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Understanding the Effectiveness and Feasibility of a Navigator Program for Parents of Autistic Children

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Abstract

Systems navigation can be difficult, especially for low-resourced families (i.e., families who are "low income" or meet one of the following indicators: mother has a high school diploma or less; primary caregiver is unemployed; or the family receives governmental assistance). Navigators may help families access services; however, the training of navigators is unclear. The purpose of this study was to determine the effectiveness and feasibility of Supporting Parents to Access and Navigate Services (SPANS), a program to develop navigators. Altogether, 19 low-resourced parents of autistic children participated in SPANS. Participants demonstrated significantly improved knowledge about autism services and perceived advocacy for other families and systemic change. There was high attendance, low attrition, high acceptability, and high fidelity. Implications are discussed.

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Understanding the Effectiveness and Feasibility of a Family Navigator Program for Parents of Children with Autism

Parent knowledge impacts *how* and *what* services their children with autism access (Burke, Patton & Lee, 2016). Unfortunately, it can be difficult for parents to learn how to navigate service delivery systems (Clark & Adams, 2020). Barriers to service access include: disparities in accurate and timely diagnoses (Pearson & Meadan, 2018); limited training about autism among healthcare providers and educators (Pearson & Meadan, 2018); and parents' limited resources and knowledge of autism and related services (Carr & Lord, 2016; Zuckerman et al., 2014). Without access to needed services, children with autism may regress in their skills (St. Amant et al., 2018).

Barriers to service access are especially prevalent among low-resourced families of children with autism. Kasari and colleagues (2014) defined “low-resourced” as being “low income” or having one of the following indicators: mother held a high school diploma or lower; primary caregiver was unemployed; or the family received governmental assistance. Low-resourced parents of autistic children face compounded and unique barriers including: service providers' limited understanding of families’ race, social class, and experiences (Blanchett et al., 2009), managing the competing needs of family members (Karp et al., 2018), language barriers (St. Amant et al., 2018), and financial limitations to pay for services (Singh & Bunyak, 2019).

Increasingly, family navigator programs have been used to improve access to services (e.g., Feinberg, Kuhn et al., 2021; Lopez et al., 2019; Magaña et al., 2021). A navigator is an individual who uses a case management approach to increase access to services over a time-limited period (Broder-Fingert et al., 2020). Navigators support families by conducting linguistic and cultural broking, meeting with families, identifying barriers, providing emotional support and coordinating care (Broder-Fingert et al., 2020). To support families in these ways, navigators may need several skills. Such skills may include being knowledgeable about service delivery systems, advocating with families to identify and overcome barriers, and being empowered to coordinate care. Family navigator programs have demonstrated positive outcomes such as early autism diagnoses among low-income and ethnic minority families (Feinberg, Augustyn et al., 2021), emotional support for families (Magaña et al., 2014), and improved knowledge about rights and increased access to services (Lopez et al., 2019). However, there is limited information about how navigators are developed to support families. For scalability, it is important to understand how to effectively prepare navigators—especially navigators who will address the unique and exacerbated barriers to service access among low-resourced families. Thus, the purpose of this study was to determine the preliminary effectiveness and feasibility of a navigator training program.

A navigator needs to be knowledgeable about available services. In a study of family navigators to expedite access to autism diagnostic services, the navigators were trained to be knowledgeable about autism diagnosis and treatment services (Broder-Fingert et al., 2020). In addition to being knowledgeable, a navigator also needs to be able to advocate for services. Families of children with autism face complex service delivery systems. Navigators must support families not only by helping them advocate (Jamison et al., 2017), but also by teaching families to advocate for themselves (Russa et al., 2015). Finally, a navigator needs to be empowered to coordinate care. Low-resourced families often face systemic barriers which may disempower them from actively seeking for services (Goldman et al., 2020). Similar to advocacy skills, navigators need to feel empowered to support families as well as help empower families to overcome such obstacles. Because of the time-limited nature of family navigators, it is important not only for navigators to be knowledgeable, able to advocate and empowered themselves but also to impart these skills on the families with whom they work.

