

Exploring Perspectives on Child Care With Families of Children With Autism

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Abstract

Early childhood programs serve increasing numbers of children with autism spectrum disorders (ASD) and their families. While many programs have made significant progress in providing educational services responsive to the needs of children with ASD, concerns persist about whether early education programs can meet the educational needs of such children and collaborate effectively with their families. The authors explored self-reported experiences and concerns of families who have children diagnosed with ASD and their experiences with preschool educational services in a northern county of a southeastern state. In focus groups, participants discussed program/family relationships, their priorities for their children, and how these needs and priorities were addressed, or not addressed, in the programs serving their children. Findings indicate that families were concerned with their children's access to the educational environment, the availability of emotional and social development support for children with ASD, and the overall reflection of inclusion as a program philosophy in the program settings.

Introduction

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Children diagnosed with autism spectrum disorders (ASD) are the most rapidly growing group of students served in special education (Barnhill, Polloway, & Sumutka, 2011; Ludlow, Keramidis, & Landers, 2007). For 2010, the overall prevalence of ASD at 11 different U.S. monitoring sites was 1 in 68 children aged 8 years (CDC, n.d.).

The increased rates of ASD diagnosis have led families and policy makers to call for initiatives to increase knowledge and understanding of the needs of children with ASD and enhance the effectiveness of interventions and related services (Bloch & Weinstein, 2010; Boyd, Odom, Humphreys, & Sam, 2010). Families' unique expertise and insights can help teachers and specialists better understand the strengths and needs of children with ASD (Becker-Cottrill, McFarland, & Anderson, 2003; A. Turnbull, H. R. Turnbull, Erwin, Soodak, & Shogren, 2011; Woods & McCormick, 2002). Information from families can also benefit practitioners and teacher educators who seek to promote parental participation in assessment, evaluation, goal identification, or service planning for children with ASD.

The developmental and academic benefits of inclusive settings for young children with disabilities have been documented by an extensive body of literature (Buysse & Hollingsworth, 2009; Etscheidt, 2006). In their joint statement on inclusion in early childhood education, the Division for Early Childhood of the Council for Exceptional Children and the National Association for the Education of Young Children assert the critical importance of meaningful interaction between young children with disabilities and their typically developing peers (DEC/NAEYC, 2009; Kohler, Greteman, Raschke & Highnam, 2007; Kohler, Strain, & Goldstein, 2005).

Research suggests that significant numbers of parents are dissatisfied with limited inclusivity in their children's placements. In an analysis of services received by families of 3,104 preschool children with autism and parents' satisfaction with these services, Bitterman, Daley, Misra, Carlson, and Markowitz (2008) found that while most of the parents reported receiving good or excellent services, more than a quarter thought their children did not spend enough time with typically developing peers. These parents also reported spending significant amounts of time identifying and obtaining services for their preschool children (Bitterman et al., 2008). Some research indicates that, compared with families of children with other disabilities, families of children with ASD are more likely to experience delays and other difficulties with referrals and appropriate education services as well as financial struggles. Parents of children with ASD are also more likely to reduce workload or even stop working to attend to their children's needs when needed services are not in place (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan et al., 2008; Lord & Bishop, 2010).

Challenges to Inclusion

High-quality programs with appropriately trained professionals have potential to address the needs of the growing number of children with disabilities and their families in early childhood programs (Buysse & Hollingsworth, 2009; Buysse, Skinner, & Grant, 2001). Teacher educators and professional organizations have sought to infuse the goal of inclusion into teacher preparation and professional development programs. In particular, they have advocated a culture of inclusive practice with instructional strategies and curriculum that address the needs of all children. Moreover, training to prepare teachers to meet the needs of young children with disabilities is viewed as critical in developing positive attitudes toward inclusion (Baker-Ericzén, Mueggenborg, & Shea, 2009; Cross, Traub, Hutter-Pishgahi, & Shelton, 2004). However, full inclusion of young children with ASD remains challenging. Insufficient planning and instructional time and lack of training for early childhood special educators and specialists are among the identified barriers to addressing the needs of children with ASD (Anderson, Moore, Godfrey, & Fletcher-Flinn, 2004; Kemp & Hayes, 2005; Kishida & Kemp, 2009). Research also suggests that support for positive social and emotional development of children with ASD may be inadequate because of insufficient resources and limited training opportunities for early childhood teachers (Blair, Lee, Cho & Dunlap, 2011; Brown, Odom, & Conroy, 2001; Wolery & Gast, 2000).

