



## REVIEW ARTICLE

# Autism Spectrum Disorder: An Overview of Early Detection, and Role of Nurses

Reena Ravi S\*, Theresa Leonilda Mendonc

Laxmi Memorial College of Nursing A J Towers, Balmatta, Mangalore

**\*Corresponding author:**

Prof. Reena Ravi S, Ph.D. Scholar, Laxmi Memorial College of Nursing A J Towers, Balmatta, Mangalore. Email Id: reenaravi2006@gmail.com.

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### Abstract

Autism spectrum disorder (ASD) is a neurological and developmental illness that affects social relationships and communication, as well as a variety of challenging behaviors. Children are not screened for ASD, despite the fact that it is generally recommended. The best outcomes for people with ASD come from early intervention, and developmental surveillance and screening are essential before intervention. Nurses are the primary healthcare providers for children, and they are in a unique position to encourage their development. They have regular contact with children before they start school and can deliver family-centered, comprehensive, coordinated care, including a more thorough medical assessment if a screening suggests a child is at risk for a developmental condition. The diagnosis of ASD is on the continual rise, usually diagnosed in the younger years of life, but this is not always the case. Regardless of when the diagnosis is received, it is important to remember that individuals diagnosed with ASD continue to grow into adulthood and experience many of the same illnesses and disorders as the rest of society thus rendering the nurse the possibility of interacting with this special population sometime throughout his or her career.

**Keywords:** Autism, Overview, Detection, Nurses, Role

### Introduction

Autism is a long-term condition that first appears before the age of 3 years. Repetitive behavior patterns such as repetitive hand or body movements, as well as communication and social interaction challenges are the hallmarks of autism spectrum disorder (ASD).<sup>1</sup> The typical symptoms of ASD include a delay in the onset of babbling and a reduction or absence of pro-speech gestures like pointing, exhibiting, nodding, and other similar actions.<sup>2,3</sup> Behavior problems in children with ASD that impede everyday living abilities have an impact on learning, reasoning, and problem-solving ability.<sup>4</sup> Autism affects people from all racial, social, and ethnic backgrounds.

The absence of “joint attention of the child to coordinate

with a social partner in reaction to an item or event” is essential to take into account when diagnosing autism in very young children. Around the age of two, the absence of linguistic skills may lead to the diagnosis of ASD. Additionally, children with ASDs frequently repeat words in a peculiar or the same intonation as what they hear.<sup>5</sup> Some ASD-afflicted children exhibit stereotypical or ritualistic behaviors, like lining up, banging, and mouthing things. They favor playing by themselves and find it challenging to mouth and integrate objects.

The warning signs at a particular developmental stage, especially between 12 and 18 months, might range from the absence of usual behaviors to the presence of abnormal behaviors. Several behavioral irregularities should be taken into account together rather than just

one specific red flag sign. According to their parents, between the ages of 24 and 25 months, one-third to one-fourth of the children with ASDs experience a significant loss or setback in language development.<sup>6,7</sup> Studies show that the early warning signs and symptoms of ASDs appear between the ages of 12 and 18 months.<sup>8,9</sup> As autistic children learn to speak, they may also have a peculiar tone that can be anything from robotic or flat to high-pitched or 'sing-song'.

#### **Examples of risky behaviors between the ages of 0 and 24 months include the following:**

- Impaired social-communication development including abnormalities in eye-gazing, naming, social smiling, and social interest, as well as a 12-month decline in the expression of pleasant emotion.
- Recurring interests and actions such as abnormal toy and object investigation, extended visual inspection, and unusually frequent actions.
- Delays in play skills including a rise in unproductive play, a decline in the play directed by others that is productive, and an increase in play with toys and motor imitation that is productive.

