger who were diagnosed with or screened for an increased likelihood of autism (based on age-specific standardized instruments) were eligible to participate in *PTA*. We included children who were at an increased likelihood for autism because of well-documented delays in diagnosing Black children (Constantino et al., 2020). Additionally, parents must have resided in one of 38 Baltimore neighborhoods which Census data identified as having 20% or higher levels of child poverty (Baltimore Neighborhood Indicators Alliance, n.d.), due to the dearth of autism research on low-income families (Nguyen et al., 2016) and substantial evidence of the negative effects of concentrated poverty on child outcomes (e.g., see Sampson et al., 2008). We distributed recruitment flyers containing study team contact information to clinics, daycare centers, community events, and schools; solicited clinical, school and community referrals; and created a study-specific Facebook page.

Seventeen individuals contacted us about the study; however, six did not meet eligibility criteria, one moved, and three chose not to participate. (See [Dababnah et al., 2021] for further information.) Thus, seven caregivers, all

mothers who identified as Black (including one who also identified as Asian), participated (Table 1). Most participants had a high school education or less ($n = 5$), were unemployed ($n = 4$), or had annual household incomes less than \$35 000 ($n = 4$). The majority lived with a partner ($n = 3$) or were married ($n = 2$), while the remaining two were single. The participants all reported their children had an autism diagnosis. As parent report is generally accurate (Daniels et al., 2012), we did not administer the standardized autism screening tools for inclusion of any participants. The autistic children were on average 5 years old and majority male ($n = 5$).

We recruited peer mentors, who we referred to as Parent Leaders (PLs), through our community-based advisory board and other local connections. PLs met the same inclusion criteria as participants (i.e., residence in target Baltimore neighborhood, primary caregiver of Black autistic child); however, the children of PLs were required to be 9 years or older. Ultimately, our program team trained five PLs, all mothers, to deliver *PTA*. We held two days of in-person, group training (16 hours) for four PLs, which focused on the first half of the program. (We trained one PL, who was hired later, individually in person). As we recruited participants, we matched them with one of three PLs (as two withdrew due to work scheduling conflicts), with consideration of various factors (e.g., schedule, neighborhood location, family structure, child characteristics). Once the PLs began to deliver *PTA*, we then trained them individually in person over one day (8 hours) on the second part of the program, to follow up on their engagement with parents and the remainder of *PTA* content. We regularly checked in with PLs if we had any concerns, or likewise if they expressed any problem on their post-session fidelity checklist.

Procedures

Research procedures

The first author met each PL and reviewed the intervention and research procedures. Each PL consented to join the study and provide two sources of data (fidelity and interview). While we did not compensate PLs for completing measures, we paid them for their time to participate in the trainings and deliver the intervention. Once a potential participant contacted the research team, we screened participants individually using a checklist of eligibility criteria, reviewed program information, and obtained informed consent. Then, a research team member scheduled a time to collect baseline questionnaires in person in an interview format. The research team collected post-intervention measures and conducted

TABLE 1 Participant sample characteristics

Variable	n (%)	M (SD)
Parent characteristics (<i>N</i> = 7) ^a		
Race and ethnicity ^b		
Black or African American	7 (100)	
Asian	1 (12.5)	
Marital status		
Never married	2 (28.6)	
Living with someone	3 (42.9)	
Married	2 (28.6)	
Highest education completed		
Less than high school	1 (14.3)	
High school	4 (57.1)	
Graduate/professional school	2 (28.6)	
Employment status		
Employed full-time	3 (42.9)	
Unemployed	4 (57.1)	
Income		
<\$5000	2 (28.6)	
\$20 000–24 999	1 (14.3)	
\$30 000–34 999	1 (14.3)	
\$35 000–39 999	1 (14.3)	
\$50 000–59 999	1 (14.3)	
Decline to answer	1 (14.3)	
Number of children in household		2.89 (1.57)
Autistic child characteristics (<i>N</i> = 7) ^c		
Gender		
Male	5 (71.4)	
Female	2 (28.6)	
Age, in years		5.25 (1.83)
Race and ethnicity ^b		
Black or African American	7 (100)	
Child age at first caregiver developmental concerns, in months		14.75 (7.57)
Child age at autism diagnosis, in months		44.38 (17.14)
Parent-reported child verbal abilities		
Nonverbal	1 (14.3)	
Single words	2 (28.6)	
Simple phrases	3 (42.9)	
Simple sentences	1 (14.3)	

^aAll caregivers reported they were mothers to the child with autism.

^bMore than one response allowed; thus, percentages might not add to 100%.

^cSix mothers had one autistic child; one mother had two autistic children, but only reported on one.

interviews after completion of their last *PTA* session via video conference due to the COVID-19 pandemic. Participants received up to \$100 for completion of all measures.

