Published in final edited form as:

Res Autism Spectr Disord. 2016 May 1; 2: 87–96. doi:10.1016/j.rasd.2016.02.003.

A Pilot Study Promoting Participation of Families with Limited Resources in Early Autism Intervention

Themba Carr^{a,*} and Catherine Lord^{a,*}

^aUniversity of Michigan, Department of Psychology, University of Michigan Autism and Communication Disorders Center, Ann Arbor, Michigan

Abstract

Background—Relatively little research about autism early intervention has occurred in families of low socioeconomic status. Barriers to participation for under-resourced families (i.e., families with low incomes or limited education), pose a significant problem. The purpose of this pilot study was to apply empirically supported methods promoting participation of families with low-income and low-education levels to an established intervention for children with autism spectrum disorder (ASD).

Method—Participant recruitment specifically targeted families whose income was equal to or below two times the federal poverty line and whose caregiver(s) had no more than two years of college attendance. An evidence-based intervention was modified to be more accessible to participating families. Adaptations focused on decreasing access barriers, decreasing attrition, and promoting positive change within families. Success of the program was measured quantitatively and qualitatively.

Results—Twenty-seven families were referred to the project, 13 of which did not meet eligibility requirements. Eight families enrolled, maintained participation for the majority of the project and provided positive qualitative feedback of their experiences. Project and treatment attrition were calculated at 62% and 12.5%, respectively. Treatment attendance was high, but length of time to complete treatment was greatly influenced by the number of session cancellations.

Conclusions—The exploratory project demonstrated that practical modifications to standard early intervention protocols can promote engagement in families with limited resources. Recommendations for programs seeking to implement interventions in under-resourced communities are discussed.

*Themba Carr (Corresponding Author, Present Address), Center for Autism Research and Treatment, Semel Institute for Neuroscience and Human Behavior, University of California Los Angeles, 760 Westwood Plaza, Semel 67-464, Los Angeles, CA, 90024, USA, tcarr@mednet.ucla.edu, Phone: 310-206-6104.

*Catherine Lord (Present Address), Center for Autism and the Developing Brain, Weill Cornell Medical College, New York-Presbyterian Hospital/Westchester Division, 21 Bloomingdale Road, White Plains, NY USA, cal2028@med.cornell.edu, Phone: 914-997-5848

Publisher's Disclaimer: This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final citable form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

Keywords

Autism; Early intervention; Under-resourced communities; Low-income

1. Introduction

As early intervention programs are tailored for individual children with Autism Spectrum Disorders (ASD), they should meet the needs of families with limited resources. There have been several calls for more diverse study participants in research on early intervention (Lord & Bishop, 2010; National Research Council, 2001; Tek & Landa, 2012), yet participant samples continue to include a predominance of families from White, highly educated, upper-middle class backgrounds. Barriers to intervention research and community-based services for under-resourced families (i.e., families with low incomes or limited education), pose a significant problem.

The need for intervention research to improve access barriers within these populations has been well substantiated in epidemiological reports. In the United States, Black and Latino children, who are overrepresented in low-income communities, receive diagnoses significantly later than their Caucasian counterparts (Liptak, et al., 2008; Mandell, et al., 2009; Mandell, Listerud, Levy, Pinto-Martin, 2002). In children who have received a diagnosis of ASD in early childhood, treatment services are often limited for ethnic minority children, both in terms of access to and amount of intervention (Carr & Lord, 2013) and reported quality of care (Magaña, Lopez, Aguinaga, & Morton, 2013).

Reasons for barriers to early intervention services are multifaceted. Many families of children with ASD experience difficulty obtaining referrals for services because experienced providers are not available within poorer communities (Ruble, Heflinger, Renfrew, & Saunders, 2005). When providers are available, the high cost of ASD services often limits poorer families from obtaining care (Flanders, Engelhart, Pandina, & McCracken, 2007). Disparities in service use may also be related to factors of race/ethnicity, culture, education, and SES (Kilbourne, et al., 2006). Children of mothers with lower education levels are less likely to have documentation of ASD, suggesting that mothers with less education may be less able to advocate for proper diagnosis and access to services (Mandell et al., 2009). Cultural background may also influence a parents' interpretation of the child's symptoms, the manner in which a parent responds to such symptoms, and the manner in which a parent communicates such symptoms to a professional (Mandell & Novak, 2005).

To date, few studies have directly examined how to overcome barriers to ASD intervention in families who are under-resourced, but multiple reviews have been conducted across a range of family and child therapy models for other disorders (Ingoldsby, 2010; Nock & Ferriter, 2005; Snells-John, Mendez, & Smith, 2004). In general, commonly used strategies to increase engagement and attendance include the provision of transportation, childcare, and low-cost services, and offering home-based sessions (Snells-John, et al., 2004). Strategies for increasing retention (i.e., decreasing attrition) include reducing time spent on waiting lists and offering incentives for ongoing attendance or completion of treatment. Attention to individual family needs and focusing on family strengths also serve as

particular methods for empowering families and promoting change in how families or caregivers perceive the benefits of family or child therapy. Despite these efforts, rates of attrition reported from psychotherapeutic interventions targeting under-resourced populations are still quite high, ranging from 50 to 70% (Fox & Holtz, 2009; Lyon & Budd, 2010).