India has a population of around 1.3 billion, with children under the age of 15 making up nearly one-third of the total population. According to estimates, more than 2 million children in India may be afflicted by ASD.<sup>10</sup> Since the majority of the published studies on ASD rely on hospital-based data, it is difficult to determine how common this disorder is in India. Only a few studies have looked specifically at its incidence in community settings.<sup>11,12,13</sup> Hence, evidence-based estimates of the prevalence of ASD in India's population are lacking. Furthermore, it is challenging to determine the exact prevalence of ASD due to the inconsistent use of properly validated and translated diagnostic methods for autism.<sup>14</sup> As a result of the ASD diagnosis being delayed at an early age, the illness is also not fully recognized.<sup>15</sup>

A delay in diagnosis of ASD is associated with parental worries stated between the ages of 12 and 18 months. Some critical junctures in this phase include the moment when the parents' first concerns surface the first consultation with the pediatrician, the evaluation by the pediatrician of the symptoms, the referral to the hospital, the diagnosis, and the following referral to the treatment

program. As resources must be set aside to provide these children with health care, educational support, and rehabilitative services. Many parents claim that they were not aware of their child's weird behavior until they were toddlers or older.<sup>16</sup> Autism spectrum disorder (ASD) not only has an impact on the child and his or her family but also has direct and indirect financial ramifications for the nation.<sup>17</sup> It affects the nation's ability to afford the costs of healthcare and educational support and rehabilitation services.

A total of 100 autistic children participated in a case-control study at a pediatric hospital where they underwent the following tests to determine their diagnosis using the Diagnostic Statistical Manual of Mental Disorders-IV-Text Revised (DSM: IV-TR) criteria, their intelligence quotient (IQ) using the Stanford-Binrent intelligence scale, and the severity of their autistic symptoms using the Childhood Autism Rating Scale (CARS). 46% of children with autism began to show up symptoms at the age of one and a half years and 32% at two years. Nearly 55% of the children had mild to severe mental impairment (IQ = 20–70), 36% had cognitive levels below average (IQ = 71–89), and 9% had average intellect (IQ = 90–109).<sup>18</sup>

#### **Prevalence and facts**

The number of instances of autism that are recorded is rising sharply, and this rise is mostly due to changes in diagnostic procedures, referral patterns, service accessibility, age at diagnosis, and public awareness. It is estimated that 1% to 2% of the world's population is affected by ASDs. According to the Centers for Disease Control (CDC)'s Autistic and Developmental Disabilities Monitoring (ADDM) Network, 1 in 44 children has an ASD diagnosis. One out of every 160 children worldwide is thought to have an ASD.<sup>19</sup> A global prevalence of 7.6 incidences of ASD per 100 people (1 in 132) was calculated using epidemiological data.<sup>20</sup>

- Autism has been identified in one in every 27 males and one in every 116 females.
- Boys are four times as likely as girls to receive an autism diagnosis.
- Even though autism may be reliably diagnosed as early as the age of 2, the majority of children were only diagnosed when they turned 4.
- An intellectual deficiency affects 31% of children with ASD (IQ= 70), 25% have borderline scores

(IQ= 71–85), and 44% have ordinary to above average IQs (IQ >85).<sup>20</sup>

To ascertain the prevalence of ASD in the Indian community, a systematic review was conducted. One of the four studies reviewed both urban and rural populations, whereas the other three focused solely on metropolitan areas. In comparison, four studies conducted in an urban setting revealed a pooled percentage prevalence of 0.09 in children aged 0–15 years, while the study from a rural setting showed a pooled percentage prevalence of 0.11 in children aged 1–18 years. The lack of comprehensive population-based epidemiological studies on ASD in India emphasizes the urgent need to investigate the prevalence of the disorder. The appropriate collection of data on the prevalence of ASD in India will improve the growth of rehabilitation services in our nation.<sup>21</sup>

### ASD Risk Factors

Most parents of autistic children do have unanswered questions including, “How did my child develop autism?” “My youngster had even begun to learn a few phrases and was completely well. What suddenly occurred?” “Is autism inherited?” “Could it possibly have been avoided?” “Could my other kids have autism too?” Many of these concerns remain unanswered by medical science, and while the ‘why’ may not yet be established, continuous research is revealing that there is basic dysfunction in the brains of children with autism.