Additionally, it is also important for a navigator training to be feasible. Feasibility includes an assessment of the target population and corresponding fit of the program via program evaluation (Goddard & Harding, 2003). For navigator programs, this may mean having high attendance and low attrition as well as being acceptable to participants (Burke, Goldman et al., 2016). In addition, a navigator training must have high fidelity (Broder-Fingert et al., 2018). To date, there is limited research about navigator programs; most research focuses on the effect of family navigation. Hospital social workers often act as family navigators. In some ways, social workers may be natural navigators given their professional training in helping individuals cope with challenges. Accordingly, no specific training may be provided to social workers to become navigators. However, social workers may not have the lived experience of raising an autistic child. Given the value of peer support, increasingly, there is an interest in having parents of children with disabilities serve as navigators (e.g., Magaña et al., 2014). Thus, navigator training is needed, and relatedly, it is important to gauge the feasibility of a navigator program to help ensure its successful application for the real world.

With navigator programs becoming increasingly common and navigators being written into legislation (Barth et al., 2020), it is important to understand how to effectively develop navigators. In this study, we explored the effectiveness and feasibility of the Supporting Parents to Access and Navigate Services (SPANS), a program geared to developing family navigators for low-resourced families of 3-5 year olds with autism. Specifically, the research questions were: (1) Among low-resourced parents of children with autism, to what extent did the navigator program increase their knowledge of services, perceived skills, perceived capacity, advocacy, and empowerment? And (2) Among low-resourced parents of children with autism, to what extent was the navigator program feasible with respect to attendance, attrition, acceptability and fidelity? We hypothesized that the program would lead to significant increases in knowledge of services, perceived skills, perceived capacity, advocacy, and empowerment. We also hypothesized that the program would have high attendance, low attrition, high satisfaction and high fidelity.

Method

Participants

To be included in this study, individuals needed to: have a child with autism who was older than 5 years of age and received an autism diagnosis from a healthcare provider, participate in the family navigator training, and identify as “low-resourced” (i.e., low-income and/or one of the following criteria: the mother had a high school diploma or less; the primary caregiver was unemployed; and/or the family received governmental assistance, Kasari et al., 2014). Because of the multi-pronged definition of “low-resourced”, not all participants may be “low-income”. Participation was limited to parents of children 5 years old and older to ensure that the participants had sufficient experience in navigating service delivery systems to, ultimately, help families of 3-5 year olds with autism. To determine the autism diagnosis, all participants met the cutoffs using the Social Communication Questionnaire (SCQ; Rutter et al., 2003) which was delivered by the study coordinator upon a participant inquiring about the study.

Altogether, 33 individuals contacted the study coordinator, met all of the inclusionary criteria, and signed the consent form to participate in the project. Before beginning the SPANS program, one participant withdrew from the study due to the time commitment for the SPANS program. Only 20 participants attended the first SPANS session. Specifically, seven of the participants indicated that they could not attend the time of the training (i.e., Tuesday mornings). Of these participants, many indicated that they would like to join the training in the future. One participant indicated she could not commit to such intensive training especially given the small stipend; she stated, “I love the idea of participating…[but] that is a lot of hours and work to commit to the program for the small stipend.” The other individuals did not provide a reason for their lack of participation.

In total, 19 participants completed all study requirements. Of note, there were no significant differences between the initial sample of 33 families and the final sample of 19 participants. Participants were from a midwestern state. On average, participants were 47.84 years of age (*SD* = 7.34, range from 31 to 62). Most participants were female (94.74%, *n* = 18) and married (68.42%, *n* = 13). Of the participants, most (63.16%, *n* = 12) reflected racial minority backgrounds. On average, most offspring with autism were male (68.42%, *n* = 13), and their mean age was 13.3 years (*SD* = 5.43, range from 5 to 22). See Table 1.

Recruitment

Participants were recruited through disability agencies and community organizations. Recruitment methods included word-of-mouth as well as sharing information about the study via social media, flyers and websites. To focus on recruiting low-resourced participants, disability agencies and community organizations that specifically served such families were targeted for recruitment. Such organizations included non-profits that support families of color of autistic children, agencies that serve families in low-income areas of the state, and professionals who work with families receiving governmental services. Notably, we offered to loan families devices and data plans to participate in the program. For their participation in the pre-survey, attending the navigator training, and completing the post-survey, each participant received a $100 giftcard.