Within the field of ASD, limited research exists on access to services in under-resourced families. Some literature addresses intervention with multicultural students (Wilder, Dyches, Obiakor, & Algozzine, 2004), or presents single case studies in which cultural and socioeconomic contexts were applied to the delivery of treatment (Santarelli, Koegel, Casas, & Koegel, 2001). Even in studies specifically designed to recruit and implement intervention research in under-resourced populations, success in recruiting and retaining the participation of families with low-income has been limited (Kasari et al., 2014; Carr et al., 2015).

To address these issues, we conducted a simple nonrandomized pilot intervention to apply empirically supported methods to promote treatment attendance and adherence in families reporting low incomes and low levels of education. Families participated in the intervention and then were interviewed to learn more about their experiences to inform the development of larger studies in this area. This pilot project yielded several important insights into conducting research in under-resourced communities.

2. Method

2.1 Participants

Participant recruitment specifically targeted families from low socioeconomic backgrounds. To identify the sample, selection criteria at the family level included: a) family income equal to or below two times the federal poverty line; b) caregiver(s) with no more than two years of college attendance; family place of residence no more than 60 miles from the university clinic; and d) English as the predominantly-spoken language. At the child level, selection criteria for participation included: a) a diagnosis of ASD; b) between 18 and 42 months of age; and c) adequate hearing, vision, and motor control to make simple actions (e.g., giving, walking). Referrals were received through local health clinics, school districts, and Early On, a Part C funded state agency providing early intervention services for infants and toddlers exhibiting developmental delays. Upon referral, families were administered an intake phone interview to assess family level eligibility. If criteria were met, an initial diagnostic assessment with a licensed clinician was scheduled. Twenty-seven families were referred to the project, 13 of which did not meet eligibility requirements (five exceeded the education requirement, one exceeded income, four exceeded income and education, one child exceeded age, and two were not interested in participating). Of the 14 eligible families, 13 participated in the initial assessment. Assessments were conducted at the research clinic or in the home if families were unable to travel. Assessments took place over two half-day sessions of three to four hours and included a parent interview that consisted of the Autism Diagnostic Interview-Revised (ADI-R; Le Couteur, Lord, & Rutter, 2003) and the Vineland Adaptive Behavior Scales (VABS; Sparrow, Cicchetti, & Balla, 1984) and child observation and testing that consisted of the Autism Diagnostic Observation Schedule (ADOS; Lord et

al., 2000) and cognitive testing, respectively. All families participated in a feedback session with the licensed clinician in which a DSM-IV ASD diagnosis (e.g., Autistic Disorder, Asperger's Disorder, or Pervasive Developmental Disorder-Not Otherwise Specified) was given based on the clinician's review of all data. Recommendations for future intervention and support were made. At that time, the family was also offered the opportunity to participate in the intervention.

All 13 families agreed to participate in the study. Four families discontinued participation prior to beginning treatment. For three of those families, reasons cited for discontinuation were time constraints. In the fourth family, the child was accepted into another treatment program. There were no significant differences in demographic profile between these families and those who continued in the project. Of the remaining nine families, eight completed treatment and five completed the follow-up. One family withdrew during treatment because it became apparent English was not their predominant language in the home and none of the interventionist staff were proficient in the family's predominantly spoken language.

Of the eight families who entered treatment, all caregivers were the biological mothers of the affected child. Family incomes ranged from less than \$10,000 to \$35,000 ($M = \$18,300$) and all families except for one received some form of public assistance (i.e., Medicaid, Food Stamps, Supplemental Security Income). All families lived in Southeast Michigan. Seven of the families lived within approximately 20 miles of the university clinic, while one family lived nearly 60 miles away. Child participants were all male and ranged from age 24 months to 40 months ($M = 29.1$) at the initial assessment. All children received a diagnosis of ASD at the initial assessment, and four of the eight children were assessed as having cognitive skills within the range of intellectual disability. Table 1 provides a full summary of caregiver and child characteristics for families who completed the intervention and for those who discontinued participation (data from the withdrawn family are not included).

2.2 Intervention Development

The intervention was modeled after the Early Social Interaction (ESI) Project (Woods & Wetherby, 2003; Wetherby & Woods, 2006; Wetherby et al., 2014), a parent-mediated naturalistic developmental behavioral intervention targeting social communication skills in children with ASD who are younger than three years old. A central component of ESI is that it addresses deficits in social and communication skills within the context of a family-centered, natural environment. Thus, in comparison to other parent-mediated models targeting one specific core deficit of autism (i.e., joint attention) in one context, a strength of ESI is that it focuses on a variety of social communication deficits within common day-to-day activities of family life.

During the time of the present study, ESI was being implemented on-site as part of a large-scale multisite randomized controlled trial comparing the effectiveness of two conditions, home-based parent-mediated versus group education (Wetherby et al., 2014). Families of children between 16 and 20 months old were randomly assigned to one condition for nine months and then crossed-over to the other condition for an additional nine months. During

both conditions, families were required to travel to the university clinic for monthly assessments and for some intervention sessions.

While ESI provided thorough, intensive long-term care to the families enrolled, some families, especially those from low-income populations, could not meet the time commitment required to participate in the nine-month treatment conditions nor could they meet the requirement of traveling to weekly sessions and monthly assessments. These factors limited the project's accessibility to those families who are traditionally under-represented in ASD research and led to the development of the present pilot project focusing on the feasibility of recruiting and retaining low-income families. In this study, the strategies and goals in the parent-mediated component of ESI were employed, with several adaptations to increase participation for under-resourced families.

