**Introduction**

Toddler years are a time for exploration by engaging with others and the world around them. By 12 months of age, children typically respond to simple words, use gestures and sounds to communicate, and play simple games[[1]](#footnote-0) with their caregivers. On the other hand, children with Autism Spectrum Disorder (ASD) often have difficulties responding to their names, making eye contact with others, and communicating their needs.

ASD is a life-long developmental disorder and children may show early signs during their toddler years, between 12 to 30 months. Common symptoms include difficulties communicating with others around them, and showing limited and repetitive behaviors, and having limited interest or play repertoire (DSM-V)[[2]](#footnote-1). The prevalence of ASD continues to increase, from 1 in 150 children in 2000 to 1 in 54 children in 2016.[[3]](#footnote-2) Research shows that early identification of ASD between 12 to 30 months plays a critical role in improved long-term outcomes, and early intervention is found to be effective in reducing ASD symptoms over a lifespan due to the malleability of the brain during this early period of development[[4]](#footnote-3). Research further shows that Autism Diagnostic Observation Schedule (ADOS)[[5]](#footnote-4) is an effective diagnostic tool to assess children between 12-30 months. In spite of such strong evidence, children are often not identified until after their 3rd birthday[[6]](#footnote-5).

**What Do We Know about Early Identification of ASD?**

1. **What Are the Early Signs of ASD?**

 What are some early signs of ASD to look out for? Research shows that core symptoms of ASD usually emerge at around 12 months, and the initial presentations greatly vary from child to child.[[7]](#footnote-6) In some cases, children may appear to have typical development, then start losing skills by 18 months[[8]](#footnote-7). Some early concerns may include limited joyful expressions at others, limited imitation of sounds and movements of others, limited eye contact or response to their name, and repetitive behaviors and delayed babbling. Experts recommend that parents look out for the common signs that have been linked to a diagnosis of ASD as early as 6-12 months. Table 1 summarizes some common early signs in children at risk for ASD during their toddler years.

|  |
| --- |
| **Early Signs of ASD** |
| **Ages** | **What to look out for** |
| 6-12 months | * Limited smiles and giggles directed at caregivers
* Limited eye contact or responding to name
* Limited back-and-forth babbling, making sounds, or facial expressions
* Limited use of gestures (e.g., pointing, reaching for an object, waving at someone)
 |
| 9-12 months | * Engaging in repetitive behaviors (e.g., spinning objects, flapping hands, jumping up & down)
* Playing with toys in atypical ways (e.g., placing a sound toy by their ear, looking at a toy very closely, pressing the same button repetitively)
 |
| 12-18 months | * No first word yet
* Limited use of gestures to ask for something (e.g., pointing at desired items, putting arms up to be picked up by caregivers)
* Limited pretend play
* Does not initiate interaction or share interests with others
* Does not respond to others’ interactions or simple questions
* Gets upset by minor changes
 |
| 18-24 months | * Limited spontaneous use of functional two-word phrases
* Meaninglessly repeating words or phrases previously heard from TV, videos, caregivers, etc.
 |

Table 1. Early signs of ASD by age. Data was drawn from Zwagenbaum et al. 2015 & 2019; Hyman et al. 2020.

1. **How Early is Early? Is the Diagnosis Reliable at Such a Young Age?**

Many researchers have found scientific evidence on the benefits of early identification of ASD. The American Academy of Pediatrics (AAP)[[9]](#footnote-8) recommends universal screening for ASD for all children between ages 18-24 months in order to promote early detection of signs of ASD. This way we can ensure that all children, including those from underrepresented socioeconomic and racial groups can receive equitable access to timely support and interventions.

