Transition to Early Schooling for Children with ASD

Michelle Heyman, Yasamin Bolourian, and Jan Blacher

Abstract The transition to school can be difficult for any child, but children with autism spectrum disorder (ASD) encounter additional problems and obstacles during this time. ASD is a lifelong disorder. Yet, the earlier a child with ASD receives intervention, the more promising the long-term outcomes. One way for children to be identified with ASD before entering school is through yearly appointments with their primary care doctor. Under federal legislation of IDEA, children from birth to age three with, or at risk of having, developmental delays have a legal right to early intervention. However, not everyone has equal access to services. Geographical location, race, and socioeconomic status are a few factors that contribute to uneven access to interventions for families. Culturally sensitive providers should be aware of early signs of ASD and be knowledgeable about referring families to appropriate education and treatment. Ultimately, to close the service gap, parents who have children with ASD should be aware of their rights and how to navigate the system to receive treatment.

Introduction

All children experience a transition to early schooling, although the point of transition may vary. Some children remain at home with their caregiver until mandatory kindergarten, some attend preschool prior to kindergarten, and some may experience daycare from infancy onward. Regardless, it is not uncommon for many children to find the demands of kindergarten rather rigorous—to listen, to get along with others, and to exert a fair degree of self-regulation (McIntyre, Blacher, & Baker, 2006; Rimm-Kaufman, Curby, Grimm, Nathanson, & Brock, 2009; Rosanbalm & Murray, 2017).

Transitioning for children with autism spectrum disorder (ASD) may be a more challenging time for parents and children. Most of the skills that require "fine-tuning" upon school entry, including social skills and self-regulation, are likely to be far less

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M. Heyman (✉) · Y. Bolourian · J. Blacher
Graduate School of Education, University of California, Riverside, Riverside, CA, USA
e-mail: mheym001@ucr.edu

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well developed in children with ASD (Larcombe, Joosten, Cordier, & Vaz, 2019). Some studies indicate that children with ASD may be less emotionally ready to engage with their peers upon school entry, while others may have difficulty with on-task and direction-following behaviors (Kemp & Carter, 2005; Marsh, Spagnol, Grove, & Eapen, 2017). What is absolutely critical is that teachers, parents, and other professionals (e.g., speech therapists, behavior therapists, psychologists, the kindergarten teacher, preschool teacher) work harmoniously to prepare children with ASD for this transition, and all this is largely dependent on *when* the child was first diagnosed with ASD.

The Role of Autism Identification and Early Schooling

In considering how ASD may affect the transition to early schooling, it is important to understand what constitutes the diagnosis and how the timing of diagnosis may impact the process. ASD is a lifelong condition characterized by pervasive impairments in social communication and interaction, along with restricted patterns of behaviors and interests (American Psychiatric Association [APA], 2013). Symptoms of ASD that are most prominent in early development are social and communication deficits (Martínez-Pedraza & Carter, 2009; Woods & Wetherby, 2003). Although many parents report autistic-like concerns in children as young as 18 months, professionals often delay giving a diagnosis and take a “wait and see” approach until the child is older. A delay in initial diagnosis can be attributed to the array of behaviors demonstrated by each child with ASD, uninformed professionals, or inappropriate referrals provided to the family (Woods & Wetherby, 2003).

Current diagnostic assessments are reliable when administered by appropriately trained professionals to children from about 18 to 24 months, and these children are more than likely to retain their diagnosis as they age (Lord & Luyster, 2006; National Research Council, 2001; Woods & Wetherby, 2003). Factors that may influence the time of diagnosis during early childhood include the family’s socioeconomic background, race/ethnicity, and child gender (Rosenberg, Kaufmann, Law, & Law, 2011). For example, research has consistently shown that age at diagnosis is delayed for racially/ethnically diverse children and females (Hyman, Levy, & Myers, 2020; Mandell, Listerud, Levy, & Pinto-Martin, 2002; Rosenberg et al., 2011). It is also important to note the cultural context of ASD, as some parents (e.g., White versus Latinx) may report different symptoms (see chapter “Clinical and School Identification and Intervention for Youth with ASD: Culturally and Linguistically Responsive Interdisciplinary Considerations”; Blacher, Stavropoulos, & Bolourian, 2019).

