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Improving Early Autism Diagnosis in Underserved Communities Through the Use of “Learn the Signs. Act Early.” Developmental Milestone Tracking Tool

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Abstract

Many children entering early childhood education programs have symptoms of autism spectrum disorder yet remain undiagnosed. Research suggests this is especially true for low-income and minority children who may not participate in regular pediatric check-ups, have parents with low health literacy, or who may experience provider bias. Thus, they are diagnosed at a later age compared to upper-class White children. Early autism-specific intervention services can have a profound and lasting impact on long-term developmental outcomes for children with autism. Identification of the symptoms of autism is key to triggering the autism evaluation process that leads to a formal autism diagnosis and autism-specific early intervention services. The Maternal and Child Health Bureau (MCHB) endorses the use of the “Learn the Signs. Act Early.” developmental milestone tracking tool to increase autism awareness and improve autism screening and evaluation rates in underserved communities. Studies funded through MCHB have found that increasing early educator and parent knowledge of normal developmental milestones and the signs and symptoms of autism increases self-efficacy in conveying developmental concerns to a healthcare provider, health ambassador, or an educational administrator.

Keywords: autism, early identification, early childhood education, and “Learn the Signs. Act Early.”
Introduction

Autism spectrum disorder can accurately be identified within the first two years of life using the Modified Checklist for Autism in Toddlers-Revised (M-CHAT-R) screening tool (Robins et al., 2014). However, the median age of diagnosis in the United States is after the fourth birthday, with minority and low-income children being diagnosed even later (Robins et al., 2014). It has been well-documented that long-term outcomes for children with autism significantly improve through early intervention services like behavior, speech, and occupational therapies (Antezana et al., 2017; Casagrande et al., 2017; Mathews et al., 2018). More recent studies propose that toddlers benefit most from these services due to neuroplasticity and rapid brain growth during this developmental phase of life (Henredon et al., 2019; Twardzik et al., 2017). Children diagnosed and receive autism-specific services after two years of age may still benefit from this treatment but the rate of improvement and the overall outcome will not be as high (Henredon et al., 2019).

Disparities in Age at Diagnosis and Services Received

The use of autism-specific early intervention services is the best predictor of successful outcomes for children with autism. However, race, ethnicity, and socioeconomic status prevent many children from being diagnosed with autism and becoming eligible to receive autism-specific early intervention services before 36 months of age (Bishop-Fitzpatrick et al., 2018; Casagrande et al., 2017; Durkin et al., 2015). On average, children from White, upper class, college-educated families are diagnosed one to two years earlier than African American or Hispanic children. Nevertheless, parents from all three groups typically report developmental concerns during their first year of life (Bishop-Fitzpatrick et al., 2018; Janvier et al., 2016; Johnson et al., 2015). White, affluent children also receive more autism-specific early
intervention services than African American or Hispanic children (Bishop-Fitzpatrick et al., 2018). Additionally, African American children and children whose parents did not finish high school are more likely to have special education services discontinued prematurely, which potentially limits the child’s ability to obtain maximum cognitive and behavioral outcomes (Anderson, 2014).

**Barriers to Healthcare Services**

Barriers to healthcare services for low-income and minority families have been well documented. Families living in rural and low-income areas have fewer practitioners trained in autism-related care and fewer community resources for children with autism (Durkin et al., 2015). Bishop-Fitzpatrick et al. (2018) and Casagrande et al. (2017) propose that some low-income and racial/ethnic minority groups may miss well-child check-up appointments due to the lack of transportation, the inability to pay for healthcare services, or misunderstanding the importance of routinely monitoring the child’s growth and development. More recent studies found a significant relationship between knowledge of developmental milestones, cultural beliefs, and maternal education, with a higher parent education level associated with greater knowledge of developmental milestone and higher completion rates of the autism screening and evaluation process (Chlebowski et al., 2013; Daniels et al., 2014; Donohue et al., 2019; Herlihy et al., 2014; Janvier et al., 2016; Khowaja et al., 2015; Robins et al., 2014).