2.2.1 Adaptations for overcoming barriers to access—Modifications were made for location and transportation. All treatment sessions were conducted in homes and families were compensated for funds spent on traveling to assessments. For one family who did not have access to a car and lived approximately 10 miles from the clinic, a local cab service was provided for their scheduled assessments. The age range of children eligible to participate was expanded to reach families who were outside of the upper age limit of the larger trial and to reach families of children who had not yet received a diagnosis of ASD through their local community early intervention programs by 18 months.

2.2.2 Adaptations for decreasing attrition—We did not use a treatment waitlist because families with limited resources might have been lost to participation when not receiving the targeted intervention immediately upon entrance to the program. To lessen the burden placed on families experiencing significant work or family stressors, we limited the time spent in the project. Rather than having caregivers commit to the 18 months of treatment required from the larger RCT, the modified study required a 6-month commitment, only three of which required weekly participation from the families.

We anticipated that cancellations and no shows would occur more frequently during the course of the intervention, therefore, we maintained a liberal cancellation policy. Specifically, we committed to providing each family with 24 treatment sessions, regardless of the number of cancellations or the length of time required to complete those sessions.

Families were provided with a monetary incentive for completing pre-treatment, post-treatment, and follow-up assessments. Because participation in assessments required families to travel to the research clinic located on the university campus, the financial incentive was designed to compensate for time and travel expenses (i.e., gas money). Because we wanted our adaptation to be feasible in real world settings, incentives for completion of treatment sessions were not offered.

2.2.3 Adaptations for promoting change—In contrast to studies in which obtaining community intervention in addition to research intervention was prohibited, we empowered caregivers to become advocates for their children by assisting them in identifying and enrolling in all available community-based ASD resources for which they were eligible.

Support provided was informational (i.e., informing families of the programs that were available), logistical (i.e., placing phone calls and sending emails to providers who were difficult to reach, helping to complete applications, photocopying reports), and collaborative (i.e., serving as the liaison between providers and caregivers, attending Individual Education Plan meetings). Each family was also provided with practical information and a resource guide to local ASD services including information regarding payment requirements and potential available scholarships for participation (e.g., scholarship funds for an ASD summer camp).

2.3 Intervention Procedures

2.3.1 Treatment Phase—Families were asked to participate in 24 total (two per week) home-based sessions. During the 60-minute sessions, the interventionist worked with the caregiver on how to promote social-communication skills in their child. In accordance with the tenets of ESI, importance was placed on choosing activity routines that were motivating and developmentally appropriate for the child and feasible for caregivers to implement in their homes (e.g., play with toys, meal times, play with people; See Woods and Wetherby (2003) for a description of intervention routines). Data were collected on the child and participating caregiver. If other family members were present during sessions, however, they were not excluded from sitting in on, or participating in the session. Many activity routines were structured around who was present during the session. For example, if siblings were present (as was the case in four of the families), they were invited to join in social games such as Ring-Around-the-Rosie or Hide-and-Seek. If additional caregivers were present, they were also included in discussions about treatment strategies. As mentioned in section 2.2.3, during the treatment phase interventionists also assisted families in accessing support services from the local community.

2.3.2 Follow-up Phase—The follow-up phase consisted of home visits conducted once per month for three months immediately following the treatment phase. The focus of follow-up visits was for the interventionist to provide consultation on the child's progress. Between monthly visits, the interventionist communicated via telephone or email to support families as they enrolled in local ASD services and planned for their child's transition to Part B special education services. Additionally, interventionists encouraged the caregivers to continue using treatment strategies during everyday activities and routines.

2.4 Measures

2.4.1 Attrition—Attrition was measured in two ways: a) project attrition was calculated using the full sample of the 13 families who participated in an initial assessment and agreed to take part in the intervention, and b) treatment attrition was calculated by comparing the number of families who entered the treatment phase (with the exception of the family withdrawn from the study) to those who did not complete all 24 in-home intervention sessions.

2.4.2 Attendance—Treatment attendance was measured by calculating the number of sessions completed per family, number of cancellations/no shows, and length of time to complete all 24 treatment sessions during the treatment phase.

2.4.3 Adherence—Treatment adherence was measured through a caregiver log used to document the number of hours during which caregivers implemented treatment strategies outside of sessions with the interventionist. Hours reported were considered “engaged time” between caregiver and child and counted toward the amount of weekly intervention each child received.

2.4.4 Caregivers’ Perceptions of the Intervention—Caregivers were interviewed at the end of intervention to assess their perceptions of the project. The interview consisted of 20 questions designed to obtain the caregivers’ evaluation of their overall project experience, as well as their opinions regarding each respective aspect of the project (i.e., treatment, follow-up, and clinic evaluations).

2.5 Analyses

Given the exploratory and descriptive nature of the pilot study, a mixed-methods design best fit the need to measure the success of the program and to guide future directions.

2.5.1 Quantitative Analyses—Descriptive analyses were used to describe patterns of attrition, attendance, and adherence and included computations of means and standard deviations.

2.5.2 Qualitative Analyses—A phenomenological approach was taken in conducting and analyzing the exit interviews. Interviews were conducted at the end of the follow-up phase and took place in the families’ homes. Using the procedure outlined by Creswell (2007), each video was transcribed into a written document. Five staff members read each transcript and identified significant statements. During a group discussion, significant statements were categorized into codes, which were then reduced to overarching themes. Transcripts were re-analyzed using final codes and themes. Inter-rater reliability in code and theme identification ranged from 47–91% ($M = 68\%$). Disagreements were discussed until consensus was achieved.