Procedures

University Institutional Review Board approval was received for this study. Upon receiving information about the SPANS program, interested individuals contacted the research team. A researcher conducted a screening to ensure the individual met the inclusionary criteria. If the individual met the inclusionary criteria, the researcher sent the consent form, demographic questionnaire and pre-survey to the participant. At the end of each SPANS session, participants completed an anonymous, formative evaluation to provide feedback about the session. After all 12 SPANS sessions were completed, participants completed the post-survey and a summative evaluation.

The SPANS Program

The SPANS program consists of 24 hours of instruction about providing instrumental and affective support to navigate service delivery systems to support low-resourced families of 3-5 year olds with autism. The SPANS program was developed based on the extant literature about interventions to support families of autistic youth (e.g., Feinberg, Kuhn et al., 2021; Taylor et al., 2017). Twelve, low-resourced parents of youth with autism gave extensive feedback to inform the SPANS curriculum (Author, submitted). Specifically, the twelve parents participated in individual interviews as well as an advisory board meeting to voice their input. They reached consensus on relevant content for the program. As a result, we added content to the program (e.g., for health insurance, discussing dental care; for Medicaid waivers, discussing child and adult waivers). Notably, their input aligned with the core components of family navigation (e.g., they also reported the need for cultural and linguistic brokering, Broder-Fingert et al., 2020). SPANS topics include: school services; evidence-based treatment services for young children with autism; assistive technology; Supplemental Security Income (SSI) for children and their families; respite; child Medicaid waivers; health insurance; advocacy; identifying barriers to service access; establishing rapport with families; recreation and special recreation; and providing emotional support to families. See Table 2.

To focus on low-resourced families, the SPANS program included specific information. For example, programs specifically for low-income families were targeted for inclusion in the program. Such programs included SSI which rely on family household income thresholds. For other programs, SPANS reflected low-cost or free ways to access services. For example, for assistive technology, the curriculum reflected using private insurance to access technology, using Medicaid to access technology, and borrowing technology from the statewide assistance technology center. For content related to identifying barriers, the barriers were specific to low-resourced families.

The SPANS program was delivered via twelve, 2-hour weekly zoom sessions. The SPANS program was facilitated by two low-resourced parents of youth with autism. At the beginning of each session, a short introduction video (5-8 mins) was shared to provide an overview of that session. The facilitators then answered questions about the video. The facilitators introduced the local content expert for the session. The facilitators chose the local content experts-- professionals from relevant organizations (e.g., a representative from the state respite coalition to discuss respite). The content experts created their own presentation materials; however, they were given the goals of the session and told that their respective session needed to address each goal. The goals are available, upon request. Toward the end of the session, a final question and answer session was commenced.

Measures

Data were gathered using pre and post surveys to measure the effectiveness of the SPANS program. To measure the feasibility of the SPANS program, formative and summative evaluations were conducted with the participants. In addition, we (the research team) collected attendance, attrition, and fidelity data.

Pre and Post Survey of Effectiveness

To a large extent, the pre and post surveys were identical. Only the pre-survey included demographic questions about the parent and their child; this information was used to characterize the sample. The survey took 25-30 mins to complete. The survey included measures about: knowledge of evidence-based services for children with autism, perceived skills to identify, access, and receive services, perceived capacity to navigate service systems, advocacy, and empowerment. Measures are available, upon request to the authors.

Knowledge of Evidence-based Services for Children with Autism. Comprised of 20 multiple choice questions about knowledge of service delivery systems, this measure was adapted from existing navigator and parent advocacy programs (e.g., Burke, Goldman, et al., 2016; Taylor et al., 2017). Sample questions included: “How many days does the school have to conduct an evaluation after receiving parent consent?” and How is a child eligible for SSI?”. The final score reflects a sum of the correct responses; the range was from 0-20. In this study, the Kuder-Richardson coefficient was .72.

Perceived Skills to Identify, Access, and Receive Services. Comprised of 10 items, this measure of perceived skills has been used in other studies about parent advocacy and navigation (Burke, Goldman, et al., 2016; Taylor et al., 2017). Items included “I am able to advocate for my child’s needs in trying to get services” and “I am able to assert myself in trying to get services and/or support for my child”. Each item was rated on a five-point Likert scale (1 =

completely disagree to 5 = completely agree) about how well the participant can access services. The final score reflects the sum of the items; the range was from 10 to 50. The Cronbach's alpha was .81.