Intervention procedures

PLs delivered *PTA* to participants sequentially in one-on-one sessions that took approximately two hours each. We recommended weekly meetings, but parents and PLs rescheduled with one another occasionally due to time conflicts. Participants received a parent manual (containing *PTA* content and homework materials, such as behavior charts) and a resource folder. PLs had a facilitator manual, resource folder, and iPad to show videos. While all PLs began program delivery in person (usually in parents' homes), some parents later began to request meeting by video chat when they had scheduling conflicts. All parents had met with their PL in person at least once by the time we moved entirely to virtual delivery due to the COVID-19 pandemic in March 2020. We ended program delivery due to funding restrictions in August 2020. Only three of the seven parents completed all *PTA* sessions by this time. On average, the participants completed 9.6 out of 14 sessions (range: 4–14). Cancellations and missed appointments were common; extensive details on participants' attendance can be found in (Dababnah et al., 2021).

Measures

Fidelity checklist

Each PL completed an online, *PTA*-specific form after every session with a checklist of 15 yes/no items on preparation, program delivery, and follow-up (see Table 2 for items). The checklist was developed for the original *PTA* program (Magaña et al., 2020). We did not modify the checklist for the present study as the items were relevant to implementation of the protocol adapted for Black families. The form also had a space to record notes about session content, participant needs (e.g., housing assistance), and/or PL requests (e.g., additional program materials). In addition, our research team observed two *PTA* sessions per family and completed the same 15-item checklist, as well as observation notes as needed.

Acceptability measure

Parents completed the 15-item Social Validity Questionnaire (SVQ; Magaña et al., 2017) to measure *PTA*

TABLE 2 Fidelity assessment

	Parent leader-reported fidelity (M %)	Research team-observed fidelity (M %)
1. I was prepared and brought all required materials to the home visit.	100	100
2. I began home visit with a warm greeting and “check in.”	100	100
3. I gave parent the opportunity to report on the homework assignment.	97	100
4. I provided parent with positive feedback and helped them problem-solve any issues with homework.	100	100
5. I followed up with parent on questions from previous home visit (if applicable).	100	N/A ^a
6. I reviewed objectives of the session.	100	83
7. I presented information (from the manual or DVD) to explain the key points of the intervention/practice.	100	100
8. I encouraged discussion, comments, questions, and concerns by using questions, examples and dialogue.	100	100
9. I engaged the parent in activities from the manual (if applicable).	100	100
10. I noted down questions I was unable to answer and let the parent know that I will consult and follow-up.	100	0
11. I explained clearly this visit's homework assignment.	98	50
12. I helped parents problem solve when and how to complete the homework assignment.	100	100
13. I interacted with parent in a nonjudgmental and constructive manner.	100	100
14. I did not attempt to provide counseling, but offered professional resources for parent when needed.	100	100
15. I covered all of the content from the session within timeframe.	98	100
Total fidelity scores, mean %	98	95

Note: “Non-applicable” response was not included in calculation.

^aObserver checked “not applicable” to all participants.

acceptability at post-intervention only (see Table 3 for items). The six response options ranged from “strongly disagree” to “strongly agree.” The maximum total score is 90, and the reliability was $\alpha = 0.57$.

Pre–post quantitative measures

In addition to baseline demographic data, *PTA* participants completed five pre- and post-program quantitative measures. We used freely available measures to reduce the burden on agencies and community organizations to incorporate evaluation into future *PTA* delivery.

Maternal Autism Knowledge Questionnaire (MAKQ; Kuhn & Carter, 2006)

This 41-item measure assesses knowledge about autism diagnosis, symptoms, treatments and interventions, and etiology. The answer choices are “true,” “false,” or “do

not know.” An example “false” item is, “Children with autism cannot show affection.” Scores range from zero to 41, with higher scores indicating more knowledge. Reliability for our sample was $\alpha = 0.80$.

Autism Parenting Stress Index (APSI; Silva & Schalock, 2012)

The 13-item APSI measures parent stress related to core autism symptoms, and comorbid behavioral and physical issues. The five answer options range from “not stressful” to “so stressful sometimes we feel we cannot cope.” An example item is “sleep problems.” Scores range from zero to 45. Higher scores indicate higher levels of stress. Our sample alpha was 0.94.

Center for Epidemiological Studies-Depression (CES-D; Radloff, 1977)

The 20-item CES-D measures depressive affect, somatic symptoms, positive affect, and interpersonal relations.