3. Results

3.1 Quantitative Results

3.1.1 Attrition—Thirteen families participated in the initial assessment and agreed to take part in the intervention. Regarding project attrition, five families remained enrolled in the project through the follow-up phase (four families discontinued participation during baseline, two during treatment, and two during follow-up), yielding a project attrition rate of 62%. Regarding treatment attrition, seven of the eight families who entered the treatment phase completed all 24 intervention sessions, yielding a treatment attrition rate of 12.5%. The remaining family completed 21 sessions.

3.1.2 Attendance—The amount of time it took each family to complete participation in what was intended to be a six-month study ranged from 3.6 to 9.1 months ($M = 6.99$, $SD = 2.18$). Variation in length of enrollment was due to the number of treatment session cancellations. Out of 24 treatment sessions, cancellations ranged from 2–20 ($M = 11.12$, $SD = 7.04$). The most frequent reason for cancellation reported was when either the mother or

child was sick (See Table 2). It is notable that for the vast majority of cancelled sessions, caregivers contacted interventionists prior to the session date to notify them of the cancellation; only one instance of a no-show appointment occurred during the entire duration of the project.

3.1.3 Adherence—Regarding treatment adherence, the amount of time caregivers reported they spent engaged in the eight activities outside of treatment sessions also varied considerably. The average time spent per week ranged from 5.97 to 22.02 hours ($M = 12.76$, $SD = 4.71$; see Figure 1).

3.2 Qualitative Results

A total of 17 subthemes were identified in the exit interview transcripts and categorized into four main themes. These included: Understanding Child's Impairment, Advocacy and Empowerment, Negative Aspects of the Project, and Positive Aspects of the Project (Table 3).

3.2.1 Understanding child's impairment—A strong theme that emerged was an understanding of the children's impairments that included acknowledging features of ASD (i.e., insistence on routine, decreased social engagement, associated delays in cognitive ability) and their impact on current and future expectations. Several caregivers commented on how their perspectives of their child had changed. For example, moving from thinking of the child as one who acts out or is deliberately disruptive to one who requires more time and patience to be able to understand his environment. Change in perspective was not limited to the participating caregiver. Several caregivers commented on how other family members (i.e., a partner, siblings, grandparents) gained greater understanding of the child's abilities and consequently and on how to foster more positive interactions.

3.2.2 Advocacy and empowerment—Caregivers described taking ownership in obtaining services for their children while they were young and in making decisions about what was important to focus on in their child's treatment. Several caregivers developed a strong sense of ASD advocacy, becoming committed to spreading general knowledge and awareness, while others became empowered to educate others about their child's specific disability.

3.2.3 Negative aspects of the intervention—Caregivers' report of negative aspects of the intervention pertained predominantly to difficulties with the structure of the intervention. Scheduling in-home sessions often interfered with work schedules, while the experience of having a clinician in the home was sometimes perceived as uncomfortable. Several caregivers mentioned the tediousness of completing research questionnaires, but recognized that they collected important information.

3.2.4 Positive aspects of the intervention—For all of the caregivers, participation in the project provided benefits of knowing what steps to take after receiving a diagnosis, positively changing their behaviors as caregivers, and seeing change in their children. All of the caregivers noted changes in their child's behavior and ability, from increased

communication to ease in adjusting to unexpected situations. Establishing positive relationships with the interventionists and the university research clinic were also mentioned as benefits to involvement in the research project.

4. Discussion

Few parent-mediated models of intervention for young children with ASD have focused on the implementation of such programs in families who are under-resourced (i.e., families with low incomes or who have limited education). This nonrandomized pilot study involved the development and implementation of an early intervention program for families with extremely limited resources and focused on the effectiveness of the program in recruiting and retaining participants in the study. Families maintained participation in the intervention and reported positive impact to themselves, their children and their families.

Specific strategies to increase participant retention and decrease attrition, including providing sessions in-home, reducing travel requirements, maintaining a liberal cancellation policy, and providing financial incentives for completion of assessments, were implemented over the course of the intervention. Out of 13 families screened eligible for participation, the project was successful in enrolling eight families who maintained participation for the majority of the project. The sample enrolled was distinctly different from those traditionally included in the ASD literature. Most intervention studies include highly selected samples of families, with the majority of the families from white, upper middle class background with higher education levels (Lord, et al., 2005). In this sample, the majority of the caregivers were high school graduates with no more than several college credits. Family incomes were close to the federal poverty line.

Regarding project attrition, which measured attrition from the initial assessment through follow-up, our rate of 62% was comparable to those reported in non-ASD specific interventions serving low-income populations, in which attrition rates ranging from 50 to 70% have been reported (Fox & Holtz, 2009; Lyon & Budd, 2010). All families who discontinued (with the exception of the family withdrawn by the research team during the treatment phase) left prior to or during baseline. These families did not differ from the families who continued to participate in their access to resources before treatment, age, education level, or income so we cannot infer that differences in family characteristics contributed to their decision to discontinue. The family who left prior to the first baseline visit reported her child had been accepted into an alternative intensive therapy program. The remaining three families discontinued after one or two baseline visits. It is possible that the experience of having to wait two to four weeks for the onset of treatment negatively impacted these families' likelihood to initiate and complete intervention. Alternatively, the experience of being videotaped without receiving any instruction or feedback may also have been a negative experience. Both of these possibilities have implications for research and community-based interventions. Research projects requiring longer baselines or participation in a control condition may result in higher rates of attrition from families in need of immediate assistance. Similarly, community-based programs in which treatment waitlists are a necessity may lose families who are in great need of care.