These challenges are confirmed by reports from parents of young children with moderate and severe disabilities, indicating that finding high-quality child care programs for their children can be particularly difficult, due in part to child care providers' attitudes toward inclusion and the lack of resources for addressing these children's complex needs and abilities (Baker-Ericzén et al., 2009; Mulvihill, Cotton, & Gyaben, 2004; Odom, Vitztum, et al., 2004). Families of young children with ASD report significant challenges in accessing and maintaining enrollment in high-quality service programs (Braddock & Twyman, 2014; Murphy & Ruble, 2012; Ruble, Heflinger, Renfrew, & Saunders, 2005; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

Experiences With Services

Infants, toddlers, and preschool children and their families may receive services (e.g., diagnostic services) under federal and state-funded programs under Part C and Part B of the Individuals with Disabilities Education Act (2004) or through private programs.

Diagnosis. Early diagnosis by specialist ASD teams including trained physicians or psychologists is seen as crucial for children with ASD; timely referral for early intervention services has been shown to lead to improved language, social, and adaptive functioning and increased likelihood of successful inclusion (Schwartz, Sandall, McBride, & Boulware, 2004; Strain & Bovey, 2011). However, families have historically experienced challenges at various levels of special education services, and the diagnosis phase can be particularly stressful. While recommended practices for ASD screening and evaluation of young children include use of formal developmental screening tools and specific procedures, a large proportion of physicians do not employ them consistently (Lord & Bishop, 2010; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). The route from detection of early signs to provision of early intervention services can vary across states and education or health care systems. Families often rely on teachers and educational professionals to inform them of developmental concerns for their children, although educators may not be prepared to identify early signs of developmental needs or to relay concerns to families or other professionals. Diagnosis can be delayed by the need to navigate multiple evaluation procedures involving several professionals; extended time may also be required to accurately determine what a child's needs are (Siklos & Kerns, 2007). In a study of parents' experiences with special education services for their children with disabilities, A. Webster, Feiler, V. Webster, and Lovell (2004) found that most of the families had to wait more than one year for a formal evaluation and diagnosis.

Family engagement. Family engagement in early education programs for children with disabilities is generally considered extremely important (Hedges & Gibbs, 2005). Early childhood educators and interventionists are expected to engage parents in a range of services for their children at various levels, including assessment, evaluation, identifying goals, or service planning. Parent education programs have been important elements of therapy for children with ASD, although not all parents have the time, energy, and resources to participate (Whittingham, Sofronoff, Sheffield & Sanders, 2009). Parent-implemented interventions have been effective for young children with ASD (Boyd et al., 2010); however, parents of children with ASD have reported significant challenges to partnering with teachers and specialists.

This study addressed the following questions regarding the experiences of families with young children with ASD in child care settings: (a) What are the families' perceptions of child care providers' willingness to accept their young children with ASD? (b) What are the families' perceptions of child care providers' willingness and ability to support young children with ASD? (c) What do families recommend for child care providers to better meet the needs of young children with ASD?

Methods

Study Design

The researchers employed qualitative methods to explore the views of parents of preschool children with ASD in child care programs. Focus groups were conducted to collect comprehensive data from parents to enhance understanding of the family perspectives based on their experiences. Focus groups are viewed as particularly useful for obtaining in-depth information on participants' perspectives and exploring ideas relevant to a topic (Christinsen, Johnson, & Turner, 2011).

Setting and Sample

Research sites. This study took place in the United States, in a state that includes a population of almost 630,000 children under 5 years old and has high rates of cultural and linguistic diversity. The parent focus groups were conducted in one county with a population of more than 488,000, of which 6.8 percent are children under 5 years old. The focus groups took place at a community building of a partnering community agency.

Participants. Participants in this research (N=22) were parents of children with ASD who have attended preschool programs. Almost all participants in this study were European American (n=19), with one African American participant, one Asian, and one of Latino heritage. All but one were female. Almost half of the participants (n=10) were residents of urban areas; seven lived in suburban areas, and five in rural areas. Six participants reported having children ages 20 months to 4 years old, and 19 reported having children ages 5 and older; some had more than one child across these categories. All had children who had been diagnosed with ASD before age 6; three of the children had additional diagnoses. One child's diagnosis was yet to be established. Twelve were diagnosed before age 2½, and 14 at age 3 or older. Participants reported having their children enrolled in private early childhood education programs (n=6), public early childhood education programs (n=3), private child care programs (n=6), early childhood education programs supported by both public and private funding (n=5), and child care programs supported by public funding and partial private funding (n=2).