Perceived Capacity for Accessing Services. The Vanderbilt Mental Health Services Efficacy (VMHSE; Bickman et al., 1998) was used to measure perceived capacity to help other families access services. Items included "I believe that I can help service providers in treating my child" and "I know that I can do what needs to be done to work with my child's services." The VMHSE has been used in navigator models among families of individuals with mental health diagnoses (Rodriguez et al., 2011). Comprised of 25 items on a five-point Likert scale (1 = strongly disagree to 5 = strongly agree; the range was from 25-125), the Cronbach's alpha was .75.

Advocacy. The Disability Advocacy Scale was used to measure the frequency of advocacy activities. Each item was rated on a five-point Likert scale (ranging from 1 = not at all to 5 = very often). The Disability Advocacy Scale reflects the subscales of advocacy: advocacy for one's own child (e.g., "I have searched the internet to find agencies and or services to meet my child's needs"); advocacy for other families (e.g., " I have talked with other parents about agencies and/or services to meet their child's needs"); and advocacy for systemic change (e.g., "I have written to legislators about disability issues," Balcazar, Keys, Bertram, & Rizzo, 1996). Separate items were scored for each subscale with five items per subscale; a higher score indicates greater advocacy. For each subscale, the range was from 5-25. In this study, the Cronbach's alphas were .69 (advocacy for one's own child), .71 (advocacy for other families), and .79 (advocacy for systemic change).

Empowerment. The Family Empowerment Scale (FES, Koren et al., 1992) is comprised of 24 items using a five-point Likert scale (ranging from 1 = not at all to 5 = very true). The FES was used to measure empowerment in relation to the family (range from 12-60) and services (range from 12-60). Items included “I feel that I have a right to be informed of all services available and approve of all services my child received” and “When problems arise with my child, I handle them pretty well.” The summed total of the items was used for each subscale. The Cronbach’s alphas were .90 and .83, respectively.

Measures of the Feasibility of the SPANS program

Attendance and Attrition. The study coordinator monitored the attendance for each SPANS session. Attendance was calculated as the percentage of total number of SPANS sessions attended for each participant divided by the total number of SPANS sessions (i.e., 12 sessions). Attrition was calculated as the number of individuals who completed SPANS divided by the number of individuals who attended the first session of the SPANS.

Formative and Summative Evaluations. Participants completed formative and summative evaluations. On the formative evaluation, participants rated their satisfaction on a five-point Likert scale with respect to the content, speaker, and presentation. The summative evaluation was comprised of open and close-ended questions about satisfaction with the program including speakers, content, logistics, and overall satisfaction. The formative and summative evaluations reflect evaluation measures used in previous advocacy and navigator programs (e.g., Burke, Goldman et al., 2016; Taylor et al., 2017).

Treatment Fidelity. To assess treatment fidelity, we used two methods: intervention checklists and reliability checks (Gersten et al., 2005). For all sessions, a study coordinator checked whether each SPANS session met its checklist of goals (per the SPANS manual, which is available upon request). Two graduate students, naïve to the study, listened to the audio recording of each session and assessed whether the goals were met. Six sessions were assessed for each graduate student. Because all sessions were recorded, fidelity of the SPANS to the manual can be confirmed. The inter-rater reliability was 100%.

Analyses

To determine effectiveness, paired *t*-tests were conducted between the pre and post survey scores. For the effect size (ES), we used Cohen's *d* wherein the magnitude of effect sizes were categorized as: .2 was small, .5 was medium, and .8 was large. For the formative and summative evaluation data, we conducted descriptive statistics (e.g., means, percentages). For the open-ended responses on the evaluations, two authors conducted constant comparative coding (Patton, 2002). Independently, the two authors read the responses numerous times to familiarize themselves with the data (Tesch, 1990). For each piece of data, they compared it with all other data (Creswell, 2003). Each piece of data represented a single concept and was notated with a phrase. New data were compared to coded data to determine if the new data represented a new idea or should be combined with an existing code. Codes were grouped into categories and categories were organized into themes grounded in the data.