Importantly, a delay in the detection of ASD affects *when* families and children can start receiving intervention services. Children diagnosed at an earlier age have more promising trajectories, largely due to earlier access to appropriate interventions. Specifically, these children often show more improved cognitive and language outcomes compared to children diagnosed later in life (Hyman et al., 2020; Turner & Stone, 2007; Warren et al., 2011). Access to early intervention can also help reduce familial stress, as well as future financial burden for the community in terms of education costs (Järbrink, 2007; Koegel, Koegel, Ashaugh, & Brahshaw, 2014; Rosenberg et al., 2011). Thus, as the growing body of evidence suggests, early identification and treatment of ASD is crucial to the wellbeing of individuals with ASD, their families, and, arguably, the public.

With that being said, in 2020, the Association of American Physicians (AAP) published a historic update to their clinical recommendations on ASD. In their report (Hyman et al., 2020), the authors endorsed providing early intervention or school-based services to children who have documented delays even before an official diagnosis of ASD is given. This shift among pediatricians shows support for the body of evidence for the early treatment of ASD symptoms and attempts to break barriers to service access in early childhood years.

One way to improve the identification of ASD is to increase awareness and knowledge of expected developmental milestones among medical and school-based service providers. It is critical for professionals to understand behaviors that indicate early signs of ASD versus behaviors that are part of a child's normative development (Martínez-Pedraza & Carter, 2009; National Research Council, 2001). In an effort to improve early identification of ASD, the CDC launched a health education campaign to help families, healthcare providers, and early childhood educators identify and monitor developmental milestones called "Learn the signs. Act Early." Their program includes free and simple online checklists, training videos, and tracking tools (Center for Disease Control and Prevention, 2019). For example, an early sign of ASD is echolalia, which is the repetition of heard words or phrases. While first learning a language, it may be normative for a child to repeat another's spoken words. However, if the child mimics the precise intonation and inflection of heard words, it may be an indicative symptom of ASD (Martínez-Pedraza & Carter, 2009). In order to recognize the spectrum of symptoms in the early years, ASD-specific training needs to be provided to medical and school-based professionals. Collaborations with trained professionals across fields of medicine, behavioral health, and education can assist with making earlier, more accurate diagnoses and improving health outcomes for families and young children with ASD (National Research Council, 2001). This chapter will discuss interdisciplinary issues pertaining to early schooling for children with ASD, and will conclude with recommendations for how to promote interdisciplinary care among relevant providers during the time of transition, thus reducing overall transition challenges.

Legal Mandates Guiding the Process of Early Schooling

In the United States, the Individuals with Disabilities Education Act (IDEA, 2004) is the nation's education mandate for providing free, appropriate public education to all children with disabilities. There are two parts of IDEA that support families of children transitioning into the school aged years, with the intention of providing continuity of supports and services in the community and school settings.

Infants and Toddlers

Part C of IDEA (2004) is intended for children from birth to 3 years of age and mandates that early intervention (EI) be provided to families of children who are considered at risk, who have a developmental delay, or who have a physical or psychological/mental condition associated with developmental delay (Scarborough, Hebbeler, & Spiker, 2006). EI has been shown to improve long-term child emotional, cognitive, and social development. Examples of EI services include screenings and assessments, therapy (e.g., physical, occupational, and speech/language therapy), and transportation (National Research Council, 2001). If the child qualifies for these services, a written Individualized Family Service Plan, or IFSP, will be developed by a team of providers, depending on the child and family's needs, to legally document which services the state will provide. The IFSP is a document indicating goals as specified jointly by the parent(s) and service providers (Lipkin & Okamoto, 2015).

Research has demonstrated that variability exists with regards to the Part C eligibility criteria used to identify children with developmental delays (Adams & Tapia, 2013; Stahmer & Mandell, 2007). For example, some states define developmental delays quantitively (e.g., the number of standard deviations the child is away from the normative development) or it is defined in more vague terms (e.g., not demonstrating expected behaviors based on chronological age). States also range on the type of professional who can determine if the child meets the state's eligibility of developmentally delayed (e.g., licensed health care provider, "qualified personal") (Shackelford, 2006, p. 12). Such inconsistencies in what populations are served make it difficult to evaluate and compare the effectiveness of EI programs. However, findings from a meta-analysis of studies on early intervention for children with ASD (mean age of 37.4 months) revealed stronger cognitive and adaptive behavior outcomes for programs associated with universities, hospitals, and research, compared to community-based settings (Nahmias, Pellecchia, Stahmer, & Mandell, 2019).