TABLE 3 Acceptability of intervention strategies; Social Validity Questionnaire

	<i>M</i> (<i>SD</i>)
1. Given the learning needs and behavior problems of my child, I found the intervention strategies acceptable.	5.6 (0.89)
2. I am willing to carry out these intervention strategies.	5.6 (0.89)
3. I think there may be disadvantages to the intervention strategies. ^a	4.2 (1.30)
4. The amount of time needed to implement these intervention strategies is acceptable.	5.8 (0.45)
5. I am confident that the intervention strategies will be effective for my child.	5.6 (0.89)
6. I think these intervention strategies may produce permanent improvements in my child's behavior.	5.8 (0.45)
7. I think it will be disruptive to our home life to carry out these intervention strategies. ^a	5.6 (0.55)
8. I like the procedures used in the intervention strategies.	6.0 (0.00)
9. Other people in the household would like to help carry out these intervention strategies.	4.8 (0.84)
10. I think there will be undesirable secondary effects when using these intervention strategies. ^a	5.0 (1.22)
11. I think my child will experience discomfort during these intervention strategies. ^a	5.0 (2.24)
12. I am willing to change our routine in order to carry out these intervention strategies.	5.2 (1.30)
13. These intervention strategies will fit in with our actual routine.	5.2 (0.84)
14. These intervention strategies will probably teach my child appropriate behaviors.	5.6 (0.89)
15. The goal of these intervention strategies fit in with my goals to improve my child's behavior.	5.8 (0.45)
Total acceptability scores	80.8 (5.54)

^aReverse code.

The four response choices range from “rarely or none of the time” to “most or all of the time.” An example item is “My sleep was restless.” The maximum score is 60, with higher scores indicating higher levels of depression. Our sample alpha was 0.81.

Family Outcomes Survey-Revised (FOS-R; Bailey et al., 2011)

The 24-item FOS-R, used in previous *PTA* studies (Magaña et al., 2017, 2020), measures five outcomes: (1) “understanding your child’s strengths, needs, and

abilities”; (2) “knowing your rights and advocating for your child”; (3) “helping your child develop and learn”; (4) “having support systems”; and (5) “accessing the community.” The five response items ranged from “not at all” to “completely.” An example item is “I am able to tell when my child is making progress.” Our sample alphas ranged from 0.73 to 0.91 on the five subscales.

Nisonger Child Behavior Rating Form (NCBRF; Aman, 1996)

The NCBRF asks parents to report on their child's behavior in the past month. The two social competence subscales (10 items) are “compliant/calm” and “adaptive social.” The four response choices range from “not true” to “completely or always true.” An example item is “shared with or helped others.” The six problem behavior subscales (66 items) include “conduct problem,” “insecure/anxious,” “hyperactive,” “self-injury/stereotypic,” “self-isolated/ritualistic,” and “overly sensitive.” The four answer choices range from “did not occur” to “a lot.” An example item is “argues with parents, teachers, or other adults.” Subscale alphas ranged from 0.81 to 0.95.

Post-program interviews

Research team members conducted one-on-one interviews with all parents and two PLs after they participated in *PTA*. (We were unable to reach the third PL.) We used a semi-structured, six-question interview guide (available upon request from first author), adapted for this study from our previous research (Dababnah & Parish, 2016), to solicit feedback on helpful program content and areas in need of improvement. The interviews lasted on average 28 minutes, ranging from 11 to 46 minutes.

Data analysis

We used SPSS v.26 to analyze our quantitative data and NVIVO for the qualitative data. We summarize our analytic approaches below for each set of data.

Quantitative data (pre-post measures and fidelity checklists)

We used an intent-to-treat analysis, which included all participants who started the intervention regardless of whether they completed all sessions. As stated earlier, only three participants completed all sessions; however, we obtained pre- and post-intervention data and conducted interviews with all participants. We used descriptive statistics to analyze

participants' baseline demographics, acceptability, and the closed-ended items on the fidelity checklists. We utilized Wilcoxon rank sum tests to evaluate pre-post-program changes on our five standardized measures. We considered a p -value of less than 0.05 statistically significant. However, because the sample size was too small to detect most differences, we also calculated effect sizes (Cohen's d), which may be more meaningful in interpreting results (Ferguson, 2009).

Qualitative data (interviews and fidelity checklists and observations)

Each digitally recorded interview with participants and PLs was professionally transcribed. Two research team members reviewed each transcript before uploading them and interview field notes into NVIVO. In addition, we uploaded research team members' written fidelity observations, as well as PLs' open-ended responses on their fidelity checklists. We used a modified grounded theory approach (Corbin & Strauss, 2015) to analyze these data. The first author developed and refined an initial codebook. To do this, she used an open coding strategy, whereby she coded words and short phrases relevant to the research questions. Through an iterative process, she inspected the data multiple times to refine the codebook. She then met with the second author to discuss the codebook and the relationship between codes, returning to the data several times to explore areas of concordance or divergence. Finally, the first author discussed the themes with the second and third authors before completing the analyses.

To increase the trustworthiness of the data, the first author maintained memos about codes and emerging themes throughout the process to create an audit trail of analytic decisions. We also actively looked for responses that did not align with emerging themes, in order to identify areas of divergence. Finally, we note that all researchers involved in data collection and analysis were social work professionals, women, and members of racially or ethnically minoritized communities. We discussed our professional and personal positionality with respect to the participants and perception of the findings throughout these processes.