Results

Effectiveness of the SPANS program

Across all of the dependent variables, there were increases from the pre to the post survey. However, only a few of these increases were statistically significant. Specifically, with a small-medium effect size (*ES* = .38), participants demonstrated significantly improved knowledge about autism services ($p = .05$). In addition, with medium *ES*s, participants demonstrated significantly improved advocacy for other families and advocacy for systemic change (*p*'s = .02 and .05, respectively). See Table 3.

Feasibility of the SPANS program

Attendance and Attrition. Overall, 94.73% of the participants attended more than 80% of the sessions. The attrition rate was 5% (*n* = 1).

Treatment Fidelity. Fidelity to each session was 100%.

Acceptability of the SPANS program. In the formative evaluations, participants indicated their satisfaction with each SPANS session. Overall, most (87%) participants were "highly satisfied" or "satisfied" with each session. In five sessions (i.e., Evidence-based Treatment Services, School Services, Advocacy, Identifying Barriers to Service Access, and Conclusion), some participants reported being "somewhat satisfied". None of the participants reported being "not satisfied". See Figure 1.

For the five sessions wherein there were responses of being "somewhat satisfied", we examined the open-ended responses in relation to the question, "What improvements would you suggest?". Responses clustered around two themes: (1) consider splitting this session into two sessions given the tremendous amount of information; and (2) provide more targeted information about the service in relation to low-resourced families. Regarding the former, for example, a participant wrote, "Break this lesson up into 2 days because there's a lot of info on this topic." Regarding the latter theme, for example, a participant wrote, "Adapt materials so they are tailored to our target audience—low income families."

For the summative evaluation, 13 of the 19 participants completed the evaluation. With respect to the local content experts and relevance of topics, all participants reported that the speakers and topics were "always" or "mostly" relevant to their development as navigators.

While most participants reported that there was sufficient time for each topic, 15.38% (*n* = 2) of the participants reported that sessions were “too short”. Overall, all participants were “highly satisfied” or “satisfied” with the SPANS program. See Table 4.

We explored the open-ended responses to several summative evaluation questions. Given that some participants reported that the sessions were too short, we explored their open-ended responses to “Would you devote any more time to a specific topic?”. Two participants wanted more time devoted to SSI, one participant wanted more time devoted to school-based services and one participant wanted more time devoted to establishing rapport with families. We also explored responses to the question “Should we change the number of sessions in the training?”. Most participants reported “no”. However, two participants suggested expanding the SPANS program to 13 sessions. One participant suggested reducing it to 10 sessions but did not propose which content should be cut.

While all participants reported being satisfied with the SPANS program, we were interested in knowing whether the program met the participants’ expectations. Consequently, we explored their responses to the question “Did the training meet your expectations? Why or why not?”. With the exception of one participant, all participants reported “yes”. For example, one participant reported, “Yes. It was invigorating to have an open dialogue about all of the subjects covered.” Another participant reported, “I learned things not only to help with my own child but to also help other families.” One participant reported the need to work with families before being able to answer the question: “Not sure. I’m a little concerned about doing this and not knowing the answers.”

Participants reported the types of ongoing supports they anticipated needing to be effective navigators. All of the responses related to having a support network for check-ins.

Responses included “Someone to answer questions I am unsure of”, “Check-ins, knowledge database or group page to share info or ask questions. A sort of, ‘What would you do?’”, and “Speaking with fellow navigators from time to time”.

Discussion

As family navigators become more common and available via legislation, it is important to understand the effectiveness and feasibility of programs to develop navigators. The purpose of this study was to evaluate the effectiveness and feasibility of the SPANS program wherein low-resourced parents of autistic youth completed a program to develop the knowledge and skills to become navigators. We had three main findings.

First, the SPANS program was effective in significantly increasing knowledge (with a small effect size) and perceived advocacy (with a medium effect size) among the participants; increases (albeit not significant) were also found with respect to empowerment, perceived skills, and perceived capacity. This finding aligns with prior research suggesting that navigator and advocacy programs can improve knowledge and advocacy among parents of children with disabilities (e.g., Burke, Goldman, et al., 2016; Taylor et al., 2017). This finding extends the literature demonstrating that such programs may be effective among low-resourced parents. Indeed, much of the literature about parent programs reflects parents of children with disabilities with high formal education and/or household incomes (Goldman et al., 2020). However, research is needed to determine whether such significant increases meaningfully impact a navigator’s ability to support families. This study suggests that such programs may be effective regardless of socioeconomic background.