Treatment attrition, defined as dropout during the scheduled 12-weeks of intervention, was measured at 12.5%. This was lower than the rates for the larger trial, reporting the number of families who discontinued intervention at 24% and 14% for the in-home and group conditions, respectively (Wetherby et al., 2014). It is beyond the scope of the data to suggest our rate of treatment attrition was directly influenced by our modifications to the study protocol, but it is encouraging that with a low-resourced sample, we obtained treatment attrition rates comparable to the larger trial, and several other large-scale randomized controlled ASD trials in the field (Carter et al., 2011; Dawson et al., 2010; Kasari et al., 2010). One of the strengths of our project was the presence of a strong referral system. The project benefitted from having a relationship with a developmental pediatrician whose community-based clinic was located in a region with higher percentages of families with low-income and limited education. She was also well informed about ASD and had a team committed to helping patients access ASD-specific services. Referrals from the developmental pediatrician also resulted in children being identified at risk for ASD at young ages. In recognition that children from under-resourced populations are often not diagnosed with ASD until school-age (Mandell, et al., 2002), we had expanded our age eligibility up to four years old, which is significantly higher than most early intervention programs. Despite this expansion, the average age of children referred to our project was 29 months. Future studies should carefully consider how the availability of referral sources may drive specific enrollment criteria.

In addition to promoting participation maintenance, another strength of our project was the increase in quantity and quality of ASD services received by the participating families. Treatment adherence, as measured by the number of hours caregivers reported engaging their child in routines and activities each week (i.e., engaged time), was approximately 13 hours across all families. Prior to intervention, none of the caregivers reported their child receiving more than five hours per week of ASD intervention. Thus, the receipt of 13 hours of parent-mediated intervention per week was an increase. Through the project, interventionists provided more intense, and ASD-specific care than what is typically available through Part C-funded agencies. For several of the caregivers, receiving an official ASD diagnosis at the research clinic and “knowing what steps to take” after the diagnosis, were valued aspects of the intervention program. During the treatment and follow-up phases, interventionists also assisted families to identify and enroll in any appropriate ASD resources for which they were eligible. As a result of support provided by the interventionists, each family was enrolled in at least three additional programs from what they reported at the initial assessment, including Part C-funded intervention, Part-B funded Special Education preschool classrooms, or enrollment into Social Security Disability Insurance. In addition to the tangible addition of these services, families reported that the intervention provided gave caregivers a sense of support and advocacy.

The implementation of a liberal cancellation policy enabled interventionists to continue seeing families after numerous schedule changes. The shortening of active treatment duration from nine months to three months also seemed to ease the pressure on participating families. Though they were appreciative of the weekly treatment sessions, several caregivers indicated looking forward to a schedule that was less demanding to maintain. The provision of two weekly treatment sessions over the course of three months is similar in frequency and

duration to what has been implemented in several other parent-mediated interventions (Carter, et al., 2011; Kasari et al., 2010; Schertz & Odom, 2007), but questions remain regarding ideal dissemination schedule. In the current project, the interventionists would have welcomed more time to work with each caregiver to be able to target a broader depth of objectives. From the caregiver's perspective, however, it seems that 24 twice-weekly treatment sessions spanned an appropriate and feasible amount of time.

4.1 Limitations

Though we strove to recruit families from communities that have traditionally been underserved, our definition of under-resourced prevented some families in need of intervention services from participating. 13 families were screened ineligible for participation, six of which met one criterion for being under-resourced, but not the other (i.e., met criteria for income, but exceeded education cutoff). Furthermore, because all of the research staff were monolingual, families for whom English was not the predominantly spoken language—one of the largest demographics of traditionally under-resourced families (Magaña et al., 2013)—were also restricted from participating.

While the present study demonstrated the effectiveness of strategies to decrease treatment barriers within the context of a research study, there may be limitations in implementing the same strategies in community-based settings. In agencies with limited financial resources, providing compensation for travel or paying staff for their time even when treatment sessions are cancelled may not be feasible. Our liberal cancellation policy helped to keep families involved, but such a policy is likely not sustainable in clinical agencies that are reimbursed only for face-to-face treatment. Different modes of contact, such as telephone, or web-based models of treatment dissemination, are gaining traction in the field (Jang et al., 2012; Vismara, Young, & Rogers, 2013) and may provide innovative solutions to the problem of session cancellation. If reimbursed, these approaches may be more feasible for community-based agencies.

Our study would have also benefitted from greater community input regarding which modifications we chose to implement. The present study relied on previous literature to develop modifications. The formation of a community advisory board, or the use of Community Based Participatory Research (CBPR; Israel et al., 2005) methods to involve community members in the development of intervention modifications may have increased participant engagement to a greater degree.

Finally, because this was a nonrandomized pilot study, we did not have a control group, thus we were unable to measure directly whether engagement was increased by our specific modifications. Furthermore, we were unable to examine how participant engagement may have impacted caregiver and child outcomes. Such outcomes were examined in preliminary analyses and have been reported elsewhere. In brief, preliminary analyses revealed that while caregivers were successful in acquiring targeted treatment strategies over the course of their involvement in the project (Carr, 2011), child outcomes (e.g., cognitive ability, adaptive behavior, social affect, and repetitive behaviors) remained unchanged (Dent, Carr, Leitman, & Lord, 2012). A critical next step will be to recruit a larger participant sample to be able to examine directly how treatment engagement impacts treatment outcome.