Autism is characterized by functional problems in particular brain regions, despite the appearance of a normal brain structure. Functional neuroimaging methods like Positron emission tomography - Computerized Tomography (PET-CT) scans and functional Magnetic resonance imaging (MRIs) of the brain can be used to get this information on how different parts of the brain function. These imaging investigations enable the examination of the autism-related aberrant pattern of cortical activation. According to the research, the frontal lobe, the cerebellum, and the innermost region of the brain known as the mesial temporal lobe, which is important for learning, understanding, memory, social interaction, and abstract thought work less efficiently (responsible for balance, coordination, muscle tone, and speech). Consequently, the issues exhibited in these locations are caused by their dysfunction.<sup>22</sup>

Numerous factors raise a child’s risk of getting ASD. The majority of autism cases appear to result from a confluence of environmental variables that affect early

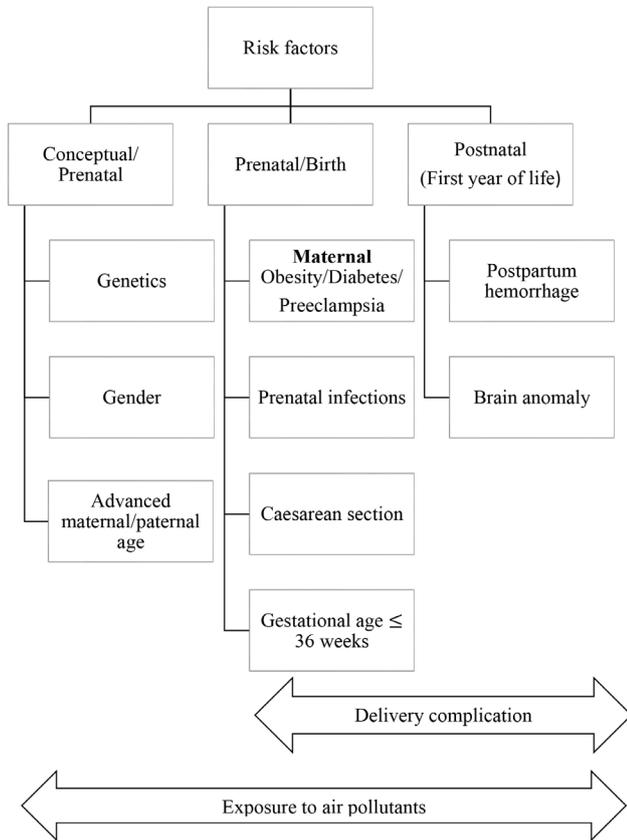
brain development and autism risk genes.<sup>23</sup> The frequency of various maternal and birth risk factors were elicited from mothers in each category, and the screen-positive group had a significantly higher prevalence of birth-related risk factors, such as the need for resuscitation at birth, NICU (neonatal intensive care unit) stays of more than 12 hours, failure to initiate breastfeeding within 30 minutes of delivery, and the presence of neonatal seizures. Other post-natal factors such as a history of post-natal radiation exposure, the occurrence of seizures during infancy, maternal concerns about the child’s development, a lack of exclusive breastfeeding, excessive crying during infancy, head banging, and breath-holding spells were all significantly higher in the screen-positive group than the screen-negative group.<sup>24</sup>

In a study, a high maternal age ( $\geq 35$  years) at birth was observed in 23% of autistic children versus 9.5% of controls. Additionally, 91% of cases had an advanced paternal age ( $\geq 35$  years) at birth compared to 83.5% of the control group and the difference was statistically significant. The risk of autism was found to be statistically strongly correlated with a positive family history (16% of cases compared to 1% of controls). Children with autism experienced delays in all examined developmental milestones compared to the control group. In terms of natal variables, cases were considerably more likely than controls to have had cesarean deliveries and a history of low birth weight. Postnatal variables like a history of hypoxia, jaundice, and resuscitation were also considered to be significant ASD risk factors.<sup>18</sup> (Fig 1)

### Early detection and intervention are crucial.

Early detection and intervention for ASD are turning into public health concerns because of its high prevalence and huge cost to society. Given that ASDs are a spectrum of illnesses with numerous distinct individual variances, diagnosis before the age of three is still challenging. Universal screening and surveillance are needed to identify children who are at risk for ASD. Children with ASD confront a variety of challenges during early screening and intervention. To create effective plans that ensure children with ASD and their families receive the attention they need to achieve the greatest treatment outcomes, it is very important to comprehend and consider current screening, diagnostic, and treatment outcomes.

