

Identifying autism spectrum disorder in undiagnosed adults

By Laura Foran Lewis, PhD, RN

Autism spectrum disorder (ASD) affects 1 in 59 children and the latest prevalence studies estimating that 1 in 100 adults are affected.^{1,2} Many adults with ASD are undiagnosed and present in primary care offices without knowing they are on the ASD spectrum. Experts estimate that for every three diagnosed cases of ASD, there are two additional undiagnosed cases.³ This brief overview describes how individuals with ASD can be identified in

syndrome, pervasive developmental disorder, and autistic disorder.⁴ Now, a single diagnosis of ASD captures all of these profiles.

ASD occurs on a spectrum, so some individuals show symptoms of extreme impairment (for example, being unable to speak or having an absence of interest in social relationships), whereas others show only mild external symptoms and experience primarily internal symptoms (for example, high levels of social anxiety and/or depression).

“odd” without anyone recognizing their behaviors as symptoms of ASD. For middle-aged and older adults, a lack of awareness and a changing definition of ASD may have contributed to missed diagnosis during childhood. Autism was not recognized in the *DSM* until 1980, and even then, it was only recognized as “infantile autism.”⁹

Asperger syndrome, which identified milder cases on the autism spectrum, was not added to the *DSM* until 1994.⁹ Therefore, many adults grew up during a time when parents, educators, and HCPs were not likely aware of symptoms of ASD in children without intellectual impairment. Some may have been misdiagnosed with other conditions (for example, obsessive-compulsive disorder, attention-deficit hyperactivity disorder) or may have had parents who were unwilling to pursue diagnosis during childhood due to fear of stigma and discrimination.¹⁰

Still, others with mild symptoms and sufficient social supports may not have shown signs of impairment until later years when social demands increased. For example, a young adult may begin to show deficits after moving out of his or her parents’ home, when he or she becomes responsible for managing his or her own schedule, and needs to adjust to new living arrangements. Therefore, although symptoms

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primary care settings and to guide healthcare providers (HCPs) in determining next steps when they suspect undiagnosed ASD in adult patients.

■ What is ASD?

ASD is a neurodevelopmental disorder that is characterized by impairment in social skills, repetitive patterns of behavior, sensory issues, and restricted interests that affect the individual’s ability to function in social, occupational, or other settings.⁴ *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* eliminated the subcategories of ASD, which were previously known as Asperger

It is worth mentioning that intellectual disability is not a characteristic of ASD. Although it is a common comorbidity, approximately half of individuals with ASD have average to above average intelligence.⁵ Many individuals with ASD are able to live independently, find employment, and engage in romantic relationships.⁶⁻⁸

■ Presentation of ASD in adults

Even though symptoms are present beginning in early developmental stages, there are many reasons that adults with ASD are not diagnosed during childhood. These individuals may be viewed as being “quirky” or

might have existed during childhood, impairment might have seemed to appear for the first time during adulthood. College educators, roommates, significant others, or employers may be the first to recognize signs of ASD.

Symptoms that are considered classic for autism in children are often not present in adults with ASD, especially in individuals who were undiagnosed in childhood. Adults may learn behaviors that help them mask symptoms, such as mimicking small talk or rehearsing conversation topics prior to social engagement. Just because an individual may appear to blend in socially does not necessarily rule them out for a diagnosis of ASD.

Females in particular may be able to camouflage symptoms so they are not outwardly detectable but may describe feeling a sense of social isolation or intense social anxiety.¹¹ These internal symptoms should not be ignored and warrant screening for ASD (see *Examples of ASD symptoms in adults*).¹²⁻¹⁵

■ Disclosing a suspected diagnosis

There is no “cure” or treatment for ASD, but there are benefits to individuals of all ages in discovering a diagnosis. Even in mild cases, a diagnosis of ASD can improve the quality of life and mental health outcomes for adults with ASD symptoms.¹⁶ Individuals who are unaware of their diagnosis often falsely believe there is something wrong with them or view their social challenges as personal failures.

Examples of ASD symptoms in adults¹²⁻¹⁵

Challenges with expressive communication	<ul style="list-style-type: none"> • Lack of filter when speaking, which may come across as rude at times • Flat affect or monotonous tone in voice, so that inflection does not match feelings • Difficulty maintaining conversation, particularly small talk (may respond with inappropriately short answers to questions or engage in long monologues), and difficulty staying on topic • Some language may seem rehearsed or scripted • Avoids eye contact or may use inappropriately intense eye contact • Difficulties identifying or articulating own thoughts and feelings • Recalls names, facts, and/or other trivial information
Difficulty interpreting communication	<ul style="list-style-type: none"> • Difficulty reading nonverbal communication, such as facial expressions, body language, and social cues • Difficulty understanding the intentions, thoughts, and feelings of others • Takes things literally and struggles to understand figurative language
Restricted repetitive behaviors or interests	<ul style="list-style-type: none"> • Insists on sameness or routine and experiences stress when that routine is disrupted • Intense interest in a particular hobby, object, or area of study <ul style="list-style-type: none"> –This may be an interest in something general or very specific, abnormal in its topic of focus, and/or the extent of the obsession
Hypersensitivity or hyposensitivity to sensory stimuli	<ul style="list-style-type: none"> • Easily distracted by sensory stimuli (sound of clock ticking or light flickering) • Displays self-stimulatory behavior (also known as “stimming”) <ul style="list-style-type: none"> –This is a repetitive motor movement or sound used to regulate sensory input. While hand-flapping may be more classic in children, adults often learn to adapt and hide this behavior. For example, stimming may manifest in adults as a repetitive rubbing of the hands on the thighs, rubbing fingers together inside a pocket, or foot-tapping • Prefers to dress in a way that is comfortable, even if it is not necessarily appropriate to the setting (may wear clothes that do not match, for instance, may wear a T-shirt to a formal event)
Internalized symptoms that may not be outwardly apparent	<ul style="list-style-type: none"> • Discomfort during conversation, social anxiety, social phobia, or exhaustion after social activity • Challenges regulating emotion and may be prone to emotional outbursts (“meltdowns”) or to retreating and blocking out all surroundings (“shutdowns”) • Anxiety and/or depression
Other common symptoms	<ul style="list-style-type: none"> • Challenges planning, organizing, or maintaining focus (may arrive late to appointments or miss appointments) • Irregular sleep patterns • Clumsy gait or poor physical coordination

This table provides examples of how ASD may manifest in adults, focusing primarily on adults with no intellectual disability. This list is not exhaustive and is not intended to be used as a diagnostic tool.