It is highly recommended that children with ASD be immediately referred for EI. Referrals are most commonly made by family members or healthcare professionals and less frequently by professionals within the education system, although, this situation will likely change with the more widespread awareness of ASD (Stahmer & Mandell, 2007). It is also less common for infants and toddlers to be in formal school settings, and thus, pediatricians and primary care physicians have an obligation as one of the first providers to observe atypical developmental behaviors and implement a screening assessment.

The services and supports that families are given through EI assist the child with long-term development (e.g., emotional, cognitive, and social; National Research Council, 2001). Research has shown that children with ASD who are minimally verbal are more likely to improve language skills if they receive intervention before entering the school system (at about 5 years of age) in comparison to children who start services after the age of five. Additionally, EI can help prevent the development of secondary symptoms associated with ASD (e.g., behavioral issues).

Preschool-Aged Children and the Transition to Kindergarten

Under IDEA Part B, children with disabilities between the ages of 3 to 22 years old have access to a free and appropriate public education (FAPE) within the least restrictive environment (LRE) through the school district (Lipkin & Okamoto, 2015; Trohanis, 2008, p. 143). FAPE is not plainly described within the IDEA legislation, but it refers to equal educational opportunity, at no cost, to every child (Lipkin & Okamoto, 2015). Another component of IDEA, Part B, is LRE. The aim of LRE is to integrate children with disabilities into the regular education environment "to the maximum extent possible" (Lipkin & Okamoto, 2015, p. e1651). Ideally, the child should spend a full school day in general education, but sometimes the child spends 50% or more in Special Education. An Individualized Education Program (IEP) is developed based on the child's needs, as determined by appropriate assessments. Similar to the IFSP, an IEP is a legal document that specifies the services that the school district will provide. However, the IEP document is more specific, it involves a range of interdisciplinary professionals and evolves as the child goes through school. School-based support and intervention may be deemed necessary to ensure the educational success of the child. As described by IDEA, states are in control of defining the eligibility criteria for such services (Lipkin & Okamoto, 2015).

The transition to early schooling is a crucial time for determining the portion of the school day that the child will have access to typically developing peers (LRE). It is critical for children with disabilities to have access to typically developing peers to assist with further development of the child's language and social skills. Finally, the IEP document helps to ensure some continuity of care, by hopefully continuing the types of services provided in early intervention, e.g., behavioral intervention, speech within the school system. One longitudinal study with a positive outcome followed children from preschool into kindergarten. In kindergarten, it was demonstrated that the child's classroom placement and services provided were consistent with those received prior to entry to early schooling (Towle, Vacanti-Shova, Higgins D'Alessandro, Ausikaitis & Reynolds, 2018).

Continuity of Care

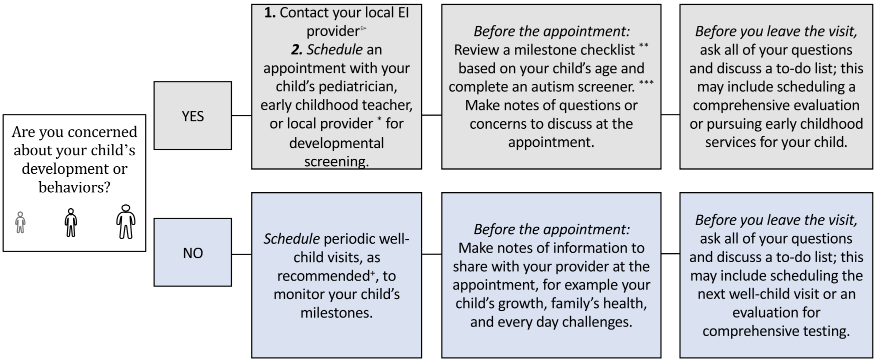
ASD is a disorder that involves two main systems of care. The earliest is the medical system because physicians are most likely to see children prior to school age and are often involved in either diagnosing or referring the child for a more comprehensive evaluation. Once early intervention ensues, however, treatment is primarily educational. To maximize success for children with ASD, children need to be first identified and found.

