

***Supporting Preschool Children with Autism Spectrum Disorders
(ASD) and Their Families***

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Abstract

The increased prevalence of children with Autism Spectrum Disorder (ASD) calls for improvement in implementing early interventions, which are critical in improving long-term outcomes. This includes providing better and appropriate education and services for children with ASD, as well as providing supports for their parents and families. The importance of this comes from the understanding that raising a child with ASD affects the entire family. Without the support, parents and families are at a heightened risk of mental health problems, such as stress and depression. Experienced in working with general and special education children, specifically children with ASD, we sought three suggestions that may help parents with a child with ASD. We can aid parents of children with ASD by providing services that help understand the IEP process, finding an appropriate future placement, providing structured teaching during home visits, and helping them become an advocate for their child.

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While once considered a rare childhood disorders about 30 years ago, it is now estimated that one in every 88 children in the United States is diagnosed on the autism spectrum (“Autism Spectrum Disorders,” 2010). In other words, over one and a half million children in the United States are affected by ASD (Willis, 2009). This change is visible through the growing population of children with ASD attending the public schools, with five times as many children and youth diagnosed being served under the Individuals with Disabilities Education Act (IDEA) in 2006-2007 – a significant increase from 10 years prior (Chandler-Olcott & Kluth, 2009). The greater rate of diagnoses precludes to the growing concern of implementing effective early interventions critical in improving long-term outcomes. This includes providing better and appropriate education and services for children with ASD in addition to supports for their parents and families, which may improve the quality of life for the whole family (Myles, Grossman, Aspy & Henry, 2009).

Autism Spectrum Disorders (ASD) and Lifelong Challenges

Autism Spectrum Disorders (ASD) is the umbrella term for all neurodevelopmental disorders such as the Pervasive Developmental Disorders of Autism, Asperger's Syndrome, and Rett's Syndrome and Pervasive Developmental Disorders-Not Otherwise Specified (PDD-NOS) (Chandler-Olcott & Kluth, 2009; Myles et al., 2009; Roberts, Keane, & Clark, 2008). The severity and combination of any of these impairments vary. Almost all children with ASD will express multiple social and communication impairments; restrictive interests and repetitive behaviors are the most variable across children ("Autism Spectrum Disorders," 2010). Repetitive behaviors include "flapping one or both hands, pulling or tapping the ears, rocking back and forth or from side to side, sniffing the air, or sucking on the upper lip" (Willis, p. 3, 2009).

Additionally, even high-functioning individuals with ASD still face significant lifelong challenges (Newschaffer, Fallin, & Lee, 2002). Lifelong challenges include: (a) a lack of social-emotional reciprocity, a limitation in imitative and/or imaginative play, failure to seek shared enjoyment, and/or poor use of nonverbal communication; (b) a delay in language development, difficulties initiating or keeping conversation, and/or a usage of stereotyped speech or delayed echolalia ("Autism Spectrum Disorders," 2010; Ingersoll & Lalonde, 2010; Papageorgiou & Kalyva, 2010; Roberts et al., 2008; Simpson, de Boer-Ott, & Myles, 2003); (c) difficulty in successfully following and mastering an unmodified school curriculum, and/or exhibiting irregular patterns of cognitive and educational strengths and difficulties, including splinter skills and discontinuous abilities ("Autism Spectrum Disorders; Roberts et al.; Simpson et al.); and (d) an unusual preoccupation or obsessive insistence on restricted and repetitive interests and behaviors, repetitive finger, hand, or whole body movements, and/or compulsive behaviors and rituals, including self-stimulating responses ("Autism Spectrum Disorders; Papageorgiou & Kalyva; Pituch, Green, Didden, Lang, O'Reilly, Lancioni, & Sigafos, 2011; Roberts et al.; Simpson et al.).

Difficulties with Raising Children with ASD

Parents and families raising children with ASD share their child's lifelong challenges in addition to their own, such as finding appropriate care. Several studies uncovered that dealing with such challenges places parents at a higher risk for mental health problems, such as stress and depression (Ingersoll & Hambrick, 2011; Mandell & Salzer, 2007; Meirsschaut, Roeyers, & Warreyn., 2010), more than parents of typically developing children or children with other types of developmental disorders (Papageorgiou & Kalyva, 2010). An examination of mothers' perceptions of the impact of autism on the family and their personal lives found that mothers of children with ASD reported elevated stress levels and were at an increased risk for depression (Meirsschaut et al., 2010). More so, the study acknowledged that having a child with ASD does not only affect the parents, but that the well-being of the family in its entirety can be threatened, potentially leading to impairments in family functioning. Some of these perceived impairments are described as having to give up normal family activities and outings, a lack of spontaneity or flexibility in family life, a lack of outside or personal social activities, marital strain, and difficulties maintaining employment (Miersschaut et al.).