**Heterogeneity in Autistic Behaviors and Characteristics**

Autistic symptoms and functional impairment vary significantly from child to child. Some children may show autistic symptoms from birth. However, many children with autism meet normal developmental milestones during the first two years of life (Centers for Disease
Control and Prevention [CDC], 2019a). These children often develop language skills, make eye contact, respond to their name being called, and play with toys appropriately (CDC, 2019a).

Subsequently, between 18 and 24 months of age, autistic symptoms (Table 1) begin to appear, and a change in behavior occurs. The child may lose verbal skills, become upset by small changes in routine, or no longer turn when his name is called (CDC, 2019a). As the child continues to age, new symptoms may emerge while other symptoms disappear. Inconsistencies in symptom presentation are confusing for parents, educators, and healthcare providers (Baio et al., 2018; CDC, 2019a; Hendren et al., 2019).

For children with milder autistic symptoms, behaviors at home may not be consistent with school or other public places. These behaviors may appear to worsen when the child is in an unfamiliar setting, is anxious, is getting sick, or is in pain. Conversely, symptoms may appear milder when the child is in the comfort of their home, where they can choose their routine (Bauman, 2015; Hendren et al., 2019). In some children, changes in behavior and affect may be so subtle that parents and educators alike may contribute the changes in behavior to the “terrible two’s” instead of recognizing that these behaviors are associated with cognitive delays (CDC, 2019a).

Bauman (2105a) and Hendren et al. (2019) suggests that early identification of autistic symptoms is further complicated when children exhibit an uneven development of skills where the child meets new development milestones in some areas while regressing in skills or failing to meet new milestones in other areas. In the past, many healthcare providers and educators chose the “wait and see” approach to determine if the child would “outgrow” these behaviors. Today, autism experts strongly recommended that the child receive an autism evaluation at the first sign of developmental concern (Bauman, 2015; CDC, 2019a; Hendren et al., 2019).
Table 1

Red Flags of Autism in Toddlers

<table>
<thead>
<tr>
<th>Social Skills</th>
<th>Communication</th>
<th>Unusual Behaviors</th>
</tr>
</thead>
<tbody>
<tr>
<td>● Does not respond to name by 12 months of age</td>
<td>● Delayed speech and language skills</td>
<td>● Lines up toys or other objects</td>
</tr>
<tr>
<td>● Avoids eye-contact</td>
<td>● Repeats words or phrases over and over (echolalia)</td>
<td>● Plays with toys the same way every time</td>
</tr>
<tr>
<td>● Prefers to play alone</td>
<td>● Reverses pronouns (e.g., says “you” instead of “I”)</td>
<td>● Likes parts of objects (e.g., wheels)</td>
</tr>
<tr>
<td>● Does not share interests with others</td>
<td>● Gives unrelated answers to questions</td>
<td>● Is very organized</td>
</tr>
<tr>
<td>● Only interacts to achieve a desired goal</td>
<td>● Does not point or respond to pointing</td>
<td>● Gets upset by minor changes</td>
</tr>
<tr>
<td>● Has flat or inappropriate facial expressions</td>
<td>● Uses few or no gestures (e.g., does not wave goodbye)</td>
<td>● Has obsessive interests</td>
</tr>
<tr>
<td>● Does not understand personal space boundaries</td>
<td>● Talks in a flat, robot-like, or sing-song voice</td>
<td>● Has to follow certain routines</td>
</tr>
<tr>
<td>● Avoids or resists physical contact</td>
<td>● Does not pretend in play</td>
<td>● Flaps hands, rocks body, or spins self in circles</td>
</tr>
<tr>
<td>● Is not comforted by others during distress</td>
<td>● Does not understand jokes, sarcasm, or teasing</td>
<td></td>
</tr>
<tr>
<td>● Has trouble understanding other people’s feelings or talking about own feelings</td>
<td></td>
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</tr>
</tbody>
</table>

*Note: Adapted from the Signs and Symptoms of Autism Spectrum Disorders (CDC, 2019a)*