5. Conclusions

The purpose of this study was to conduct a nonrandomized pilot study testing the feasibility of recruiting families who seldom participate in intervention research. The implementation of several practical key features, including providing sessions in-home, reducing travel requirements, maintaining a liberal cancellation policy, and providing community resource support facilitated high levels of treatment engagement from families reporting low income and low education. Overall, this study demonstrates that with funding, effort, and understanding, families who have traditionally been underrepresented in ASD intervention research can have a voice and contribute to the development of ASD interventions benefitting families of all backgrounds.

Acknowledgments

We are grateful for the participation of the families involved in this research project. We wish to thank the UMACC and FSU staff members who supported and contributed to the implementation of the project, particularly Alyssa Barriger, Alexa Dent, Alex Jeanpierre, Kristina Lopez, and Kathryn Larson. We also thank Jeanne Miranda, Clare Harrop, and Vanessa Hus Bal for their assistance in manuscript revision. This research was supported by grants from the National Institute of Health (5R01MH078165-05) and Autism Speaks (5776).

References

- Bishop SL, Richler J, Cain AC, Lord C. Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal of Mental Retardation*. 2007; 112:450–461. [PubMed: 17963436]
- Blacher J, McIntyre LL. Syndrome specificity and behavioral disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disabilities Research*. 2006; 50:184–198.
- Carr, T. The Development and Implementation of an Early Intervention Program for Underserved Families of Children with Autism Spectrum Disorder (Doctoral Dissertation). 2011. Retrieved from <http://deepblue.lib.umich.edu/handle/2027.42/89803>
- Carr T, Lord C. Longitudinal study of perceived negative impact in African American and Caucasian mothers of children with autism spectrum disorder. *Autism*. 2013; 17:405–417. [PubMed: 22751751]
- Carter AS, Messinger DS, Stone WL, Celimli S, Nahmias AS, Yoder P. A randomized controlled trial of Hanen's 'More Than Words' in toddlers with early autism symptoms. *Journal of Child Psychology and Psychiatry*. 2011; 52:741–752. [PubMed: 21418212]
- Centers for Disease Control and Prevention. Prevalence of Autism Spectrum Disorders - Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2008. *Surveillance Summaries, MMWR*. 2012; 61:2–19.
- Creswell, JW. *Qualitative inquiry and research design: Choosing among five approaches*. 2nd. Thousand Oaks, CA, US: Sage Publications, Inc.; 2007.
- Dent, A.; Carr, T.; Leitman, S.; Lord, C. Effects of Parent-Mediated Early Intervention on Child Behavioral Outcomes in an Underserved Population; Poster presented at International Meeting for Autism Research (IMFAR); Toronto, Canada. 2012 May.
- Dawson G, Rogers S, Munson J, Smith M, Winter J, Greenson J, Varley J. Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. *Pediatrics*. 2010; 125:e17–e23. [PubMed: 19948568]
- Flanders SC, Engelhart L, Pandina GJ, McCracken JT. Direct health care costs for children with Pervasive Developmental Disorders: 1996–2002. *Administration and Policy in Mental Health and Mental Health Services Research*. 2007; 34:213–220. [PubMed: 17082979]
- Fox RA, Holtz CA. Treatment outcomes for toddlers with behavior problems from families in poverty. *Child and Adolescent Mental Health*. 2009; 14:183–189.