Screening and Evaluation

Under IDEA, Child Find is an obligation for state agencies to identify children at risk of developmental delay in order to refer them for further evaluations and supports (Dosreis, Weiner, Johnson, & Newschaffer, 2006). For children under 3 years of age who are demonstrating behaviors of concern or are not meeting developmental milestones, parents have two options. Parents may request a free evaluation from their local EI provider or schedule a well-child visit with the child's pediatrician. At well-child visits, parents have the opportunity to voice their concerns about their child's development and discuss behavioral concerns. For primary care physicians, it is vital to educate parents about typical developmental milestones versus atypical development, and to provide a universal screening questionnaire or checklist to determine whether existing developmental or behavioral concerns may require formal supports. For first time parents, well-child visits may be even more important because they may not be as familiar with or informed about behaviors that require developmental monitoring (Barton, Dumont-Mathieu, & Fein, 2012). Despite how critical these visits are for children and parents, data from the Child and Adolescent Health Measurement Initiative (2016/2017) indicate that the national prevalence of developmental screenings by healthcare providers is low, with only about 35% of parents of children (ages 0–5) indicating that their doctor asked about developmental or behavioral concerns, and 31% of parents of infants and very young children (ages 9–35 months) indicating that they had completed a developmental screening tool. Reported barriers to pediatric screenings include increased physician time needed to implement testing and staffing needed to address potential issues or questions that may arise from the screening (Barton et al., 2012).

After the completion of a developmental screening, the primary care physician may make a referral for a comprehensive diagnostic evaluation in order to receive a medical diagnosis; this can be done by a screening clinic, specialist, or an EI team. A medical diagnosis is often considered the first step toward obtaining services for ASD, though it is not always required. The diagnostic evaluation should be done by a licensed physician, trained psychologist, or an educator who has experience or training in conducting developmental evaluations and assessing developmental disabilities. The evaluation should involve a review of developmental history and records, a parent interview, play-based observations, and assessments of cognitive and adaptive functioning. A neurological assessment or genetic consultation may be recommended to rule out biological or medical diagnoses. Based on the assessment results, a comprehensive report is developed for families to submit to the child's insurance company and to begin the provision of any needed family-based services (National Research Council, 2001). Figure 1 shows the steps families can take if their child is under 3 years old.

For children between the ages of 3 and 5 years, the screening and assessment process may differ depending on when parents initiate evaluation and services with the public schools. First, parents should discuss any behavioral observations and developmental concerns with a pediatrician or, if the child attends daycare or preschool,



▻ To find your local Early Intervention provider (EI): https://www.cdc.gov/ncbddd/actearly/parents/states.html
* To find your local early childhood provider: https://www.autismspeaks.org/state-early-intervention-information
** CDC Milestone Checklist: https://www.cdc.gov/ncbddd/actearly/pdf/checklists/Checklists-with-Tips_Reader_508.pdf
*** Free online autism screener, MCHAT: https://mchatscreen.com/
\+ AAP Schedule of Wellness Visits: https://www.healthychildren.org/English/family-life/health-management/Pages/Well-Child-Care-A-Check-Up-for-Success.aspx

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Fig. 1 Flowchart of the Early Developmental Screening Process for Families

a teacher. Depending on the pediatrician, a screening for ASD may be conducted, or a referral may be provided to the specialist (National Research Council, 2001). Alternatively, parents may submit a written letter to the school district detailing specific concerns and request an evaluation. The school district has the right to deny the parent's evaluation request, so it is important to include any previous records that support the parents' concerns. If the request is accepted and the evaluation indicates that there is a disability or delay, special education services will be provided to address issues before the start of kindergarten (Lipkin & Okamoto, 2015).

The selection of ASD-specific screening and diagnostic instruments is dependent on the diagnostic provider. Table 1 summarizes some validated screeners that can be used by healthcare and school-based professionals to identify behaviors indicating child risk for ASD. The Table also indicates gold-standard ASD assessments that should be administered by a trained provider if the child is deemed to be at risk. Such screening and diagnostic tools are described in detail in chapters "Screening and Surveillance" and "Interdisciplinary Evaluation of Autism Spectrum Disorder".