Notably, this study aligns with prior research suggesting that navigator programs may be effective among racially diverse, including racial minority populations. In this study, the majority of participants reflected racial minority backgrounds. A few studies about navigator programs have focused on specific racial minority groups (e.g., Parents Taking Action among Latinx families of children with autism, Magaña et al., 2017). It is important to test navigator programs with racial minority families especially given that such families often receive significantly less services than their White counterparts (Schott et al., 2021). Given the multiple systemic barriers faced by families of color in accessing services, it is critical to help ensure equity of access to services.

Second, while SPANS is an intensive, 24-hour training, it was feasible according to participants. Overwhelmingly, there was high attendance, low attrition, fidelity to the curriculum, and positive acceptability ratings. This finding is important because it demonstrates that the SPANS program could be feasible in the real-world among low-resourced families. Because low-resourced families often face many systemic barriers to attending training programs (e.g., lack of transportation, limited time, Leiter & Wyngaarden Krauss, 2004), it is important to ensure that navigator programs can be feasible for them to attend.

Interestingly, some participants suggested extending the SPANS program to include more sessions. Such feedback has occurred in other advocacy program interventions (Rios, Burke, Aleman-Tovar, 2021). On average, advocacy programs are 15 hours long (Rios & Burke, 2021). Thus, SPANS is already on the long side in comparison to similar programs. Expanding the duration of the SPANS program should be tested in a future iteration of SPANS to ensure that the program would still be feasible even if it included additional sessions.

Third, navigator programs seem to be effective and feasible among low-resourced families; navigator program content should reflect the specific barriers facing low-resourced families of autistic youth. To this end, the SPANS program content specifically addresses barriers to services among low-resourced families as well as services that may be more applicable to low-resourced families (e.g., SSI for the child which is only available to low-income families as the family household income is a key determinant for SSI eligibility).

However, while the SPANS program was effective and feasible for low-resourced families, more work is warranted. As one participant noted, there may have been an insufficient focus on low-resourced families. One explanation for this may be the definition of “low-resourced”. In this study, we used the definition of “low-resourced” from Kasari and colleagues (2014). In this definition, “low-income” is only one of the criteria to meet eligibility. Other criteria included limited formal education, lack of employment, and receipt of governmental assistance. Because of the multi-pronged definition of “low-resourced”, there was considerable diversity in our sample. In many ways, our sample was similar to Kasari’s sample (e.g., both samples were approximately 36% White, and roughly half were low-income). Regardless, it may have been helpful if, at the beginning of the SPANS program, we provided our definition of “low-resourced” and clarified that it does not only include individuals with low-income backgrounds.

While providing a launching point to understanding family navigator programs, this study had a few limitations. The formative and summative evaluations were anonymous; thus, we cannot discern which participants did (and did not) complete the evaluations. Given that only 13 participants completed the summative evaluation, it may be possible that participants who were dissatisfied with the training did not complete the summative evaluation. Also, the measures were parent self-report. For advocacy, for example, it may be more helpful to have an in vivo measure (e.g., a role play or structured observation) to better gauge how participant advocacy changes as a result of the SPANS program. This study had a small sample size; thus, the study may have been under-powered to detect an effect. Also, the study had no control group; accordingly, the results of the study cannot confidently be attributed to participation in the SPANS program. There may be other skills that navigators need in addition to knowledge, advocacy and empowerment; future research should identify and test whether navigator programs increase other skills.

Directions For Future Research

More research is needed to understand the effectiveness and feasibility of the SPANS program. As noted by one participant, it is important to collect follow-up data with the SPANS graduates as they serve as navigators. In this way, we can test the maintenance of SPANS effects especially as participants apply their newfound knowledge and skills. Further, we may see delayed effects on some of the outcome variables. For example, Jamison and colleagues (2017) tested a family-peer training program for culturally and linguistically diverse families. Similar to our study, they did not find significant increases in participant empowerment. They suggested that a longer follow-up period may be needed to see increases in empowerment. By collecting data with SPANS graduates over time, especially as they support families of young children with autism, we may be able to measure more distal effects of the program. Regarding feasibility, individual interviews or focus groups with the participants may help explore their perceptions of the social validity of the SPANS program. Such data may also inform revisions to ensure that the SPANS program specifically addresses the needs of low-resourced families.