RESULTS

Fidelity of program delivery

PLs' average fidelity score from their self-reported post-session checklists was 98% (Table 2). Similarly, researchers recorded an average 95% fidelity score during

their observations. Below, we summarize emerging themes from researchers' fidelity observations, which were overall consistent with high reported program fidelity on the checklists.

In terms of delivery methods, even prior to the COVID-19 pandemic, parents and PLs began to meet online at times due to frequent cancellations. For example, online meetings enabled a working parent to meet her PL during weekday lunchtimes. We observed a home visit and an online session for the same participant and did not note any fidelity differences. We also observed that online meetings offered some flexibility. For example, when a parent did not come on time for an online session, the PL contacted the parent and learned the parent had scheduled the time wrong. Rather than canceling, they held the meeting 1 hour later.

All PLs were well-prepared with required program materials (i.e., manual, tablet, resource folder). They appeared familiar with the content, although they delivered it differently. For example, two PLs read manuals nearly verbatim, while one PL summarized the content in some areas. Participants seemed satisfied with both approaches.

PLs all actively engaged parents by encouraging questions and discussion. PLs often shared their experiences in response to parents' questions. For example, one parent asked how to communicate with their child while she is cooking, and the PL offered her strategies. Yet, we observed times when PLs did not follow up on questions or explain homework clearly (Table 2).

Finally, we noticed some factors occasionally distracted parents and PLs during program delivery. For example, young children at times required parents' attention during PLs' home visits. Furthermore, technical issues (e.g., internet instability) delayed some online sessions.

Acceptability of intervention strategies

Participants overall were highly satisfied with the intervention strategies, with an average total SVQ score of 80.8 (Table 3). Participants rated most SVQ items five points or above out of six points ("agree" to "strongly agree"). Consistent with their SVQ responses, nearly every interviewee said they felt an appropriate amount of time was dedicated to each topic. For example, one parent remarked, "[My PL and I] would work on [session content] that week and then we would come back next week, go over it as an overview, and then add to something else. I liked that, because ...it takes [children] time to pick up on things." Likewise, a PL noted it was important to organize the content into sections and provide examples, saying:



[The speed] felt fine for me, because ...in any of the sections where it seemed like it was super information heavy ...there were bullets ...to give the gist of what it was we were discussing. There's examples there that were really good to just couple with whatever the headings or the topic is to help keep going and getting the gist of what we are covering in that specific section without losing the parent ...

While most parents were satisfied with the program's speed, one parent commented the sessions were not equally divided, saying: "Some of the topics took maybe twice as long as the different sessions ...sometimes we had to split them up and do a two- or three-part session for one session." This parent added, "[My PL and I] adjusted and if we felt like we needed to spend more time on something, we did." Similarly, a PL emphasized adjusting content as needed:

Sometimes when I would go over chapters, especially the ones that were speaking when your child's nonverbal and it would go into great detail. That always helped the children that were nonverbal. But, I did have some parents that their child was verbal and spoke very well. So, I kind of would skip some of those, but I just did not want them to feel that I was rushing through it, but I kind of let them know, "Well, this is for nonverbal and it really doesn't apply to your child. So we'll just skip to this section."

This PL noted it was important for her to go through the content as written and adjust as necessary, as "Everything builds up so it's almost like you can't really leave something out."

Interviewees also identified factors that improved their access to program content. Some mentioned how having their own manual, which included homework assignments, facilitated their learning. They discussed how they used the manual between sessions, including during visits with their child's providers. One mother said: "I tried to use all the strategies that was in the book. And from time to time, I'll go and look in the book ...And some stuff I wrote down as well when we were talking" A PL suggested that in addition to the manual's glossary, the manual would be more accessible with definitions in the main text, saying:

It's not that we need to change the words ... because this is the language that the schools would use when they discuss the child and

the doctors might use it. But maybe in parentheses, putting a definition just to help the parents know what that word is, even when they go back and read it even on their own time.

Finally, interviewees made suggestions to improve *PTA*. Some noted the lack of "tangibles" was a barrier for them, as one mother explained about social stories:

[My PL and I] had brainstormed a few ideas that could probably help [my son]. But actually going through and trying to get pictures of bath time and then haircuts and trying to put it together within the week between the sessions was ...just difficult to get started. And it was something that we thought could really help him The ball was completely in my court....I'm not sure, maybe bringing a camera to the session So we could be like...here's his actual tub just to get started, because I did not have a way of doing so.

A PL made a similar comment about creating social stories and schedules, and suggested, "If we could leave materials [at parents' homes], I think that would have brought it a step further and maybe even they would have been able to utilize that information better and maybe make it like a homework assignment." Another parent recommended to "include [their children, including siblings] in some games or something that they can better understand" in the play-focused sessions. Lastly, a parent provided a suggestion for homework, saying:

[Homework] was helpful when I did not treat it like homework Because there were things where it was like, "Okay, we'll try to do this ... and then next time we meet we'll go over the results of how they went." So when just trying to treat it as an assignment from therapy, as opposed to this is willy-nilly gig where you can cancel, if there's a problem Homework is school. Just treat them more like it was therapeutic or therapy... That helped me with submitting everything that we had to do.