Utilization of Services

Medical Care

Children with ASD are at increased risk for co-occurring medical conditions (see chapter "Medical Comorbidities in Pediatric Autism Spectrum Disorder") and, thus, have higher costs of healthcare services, including hospitalizations, clinic visits, and prescription medication (Croen, Najjar, Ray, Lotspeich, & Bernal, 2006). Such

Table 1 Validated screening and diagnostic tools for ASD

Assessment	Description
Modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F; Robins, Fein, & Barton, 2009)	A 2-part parent-report screening tool: (1) a 20-item questionnaire, and (2) if the child is indicated at risk, a more detailed interview with the parent. Available for download for clinical, research, and educational purposes (www.mchatscreen.com)
Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003)	A 40-item parent-reported screening questionnaire that evaluates communication skills and social functioning. Can be administered in school and clinic settings
Childhood Autism rating scale, Second Edition (CARS2; Schopler, Van Bourgondien, Wellman, & Love, 2010)	A 15-item parent-completed rating scale that considers child behaviors (e.g., frequency, intensity, peculiarity, and duration) when formulating a potential diagnosis. Can be administered in school and clinic settings
Autism behavior checklist (ABC; Krug, Arick, & Almond, 1980)	A 57-item checklist, completed by a parent or teacher, often used in schools to help identify ASD among children with severe disabilities
Gilliam Autism rating scale-Third Edition (Gilliam, 2014)	A 58-item test, completed by parents or teachers. Used to screen for ASD in individuals, from 3 to 22 years of age with behavioral concerns
Autism diagnostic observation schedule, Second Edition (ADOS-2; Lord et al., 2012)	Gold-standard diagnostic tool, used by a trained professional, to determine if individuals meet diagnostic criteria for ASD. Semi-structured, play-based set of observations
Autism diagnostic interview-revised (ADI-R; Rutter, Le Couteur, & Lord, 2003)	A semi-structured interview (93 items), administered by a trained professional, with parents of children suspected of having ASD

expenditures for families of children with ASD are significantly greater than for families of children without ASD (Shimabukuro, Grosse, & Rice, 2007). Prior studies also reported that children with ASD have higher utilization of acute care, such as emergency department visits, than the general population (Deavenport-Saman, Lu, Smith, & Yin, 2015). This remains to be true when controlling for demographic characteristics and comorbid physical and mental conditions (Cummings et al., 2016).

Health care provided through an emergency or urgent-care facilities is often costlier and less effective. In ASD research, factors associated with fewer, non-urgent emergency visits include being older (six years of age and above) and individuals identifying as non-Hispanic. A great majority of visits by children with ASD also classified as primary care treatable, indicating that the use of emergency care was not required (Deavenport-Saman et al., 2015). Such findings may indicate that families of children with ASD need better, earlier access to effective healthcare services that may decrease the need to seek emergency care. In addition, in a sample of 396 adolescents and adults with ASD, Lunsky and colleagues (2015) found that one of the strongest predictors of emergency service use was previous emergency visits. Thus, improving healthcare access and utilization in early childhood years may divert the course of frequent and sometimes preventable emergency department visits.

Psychiatric Care

Children with ASD also experience significant co-occurring mental health conditions (see chapters "Interprofessional Roles to Support Psychotropic Medication Prescribing for ASD" and "Psychopharmacology of Autism Spectrum Disorder"). Previous research has shown that children with ASD utilize primary and specialty care (e.g., psychiatric visits, neurology visits) at higher rates than children without ASD (Croen et al., 2006; Gurney, McPheeters, & Davis, 2006; Kalb, Stuart, Freedman, Zablotsky, & Vasa, 2012; Lavelle et al., 2014; Liptak, Stuart, & Auinger, 2006). In a comparison of more than 30,000 children with or without ASD (ages 2–18) enrolled in the Kaiser Permanente Medical Care Program, Croen and colleagues (2006) found that children with ASD were significantly more likely to have a comorbid psychiatric diagnosis, such as a mood or impulse disorders. Specifically, for 2 to 4 year old children with ASD, psychiatric outpatient visits were 13 times more frequent than for children without ASD; for all other ages, psychiatric visits were 7 times more frequent in the ASD group. These findings point to the need for improving pediatric psychiatric services within networks of care for children with ASD. In addition, the mental health needs of the child with ASD affect families as well (Blacher & Baker, 2017), and thus, treatment should wrap around the needs of parents. Finally, the school professionals also need to be made aware of comorbid disorders in children with ASD. Notably, internalizing disorders may be under-reported by teachers (Llanes, Blacher, Stavropoulos, & Eisenhower, 2018). Additionally, children with ASD, with or without concomitant intellectual disability, have high rates of comorbid psychiatric disorders (Baker & Blacher, 2019), although more research on this topic relevant to young and school-age children with ASD is needed.