**Bridging the Gap Through Early Childhood Educators**

Improving access to early screening, evaluation, and intervention services is key to optimizing developmental outcomes for underserved populations and reducing lifetime costs associated with the care and treatment of individuals with autism (Durkin et al., 2015; Koegel et
al., 2014; Mathews et al., 2018). Community-based settings like early childhood education centers provide a unique opportunity to reach children and families who may not receive routine autism screening in a more traditional healthcare setting (Bishop-Fitzpatrick et al., 2018; Durkin et al., 2015; Janvier et al., 2016; Zuckerman et al., 2018). Children attend early education programs regularly, and parents often develop a trusting and respectful relationship with their child’s teacher. Furthermore, drop-off and pick-up times create a natural setting to discuss developmental concerns and to provide developmental education to improve parent knowledge and self-efficacy (Daniels et al., 2014; Donohue et al., 2019; Herlihy et al., 2014; Janvier et al., 2016; Khowaja et al., 2015; Zuckerman et al., 2018).

**Monitoring with an Evidence-Based Developmental Milestone Tool**

Monthly monitoring of developmental milestones through the use of a standardized tracking tool can help identify changes in a young child’s growth and development over time and lead to earlier referrals for an autism evaluation (CDC, 2019b; Zuckerman et al., 2018). Early childhood educators monitor a child’s growth and development as they watch the child play, participate in classroom activities, and socialize with other children each day. Nevertheless, few early childhood programs incorporate a tool to track developmental progress over time. The Centers for Disease Control and Prevention (CDC) recognizes this as a missed opportunity for identifying a regression in skills or the failure to meet new milestones on time and encourages adaptation of the evidence-based developmental milestone educational awareness program and tracking tool called “Learn the Signs. Act Early.” (CDC, 2019b).

The “Learn the Signs. Act Early.” educational material has successfully been integrated into pediatric practices, at-home visits, Head Start and Women, Infant, and Children (WIC)
programs, medical residency programs, college courses, and in mass mailings to new parents (CDC, 2019b). The Maternal and Child Health Bureau strongly endorses the use of the “Learn the Signs. Act Early.” program to increase autism awareness and improve autism screening and evaluation rates in underserved communities (United States Department of Health and Human Services [DHHS], 2018). Studies funded through the Maternal and Child Health Bureau have found that increasing early educator and parent knowledge of the symptoms of autism increases self-efficacy in conveying developmental concerns to a healthcare provider, health ambassador, or an educational administrator (Baio et al., 2018; DHHS, 2018; Zuckerman et al., 2018).

The “Learn the Signs. Act Early” educational material includes milestone checklists with possible red flags that monitor each life stage (CDC, 2019b). This material is free to download and print from the CDC’s website and is distributed without written approval. Each month, the early educator can update the tracking tool to show new skills observed and review previously achieved skills to determine if any regressions in skills have taken place. Teachers should encourage parents to track milestones at home since a child’s behavior can vary dramatically according to the setting. The standardized tool also makes for easier conversation starters when addressing parents’ developmental concerns as the tool flags behaviors that should be addressed (CDC, 2019b).

**Summary**

Autism spectrum disorder can accurately be identified by two years of age. Yet, the majority of children are diagnosed after their fourth birthday, with low-income and minority children being diagnosed even later (CDC, 2019a). Many underserved populations miss routine well-child check-up appointments due to lack of transportation, financial barriers, cultural beliefs, or low health literacy (Bishop-Fitzpatrick et al., 2018; Casagrande et al., 2017; Khowaja
et al., 2015). Community-based settings like early childhood education centers provide a unique opportunity to reach children and families who do not participate in routine healthcare visits. The evidence-based “Learn the Signs. Act Early.” milestone tracker can assist early childhood educators in early recognition of regressive behaviors or failure to meet new milestones, potentially improving long-term outcomes through an earlier autism diagnosis (CDC, 2019b). To learn more about “Learn the Signs. Act Early.” educational program and to download a free copy of the and milestone tracking tool visit https://www.cdc.gov/ncbddd/actearly/index.html.

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Code Availability
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Authorship
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**IMPROVING EARLY AUTISM DIAGNOSIS**

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