Procedures

A purposeful homogeneous sample of participants was recruited through an announcement about the research posted in the newsletter of a local community service organization. The research team worked with that agency to organize the focus group sessions. Each session lasted approximately one and a half hours. The research team included two lead researchers and two research assistants, all of whom were trained for their roles in the study. Research assistants took field notes while a lead researcher led five focus groups of between five and nine participants. Sessions were audiotaped and data was transcribed into electronic files.

The focus group discussion began with broad, open-ended questions and continued with in-depth questions regarding the experiences of families with preschool programs. Questions addressed (a) families' overall experience with the programs their children were currently attending or their recollections from the past three years; (b) families' hopes and expectations regarding early childhood care and education services; (c) families' desires regarding their children's and families' needs regarding the child care services provided, or not provided; (d) families' perceptions of how well prepared the professionals working with their child were; (e) families' descriptions of the barriers the early educators might have encountered when trying to address family expectations or the children's needs; (f) families' descriptions of the strengths of the programs in addressing the needs of children and their families; and (g) families' recommendations for ways child care providers might better meet the needs of children with ASD and their families.

Data Analysis

All collected data were transcribed verbatim from audiotape to electronic text files. Two team research members analyzed one focus group transcript (25% of the data) independently for interrater reliability. The transcripts were set in a three-column table with the verbatim transcription in the first column. During multiple readings, researchers noted and coded common elements; recurring patterns were identified as specific themes. The researchers discussed disagreements across the themes until reaching full agreement. Transcripts of the remaining focus groups were equally divided and analyzed by two research team members. A final index of themes and codes was developed from comparison and discussion of the analyzed data.

Findings

We identified five major themes about the participants' experiences with child care programs serving their young children with ASD.

Child care providers' lack of knowledge about the characteristics of ASD affects families' initial experiences.

Parents thought child care professionals needed to know more about the appropriate instructional strategies, services, and resources that are critical for serving children with ASD and their families.

After recognizing this lack of knowledge among child care professionals, parents advocated for their child by finding resources and information themselves.

Parents want teachers to love, respect, and acknowledge the unique needs of their child.

It's important to parents that their child with ASD has peer friendships.

Child Care Providers' Recognition of ASD Characteristics

Focus group participants emphasized the importance of teachers' ability to recognize and understand the early signs of ASD. In some cases, professionals' lack of knowledge about ASD affected families' awareness of their children's needs; one of the parents stated, "I needed someone to raise the red flag, and no one did that." However, some participants indicated that, even when teachers were knowledgeable about early signs of ASD, process-related requirements impeded them from sharing that information with families. Teachers were not allowed to provide parents with their input when they suspected specific developmental problems. One participant remarked, "I think that if a teacher ... sees some things that they identify, that they should be allowed to give you that approach, and to help you and to guide you."

Parents emphasized the need for timely evaluations. They emphasized the importance of early identification and the use of appropriate screening and evaluation tools as steps toward accessing early intervention in a time frame perceived as "sensible" for their children's growth and development. For example, a parent stated:

I know it's gonna vary parent to parent, but I guess my point is some sort of consistent evaluation that can be marketed to these preschools or required of these preschools just because early intervention we're seeing so much now is so important, and somehow stemming the tide a little bit when it comes to these children.

Participants reported challenges associated with teachers' ability to discriminate between behavioral indicators of ASD and typical developmental responses of children in their programs. Some reported that teachers may have overlooked the needs of children who, though not developing typically, did not exhibit hard-to-manage classroom behaviors, such as disruptive responses. One participant summarized:

I think sometimes a teacher might think they're OK because they're not screaming and tantruming and they're not hitting or biting someone else, but when you look at that child, are they doing anything productive? Or are they just engaging in self-stimulatory behaviors in the corner? And if the teacher is OK with that, because it's manageable, [...] I think that's a problem, because that's not being a successful experience.

Child Care Providers' Knowledge of Strategies, Services, and Resources

Participants frequently expressed the wish that teachers serving their children had greater knowledge of strategies, services, and resources to address the needs of children with ASD. Regular communication between school and home, generally considered strategically important for working with children with ASD, was frequently described as challenging. Often teachers did not recognize or acknowledge the importance of regular communication with families about the child. One participant commented: "So I feel like that's one of the biggest problems with him at that school is that I just, I never know what happened at school."