Coordinated Care

In contrast to care provided through emergency departments, the medical home model concentrates on primary inter-coordinated care. The medical home model, originated by the AAP, defines this mode of primary care as accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective (Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). Importantly, the most recent statement from the AAP indicates that the medical home system should allow parents to be able to develop a relationship with their child's physician that is characterized by mutual responsibility and trust. These perspectives on healthcare have the potential for substantial changes within the lives of families who have children with special needs. For example, Cheak-Zamora and Farmer (2015) found that access to family-centered care and care coordination was associated with lower unmet healthcare needs of children with ASD. A recent national survey supported by the Health Resources and Services Administration indicated that about 43% of children (ages 0–17) with special health care needs received care within a medical model, although some state-by-state variability exists (60.9% in Nebraska versus 24.6% in Nevada; Child and Adolescent Health Measurement Initiative, 2017).

Despite the comprehensive conceptualization of the medical home model, significant barriers to its implementation have been reported, including inadequate reimbursement for office and follow-up visits (Golnik, Ireland, & Borowsky, 2009; Medical Home Initiatives for Children with Special Needs Project Advisory Committee, 2002). Moreover, in a national survey of pediatricians and family physicians, respondents indicated a need for additional training and education about ASD, beyond training on overall special health care needs (Golnik et al., 2009). Families of children with ASD have also reported a lack of coordinated family-centered care, poor access to medical home, delayed referrals, lack of clinician knowledge about available community services, and limited confidence in the provided level of care (Brachlow, Ness, McPheeters, & Gurney, 2007; Carbone, Behl, Azor, & Murphy, 2010; Carbone et al., 2013).

Telehealth has been identified as a new, possible solution to certain barriers within systems of care (Todorow, Connell, & Turchi, 2018), such as long waitlists, transportation issues, and inadequate service access. As such, the focus of telehealth among families of children with ASD has primarily been on improving access to services among rural, underserved areas. In 2018, the Health Resources and Service Administration (HRSA) funded the Washington State Department of Health to improve access to statewide coordinated care for children with ASD through telehealth practices. Findings from the initial capacity assessment revealed that there is support among service providers and families. However, implementation issues with telehealth include technology knowledge, equipment, maintenance, billing, and reimbursement (Washington State Department of Health, 2017). In addition, telehealth has been touted as a model that can support the goals of early intervention, specifically through parent education and training. There is accumulating evidence to suggest that families can effectively help their children learn new skills in their natural environment (Boisvert & Hall, 2014). Interestingly, few studies have examined school-based telehealth services for children with ASD (Langkamp, McManus, & Blakemore, 2015).

Issues Impeding Access to Services

Effective interventions and services should be accessible across socioeconomic levels and among diverse groups. However, families of children with ASD experience substantial disparities in health care access and health promotion for several reasons. One factor associated with such disparities is geography, or location of residence. For example, families living in non-metropolitan areas report fewer service options and access, which may lead to increased use of emergency departments to address healthcare needs (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Zhang, Mason, Boyd, Sikich, & Baranek, 2017). Notably, these families likely have less access to university or research-based services, which are often shown to be more effective than community-based service programs (Nahmias et al., 2019)

In a recent review of service disparities, race and socioeconomic status (SES) were identified as the prominent disadvantaging factors for children with ASD (Bishop-Fitzpatrick & Kind, 2017). Race, and to some extent culture, have consistently been found to predict disparities in service access and receipt (Blacher, Cohen, & Azad, 2014; Blacher et al., 2019; Broder-Fingert, Shui, Pulcini, Kurowski, & Perrin, 2013; Doshi, Tilford, Ounpraseuth, Kuo, & Payakachat, 2017; Liptak et al., 2008; Magaña, Parish, Rose, Timerblake & Swaine, 2012; Magaña, Parish, & Son, 2015; Parish, Magaña, Rose, Timberlake, & Swaine, 2012). Overall, studies have indicated differences in the quantity and quality of care. Qualitatively, parents of non-White children with ASD, compared to parents of White children with ASD, are more likely to report the following: having limited access to physicians who listen; receiving less timely care; experiencing less time with child's physician; experiencing less attention to cultural and familial values; needing more information about ASD (Liptak et al., 2008; Magaña et al., 2012, 2015; Parish et al., 2012). In addition, non-White families of children with ASD, when compared to White families, are also less likely to receive specialized care (e.g., neurology, gastroenterology, psychiatry) or coordinated, family-centered care (Broder-Fingert et al., 2013; Doshi et al., 2017). In a follow-up study of trends in healthcare service access for families of children with ASD, Magaña and colleagues (2015) found that low-quality care persisted over a 5-year period, suggesting that disparities tend not to improve.