 Recent research further suggests that ASD can be reliably diagnosed earlier, by 14 -24 months.[[10]](#footnote-9) [[11]](#footnote-10) In other words, if a child was diagnosed with ASD at 14 months, there was a very low chance (1.8%) that he or she would transition into a final diagnosis of typical development at age 3. In fact, ASD diagnosis at such a young age was found to be more stable than other diagnostic categories, including language or developmental delays. In addition, children who were diagnosed between 12-18 months of age were found to have significantly less impairment than those who were diagnosed between 25-31 months[[12]](#footnote-11). Therefore, it is important to be identified as having ASD at an earlier age, possibly as soon as ASD symptoms arise between 12-30 months, so that treatments can begin when these symptoms are more amenable to intervention.

1. **The Modified Checklist for Autism in Toddler, Revised, with Follow-up™ (M-CHAT-R/F)**

The Modified Checklist of Autism in Toddler, Revised, with Follow-up™ (M-CHAT-R/F) is currently the most extensively studied and widely used measure for ASD screening. This is the updated version from the Modified Checklist for Autism and Toddler (M-CHAT)[[13]](#footnote-12) - it was revised and the follow-up verification was added in order to minimize false positive rates while retaining the high sensitivity of the tool. The M-CHAT-R/F is a free screening tool that is quick and easy to use. In Stage 1, parents answer 20 Yes/No questions about their child’s development, which take less than 5 minutes. If children screen positive in Stage 1, then the parents are asked some follow up questions, which take about 5 to 10 minutes. This screening tool is found to be effective in detecting ASD in young children from16 to 30 months, and it can be administered during their well-child visits. Children who screen positive in both stages of the M-CHAT-R/F will be offered a diagnostic evaluation for ASD. It was found that 47.5% of those who screened positive in both stages received a diagnosis of ASD, and 94.6% of them displayed developmental delays that warrant early intervention services. [[14]](#footnote-13) Therefore, implementing universal screening between the ages of 16 and 30 months using M-CHAT-R/F™ can promote early identification of ASD by making timely referrals and evaluation for those who are identified as having high risk.

1. **The Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2)**

If a child screens positive in both stages of the M-CHAT-R/F™, the next step is to be referred to a specialist for diagnostic evaluation. The Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2)[[15]](#footnote-14) is a standardized, semi-structured diagnostic tool for ASD, and it is considered the ‘Gold Standard’ by many practitioners and researchers. There are five modules in the ADOS-2, and the Toddler Module is specifically designed for children between 12-30 months of age who do not consistently use phrase speech. Along with all other modules, the Toddler Module of the ADOS-2 has been found to be a highly reliable and valid instrument for ASD diagnosis[[16]](#footnote-15) [[17]](#footnote-16) [[18]](#footnote-17). Furthermore, ASD diagnoses identified by the Toddler Module of the ADOS-2 were found to have excellent stability. More specifically, 100% of children who were diagnosed with ASD at 19 months on average with the ADOS-2 Toddler Module were confirmed to have ASD diagnosis at a follow-up evaluation at around their 3rd birthday.[[19]](#footnote-18)

1. **Challenges with Early Identification**

In spite of the evidence-based screening and diagnostic tools, the diagnostic stability of ASD in young children under age 3, and the well-researched benefits of early interventions, the median age of ASD diagnosis ranges from 34 to 88 months based on a review of 42 studies.[[20]](#footnote-19) According to the US Center for Disease Control and Prevention (CDC)’s recent report,[[21]](#footnote-20) approximately 58% of children with ASD did not have a comprehensive evaluation on record until after 36 months, although developmental concerns were mentioned to professionals by age 36 months for 85% of the children. Many researchers examined possible contributing factors to the delays in identification of ASD. The following subsections summarize disparities based on social determinants of the children and their families.

**5.1 Socioeconomic and Racial Disparities**

 A persistent gap in the age of diagnosis was found between children from high and low socioeconomic status (SES), such that children from low SES tend to be diagnosed later. [[22]](#footnote-21) [[23]](#footnote-22) [[24]](#footnote-23) Furthermore, mothers’ poor mental health [[25]](#footnote-24) and lower educational level[[26]](#footnote-25) were found to be related to delayed diagnosis and fewer services received.