Ingersoll and Hambrick (2011) found that parents of children with ASD reported less social support, either not provided or perceived to not be available to them, thus adding to the increased

risk of mental health problems. In agreement with the Meirsschaut et al. (2010) study, Ingersoll and Hambrick suggested that it would be wise to screen parents for mental health problems and make appropriate referrals so that the entire family may have a better quality of life. Papageorgiou and Kalyva (2010) considered that the stress that parents experienced from raising a child with ASD was affected by the resources available to them. Parents who received adequate social support had a greater chance of adapting to the challenges brought about when raising a child with ASD and those who participated in support groups experienced less child-related stress. Implications of these findings would help decrease parents' mental health risks. By knowing parents' needs and concerns for their child, we can strengthen resources and intervention by empowering parents with the necessary tools and support. Once diagnostic assessments are made, families of children with ASD can seek out professional assistance to help them discuss early intervention as well as educational and social services systems ("Autism Spectrum Disorders," 2010).

Strategies for Supporting Families with a Preschool Child with ASD

As educators working directly with typical children and children with ASD, the following section suggests possible supports based on our experiences, conversations, and interactions with parents (families) raising preschoolers with ASD.

Educate Parents on the Individualized Education Program (IEP) Process

In order to help parents of children on the autism spectrum, teachers can help parents understand the components of the IEP process. For most parents who are experiencing an initial eligibility conference, the IEP process can be frightening. It is often unintentionally intimidating for parents to meet an interdisciplinary group of professionals who come to the table to discuss atypical developmental aspects of their child. Often parents of children with ASD understand the comprehensive process of assessment and diagnosis that precedes the IEP. However, the IEP process that addresses needs, subsequent placement, and delivery of services may be difficult for parents to grasp with a possible misunderstanding of the actual components included in the document.

We found that there exists a lack of understanding of the following specific IEP components:

- A) How and/or why goals are developed
- B) How the location and type of placement is determined
- C) The roles of providers and how services are delivered
- D) If and/or how their child gains access to the general curriculum
- E) How to read the service grid and timesheet that indicates the amount of services provided in minutes per week
- F) How the paraprofessional staff provides support
- G) How accommodations and modifications are provided when their child joins the general education classroom for large group instruction

Many parents have expressed that they want to be able to act as advocates for their child in order to ensure that the services they agreed upon are properly delivered. In many cases, parents are put off by the formalized nature of the IEP document. By providing a parent education program,

teachers can help address the aforementioned parental concerns. For example, mini seminars may be held to rigorously explain the IEP process as well as provide a thorough factual understanding of each section of the IEP document. This service affords parents the opportunity to monitor their child's services in an informed manner, enabling them to act as a working team partner with their child's service providers. Parents' desires to function as advocates for their child becomes a powerful reality when they are well-educated on the process in formulating the IEP, provided with detailed knowledge of the discrete components of the IEP, and granted a voice through accessible IEP language and terminology.

The original documentation of the IEP process under IDEA-97 calls for parents to be members of the IEP team, a statement that assumes equal access and participation in the process. Until parents are given the tools needed to function as an equal member, true and honest access to the process is not clearly granted. Hence, teachers can guide parents to becoming an equal member and true advocate for their child, by taking on the very important role of informing and helping parents understand the components and process of IEP.

Finding an Appropriate Future Placement

As autism awareness continues to grow in the United States, many children are being diagnosed within the birth to three age range. A young child with ASD and his/her family goes through several steps to receive help.

- A) An Individual Family Service Plan (IFSP) is developed by the assessment team and services are determined by meeting the individual needs and parental goals for the child.
- B) Children will receive Early Intervention services from a variety of services providers, such as speech and language pathologists, occupational therapists, applied behavior analysis (ABA) therapists, and developmental therapists. Many of these services take place in the context of the child's home in which therapists can assess the natural, physical home environment and work side-by-side with parents to demonstrate interventions. This close relationship between parents and providers working together in the home context changes when the child turns three years of age and ages out of early intervention.
- C) The next phase – the IEP phase – ushers in a formal multidisciplinary evaluation done by the family's local school district where a subsequent placement is made and where services are delivered in the context of a public school.