- Green J, Charman T, McConachie H, Aldred C, Slonims V, Howlin P, Pickles A. Parent-mediated communication-focused treatment in children with autism (PACT): a randomized controlled trial. *Lancet*. 2010; 375:2152–60. [PubMed: 20494434]
- Ingersoll B, Wainer A. Initial efficacy of Project ImPACT: A parent mediated social communication intervention for young children with ASD. *Journal of Autism and Developmental Disorders*. 2013; 43:2943–2952. [PubMed: 23689760]
- Ingoldsby EM. Review of interventions to improve family engagement and retention in parent and child mental health programs. *Journal of Child and Family Studies*. 2010; 19:629–645. [PubMed: 20823946]
- Israel BA, Parker EA, Rowe Z, Salvatore A, Minkler M, Lopez J, Burtz A, et al. Community-based participatory research: Lessons learned from the center for children's environmental health and disease prevention research. *Environmental Health Perspectives*. 2005; 113:1463–1471. [PubMed: 16203263]
- Jang J, Dixon DR, Tarbox J, Granpeesheh D, Kornack J, deNocker Y. Randomized controlled trial of an eLearning program for training family members of children with autism in the principles and procedures of applied behavior analysis. *Research in Autism Spectrum Disorders*. 2012; 6:852–856.
- Johnson RB, Onweugbuzie AJ. Mixed methods research: A research paradigm whose time has come. *Educational Researcher*. 2004; 33:14–26.
- Kasari C, Gulsrud A, Wong C, Kwon S, Locke J. Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. *Journal of Autism and Developmental Disorders*. 2010; 40:1045–1056. [PubMed: 20145986]
- Kasari C, Lawton K, Shih W, Barker TV, Landa R, Lord C, Senturk D. Caregiver-mediated intervention for low-resourced preschoolers with autism: An RCT. *Pediatrics*. 2014; 134:72–79.
- Kilbourne AM, Switzer G, Hyman K, Crowley-Makota M, Fine MJ. Advancing health disparities research within the health care system: A conceptual framework. *American Journal of Public Health*. 2006; 96:2113–2121. [PubMed: 17077411]
- Klinger, JK.; Blanchett, WJ.; Harry, B. Race, culture, and developmental disabilities. In: Odom, SL.; Horner, RH.; Snell, ME.; Blacher, J., editors. *Handbook of developmental disabilities*. New York: Guilford Press; 2007. p. 55-75.
- Le Couteur, A.; Lord, C.; Rutter, M. *The Autism Diagnostic Interview – Revised (ADI-R)*. Los Angeles, CA: Western Psychological Services; 2003.
- Liptak G, Benzoni L, Mruzek D, Nolan K, Thingvoll M, Wade C, Fryer G. Disparities in diagnosis and access to health services for children with autism: Data from the national survey of children's health. *Journal of Development and Behavioral Pediatrics*. 2008; 29:52–160.
- Lord C, Bishop S. Social policy report: Autism spectrum disorders: Diagnosis, prevalence, and services for children with families. *Sharing Child and Youth Development Knowledge*. 2010; 24:1–21.
- Lord C, Risi S, Lambrecht L, Cook EH, Leventhal BL, DiLavore PC, Rutter M. The Autism Diagnostic Observation Schedule – Generic: A standard measure of social and communication deficits associated with the spectrum of autism. *Journal of Autism and Developmental Disorders*. 2000; 30:205–223. [PubMed: 11055457]
- Lord C, Wagner A, Rogers S, Szatmari P, Aman M, Charman T, Yoder P. Challenges in evaluating psychosocial interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*. 2005; 35:695–708. [PubMed: 16496206]
- Lyon AR, Budd KS. A community mental health implementation of parent-child interaction therapy (PCIT). *Journal of Child and Family Studies*. 2010; 19:654–668. [PubMed: 20877583]
- Mandell D, Listerud J, Levy S, Pinto-Martin J. Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2002; 41:1447–1453. [PubMed: 12447031]
- Mandell DS, Novak M. The role of culture in families' treatment decisions for children with autism spectrum disorders. *Mental Retardation and Developmental Disabilities Research Reviews*. 2005; 11:110–115. [PubMed: 15977313]

- Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGiuseppi C, Durkin MS, Kirby RS. Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health*. 2009; 99:493–498. [PubMed: 19106426]
- Magaña S, Smith MJ. Psychological distress and well-being of Latina and Non-Latina White mothers of youth and adults with an Autism Spectrum Disorder: cultural attitudes towards coresidence status. *American Journal of Orthopsychiatry*. 2006; 76:346–357. [PubMed: 16981813]
- Magaña S, Lopez K, Aguinaga A, Morton H. Access to diagnosis and treatment services among Latino children with autism spectrum disorders. *Intellectual and Developmental Disabilities*. 2013; 51:141–153. [PubMed: 23834211]
- Mullen, E. *The Mullen Scales of Early Learning*. Circle Pines, MN: American Guidance Service; 1995.
- Shavelson, R.J.; Towne, L., editors. *National Research Council. Scientific research in education*. Washington, DC: National Academy Press; 2001.
- Nock MK, Ferriter C. Parent management of attendance and adherence in child and adolescent therapy: A conceptual and empirical review. *Clinical Child and Family Psychology Review*. 2005; 8:149–166. [PubMed: 15984084]
- Rogers SJ, Estes A, Lord C, Vismara L, Winter J, Fitzpatrick A, Dawson G. Effects of a brief Early Start Denver Model (ESDM) – based parent intervention on toddlers at risk for autism spectrum disorders: A randomized controlled trial. *Journal of the American Academy of Child & Adolescent Psychiatry*. 2012; 51:1052–1065. [PubMed: 23021480]
- Ruble L, Heflinger CA, Renfrew JW, Saunders RC. Access and service use by children with autism spectrum disorders in Medicaid managed care. *Journal of Autism and Developmental Disorders*. 2005; 35:3–13. [PubMed: 15796117]
- Santarelli G, Koegel R, Casas J, Koegel L. Culturally diverse families participating in behavior therapy parent education programs for children with developmental disabilities. *Journal of Positive Behavior Interventions*. 2001; 3:120–123.
- Schertz H, Odom S. Promoting joint attention in toddlers with autism: A parent-mediated developmental model. *Journal of Autism and Developmental Disorders*. 2007; 37:1562–1575. [PubMed: 17096190]
- Snells-John J, Mendez J, Smith B. Evidence-based solutions for overcoming access barriers, decreasing attrition, and promoting change with under-resourced families. *Journal of Family Psychology*. 2004; 18:19–35. [PubMed: 14992607]
- Sparrow, SS.; Cicchetti, DV.; Balla, DA. *Vineland Adaptive Behavior Scales: Second Edition*. Circle Pines, MN: American Guidance Service; 2005.
- Tek S, Landa RJ. Differences in Autism symptoms between minority and non-minority toddlers. *Journal of Autism and Developmental Disorders*. 2012; 42:1967–1973. [PubMed: 22271196]
- U.S. Department of Health and Human Services. *Mental Health: Culture, race, and ethnicity—A supplement to Mental Health: A report of the surgeon general*. Rockville, MD: Department of Health and Human Services, Public Health Service, Office of the Surgeon General; 2001.
- Vismara LA, Young G, Rogers S. Telehealth for expanding the reach of early autism training to parents. *Autism Research and Treatment*. 2012; 2012:1–12.
- Wetherby A, Woods J. Early social interaction project for children with autism spectrum disorders beginning in the second year of life: A preliminary study. *Topics in Early Childhood Special Education*. 2006; 26:67–82.
- Wetherby AM, Guthrie W, Woods J, Schatschneider C, Holland R, Morgan L, Lord C. Parent-implemented social intervention for toddlers with autism: An RCT. *Pediatrics*. 2014; 134:1084–1093. [PubMed: 25367544]
- Wilder LK, Dyches TT, Obiakor FE, Algozzine B. Multicultural perspectives on teaching students with autism. *Focus on Autism and Other Developmental Disabilities*. 2004; 19:105–113.
- Woods J, Wetherby A. Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech, and Hearing Services in Schools*. 2003; 34:180–193.

