

Expanding Access to Clinical Services for Toddlers with Autism Spectrum Disorders

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ABSTRACT

Autism spectrum disorder (ASD) is a neurodevelopmental disorder typically diagnosed in the toddler and preschool years. Intensive early intervention (EI) using applied behavior analytic procedures is the evidenced-based intervention most effective in improving developmental outcomes. Unfortunately, there are numerous barriers to accessing EI services for toddlers with ASD. This article addresses (a) the process of developing an EI program using primarily applied behavior analytic services with multidisciplinary health care providers, (b) a description of the service delivery provided, (c) educational and training programs to increase qualified staff, and (d) advocacy efforts to improve community capacity. The EI program has sustained growth, improved child developmental outcomes, served as a training ground for EI providers, and yielded high parent satisfaction ratings. Suggestions for continued advocacy, education, research, and policy development related to the lack of access to EI for children with ASD is offered for pediatric health care providers. *J Pediatr Health Care.* (2017) ■■, ■■■-■■■.

KEY WORDS

Access to care, autism spectrum disorder, toddlers

An important role of advanced practice nurses is to ensure that patients are receiving evidence-based care that promotes optimal physical, social-emotional, and developmental functioning. With the increase in prevalence of autism spectrum disorders (ASDs; [Centers for Disease Control and Prevention, 2014](#)) many more pediatric nurse practitioners (PNPs) are called on to provide primary care services to these children and to provide referral for rehabilitative services. Furthermore,

for a PNP who practices in the subspecialty of Developmental and Behavioral Pediatrics, a significant challenge exists on a daily basis in ensuring that toddlers and preschoolers with ASD are availed access to the services that are needed. Intensive early intervention (EI) is the most effective treatment available for toddlers with autism, yet access to high-quality care and an adequate amount of services is elusive for most children and their families. This article will address this significant clinical pediatric problem and describe grassroots efforts used to overcome the lack of access of services. Furthermore, initial patient outcome data will be presented along with future recommendations for advocacy, education, and research for pediatric advanced practice nurses and health care providers.

ASD is a neurodevelopmental disability characterized by impaired social interaction and communication and stereotypic or repetitive behaviors. The symptoms typically present in the very young child and can be noticeable before age 2 years. Impairments in the social, communicative, and stereotypic or repetitive domains can often result in deficits in educational, social, and occupational functioning (American Psychiatric Association, 2013). The prevalence of ASD has increased significantly in the last decade from 1 in 150 in 2005 to current estimates at 1 in 68 (Centers for Disease Control and Prevention, 2014). The increase in prevalence is partially a result of improved identification and awareness of the disorder, which has led to a greater number of children seeking access to services (Lyll, Schmidt, & Hertz-Picciotto, 2014).

The primary evidenced-based approach to treating symptoms of ASD uses principles of learning rooted in applied behavior analysis (ABA; Estes, Munson, Rogers, Winter, & Dawson, 2015; Foxx, 2008; Maglione et al., 2012; National Autism Center, 2009, 2015; Peters-Scheffer, Didden, Korzilius, & Sturmey, 2011; Reichow & Wolery, 2009; Warren et al., 2011; Wong et al., 2013). ABA interventions target the development of social skills, communication, and adaptive skills through behavioral strategies. Intervention approaches include methods to teach positive replacement behaviors and decrease maladaptive behaviors (Foxx, 2008) using discrete-trial instruction (Sallows & Graupner, 2005; Smith, Groen, & Wynn, 2000) and naturalistic strategies (Dawson et al., 2010; Koegel, Koegel, & Harrower, 1999). EI services are recommended to begin within 6 weeks of identification of an ASD diagnosis, and the recommended amount (i.e., intensity) shown to achieve the most optimal outcomes is 25 to 40 hours per week (Dawson et al., 2010; Smith et al., 2000).

Children under 3 years of age with ASD are afforded access to EI services through public school Part C of the Individuals with Disabilities Education Act (Individuals With Disabilities Education Act, 2004). School services are typically provided in the home environ-

ment by an early childhood education provider and/or other allied health professionals (e.g., speech and language therapist, occupational therapist). Once the child is 3 years of age, preschool services through Part B of the IDEA become available; however, the intensity of services is often insufficient (Montes, Halterman, & Magyar, 2009). Although there has been a recent emphasis on increasing evidence-based practice in schools for children with ASD (Odom, Collet-Klingenberg, Rogers, & Hatton, 2010), the treatment approach and number of hours of service provided through the public school system may not be consistent with clinical service provider recommendations (Hess, Morrier, Heflin, & Ivey, 2008).

Aside from school-based services, behavioral health center-based or home-based EI services may be available for toddlers and preschoolers with ASD. In most states, private or public insurance may cover the cost of home and center-based services. For those children living in states in which there is no or limited insurance coverage (National Conference of State Legislatures, 2015) for EI services, the out-of-pocket costs can be at least \$17,000 to \$22,000 per year (Lavelle et al., 2014; Wang & Leslie, 2010).

The lack of access to EI services for children with ASD is a particularly daunting problem affecting (a) children and families in rural and urban communities (Montes et al., 2009; Murphy & Ruble, 2012; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007), (b) those of minority racial and ethnic groups (Liptak et al., 2008; Mandell, Listerus, Levy, & Pinto-Martin, 2002; Montes et al., 2009; Thomas et al., 2007), (c) families of poor socioeconomic status (Vohra, Madhavan, Sambamoorthi, & St. Peter, 2014), and (d) children of parents with low education levels (Montes et al., 2009; Thomas et al., 2007). Children with ASD are also more likely to have limited access to medical health care services and unmet health care needs compared with other children with special health care needs that do not involve emotional, developmental, or behavioral problems (Kogan et al., 2008). Moreover, children living in states without Medicaid benefits for ASD or access to services through state Children's Health Insurance Program (i.e., CHIP) face even more limited access to services (Liptak et al., 2008). Unfortunately, it is estimated that fewer than 3% of toddlers and preschoolers with ASD in the United States ever receive the behavior analytic services needed to achieve the most favorable outcomes (Easter Seals, 2011).

Most children who are diagnosed with ASD and live in states without insurance benefit mandates are unable to access EI, despite well-established research documenting the impact of such interventions on changes in cognitive, social, and adaptive skills (Dawson et al., 2010; Smith et al., 2000). Moreover, empirical research has emphasized the importance of EI: the earlier a child with ASD receives EI services, the greater the

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