Belonging to a family with low socioeconomic status (SES) has been associated with poorer quality of care and being uninsured (Liptak et al., 2008). High SES families have been shown to have greater access to care within a medical home model (Sobtoka, Francis, Vander, & Booth, 2016). However, the relationship between SES and healthcare may be mediated or partially explained by parent knowledge of service systems, such that higher SES is associated with greater knowledge about ASD-related services, which is associated with a higher number of services used (Pickard & Ingersoll, 2015).

Conclusion: Making the Transition to Early Schooling Less Challenging

During early childhood development, families of young children with ASD experience stressful situations, often before the diagnostic process begins. Even highly resourced parents face roadblocks in obtaining a diagnostic evaluation for ASD and subsequently advocating for appropriate treatments, so it is often the case that under-resourced families face even greater obstacles. The number of reported barriers to accessing and receiving quality inter-coordinated services suggests that there is room for improvement. This section contains key areas that address some of these barriers.

Parent and Community Outreach

First, it is important to equip parents with the knowledge needed to navigate service systems during preschool or early intervention in order for them to later advocate for ASD-related services and become better able to secure necessary supports on behalf of their children and families. This is vitally important when all parents do not have equal access to such service systems. In the U.S., national trends indicate an increase in racial diversity, with Latinx populations increasing by almost 20 million between 2000 and 2014 (Colby & Ortman, 2015). Recognizing service disparities related to race and the nation's diversity, there is clearly a need to train professionals to work effectively with underserved families of children with ASD using a culturally responsive approach (e.g., learning cultural beliefs about child development and disability). Moreover, as most evidence-based ASD interventions have been validated with White families, research should seek to adapt interventions for culturally and racially diverse children with ASD, and address gaps in the research related to the effectiveness of early intervention programs in the community versus academic settings (Cohen, 2013).

As described previously, families who have insufficient access to services are also likely to be from underserved communities that are often difficult to reach, perhaps due to geographic location or lack of transportation. It is crucial, then, to find ways to reach these families—through the dissemination of information on systems of care, especially to families who are disconnected from service providers. Culturally relevant programs and practices need to be developed to help these families to increase access to screening, intervention services, and advocacy. For example, Zuckerman et al. (2014) conducted focus groups targeting Latinx families whose children were diagnosed with ASD at 2.8 years, on average. Family members reported that they had limited access to information with regards to ASD within their community and received little support from their community when they wanted to discuss their child's behaviors and symptoms related to ASD. Additionally, the parents experienced difficulty when finding the care their child with ASD needed; when they found professionals to assist with their initial diagnosis, the appointments were described as being confusing, long, and tedious for the child.

An example of successful outreach to under-resourced families exists in the Inland Empire of Southern California (i.e., the counties of Riverside and San Bernardino, as well as the desert communities of Palm Springs and Coachella Valley), a population of about four million. Under the auspices of the University of California, Riverside, the SEARCH Center is an organization that is dedicated to providing Support, Education, Advocacy, Resources, Community, and Hope to families who have children with ASD. With a focus on screening and educational access for underrepresented groups, SEARCH reaches about 100 children a year at no financial cost to families. To date, slightly over 50% of children screened have been Latinx and 20% have been Spanish-speaking, and research has indicated that there are cultural differences in the concerns that parents bring to the screening clinic (Blacher et al., 2019). Through educational consultations and parent education programs, SEARCH helps affected families understand ASD, and to learn how to select appropriate programs and services designed to meet their children's developmental, behavioral, and academic needs. SEARCH is supported by institutional and research funding and has partnered with ASD-related and disability agencies in the area to promote equity and reduce disparities in the services for youth with ASD or developmental disabilities. The net result is an effort to disseminate information on ASD to regions in need in a culturally sensitive manner—to inform, educate, and link families to existing services. The more readily parents expand their networks while their children with ASD are very young, and the more they use their skills to advocate for their child, the smoother the transition to kindergarten and early schooling will be.