Screenings may be carried out by qualified professionals and competent nurses and teachers. The American Academy of Paediatrics recommends that children



**Fig 1:** Risk factors of ASD

between the ages of 18 and 24 months undergo an evaluation as part of their developmental surveillance during their routine medical checkups.<sup>3</sup> Screening can help diagnose ASD in children early. Early diagnosis and support may be beneficial for them.

An Indian, urban community-based study found that parents wait at least two years between their initial medical contact and the final diagnosis, and the average age at which the first symptoms are noticed is 24.1 months.<sup>25</sup> A study conducted in tertiary care hospitals found that these kids' typical ages at their initial medical consultation and the beginning of their disorder-specific treatment were 32.5 months and 52.75 months, respectively.<sup>26</sup> The introduction of particular medicines in various settings has been delayed despite greater knowledge and quicker diagnosis. Indian studies show that it often takes two years from the initial consultation to the start of treatment.<sup>25, 26</sup> Shortening the consultation and referral process, starting home-based interventions, and altering public health policies are just a few of the recommended measures to cut down on the wait time.

According to research, it is essential to identify ASD in children as soon as possible so that they can receive evidence-based therapy focused on enhancing their developmental performance and obtaining positive

long-term outcomes like enhanced language and social interactions.<sup>27, 28</sup> Additionally, it can aid ASD children in enhancing their quality of life and developmental processes in all facets of their lives.<sup>29</sup> Furthermore, considering that children must use their human rights to participate in play, education, and society, children with ASD benefit from the accessibility and efficacy of the early intervention.<sup>30</sup> Early detection and treatment for ASD children can have a significant positive impact.<sup>29</sup> Early interventions have the best results, regardless of where a child lies on the autism spectrum.<sup>31</sup> It is important to start ASD treatment as soon as possible.

ASDs can now be diagnosed with the use of a variety of screening and diagnostic tools. A comprehensive evaluation is necessary for suspected ASDs and includes a developmental history review, parent interviews, and a series of physical exams, clinical observations, developmental evaluations, and other procedures. A language delay is one of the most important indicators of ASD and should be identified as soon as feasible. Anomalies in language including receptive and expressive language deficits must be carefully observed. Prompt therapy can result from early detection. There are instruments designed as initial tests that are given to all children that help differentiate between the general population and children who are at risk of ASDs.

**Choosing a Screening Instrument**

The following factors should be taken into account when choosing a developmental screening tool:<sup>32</sup>

- Psychometric properties
- Domain(s)
- The setting in which the screening tool will be used
- The sensitivity
- The specificity
- The child's characteristics

There isn't a single screening method that can be used globally and be regarded specifically for the diagnosis of autism. Tools that are standardized to the local conditions and tested for their effectiveness in making the diagnosis are available. As a result of this assessment inconsistency, the prevalence of ASD may be underestimated or overestimated in certain geographic distributions. The American Academy of Paediatrics neither endorses nor approves of any specific screening tool. Other screening tools might be available, and this table (Table: 1) is not