Pre-post child, parent, and family outcomes

We collected five pre-post measures from participating parents ($n = 7$; Table 4). We also interviewed the parents and two PLs and analyzed open-ended responses from

TABLE 4 Pre–post changes in outcome variables

Outcome variables	Pre-test M (SD)	Post-test M (SD)	Wilcoxon rank sum	p value	Cohen's d
Autism knowledge	26.71 (5.59)	29.71 (3.82)	−2.04	.04	0.78
Autism parenting stress	24.57 (18.46)	24.86 (16.88)	−0.32	.75	0.10
Depression	19.50 (12.61)	15.00 (7.29)	−0.52	.60	−0.35
Family outcome total score	83.67 (20.69)	98.67 (14.07)	−1.75	.08	0.80
Understanding child's strengths, needs, and abilities	15.83 (3.31)	16.83 (2.64)	−1.47	.14	0.65
Knowing rights and advocating for child	15.33 (4.59)	22.00 (3.22)	−2.21	.03	1.61
Helping child develop and learn	15.67 (4.80)	15.17 (2.64)	−0.18	.85	−0.11
Having support systems	17.00 (6.54)	19.83 (4.36)	−0.63	.53	0.35
Accessing the community	19.83 (6.79)	24.83 (4.96)	−1.63	.10	0.81
Child behavior challenges					
Social competence total score	14.50 (7.82)	20.50 (5.50)	−1.99	.045	1.96
Compliant/calm	9.33 (4.08)	12.33 (3.08)	−2.03	.04	0.99
Adaptive social	5.17 (3.82)	8.17 (2.56)	−2.00	.046	0.91
Problem behavior total score	58.00 (34.94)	46.17 (29.00)	−0.84	.40	−0.42
Conduct problems	16.17 (11.29)	11.33 (10.84)	−1.36	.18	−0.52
Insecure/anxious	5.50 (6.44)	5.50 (5.89)	−0.74	.46	0.00
Hyperactive	17.17 (11.29)	14.17 (9.66)	−0.84	.40	−0.38
Self-injury/stereotypic	2.00 (2.45)	1.83 (2.56)	−0.18	.85	−0.07
Self-isolated/ritualistic	9.00 (5.83)	6.33 (3.20)	−0.95	.34	−0.47
Overly sensitive	8.17 (5.53)	7.00 (3.58)	−1.22	.22	−0.55

the self-reported fidelity checklists of all three PLs, to identify additional feedback on these content areas and related program outcomes. We present the integrated quantitative and qualitative results below.

Autism knowledge

All interviewees referred to gains in autism knowledge after participating in *PTA* in post-program interviews. Likewise, there was an average three-point increase in autism knowledge on the MAKQ between pre- and post-test, which was statistically significant ($p = 0.04$), there was a medium to large effect size (Cohen's $d = 0.78$; Table 4). In the post-program interview, one mother identified her primary motivation to join *PTA* was “to learn as much as I can possible to help [my child].” A PL also emphasized the importance of building parents' knowledge:

Like I always discuss with the parents...the speech therapist, the occupational therapist, special educators, they go to school and they learn about autism. They learn about

evidence-based practices and yet when we have a child and the doctor diagnoses that child with autism, that's it. That's the only thing we get is that diagnosis and the label. We do not get any of the educational pieces that specialists get.

Several interviewees mentioned diagnostic delays and poor service access, and one parent summarized how improved autism education could reduce delays and misdiagnoses and increase early intervention:

... different kids are being left behind, and finding out late, and they're getting the wrong diagnosis for things. Kids these days are getting ADD or this and that ...and that's not what it is. But people are not educated on it, and since they're not educated on it, they just give any diagnosis. And I feel [*PTA*] gives people a chance to know ...to get the help that they need ...

Nearly all of the parents said they did not have pre-existing information on autism. One parent explained she



“learn[ed] different strategies to help with my son, autism, a lot of the things I didn’t know [Clinicians] didn’t...give me details about autism. Once I found out that [child] had autism, so I kind of learned more from [PTA] than I did from the actual doctor.” Furthermore, a PL elaborated on how she felt the program created a space to correct misinformation and to empathize with parents:

[A participant] didn’t know what autism was and is still learning. She asked what causes it, but I had to explain that, unfortunately, they still don’t know what causes autism, but research is still ongoing. Of course, she asked if I thought it was related to the vaccinations. I told her that I have heard that, but do not believe that is the cause. I could feel her pain because she said every day, she tries to figure out what she did wrong during her pregnancy to cause autism. I explained to her that my son is [an adult] and I still do that to this day, but I told her that we need to leave the past in the past and focus on today.