Relatedly, future research needs to include a control group. To attribute change in outcomes to the SPANS program, it is important to conduct a randomized controlled trial (RCT). Such a trial would need to be sufficiently powered to detect a meaningful effect. This study has provided a suggested effect size to inform a pilot RCT (Leon et al., 2011). Further, in an RCT of the SPANS program, it may also be possible to identify any potential moderators of effectiveness. Inclusion of moderators may help inform for whom SPANS is and is not effective.

Implications for Practice

Practitioners may consider the effort needed to provide the SPANS program to families. This study suggests that 24 hours is a feasible amount of time for many families to complete the program. In addition to the 24 hours, practitioners would need to identify local context experts to deliver specific SPANS sessions. Further, based on the summative evaluation feedback, practitioners may also consider providing ongoing support to navigator participants after SPANS ends. Altogether, as practitioners consider replicating SPANS, it is important for them to understand the amount of effort needed to prepare the SPANS program, implement the program and provide ongoing support.

Additionally, practitioners may consider the timing of the SPANS program. Of the 13 individuals who were unable to participate, many indicated that this was due to a scheduling conflict. Practitioners may consider when is the right day/time to offer the SPANS program. During the workday may disallow working parents from participating; offering the SPANS program on a weeknight may prohibit those with childcare issues from participating. In a study of an advocacy program for Latinx families of transition-aged youth with autism, the program was offered on a weekday morning, weekday night, and weekend (Author, submitted). Of the 30 participants, 16 chose to participate on a weekday morning. However, in a study of six cohorts of an advocacy program that was similarly offered on a weekday morning, weekday night, and weekend (Burke et al., 2016), the attendance rates were consistent across each day/time. Thus, practitioners may consider the day/time that may best serve their constituencies.

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Table 1

Participant Demographics

	% (*N* = 19)
Gender	
Female	94.74% (18)
Race	
White	36.84% (7)
Hispanic/Latinx	36.84% (7)
Black or African American	15.80% (3)
Asian	5.26% (1)
More than one race (white and Latino)	5.26% (1)
Marital status	
Married	68.42% (13)
Not married	31.58% (6)
Annual household income	
Less than $15,000	5.26% (1)
$15, 000 - 29,999	15.80% (3)
$30, 000 - 49,999	26.32% (5)
$50, 000 - 69,000	21.05% (4)
$70, 000 - 99,999	5.26% (1)
over $100,000	21.05% (4)
Missing	5.26% (1)
Educational background	
Some college	36.84% (7)
4-year degree	36.84% (7)
Graduate/professional degree	26.32% (5)
Child disability*	
Intellectual disability	42.11% (8)
Developmental delay	36.84% (7)
ADD/ADHD	31.58% (6)
Learning disability	31.58% (6)
Hearing impairment	10.53% (2)
Cerebral palsy	5.26% (1)
Down syndrome	5.26% (1)
Visual impairment	5.26% (1)
Health condition	5.26% (1)

*All participants had children with autism. Participants were also asked about co-occurring disabilities. Participants could check more than one type of disability.