**Table 1:** Screening tools for ASD

Name	Age Range	Administration time	Description
Modified Checklist for Autism in Toddlers-R/F (M-CHAT-R/F)	16 to 30 months	Takes 5 minutes and scoring takes 2 minutes.	The most popular assessment for “screening age” children
Screening Tool for Autism in Toddlers and Young Children (STAT)	24 to 35 months	20 to 30 minutes; scoring time: 5 to 10 minutes	To rule out ASD in children who are >24 months old and who are thought to have a high ASD risk.
The Survey of Well-Being of Young Children (SWYC): Parent’s Observations of Social Interactions (POSI)	16 to 35 months	5 minutes to complete and score	This is a wonderful option for clinics looking for combined autism and developmental screening.
Rapid Interactive Screening Test for Autism in Toddlers (RITA-T)	18 to 36 months	5 to 10 minutes to perform and score	Screening tools for children who are thought to have a high ASD risk to diagnose ASD.
Communication and Symbolic Behaviour Scales Developmental Profile – Infant/Toddler Checklist (CSBS-ITC)	6 to 24 months	5–10 minutes to finish; 5 minutes to score	This has the youngest age range. Compared to a generic developmental screener, it is more focused on ASD.
Social Communication Questionnaire (SCQ)	4+ years	5–10 minutes to finish; 5 minutes to score	This tool is intended for older children.

all-inclusive. Users are advised to read the accessible instruction manuals before administering, scoring, and analyzing the scoring tool results to achieve the best results.

A popular screening instrument used by many pediatric centers is the Modified Checklist for Autism in Toddlers (M-CHAT)<sup>33,34</sup> which has undergone worldwide and multilingual evaluations. In this parents are asked to complete the survey. After that, pediatricians and pediatric nurses can utilize the responses to identify children who could be more susceptible to ASD. It is necessary to make a distinction between screening and diagnosis. Children that test positive for ASD may not have the disorder. Additionally, not all autistic children are always detected during testing.

The modified checklist for autism in toddlers-revised (M-CHAT-R) was used in a study to screen children between the ages of 16 and 30 months who were receiving care at a pediatric outpatient department for ASD. The study also looked for associations between prenatal, perinatal, and postnatal risk factors and ASD risk. Three hundred and fifty mother-child pairs with

kids ranging in age from 16 to 30 months were enlisted. All women received the M-CHAT-R screening tool and risk assessment checklist to check for ASD. Children were divided into two groups based on the results of the screening: ASD (high risk) and No ASD (low and medium risk). The odds ratio was used to analyze the relationship between risk factors and ASD screening. The study found that 33 (9.4%) children tested positive for ASD. It was 21 months on average. Neonatal seizures, neonatal resuscitation, late breastfeeding beginning, and a high mean paternal age at birth were all linked to ASD screening positivity. Neonatal convulsions and mother anxiety about the development of the child were linked to higher odds of screening positive for ASD after controlling for confounding factors, but exclusive breastfeeding for the first six months of life was linked to lower risks. It was recommended that children with the aforementioned risk factors should be screened for ASD as early interventions are possible.<sup>24</sup>

All three impaired social communication/social interaction symptoms such as social reciprocity, nonverbal communication, and relationships are required

to be present to meet the DSM-V diagnostic criteria and result in a diagnosis. This domain exemplifies the absence of competent social communication, one of ASD's negative symptoms. Two of the four restricted/repetitive behavior indications are required for a diagnosis under the DSM-V diagnostic criteria. This domain describes the occurrence of very intense, constant, or sensory events, behavior that is referred to as an ASD's positive symptoms. A sizable minority, if not the majority, of people with ASD exhibit a wide range of comorbid disorders or symptoms that span the cognitive, behavioral/psychiatric, and medical domains.<sup>1</sup>

The M-CHAT-R is one such screening instrument with good specificity and sensitivity.<sup>35</sup> The Indian Scale for Assessment of Autism (ISAA), a native instrument is available (Ministry of Social Justice and Empowerment 2009), but it is not very accurate in younger age groups, notably toddlers. The likelihood of the risk for ASD in toddlers has not yet been determined by community surveys in India using techniques that have been validated for use within this age group. This context helped guide the study's use of community health nurses to use the M-CHAT-R to find children at risk for ASD.<sup>36</sup>