Moreover, although the prevalence of ASD and symptom profiles and symptom severity are similar in children from a variety of racial and ethnic backgrounds, racial disparities are prominent in early identification of ASD. According to recent data from the Autism and Developmental Disabilities Monitoring (ADDM) network funded by the CDC, one-quarter of children who met the criteria for ASD surveillance did not have a formal diagnosis of ASD. Consequently, 55% of these children were not receiving any intervention services at their schools. One of the important factors that was associated with not having a diagnosis was being of non-White race[[27]](#footnote-26). More specifically, Latinx and African-American children tend to receive evaluation later than White children with ASD[[28]](#footnote-27). These demographic disparities mean that certain children may not be getting the early intervention services they need in order to reach their full potential and improve long-term outcomes.

To take a deeper dive into the racial disparities, African-American children were found to receive formal diagnosis at a mean age of 64.9 months, although parents reported expressing initial concerns about their child’s development to professionals at a mean age of 29.1 months. On average, African-American parents waited 42.3 months from their initial concerns to receiving diagnosis. Table 2 illustrates the barriers African-American families have encountered during the diagnostic process as reported by parents.

|  |  |
| --- | --- |
| **Types of Barriers** | **%** |
| Required multiple visits to see professionals before receiving the diagnosis | 41.6% |
| Experienced a significant wait time to see a professional  | 35.6% |
| Lack of available places or professionals to receive an evaluation in their area | 31.3% |
| Costs associated with the evaluation and diagnostic process | 11.6% |
| Poor quality of the evaluation(s) | 11.2% |
| Difficulties with insurance coverage | 10.8% |
| Scheduling conflicts between families and professionals | 10.6% |
| Difficulties due to lack of transportation to appointments | 6.0% |

Table 2. Barriers during ASD diagnostic process as reported by African-American parents with children with ASD. Data was drawn from Constantino et al. 2020.

 Similarly, Latinx children were found to be less often diagnosed before age 3 when compared to White children, [[29]](#footnote-28) and when they receive the diagnosis, they are more likely to have severe presentations. Although reasons for such disparities have not yet clearly been defined, it was revealed that Latinx parents with limited English proficiency who have children with ASD were more likely to experience barriers related to knowledge about ASD, navigating the medical system, receiving useful information about ASD, and trust in providers.[[30]](#footnote-29)

 Interestingly, recent findings indicate that primary care physicians (PCPs) reported more difficulties identifying signs of ASD in children from Latinx / Spanish-speaking families and African-American children than in White children. Even the PCPs with higher Spanish proficiency, or those who have 25% or more Latinx patients had significantly more difficulty assessing ASD risk in children from Latinx / Spanish-speaking families than White children.

Further, physicians were found to make slower and less frequent referrals for ASD for Black children when compared to their White counterparts. This may be due to clinician bias and symptoms of ASD in Black children being attributed to other diagnoses such as conduct disorder and other disruptive disorders.[[31]](#footnote-30) [[32]](#footnote-31) This implies that there may be provider-related factors that attribute to aforementioned racial disparities in early diagnosis of ASD.

1. **How is California Doing with Identification of ASD?**

According to the US Census data from 2019, California is the most populous state in the United States, constituting over 12% of the US population[[33]](#footnote-32). Approximately 27% of California residents are reported to be immigrants, and California residents are highly diverse in their ethnicity and socioeconomic background. Therefore, it is important to examine equitable access to early identification and intervention of ASD in California.

 Young children with developmental delays under the age of 3 are entitled to early intervention services as mandated by Part C of the federal Individuals with Disabilities Education Act (IDEA).[[34]](#footnote-33) These services are administered by the Department of Developmental Services (DDS) through 21 Regional Centers that are located throughout the state. Therefore, families in need of developmental assessments and early intervention programs can access these services through their Regional Center. A recent study examined the current policy and practice barriers to early identification of ASD in California.[[35]](#footnote-34) They interviewed early intervention managers from 18 out of the 21 Regional Centers in California regarding their current practice. According to their interview, five Regional Centers (25%) screened all children for ASD using the M-CHAT-R, usually at around 18 months of age, and nine agencies screened some children using the M-CHAT-R. In addition, as illustrated in Figure 1, more than half of the agencies (61%) did not conduct diagnostic assessment for ASD prior to age 3. The reasons for not conducting ASD screening or diagnostic assessments under the age of 3 are illustrated in Figure 2.