Learning about ASD can provide explanations for behaviors that those with ASD are already aware of and offers opportunities to better identify and leverage strengths and weaknesses.⁷ Young adults may be able to receive educational and/or employment accommodations, make adjustments in living

as reasons not to disclose or pursue a diagnosis of ASD when suspected.

When sharing a suspected diagnosis with a patient, it may help to frame the diagnostic criteria for an ASD diagnosis in a positive light, such as those criteria written by Purkis or Attwood and Gray.^{18,19} Patients

may be receptive to learning more or may even confess that they have suspected a diagnosis themselves.

Adults with ASD are often aware of their social challenges even if they are not aware of ASD. With time to process, adults may experience grief as they adjust to a new view of self, anger that the diagnosis was not recognized earlier, and/or relief that the diagnosis explains information they already knew about personally.⁷ HCPs should plan to follow up with their patients within 2 to 6 weeks after sharing a suspicion or diagnosis of ASD; this time should be used to discuss how patients are processing this new information and to answer any questions.

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situations to limit excess socialization, and make career choices based on their own strengths and weaknesses. Older adults may benefit from the opportunity for life review and understanding the impact of ASD on current and past relationships.

Adults of all ages may benefit from joining online support groups, which allow the sharing of experiences while minimizing the anxieties of face-to-face interactions. Counseling and management of frequently co-occurring symptoms, such as anxiety, depression, and suicidal thoughts, is also warranted.¹⁷ With this in mind, HCPs should never view age, lack of available treatment, or presence of only mild symptoms

should be invited to see the strengths and possibilities a diagnosis can offer. HCPs should plan to provide plenty of positive resources and information for patients and their family members to explore as they learn more about ASD as well as websites for community support (see *ASD resources and support communities*).

HCPs should be prepared for a range of reactions when disclosing a suspicion of ASD. The patient may view this as an insult and may initially be offended, particularly if they have negative misperceptions about what a diagnosis of ASD means. The patient may also immediately dismiss these suspicions. Others

Formal diagnosis of ASD

A formal diagnosis may be made by any HCP with credentials and expertise to make a diagnosis, including NPs. That being said, ASD is often misdiagnosed and may be particularly difficult to identify in adults, so primary care HCPs may prefer to make a referral to a mental health professional, such as a neuropsychologist or psychiatrist, for neuropsychological testing.²⁰ Ideally, adults should be referred to professionals who specialize in adults with ASD, but there are few clinicians with this particular specialty.

The Asperger/Autism Network offers a national directory of adult ASD specialists, and other regional organizations may also be useful in finding practitioners who specialize in adult ASD.¹² If such a practitioner cannot be found, many developmental

ASD resources and support communities	
Organization	Website
Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Healthcare Toolkit	www.autismandhealth.org
Asperger/Autism Network	www.aane.org
Autistic Self Advocacy Network Reddit: Aspergers Subreddit	www.autisticadvocacy.org www.reddit.com/r/aspergers
Twainbow	www.twainbow.org
Wrong Planet	www.wrongplanet.net

pediatricians and child psychiatrists with ASD specialties are also willing to evaluate adults.

When making a referral, patients should be advised on what to expect at the appointment. Patients should be informed that testing may include a conversation with the diagnostician, being observed while undergoing specific tasks, and/or answering oral, written, or computerized questions regarding their abilities, behaviors, thoughts, feelings, and experiences.

HCPs should advise patients to bring a family member or friend (particularly someone who knew the patient from an early age) who can share more information. This person may provide support as well as perspective on the patient's social skills and past experiences. Patients should be informed that diagnosis is often a long process and may involve several visits with a professional. Patients should also be offered support by following up during this process and offering resources with more information while they seek additional counseling.

Some adults are satisfied with a self-diagnosis only. HCPs should be aware that health insurance coverage for ASD diagnoses can vary, and cost may be a significant obstacle to formal diagnosis. HCPs should assist individuals in weighing the potential costs and benefits of a formal diagnosis. For example, a formal diagnosis is necessary for adults who are seeking Social Security disability benefits or employment accommodations through the Americans with Disabilities Act of 1990.²¹

A formal diagnosis may also be an important milestone for individuals who continue to doubt or question their self-perception as it relates to ASD.¹⁶ For those who decide not to seek a formal diagnosis, those individuals should be empowered to embrace a self-diagnosis, as it assists them in gaining self-awareness and acceptance. HCPs should provide information and resources and offer a referral for counseling to assist the individual in coping with a new self-perception.

Conclusion

HCPs must be aware that there are many adults who do not know that they have ASD who present in primary care offices undiagnosed. Symptoms typically manifest differently in adults than in children and may be more subtle and internal. Knowledge of ASD can have a significant positive impact on the lives of those with ASD and their families. If a patient is suspected of having ASD, the HCP should carefully but directly disclose this information and assist the individual with finding appropriate support for next steps. **NP**

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