Children with ASD and their families face significant personal and societal challenges.<sup>37,38</sup> This emphasizes how crucial it is to improve parental comprehension, clear up myths, and handle their stress from a cultural perspective.<sup>39</sup> Being the primary caretakers for their children and in the best position to identify their children's developmental concerns, parents are urged to adopt an evidence-based instructional guide aimed toward them. Primary care physicians must expand their services to improve early detection and intervention. Additionally, they must increase community access to screening and diagnostic facilities. One of the most frequent causes of parental strain identified by the parents of children with ASD is a lack of sufficient professional assistance. The obstacles that prevent parents and other caregivers from receiving early diagnosis and treatment for ASD must be acknowledged by medical experts. Education may improve the health outcomes for children with ASD for parents, caregivers, and medical professionals.

Many parents described the problems they experienced from the minute they suspected something wasn't quite right with their children's development to the formal diagnosis of ASD. To identify ASD early, healthcare professionals must pay close attention to parents' voiced concerns about their child's developmental irregularities.

According to the studies, parents are ignored by healthcare providers, and their initial concerns regarding ASD resulted in their child's ASD diagnosis being delayed.<sup>38,40,41,42</sup>

The mean age of diagnosis ranged from 38 to 120 months, with a declining tendency over time, according to a study carried out over 12 years. Community-based research in India reported that parents had to wait at least two years between the initial scientific contact and the final diagnosis.<sup>43</sup> The average age of the first medical consultation for these young children was 32.5 months, and the average age of the start of disorder-specific treatment was 52.75 months, according to a tertiary care hospital study.<sup>26</sup>

It is crucial to support children in reducing challenging behavior and enhancing long-term outcomes, hence reducing the need for more expensive therapies in later life. Other significant developmental abilities such as language, interpersonal communication, and speaking abilities may go unnoticed by some parents.<sup>38,40</sup> This has the potential to enhance the level of quality of life for children with ASD as well as their parents.

According to the cross-sectional research, family-centered care, a consistent source of care (accessibility), and a personal doctor or nurse (continuity) were the components of a medical home that were most significantly related to developmental screening (all medical decisions were made in partnership with the family).<sup>44</sup>

### **Barriers to early diagnosis and intervention of ASD**

Several barriers prevent early diagnosis of ASD and early interventions.<sup>40,45</sup>

#### **Barriers to early diagnosis:**

##### **1. Education**

- o Lack of professional training
- o Lack of parental education
- o Professional reluctance to make an early diagnosis

##### **2. Access**

- o Lack of medical experts to make a diagnosis
- o Limited insurance protection

##### **3. Screening**

- o Insufficient time to screen
- o Screening deficiencies in identifying early and minute symptoms
- o Deficiency of parental authority or voice

- o Fear of diagnosis in parents

#### 4. Stigma

- o Social

#### **Barriers to early intervention:**

##### 1. Access

- o Financial constraints
- o Inadequate personnel, initiatives, and funding
- o Inadequate family-focused services

##### 2. Education

- o Lack of education of pediatricians/providers

##### 3. Ineffective approaches for providing care

- o Inadequate systems for social services, intersystem communication, and health
- o Organizational culture, particularly a reluctance to implement innovative ideas

### **Role of Nurses**

Families face difficulties understanding that their child may be different when autism is identified. Mothers frequently accuse themselves of being the cause of the child's autism by allowing them to watch TV, return to work, or leave the child with a caretaker. The nurses play a crucial role in educating families about the condition, which is present at birth and doesn't manifest itself until the child is about 18 months old. The caregivers of autistic children may feel anger, frustration, and depression because of their child's disabilities and differences. Such caregivers require accurate information, training, and being aware of all aspects of their child's disabilities.

By informing and assisting the parents, families, neighbors, and other members of the healthcare community about the need for early ASD detection and treatment, nurses can act as change agents in the world. Nurturing, the initial form of well-being has an impact on both the parent and the child. Because ASD is becoming more common, doctors can anticipate that many more children will develop the disorder in the coming years. Nurses are experts in identifying the risk factors, characteristics, and most recent screening recommendations for ASDs.