Some interviewees discussed autism-related stigma in the Black community, and how stigma might lead to service delays. For example, one parent believed the program content could help parents to learn how to support their child early to “live the life that [their children] need to live ...so [parents] don’t have to feel embarrassed about their child, because that’s one thing I’ll never be, is embarrassed about any of my child’s needs or stipulations.” One PL explained how *PTA* helped her to support parents to address stigma and utilize their knowledge when speaking with providers, “When discussing other myths about autism that aren’t accurate, we discussed the public’s perception of autism and mental health especially in the Black communities [and ...] how she could use [the session’s home activity] to communicate with anyone taking care of her son ...” Likewise, a parent mentioned how she used her increased knowledge on autism to share information with others, given “a lot of people don’t believe you ...They tell you, ‘You’re self-diagnosing ...’”

Interviewees identified a cascade effect of sharing knowledge with others raising autistic children. A PL gave an example of four parents participating in *PTA*: “The word gets around, so you can imagine if they tell at least three people their experiences or what they learned. So now, we have 12 people that didn’t know about the information.” Similarly, a parent said, “... the information that ...I’m taking away from this, even if I know someone doesn’t know about *PTA*, I’m going to

pass the information along because it’s valuable, very valuable.”

Parent stress and depression

Our pre–post measures revealed almost no change on parenting stress, and a non-statistically significant decrease in depressive symptoms (Table 4). However, we found a small to moderate effect size for the change in depressive symptoms ($d = -0.35$). The change may be even more meaningful on a clinical level, as the mean was reduced from 19.5 to 15.0, and a score of 16 and above is suggested as a cutoff for risk of serious depression (Radloff, 1977). While few interviewees discussed stress or depression, one PL noted the stress content seemed especially relevant during the COVID-19 pandemic when “we are stuck at home with all the kids.” A parent observed that while the stress and depression session was not child-focused, that it might still help children, explaining:

[The session] definitely, definitely helped me help [child], by de-stressing, because then if I’m not stressed, he can feel, “Oh okay, well I know there’s something wrong. I know I’m not doing something right, but mommy’s not yelling at me like she used to do. I guess I can focus on her, and actually listen to what she’s saying, instead of her yelling at me, getting frustrated, and then having a temper tantrum.”

Family outcomes

Parents on average reported pre-post improvements on four of the five subscales of the FOS-R, with an improvement in the total score and a large effect size ($d = 0.80$; Table 4). Only the “knowing your rights and advocating for child” subscale was statistically significant ($p = 0.03$), which also had a large effect size ($d = 1.61$). Some interviewees related their increased knowledge to more confidence advocating for their children. As one parent described, “[*PTA*] gave me things that I didn’t know about, so that I could research and get information that I need I was able to figure out a lot of stuff and keep pushing.” Interviewees commonly cited obtaining service referrals from *PTA* program staff, which helped them to advocate for increased services. As one parent said, “[*PTA*] helped me find four to five other programs to get myself into and to learn. So it’s not going to stop here, and that’s what I appreciate about it.” *PTA* content also

clarified information they received from clinicians. As one parent described, “[My child’s] therapist tells me how to put things together, but doing it with [my PL] just brought it together, instead of just saying, ‘Oh, this is this pamphlet.’” Many interviewees discussed problems obtaining school-based supports, and some noted they used program strategies to advocate for their child, including one PL who said, “I personally ...pulled [the advocacy] information from our books and used it in our IEP meeting. [And ...] at least two of the parents used that information during their IEP meetings and they were able to get better services for their child.”

In addition to knowledge on advocacy, some parents referenced the content on neurodiversity, particularly related to recognition of a child’s strengths and acceptance of their challenges. One parent identified the “lesson on acceptability for your child, and trying to get other people to accept your child,” as important, explaining:

I’ve been in multiple situations where people are nasty to [child], just because they don’t understand. They think he’s ...just having a meltdown, and you’re a bad parent, and you need to discipline your child. That lesson was great, about how to get people, adults, and children, to understand who he is as a person.

Another parent discussed how the program’s lifespan approach, in which participants learn from parents of older children and are introduced in the first session to an autistic adult helped to understand and anticipate her child’s needs:

So when we were going through the steps and learning ...from the beginning of childhood up until when they’re older. I appreciate that because ...it opens my eyes up a little bit more of what I may have to deal with down the line ...[Clinics] they only give [information] to you by the age of the child, they don’t give it to you before. So with [PTA], they give you a little bit more help to know what you would have to deal with, so that you could prepare yourself.