Highlights

- Barriers to intervention are a significant problem for families with limited resources
- Low income and low education families are underrepresented in intervention research
- Practical modifications to intervention protocols increase participant engagement

Figure 1.

Treatment adherence: Caregiver-reported average weekly time engaged applying intervention strategies.

Table 1

Participant Demographics and Characteristics

	Entered Treatment (N=8)		Did Not Enter Treatment (N=4)	
Caregiver Characteristics	<i>M (SD)</i>	Range	<i>M (SD)</i>	Range
Age (years)	31.38 (4.75)	21 – 36	39.7 (19.34)	28 – 62
Ethnicity				
African American	4		1	
Caucasian	4		3	
Marital status				
Unmarried	3		0	
Unmarried, Co-living	3		3	
Married	2		1	
Education				
Some High School	0		1	
High School Graduate	3		3	
Some College	5			
Family income (yearly)	\$18,300 (10,000)	< \$10,000 – 35,000	\$23,200 (1,100)	<\$10,000 – 32,000
Number of children in family	2.38 (1.41)	1 – 5	3.25 (1.71)	1 – 5
Child Characteristics	<i>M (SD)</i>	Range	<i>M (SD)</i>	Range
Age (months)	28.38 (5.21)	24 – 40	29.75 (4.9)	23 – 34
Ethnicity				
African American	3		1	
Caucasian	3		3	
Multiracial	2		0	
Verbal IQ	40.12 (16.10)	27 – 71	53.5 (12.12)	38 – 61
Nonverbal IQ	70.13 (13.91)	50 – 96	58.0 (11.22)	43 – 74
Adaptive Behavior Composite	75.38 (8.73)	64 – 85	73.75 (10.14)	64 – 89

Table 2

Reported Reasons for Treatment Session Cancellations

Reported Reason for Cancellation	Percentage of Cancellations
Mother/Child Sick	27%
Family Need/Emergency	14%
Child Sleep Problems	11%
Other ASD Intervention/DD services	3%
Doctor's Appointment	2%
Housing/Travel Resource Problem	4%
Work Conflict	7%
Interventionist Cancelled	8%
Not Reported	24%

Table 3

Exit Interview Sample Quotations by Theme/Subtheme

Themes and Subthemes	Sample Quotations
Understanding Child's impairment	
Child's impairment	"You know where he is, as a three year old compared to other three-year olds? It's funny to see, you know, he may be three, but his brain is at like 15 months" "We had no idea what having an autistic child really meant"
Initial Concerns	"I just knew he was delayed. I had no idea how to communicate with him or talk to him".
Reaction to Diagnosis	"I already knew most of it so I wasn't shocked really. It was hard to take at first"
Child's Future	"My goals are just for him to be –just to live a normal life. To hopefully just go to normal school and be with everybody. There may be some challenges along the way but he's—he's come a far way so he's going to go even further."
Advocacy and Empowerment	
Benefits of Early intervention	"I read that it's better if you find out and get your child help when they're young because they actually may have signs of it at all time but they can be live to be productive normal people"
Advocacy	"I try get awareness out as much as I can... people will ask me questions and I'm like okay, hold on let me make sure I'm giving you the right information."
Empowerment	"Dad was in denial before and now dad's like "my son has autism you know, don't stare, if you have any questions ask me."
Benefit of other treatment programs	"He's come a long way. And not just because of you guys but now I got him more therapy."
Negative aspects of intervention	
Scheduling	"If I was not working at all it probably would have been a lot easier. There were times when you guys had to come out really late."
Difficulties implementing treatment	"It's hard to get him to sit for that long and do blocks. Besides, he likes to line them up and play different."
Questionnaires	"They were long. I didn't mind doing them but they were long."
Intervention structure	"I think the first couple of times [home visits] were kind of scary cause you're like 'wait, what does this person think of me,' you know, 'are they going to judge me,' you know?"
Positive aspects of intervention	
Change in child and caregiver	"He's got a lot more eye contact, a lot more communication, like verbally and non-verbally." "I'm more patient with him. I will have to say that. I'm way more patient now than I was before".
Family impact	"I approach him more. Actually all of us do now. Because we didn't know how to talk with him-- nobody knew how to talk to him at all."
Relationship with interventionist	"Knowing that somebody else is going to come and give me feedback on my parenting skills instead of just family members being like, 'oh, you know, you do a good job.' She actually made you feel like you're doing a good job. She gave me knowledge, help."

Themes and Subthemes	Sample Quotations
After diagnosis	As a parent with a son on the aut-, you know, on the spectrum, I didn't know where to start, where to begin, and like, I came to you guys, and like you guys, told us, this is what you do from here on out
Connection with university clinic	"I knew you guys had my back [advocating for community services]. You're my people!"