The prevalence of ASD has increased recently, therefore nurses should anticipate seeing a lot of children with the disorder. Nurses are knowledgeable about the traits, risk factors, and modern best practices for ASD screening.

Early intervention may help parents get their children the best care possible before a lot of unnecessary time is spent on therapy. It has been seen that the parents' stress levels rise as a result of the delay in reacting to their first worries, the symptomatic delay, and the failure to implement the decision with clear rules for mediation. The long and challenging process of symptom preparation aims to make the child's initial ASD diagnosis.

There is the need for support, the lack of professional access, and information from their children's health care providers. Despite the rising frequency of ASD and its long-term implications, nurse educators find it challenging to teach nursing students about the detection and treatment of ASD. A survey of 295 staff members in undergraduate, bachelor and doctorate RN programs revealed that less than 5% had master's-level knowledge of ASD, 33% had excellent information, 20% did not have exceptional knowledge, and 75% had very low or just modest knowledge.<sup>46</sup>

By being efficient at identifying risk factors and early symptoms of the illness, nurses can play the following important roles:

- Immediately address any concerns parents may have about their child's growth with other medical team members.
- Determining whether system- and location-specific screening and early intervention techniques adhere to the most recent guidelines, and, if not, challenging such practices.
- Promoting automated screening, surveillance, and action-reminder systems in the healthcare sector.
- Making caregivers aware of the dangers to children who may have ASD.
- Connecting families with local early intervention specialists and evaluation services for public schools.
- Working with social service organizations and the local government authorities to secure funds if these programs are not already available locally.
- Confirming the fulfilments of all specialist referrals, including any further recommendations for family assistance and education, such as social work.
- Requesting that all families attend all diagnostic appointments with professionals, with copies of all prior medical history, therapy, and individualized education program (IEP) reports.

- Educating individuals, families, and other professionals about the value of early intervention for kids at risk for ASD.

There is limited evidence on the effectiveness of early intervention programs with children from universal screening programs due to the paucity of research in this area. The lack of sufficient professional assistance is one of the leading causes of stress for parents of children with ASD. The hurdles that prevent parents and other caregivers from getting medical attention and obtaining early therapies for ASD must be identified by nurses.

To develop efficient solutions that ensure that the required care is provided for families of children with ASD to obtain the best treatment outcomes, it is crucial to examine and take into account current screening, diagnostic, and treatment methods. Stress among parents has been seen to increase as a result of the delay in reacting to their first concerns, delay in diagnosis, and failure to provide useful response recommendations along with the diagnosis.<sup>47</sup>

Finding help and a definitive diagnosis for their children can be challenging for many parents. Parents talked about their struggles locating services from the moment they saw something wasn't remarkably well with the growth of their child to the moment they received the ASD diagnosis. It was also claimed that the diagnostic and intervention processes were challenging due to a shortage of ASD specialists, particularly in rural areas.<sup>48</sup>

Nurses can use evidence-based hints for ASD screening to help them recommend for children ensuring that ASD is recognized early and proper intervention is initiated. Nursing schools frequently hesitate to instruct nursing students about ASD screening and therapies, despite the growing frequency of ASD and its long-term effects. Parental assessments of unusual behaviors are strong predictors of an ASD diagnosis later on. Nurses should be aware that denial and sadness can dissuade parents from reporting ASD concerns or seeking diagnostic help. Autism acceptance requires empathy and an understanding that ASD is different for everyone.

## Conclusion

Nurses can educate, support, and direct people affected by ASD to relevant resources because of the high regard that the public accords them and the positions they hold. Regardless of when the diagnosis is made, it is essential to remember that children with ASD mature into adulthood

and experience many of the same diseases and disorders as the general population. This gives nurses a chance to work with this special population at some point during their careers. By advising parents to keep an eye on children who may have ASD and teaching them how to take the necessary precautions, nurses can assist families in preventing mishaps.

## Conflicts of Interest

None

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