The participants also reported that lack of regular communication between teachers and families sometimes undermined their trust in the programs and affected their perspective on services provided. The lack of transparent, consistent communication was sometimes seen as extending to relationships among the professionals working with a child. One parent elaborated: "It's the lack of a team approach. They're supposed to be a team, you know, and it's just not there." Some participants perceived that this might have significant consequences for children with ASD whose educational success depends on the effective, coherent, and harmonious integration of specialized services: A parent remarked:

Being open to that therapy, IEP team, coming in the classroom, that's just such an important piece to make it work. If you have a teacher not real happy about an educational therapist coming in the room a couple of times a week, that's going to be a barrier.

Participants also discussed the need for teachers to use instructional strategies that accommodate the needs not only of children with ASD but all children. For example, one parent stressed the importance of sensory-based learning approaches.

They need those visuals, they need those tactile experiences where they're doing the hands-on things, and that's how they're getting their learning. Not giving them the verbal orders and telling them ... what to do and how to do it and expecting them to follow that, and I think what a lot of the centers don't realize is that it not only affects the kids with autism, it affects the other kids as well.

Similarly, participants indicated that they wanted teachers to employ developmentally appropriate curriculum and instructional strategies with their children with ASD, sometimes linking the need for such curricula and strategies to the importance of collaboration among professionals to ensure that IEP goals are achieved. As one parent said: "So, I think, having a developmentally appropriate curriculum and also having teachers that are going to embrace ... the opportunity to work with an IEP makes that be able to be successful."

Child Care Professionals' Knowledge and Parents' Need to Advocate

Some focus group participants indicated that because their children's teachers frequently were not knowledgeable about ASD, they as parents felt "on their own" as they advocated for their children by seeking available resources and information. Some parents described becoming advocates for their children because they were not provided with necessary information or appropriate support in the child care setting. Parents frequently reported that they struggled to create access to services and supports in their communities; they perceived this as an intense effort in which they faced difficulties without support. One of the parents commented: "...and we're the front people on the front line with all these kids!"

Learning that a child has been diagnosed with ASD can be traumatic for a family, many participants indicated, especially when they then face additional difficulties. One parent explained that after receiving the diagnosis, the prospect of addressing challenges with the child care program seemed beyond the family's personal resources, noting: "Probably, had I not already been traumatized from diagnosis, if I had gone to the director, I think some things would have been set straight in the classroom, but you can only fight so many fights." Parents in such situations sometimes hired a facilitator to help them obtain appropriate education services for children. One parent said: "Later I found out that most of the parents there hired their own facilitator to go in, and had I known that, I might have reconsidered [removing my child from the program]."

Teacher's Attitude Toward the Child

Focus group participants emphasized their desire that teachers love, respect, and acknowledge the unique needs of their children with ASD. They frequently described the importance of having the children and their strengths valued and embraced by teachers and peers, though they recognized that teachers and other professionals might be challenged by the children's behavioral difficulties.

Our kids are difficult sometimes to handle, and unless you have someone who is willing to see past the differences and see how wonderful they really are, you know, I mean I can understand you might be a little daunted, but they're really great kids.

In fact, parents reported that above all else, they wanted teachers to love and accept their children. One parent summarized, "I wanted someone to love them first." Another parent commented, "I really just think it's the feedback, and the caring for your child, you know, they care for every one of those children like they're their own." In general, confidence that the children were accepted and appreciated, and that teachers were understanding and compassionate, were critical to parents' comfort. As one parent said: "In a few months a different teacher came in and I just think [there's a] level of compassion and concern and they view my child like their child and they work very well."

Importance of Peer Friendships

Parents in the focus groups frequently cited development of peer friendships as an important goal they had for their children with ASD. They perceived that support and opportunities for peer acceptance and friendship were essential. One parent commented, “The teacher knows that our big goal is the social component, so she is giving me feedback on my number one concern, [which] is that I want [my child] to initiate with a peer.” Another participant stated: “I had that in my head, I was replaying that they have to be with their typical peers because that’s how they learn best.” Another parent said, regarding her child’s relationships, “I just want you to talk and have a friend, and everything else ... will fall into place.” However, many of the parents noted that this objective had yet to be accomplished. One parent said: “I just wanted him to like it, and to make a friend, and we haven’t done that yet.”

Discussion

Findings of this study are consistent with other research documenting the importance of proactively addressing the needs of children with autism in early childhood programs (Dingfelder & Mandell, 2011; Ferraioli & Harris, 2011). Early intervention services and therapies delivered in a timely fashion are crucial, yet this study and others have found that families often report that professionals do not fully address their concerns related to intervention and therapy (Reznick, Baranek, Reavis, Watson, & Crais, 2007; Schall, 2000).