Depending on the level of severity, or more commonly referred to as the level of need, the child's placement will fall either within a blended program (inclusion in regular preschool and kindergarten with relevant special education supports), or in a self-contained or instructional classroom. The goal in every special education placement is to seize opportunities for children to be included in the Least Restrictive Environment (LRE) with same-age peers without disabilities as their developmental readiness across all domains allows.

Structured Teaching, Home Visits, and Advocacy

Structured Teaching

Once a child with ASD is placed in a subsequent placement, the implementation of *structured teaching* can be used. As Willis (2009) confirmed, children with ASD are taught best in a structured environment with a predictable routine. Teachers may adapt the structured teaching intervention method developed by the University of North Carolina Division TEACCH (Treatment and Education of Autistic and related Communication Handicapped Children). Included in its approach to teaching children with ASD, the system outlines how to organize the environment, develop appropriate activities, and help explain student expectations (Stokes, 2001). Structured teaching has a clear delineation of physical space not found in a regular education classroom. Walls or partitions mark specific areas for work, play, one-on-one instruction, group activities, and gross motor/sensory activity. Willis stated, “Many children with autism respond better to real pictures than to line drawings” (p. 4). Accordingly, the classroom environment is loaded with visual communication boards and devices in an effort to support and expand communication, in turn fostering social interactions and reducing frustrations. Visual schedules are also used by the children to provide a visual representation that supports a predictable routine and as a result reduces the anxiety of what is coming next.

Home Environment and Visits

Parents need to be invited into the setting for an instructional “tour” of their child’s new environment with the targeted purpose of learning. Teachers can encourage parents how to incorporate and transfer structured teaching methods into the home environment so that their child with ASD understand what is coming next even at home through visits from the school. Teachers can discuss the effectiveness of home models of structured teaching that parents can implement and design the environment for their child.

Advocacy

Some children with ASD who are placed in self-contained settings may become ready to move into less restrictive environments and are able to join general education for portions of the day. The targeted area where the child may join general education should be based upon a clear strength. This is a decision that can be discussed with all team members and most strongly discussed with the parent. It is particularly important for the parent to grasp an accurate level of expectation for the child’s performance in general education.

In addition, it is crucial to the inclusion process to engage in ongoing conversations between teachers and parents. Regular and ongoing communication between the parties concerning the child’s strengths and progress will help answer the many possible questions parents may have:

- A) What are the areas of inclusion?
- B) How many minutes of inclusion per week will take place?
- C) What type of placement will their child receive when he/she ages out of the early childhood instructional program?

Teachers in early childhood classrooms should educate parents of the type of setting that will be most beneficial for their child when their child needs to move up to a different program or a school. This means informing and communicating with the parents if their child will be better served in a self-contained setting so that parents can visit prospective placements to monitor the necessary supports. Likewise, teachers need to let parents know if their child will be better-served in a blended or inclusive setting so that parents understand how the accommodations and modifications stated in their child's IEP should be translated into the inclusive setting in order to provide the necessary supports. Teachers and parents need to collaborate in utilizing this information as advocates for their child's future placement.

Concluding Thoughts

In spite of significant findings on ASD and its growing prevalence of concern, the amount of available related research remains in its infancy. As we continue to find supports for children with ASD, it is also important to address concerns about the child's family. Raising a child with ASD is a challenging feat that has been known to put a strain on parents' capabilities in parenting, placing them at a higher risk for mental health problems, such as stress and depression. Therefore, we may seek to find what these parents' needs are in terms of caring for their child and what specific supports they request or are available to them, and recognize that their parenting of a child with ASD impacts whole family dynamics. All children can learn no matter what abilities they have. We can aid parents of children with ASD by providing services that help understand the IEP process, finding an appropriate future placement, providing structured teaching during home visits, and helping them become advocates for their child.

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Dr. Jin-ah Kim is an assistant professor of Early Childhood Education in the College of Education at Roosevelt University. She has various experiences working with young children (0 – 8 years old). She was a classroom teacher and curriculum director at a preschool. Currently, she teaches early childhood method courses, supervises both undergraduate and graduate students at Roosevelt University and works with children and teachers at early childhood centers and elementary schools. The focuses of her research are Service-Learning, parental involvement, children's writing and math self-efficacy, as well as supporting and working with children with Autism Spectrum Disorders (ASD).

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