Figure 1. ASD diagnostic assessment prior to age 3 in Regional Centers in California. Data was drawn from Williams et al. 2021.



Figure 2. Reasons for not conducting ASD screening or assessment at Regional Centers in California. Data was drawn from Williams et al. 2021.

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**Treatment**

With the increased prevalence of ASD nationally and globally and the ability to identify younger children, it is important to focus on early intervention for children with autism. For young children with autism, beginning intervention as soon as we possibly can allows us to capitalize on the tremendous plasticity and learning ability during the infant and toddler years. Research shows that early intervention increases children’s play skills, their cognitive abilities, their speech and language, and their desire for social interaction, as well as decreasing their ASD symptoms and their behavior problems (Rogers p.49). Though changes are faster and greater for some than for others, all children who receive early intervention benefit.

 The treatment for infants and toddlers with ASD can be complex. Whether a naturalistic and behaviorist approach, there are a variety of services provided to the child that can take place in-home, school-based setting, or specialized clinic. The multidisciplinary team typically involves most of these practitioners for young children with Autism.

· Early Childhood Special Educators

· Behavioral Analyst

· Speech and Language Pathologist

· Occupational Therapist

· Physical Therapist

High quality programs use evidence-based practice models. Typically, most treatment programs for ASD incorporate teaching practices that come from the field of applied behavior analysis (ABA). “ABA is the use of teaching practice that come from the scientific study of learning to teach or change behavior. The principles of ABA can be used to teach new skills, shape existing behaviors into new ones, and reduce the frequency of problem behaviors” (Rogers p.15). Below are the following evidence-based treatments and practices and their descriptions that are most appropriate for young children diagnosed with Autism found on the Center for Disease Control site under Autism treatments and interventions.

|  |  |
| --- | --- |
| **Treatment Practice** | **Description** |
| **Discrete Trial Training (DTT)** | DTT is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts, and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored |
| **Early Intensive Behavioral Intervention (EIBI)**  | This is a type of ABA for very young children with ASD, usually younger than 5 and often younger than 3. EIBI uses a highly structured teaching approach to build positive behaviors (such as social communication) and reduce unwanted behaviors (such as tantrums, aggression, and self-injury). EIBI takes place in a one-on-one adult-to-child environment under the supervision of a trained professional. |
| **Early Start Denver Model (EDSM)**  | This is a type of ABA for children with ASD between the ages of 12-48 months. Through ESDM, parents and therapists use play and joint activities to help children advance their social, language, and cognitive skills. |
| **Pivotal Response Training (PRT)** | PRT aims to increase a child’s motivation to learn, monitor their own behavior, and initiate communication with others. Positive changes in these behaviors are believed to have widespread effects on other behaviors. |
| **\*DIR Floortime**  | Floortime focuses on emotional and relational development (feelings and relationships with caregivers). It also focuses on how the child deals with sights, sounds, and smells.(\*this is not an evidence-based treatment, but a best practice approach) |

**Treatment Outcomes**

 There is still much to learn regarding the efficacy of different long-term treatment outcomes for very young children diagnosed with Autism. The overall benefits of these various treatments outweigh no intervention at all or starting later. Current research regarding Early Intensive Behavior Intervention (EIBI) children who commenced EIBI prior to age 2, demonstrated greater gains in their cognition and language, and demonstrated improved play, joint attention, and imitation skills and fewer stereotyped behaviors at follow up (between 30 and 36 months) (Clark et.al 2018). In the popular Early Start Denver Model results have been found by studies, that an intensive intervention program for young children with ASD that incorporates play and routine based techniques built from methods of ABA, show significant improved language skills in 18-to-30-month-old children with ASD (Rogers et al., 2019). Although research is still growing in the area of treatment for young children with ASD or ASD risk, it’s clear that earlier detection, and diagnosis, coupled with EI, provides the most promise for a positive outcome at school age.