Child behavior

We found statistically significant changes in parent-reported child behavior on the social competence ($p = 0.045$), but not problem behavior ($p = 0.40$)

domains of the NCBRF (Table 4). The data showed a large effect size for the social competence total score ($d = 1.96$) and a small to medium effect for the problem behavior score ($d = -0.42$). The largest improvement was on the “compliant/calm” subscale, which was statistically significant ($p = 0.04$) and showed a large effect size ($d = 0.99$). We also identified a large effect size for improvement in adaptive social behavior ($d = 0.91$), which also was statistically significant ($p = 0.046$). We found small to medium effect sizes for reductions in conduct problems, self-isolated/ritualistic behavior, and overly sensitive behavior. Consistent with these findings, several parents mentioned the most helpful part of the program for them was learning how to address frequent child “temper tantrums” and “meltdowns.” One parent gave an example:

There’s a sheet [in PTA manual] ...which helped me track his meltdowns, that was very helpful as well, that was a huge help. Looking before, and after his meltdown, or a temper tantrum, to pinpoint what exactly happened for him to have this. Sometimes it’s not even me, or his brother, sometimes he’ll just stand, and yell, and cry, and I’m in another room, and I’m like, “Well, what’s going on?” That chart has been really helpful, and I also told [PL], I was like, “Thank you so much for having this chart, and helping me with this, and explaining it to me.” It definitely helped me help him a lot better.

In addition to tracking challenging behaviors, some interviewees mentioned how they began to understand their child was trying to communicate with their behavior. One PL described her work with a parent whose son had difficult behaviors:

It was so nice to read that chapter that stated those behavioral issues are his way of communicating because they are nonverbal, because they can’t communicate their wants and needs. So knowing that was so refreshing. Then that chapter also discussed ways to work with the child. So, when he does have those behaviors, you can actually show them and turn it around to show them a way that they can communicate. So just all of that education was eye-opening, bells, angels singing.

Additionally, one parent mentioned how the content on social situations helped her to support her son to connect with other children.

DISCUSSION

Summary of findings

The purpose of this study was to determine if a version of *PTA* adapted for Black families using a community-based process (Dababnah et al., 2021) can be implemented with fidelity, is acceptable to participants, and results in changes in parent-reported outcomes between pre- and post-intervention. With respect to the first research question, we found that PLs maintained high fidelity scores with few differences between PL and research team member ratings. We observed that PLs covered content appropriately, interacted with participants, used their own examples, were well-prepared, and creatively addressed cancellations. PLs might need follow-up training to address parents' questions and explain homework clearly.

We next examined *PTA* acceptability. We found that participants rated the intervention strategies highly for their child and family. Qualitative interviews revealed similar themes, indicating that participants jointly worked with the PL on goals, reviewed progress each week, and adjusted objectives as needed. They also reported PLs were adept at organizing content to balance out those sessions that were more content heavy, which we noted in the observations when PLs varied their delivery methods. Parents provided suggestions for future *PTA* implementation, such as providing more materials (e.g., visual schedules) and incorporating children in play-related sessions.

Our third research question asked whether there was change after the intervention on parent-reported outcomes. We found that parents' autism knowledge improved, as evidenced by statistically significant pre-post improvement, a moderate effect size, and substantial expression of knowledge gains in interviews. While we did not find improvements in the parenting stress measure, the reduction in depressive symptoms may be clinically meaningful (Radloff, 1977). Interviewees expressed the importance of the content on reducing stress and in tempering parents' reactions to their child's behaviors. With respect to family outcomes, domains that showed significant change (as evidenced by large effect sizes) related to knowing their child's rights and accessing the community. Interviews revealed that participants felt more confident advocating for their children and knowing how to research information that would help them advocate. Finally, we found parents reported that children's compliant/calm and adaptive social behaviors improved, and most problem behaviors decreased. While only the social competence domain and subscales were statistically significant, most subscales had small to large effect sizes. Similarly,

interviewees articulated the importance and helpfulness of behavioral strategies.

Key findings in context

While there is a small body of research emerging focused on culturally relevant autism intervention research (Jamison et al., 2017; Pearson & Meadan, 2021), this is the first study to our knowledge that has tested a peer-to-peer intervention culturally adapted exclusively for parents of Black autistic children. As we previously reported (Dababnah et al., 2021), recruitment to our study was challenging, and we identified several barriers, including Black caregivers' distrust of research (Shaia et al., 2020) and reluctance to join or refer others due to stigma about autism in Black communities (Burkett et al., 2015; Dababnah et al., 2018). PLs in our study experienced high cancellation and low program completion rates from participants. As a result, flexibility was important, including rescheduling home visits and utilizing virtual options. This is consistent with an effort to adapt a parent education program for low-income parents of autistic children, which recommended flexible scheduling and home visiting to increase adherence (Carr & Lord, 2016). Despite these challenges, parents reported high satisfaction levels with the intervention, and we saw meaningful pre- and post-intervention gains on parent-reported outcomes. Interviews provided more specific evidence on program benefits. Other studies that engaged low-resource families similarly reported small sample sizes with modest, but promising gains (Kasari et al., 2014; Meadan et al., 2020). Parents in the present study rated the social validity of intervention strategies relatively high, like those in the *PTA* pilot study conducted with Latinx parents (Magaña et al., 2017). An important finding in the present study was that parents reported significant differences pre- and post-intervention on knowing their child's rights, which qualitative interviews corroborated. Likewise, in the original *PTA* pilot study with Latinx parents, knowing that they had a right to ask for services, what to ask for, and how to advocate were important parent-reported outcomes (Magaña et al., 2017).