Table 2

Overview of the SPANS program

Topics	
1	**Intro to the SPANS project:** 1. Familiarize the participants with the project, including the research 2. Establish rapport among the participants and with the supervisor 3. Introduce the App 4. Briefly define autism 5. Describe goals of the navigators
2	**School Services** 1. Learn basic rights under the Individuals with Disabilities Education Act 2. Review the requirements for eligibility and evaluation under autism 3. Learn about how to write high-quality individualized education programs (IEPs) 4. Learn how to request FBAs and identify strong behavior intervention programs 5. Learn how to advocate for extended school year services 6. Learn how to request related services and ensure services are provided 7. Communicating with individual IEP team members
3	**Evidence-based treatments (EBTs) for young children with autism** 1. To identify EBTs for 3-5 years old with autism 2. To have a holistic understanding of available EBTs 3. To identify where EBTs may be provided 4. To differentiate between EBTs and non-EBTs 5. To discuss "trial and error" of finding the right mix of EBTs
4	**Assistive Technology (AT)** 1. Identify who qualifies for AT 2. Learn how to apply for AT and your rights once you receive AT 3. Explore potential AT devices
5	**Supplemental Security Income (SSI) for children and their families** 1. Identify who is eligible for SSI 2. Understand how to apply for SSI 3. Understand how to keep SSI 4. Know how to appeal SSI decisions 5. Learn how current resources may impact the future (BRIEF mention of special needs trusts/ABLE accounts)
6	**Respite/childcare/Parks and recreation including special recreation programs** 1. Identify who is eligible for respite 2. Learn how to apply for respite 3. Learn ways to identify a respite worker 4. Learn ways to identify a childcare agency 5. Understand rights by Americans with Disabilities Act for accommodations in childcare 6. Learn about special recreation and parks and recreation options 7. Provide an overview of Family and Medical Leave Act

7	**Child Medicaid waivers** 1. Identify who qualifies for waivers 2. Distinguish relevant waivers 3. Learn how to apply for Medicaid waivers 4. Briefly discuss getting on the waiting list for adult waivers 5. Learn about Family Support grants for mental health 6. Learn about Department of Rehabilitative Services waiver for physical disabilities
8	**Health insurance** 1. Identify health insurance options, including public and private options 2. Discuss dental care options 3. Review the importance of developmental pediatricians
9	**Non-adversarial advocacy** 1. Learn non-adversarial ways to access services 2. Join relevant parent support groups 3. Identify priorities with families
10	**Identify barriers to service access** 1. List common systemic barriers to service access 2. Learn how to support families in overcoming barriers: developing rapport, learning family and child needs, identify relevant agencies and services, developing a plan, educating and empowering the family, executing the plan
11	**Provide emotional support to families** 1. Learn emotional and well-being needs of families (e.g., stress) 2. Provide affective support to families 3. Teach families service coordination 4. Identify parent support groups and agencies
12	**Conclusion** 1. Consider how the App will be used with families 2. Steps to become a navigator 3. Final questions/wrap-up

Table 3

Effectiveness of the SPANS program

	Pre: Mean *(SD)*	Post: Mean *(SD)*	*t*	*p*	*ES*
Knowledge	12.47 (3.29)	13.59 (3.27)	-1.68	.05*	.38
Perceived Skills	39.92 (5.46)	41.24 (5.27)	-1.01	.16	.23
Perceived Capacity	87.79 (10.59)	88.42 (12.37)	-.132	.45	.03
Advocacy					
• Advocate for own child	24.42 (2.59)	25.55 (2.75)	-.749	.23	.17
• Advocate for other families	15.11 (3.68)	17.05 (3.54)	-2.24	.02*	.51
• Advocate for systemic change	7.63 (3.24)	9.61 (4.50)	-1.74	.05*	.39
Empowerment					
• Family	48.42 (6.97)	50.32 (5.49)	-1.21	.12	.28
• Service system	49.89 (5.35)	50.12 (5.49)	-.31	.38	.07

Table 4

Summative Evaluation Results

	Participant Ratings*
Overall, how would you rate the knowledge of the speakers?	
Below Average	0%
Average	0%
Good	23.08% (3)
Excellent	76.92% (10)
Overall, how would you rate the relevance of the speakers' presentations in developing your role as a navigator?	
Rarely Relevant	0%
Sometimes Relevant	0%
Mostly Relevant	15.38% (2)
Always Relevant	84.62% (11)
Overall, do you think that each speaker had enough time to present for each topic?	
Just right	84.62% (11)
Too short	15.38% (2)
Too long	0%
How would you rate the relevance of the topics in developing your role as a navigator?	
Rarely Relevant	0%
Sometimes Relevant	0%
Mostly Relevant	8.33% (1)
Always Relevant	91.67% (11)
Please indicate your degree of satisfaction with the training	
Not satisfied at all	0%
Somewhat satisfied	0%
Satisfied	33.33% (4)
Highly satisfied	66.67% (8)

*Not all participants answered each question.

Figure 1

Participant satisfaction across the SPANS sessions