The findings also align with other research that has found that many families' greatest concerns are related to identification of and service provision for young children with ASD and their families in child care programs (Kishida & Kemp, 2011). Concerns identified in other studies include lack of resources (e.g., insufficient time for teachers to plan instructional strategies or insufficient specialized materials) and challenges to consulting with the teachers (Kemp & Hayes, 2005; Kishida & Kemp, 2011).

This study and prior research have noted that parents want to trust that teachers are knowledgeable about and vigilant recognizing their children's needs. Indeed, professionals can play a critical role in providing families with emotional support, encouragement, and information on their child's disability and ways to identify and address the needs of their child and family (Bloch & Weinstein, 2010; Murray, Ackerman-Spain, Williams, & Ryley, 2011). However, as participants in this study indicated, child care professionals may be unable to do so.

The National Research Council (NRC) identified six priority areas of focus for interventions for young children with autism: functional spontaneous communication, social instruction, play skills, cognitive development, functional academic skills, and proactive approaches in addressing behavioral problems (Stansberry-Brusnahan & Collet-Klingenberg, 2010). The parents in our study shared recommendations that aligned with those of NRC. Among other points, they commented on the critical importance of teachers' ability to detect early signs of ASD so children could benefit from early intervention and on the need for teachers to use approaches that are specifically effective for children with autism. Study participants also emphasized the importance of their children's ability to communicate effectively and their overall socioemotional development. This suggests a critical need for professionals to be prepared to provide inclusive opportunities, ongoing evaluations and adjustments, family engagement, and consistent, systematically planned and developmentally appropriate activities for young children with ASD (Stansberry-Brusnahan & Collet-Klingenberg, 2010).

Environments that are emotionally secure and nurturing enhance child development and create opportunities for children to develop emotional and social skills vital for children with ASD. Teachers need support to be prepared to provide such opportunities. Parents also strongly emphasized acknowledging their children's strengths and celebrating their achievements. This is consistent with research findings and professional recommendations

for a strengths-based approach for working with families of students with disabilities (A. Turnbull et al., 2011). Research also suggests that parental support for children's social-emotional development and interactions with peers are critical for development in all other areas for children with ASD (Bass & Mulick, 2007; Harper, Symon, & Frea, 2008; Trembath, Balandin, Togher, & Stancliffe, 2009).

Parents' first-hand knowledge of their children's experiences and needs could make them valuable partners in preparing teachers to work with children who have ASD if teacher education programs establish collaborative relationships with parents and family members. At present, few examples can be found of systematic participation of family members in teacher training programs (Leatherman & Niemeyer, 2005; Murray, Curran, & Zellers, 2008; Niemeyer, 2001). Teacher education programs with a strong focus on family engagement have involved families in various ways, ranging from being guest speakers or panel participants to co-teaching, curriculum development, and internships. Collaborative in-service/professional developmental opportunities involving child care providers and parents of children with ASD can also build on available resources and enhance services to all children.

Implications for Future Research and Limitations of the Study

Like parents in similar studies, the participants in this study referred particularly to the importance of early identification of children with ASD (Crane & Winsler, 2008; Samms-Vaughan & Franklyn-Banton, 2008). These results suggest that early childhood program administrators should prioritize professional training that helps teachers recognize early signs of ASD and effective ways to address them.

For families in this study, the quality of socioemotional support teachers provided their children with ASD was of critical importance. The role of teachers and specialists in establishing positive relationships with and supportive environments for children should be explored further (Odom, Brown, et al., 2003; Robertson, Chamberlain, & Kasari, 2003).

Finally, collaboration between professionals and families with children who have ASD is not only recommended practice aligned with the families' rights regarding education of their children, it is also a central piece in the support teachers and other specialists can create for children with ASD (Moes & Frea, 2002; Odom, Brown, et al., 2003). Families have unique knowledge and expertise that professionals can and should incorporate in the educational environments they create for children with ASD (Iovannone, Dunlap, Huber, & Kincaid, 2003). Research should continue to explore ways to prepare educators for collaboration with families whose children have ASD.

This study of what families identify as critical issues in the education of preschool children with ASD has several limitations. Sample size was small; to increase generalizability, a larger sample should be recruited to investigate families' concerns related to inclusion of preschoolers with ASD. In addition, this study presented data collected only from families. Future research should include data from the teachers and specialists working with these children to gain a more comprehensive understanding of the different contexts for inclusion and other factors that influence the experiences of children with ASD and their families.

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