This study provides further support for the community-based approach of using peers to deliver a parenting intervention for Black families. Study participants expressed satisfaction with the relationships they developed and how their PLs guided them through the process. Their engagement with PLs is similar to those described by Latinx parents who received *PTA* (Magaña et al., 2017), as well as in other peer-to-peer programs for children with disabilities (Bray et al., 2017). As noted in our previous article (Dababnah et al., 2021), creating opportunities for parents

to connect with one another might further build peer relationships and increase collective efficacy to address unique stressors impacting racially minoritized communities. Another notable finding is the overall strong fidelity of the PLs in this study, providing additional evidence of the capacity of non-professionals to deliver an intervention.

Limitations

An important limitation is the small sample size, which did not allow us to detect most pre-post-intervention changes and limited the generalizability of findings. Using effect sizes allowed us to determine what changes may be meaningful and could be statistically significant in a future study with a larger sample. In addition, our acceptability measure had a low alpha; thus, future research should investigate how to improve the measure's reliability. Further, the COVID-19 pandemic interrupted this study during program delivery. It is unclear how the effects of the pandemic impacted participants' outcomes. Additionally, because we recruited participants from a specific region of the country, we cannot generalize results to all parents of Black autistic children. Another limitation is that the study design was a single arm, thus not allowing us to determine if results differed compared with a control group. Single-arm studies provide an important step toward developing and testing interventions by providing data about outcomes, but cannot be interpreted as evidence of effectiveness as they do not account for threats to external validity. Furthermore, despite efforts to assure participants that we wanted their honest feedback, it is possible that social desirability bias led to overly positive responses. Finally, we note that some parents did not complete the full program within the study period. Future studies should consider methods to engage a broader array of primary family caregivers and identify barriers to full participation.

Practice Implications

Cultural adaptation is an iterative process. One purpose of conducting a pilot study of a cultural adaptation is to identify areas of practice improvement. In our previous article, we detailed the barriers and facilitators of the intervention that will also be considered in the next *PTA* iteration (Dababnah et al., 2021). In this study, participants offered additional suggestions, such as tailoring materials needed to implement strategies that could be left with parents, balancing the content across sessions, and reframing “homework” so parents understand that this is part of the treatment versus a school-like activity.

Furthermore, our findings revealed that while PLs overall delivered *PTA* with fidelity, follow-up training and support might be helpful. Finally, we identified promising gains in most outcomes; however, we did not find expected improvements in parenting stress. This finding may have been related to the impact of the COVID-19 pandemic on study participants' stress. Future studies should examine if program modifications are needed to strengthen content on stress reduction.

Directions for future research

This study provided promising preliminary evidence for a parenting intervention developed for parents of Black autistic children. It demonstrated that using peer-interventionists, maintaining flexibility, and delivering culturally and practically relevant content are key strategies to better support this population. The findings from this study will contribute to knowing what outcomes may show promise in research with a larger sample. The next steps for future studies are to further adapt the intervention and test its efficacy with a larger, more diverse sample and a randomized controlled trial.

ACKNOWLEDGMENTS

We are indebted to our community advisory board, who provided us with their expertise and time in the adaptation and delivery of this intervention. We also deeply appreciate the participants and Parent Leaders in this study, who provided us with extensive program feedback. We also acknowledge the important contributions of Dr. Wendy Shaia, Raven Ormond, and Dana Hussein, who were essential in every aspect of the adaptation and program delivery processes. Finally, we note the financial support of a Competitive Innovative Research Award from the University of Maryland School of Social Work.

CONFLICT OF INTEREST

We do not have any conflicts of interest related to this study.

AUTHOR CONTRIBUTIONS

Sarah Dababnah was the Principal Investigator of this study. She led the research processes and manuscript preparation. Irang Kim managed data collection and analyses, along with Sarah Dababnah. Irang Kim co-authored the methods and results sections of the manuscript. Sandy Magaña was a study consultant, and wrote the discussion section and provided critical feedback on the manuscript. Yan Zhu co-authored the introduction section of the manuscript. All authors reviewed complete drafts of the manuscript and approved the final version.



ETHICS STATEMENT

We received approval from the Institutional Review Board at the University of Maryland, Baltimore, to conduct this study. All participants gave informed consent to join the research.

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How to cite this article: Dababnah, S., Kim, I., Magaña, S., & Zhu, Y. (2022). *Parents taking action adapted to parents of Black autistic children: Pilot results. Journal of Policy and Practice in Intellectual Disabilities*, 1–15. <https://doi.org/10.1111/jppi.12423>