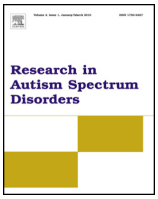
Research in Autism Spectrum Disorders 25 (2016) 87–96

Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: http://ees.elsevier.com/RASD/default.asp



A pilot study promoting participation of families with limited resources in early autism intervention

Themba Carr*, Catherine Lord[1]

University of Michigan, Department of Psychology, University of Michigan Autism and Communication Disorders Center, Ann Arbor, MI, United States

ARTICLE INFO

Article history:
Received 25 September 2015
Received in revised form 4 February 2016
Accepted 7 February 2016
Available online xxx

Keywords:
Autism
Early intervention
Under-resourced communities
Low-income

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.

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

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* 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, United States.
E-mail address: tcarr@mednet.ucla.edu (T. Carr).

[1] 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, United States.

http://dx.doi.org/10.1016/j.rasd.2016.02.003
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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, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009). 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, Switzer, Hyman, Crowley-Makota, & Fine, 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 (Carr et al., 2015; Kasari et al., 2014).

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; (c) 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, 2005) 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,