Here is a case brought to the SEARCH Center:

V. is the Latina mother of a 3 ½ -year old son, Ivan. V. spoke English, but not well. When his mother first contacted SEARCH, her specific concerns were conveyed to staff in Spanish, and included Ivan's difficulty with even the slightest changes in routine—for example, moving from play to lunch. Ivan also did not speak more than 20 words, and did not engage in any conversations or back-and-forth interactions with his siblings, parents or children in his preschool class. V. consulted her non-Spanish-speaking pediatrician when her son was 2 ½ years old. The pediatrician said that these types of delays were common, but she administered a brief developmental checklist anyway. The pediatrician admitted that she was not sure but thought the parent should be referred to the SEARCH Center, a local autism screening center, to rule out the possibility of ASD. V. waited another year before calling SEARCH. The importance of pursuing further assessment as soon as possible was not conveyed to V., and she and her immediate friends and family were not aware of red flags for ASD. The pediatrician also did not mention that the services at SEARCH were free.

During the phone-call with the SEARCH team member, V. completed the *Social Communication Questionnaire* (SCQ; Rutter, Bailey, & Lord, 2003). Based on the SCQ, Ivan appeared to be in the risk range for ASD, and a full assessment was scheduled. At the assessment appointment, the team administered the ADOS-2 (Lord et al., 2012) and a cognitive assessment to Ivan. V. completed an interview about Ivan's development, an adaptive behavior interview (*Vineland Adaptive Behavior*

Scales; Sparrow, Ciccetti, & Saulnier, 2016). Several parent-completed questionnaires focused on possible child behavior problems and autism symptomatology. Ivan did meet criteria for ASD, and also appeared to have meet criteria for a developmental delay, based on his adaptive and cognitive development. V. was shown how to contact her local regional center to request services, additional evaluations (i.e., speech), and behavioral intervention services for Ivan. Since V. was employed full-time, a behaviorally-oriented intensive early intervention center-based preschool program was recommended. Notably, Ivan missed the opportunity to enter the early intervention system at age 2 ½, and valuable time for speech and cognitive development had been lost.

Professional Training

There is still a reported need for inter-disciplinary trainings related to ASD-specific knowledge (e.g., Golnik et al., 2009), as well as to positive relationship development between professionals and family members of children with ASD. The production of ASD-specific training programs should begin in graduate school (e.g., education and psychology doctoral/master's programs, teacher credential programs, medical school). While the foundation of these programs should be content-based, courses may be enhanced by using practitioner-based research or case-based learning in order to support reflective thinking about one's own practice. By investing in training programs that increase expertise in ASD, we can help meet the service and treatment challenges these families face.

Developed by the CDC and the Health Resources and Services Administration's Maternal Child Health Bureau in 2011, the Autism Case Training (ACT) curriculum targets developmental-behavioral pediatrics and is designed to train future clinicians on the identification, diagnosis, and management of ASD through real-life scenarios. ACT has been peer-reviewed and endorsed by the American Academy of Pediatrics (Major, 2015). Pilot studies indicate that the program is found to be useful by pediatric residents and is associated with positive short-term changes in overall knowledge and perceived competence (Major, Peacock, Ruben, Thomas, & Weitzman, 2013). The ACT modules and resources (e.g., facilitator guide, discussion questions, handouts, video library) are downloadable at no cost through the CDC website (http://www.cdc.gov/AutismCaseTraining) to ensure that autism education is accessible for all practicing pediatric clinicians (see chapter "Interprofessional Education and Training").

Removing the Disconnect from Early Intervention to Public Schools

Lastly, greater communication among service providers across disciplines is needed. Engaging in a collaborative exchange with professionals across disciplines will help generate and synthesize knowledge of individual families in order to provide more appropriate supports, and these are desperately needed at the transition from preschool to "big school," or kindergarten. This will require a collaborative effort on the part of families, insurers, government, medical educators, and other systems of care who support families through early intervention. Collaborative partnerships will help to assure smooth sailing for these families.

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