**Parental and Family Involvement:**

Researchers are also beginning to focus more on EI outcomes for families of young children on the autism spectrum, which are fundamental to understanding treatment effectiveness. One key factor going forward will be supporting families through the EI process. It’s imperative to ensuring positive engagement with EI services, which ultimately facilitates optimal short term and long-term outcomes for both children on the autism spectrum, their families, and the larger community. (Wicks et al., 2021) Researchers have identified five broad outcomes that families benefit from EI services. (FOS-R; Bailey et al., 2006)

· Families understand their child’s strengths, abilities, and needs

· Families know their rights and advocate effectively for their child

· Families help their child develop and learn

· Families have support systems

· Families are able to gain access to desired services and activities in their community

When families feel confident and capable in the early years, it sets the child up for success and mitigate negative side effect of having a child diagnosed with autism. It has been reported that parents of children on the autism spectrum report greater levels of parenting stress compared with parents of typically developing children and children with a range of neurodevelopmental disabilities, intellectual disability, and cerebral palsy (Wicks, et al., 2021). The multifaceted challenges consist of (Wicks, et al., 2021)

· Higher prevalence of anxiety and depression

· Poorer overall well-being

· Families report less satisfaction with their family quality of life

· Additional family stresses related to time pressures, financial strain, increased provisions of supports, and necessary child advocacy.

· SES impact outcome of child with autism spectrum disorder

As treatments take a more family centered approach and not just focusing on treatment of children with ASD, the family system will benefit. Researchers have linked optimal child and family outcomes with family centered practices in the early intervention service delivery (Amsbary, et al., 2021). Currently, there is a growing body of research that is focusing on Parent-implemented interventions (PIIs) to understand parent’s lived experiences as implementers of the interventions their children receive. Some of the finding for PII based on parent perspectives enhanced parental capacity, knowledge and skills in interaction with and creating stronger bonds with their children (Amsbary, et al., 2021).

**Cost**

 The financial implications of the increased prevalence of autism, though rarely discussed, will be extremely important to society. (Chasson et.al, 2007). Autism is associated with a range of cost and researchers have divided those cost into six cost categories: medical and healthcare service cost, therapeutic cost, special education cost, cost of production loss for adults with ASD, cost of informal care and loss of productivity for family/caregivers, and costs of accommodation, respite care, and out-of-pocket expenses (Rogge, N & Janssen, J., 2019). In the category of medical and health related cost, the largest cost, the general finding was these costs are significantly more expensive for those diagnosis with ASD compared to the general population. The key finding from the (Rogge, N & Janssen, J., 2019) literature review was that ASD is associated with a high financial burden in a multitude of domains, resulting in overall lifetime costs of ASD for the average individual with ASD or family with a child with ASD that are substantial. It is estimated to be between $2.4 million to $3.2 million in the U.S. overall cost for the lifespan of a person with autism.

In California, a report from the Legislative Analyst Office, stated spending on special education students has increased by just over 20 percent over the last decade from $10.8 billion to $13 billion. The average cost per special education child is $26,000 and $9,00 to educate a “general education” students. The report also stated that, the majority of students have relatively mild disabilities like speech impairment and specific learning disabilities like dyslexia. However, the report noted that the number of students with severe disabilities has increased and the biggest increase has been in the proportion of children diagnosed with autism, which has risen from 1 in 600 students in 1997-98 to 1 in 50 students in 2017-18 (Source: Overview of Special Education in California, Legislative Analysts Office, 2019). Although more research is being done to narrow down the specific amount of money that would be saved by identifying and treating young children with autism between 12-18 months, its more than likely to reduce the financial long-term cost associated with ASD.

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