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Adults with autism spectrum disorder: Updated considerations for healthcare providers

ABSTRACT

Children with autism spectrum disorder (ASD) eventually grow up and need to make the transition from pediatric services to adult. This is a diverse patient population.

KEY POINTS

Autism is becoming more common, with most recent statistics showing at least 1 in 59 children affected.

Asperger syndrome is now included in the category of ASD, with possible implications for coverage of care.

Some children with ASD get better as they get older, but many do not, and some do not receive a diagnosis until adulthood.

Diagnosing ASD in adults can be difficult and involves specialists from multiple disciplines.

Social support is important. Community programs and behavioral therapies can help. Drug therapy has not been rigorously tested and is not approved for use in adults with ASD. Caregivers may also need support.

AUTISM SPECTRUM DISORDER (ASD) has increased significantly over the past 40 years. Even in the past 2 decades, the prevalence increased from 6.7 per 1,000 in 2000¹ to 14.6 per 1,000 in 2012—1 in 59 people.² Of those with ASD, 46% have an intelligence quotient (IQ) greater than 85, meaning they are of average or above-average intelligence.¹

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As more children with autism become adults, understanding this condition across the life span grows paramount. While many studies have focused on understanding how diagnosis and treatment can help young children, few have focused on adults with autism and how primary care teams can better assist these individuals. However, this is changing, with studies of the benefits of employment programs and pharmacologic treatment, and reproductive health needs of adults with ASD. Here we provide an updated review of ASD in adult patients.

■ NO MORE ASPERGER SYNDROME— IT'S ON THE SPECTRUM NOW

As the scientific understanding of autism has expanded, revisions in the *Diagnostic and Statistical Manual of Mental Disorders*, fifth edition (DSM-5),³ published in 2013, have paralleled these advances. For many adult patients with autism who were evaluated as children, these revisions have led to changes in diagnosis and available services.

In the previous edition (DSM-IV-TR, published in 2000),⁴ autistic disorder and Asperger

TABLE 1

Autistic disorder, Asperger syndrome, and autism spectrum disorder: Past and present terminology and definitions

Autistic disorder^a	Asperger syndrome^a	Autism spectrum disorder^b
Qualitative impairment in social interaction Qualitative impairments in communication	Qualitative impairment in social interaction	Persistent deficits in social communication and social interaction across multiple contexts (can specify severity as level 1, level 2, or level 3, with level 3 requiring the most support)
Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities	Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities	Restricted, repetitive patterns of behavior, interests, or activities
Delays or abnormal functioning in at least 1 of the following areas, with onset before age 3: Social interaction Language as used in social communication Symbolic or imaginative play	Clinically significant impairment in social, occupational, or other important areas of functioning No clinically significant general delay in language (eg, single words used by age 2, communicative phrases used by age 3) No clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood	Symptoms present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life) Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning Providers can now specify autism spectrum disorder with or without intellectual impairment and language impairment
Disturbance is not better accounted for by Rett disorder or childhood disintegrative disorder	Criteria not met for another specific pervasive developmental disorder or schizophrenia	Disturbances not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay

^aAbbreviated from *Diagnostic and Statistical Manual of Mental Disorders* (Fourth Edition, Text Revision), published July 2000.⁴

^bAbbreviated from *Diagnostic and Statistical Manual of Mental Disorders* (Fifth Edition), published May 2013.³

Autism remains a lifelong disorder for many

syndrome were separate (Table 1). However, DSM-5 lumped autistic disorder and Asperger disorder together under the diagnosis of ASD; this leaves it to the clinician to specify whether the patient with ASD has accompanying intellectual or language impairment and to assign a level of severity based on communication deficits and restrictive behaviors.

The shift in diagnosis was worrisome for some, particularly for clinicians treating patients with DSM-IV Asperger syndrome, who lost this diagnostic label. Concerns that pa-

tients with Asperger syndrome may not meet the DSM-5 criteria for ASD were validated by a systematic review showing that only 50% to 75% of patients with DSM-IV autistic disorder, Asperger syndrome, or pervasive developmental disorder not otherwise specified (PDD-NOS) met the DSM-5 criteria for ASD.⁵ Most of those who no longer met the criteria for ASD carried a DSM-IV diagnosis of Asperger syndrome or PDD-NOS or had an IQ over 70.⁵ Nevertheless, these individuals may struggle with impairing symptoms related

to repetitive behaviors or communication or may be affected by learning or social-emotional disabilities. Additionally, even if they meet the criteria for ASD, some may identify with the Asperger syndrome label and fear they will be stigmatized should they be classified as having the more general ASD.^{6,7}

Although future revisions to the DSM may include further changes in classification, grouping adults with ASD according to their functional and cognitive ability may allow for pragmatic characterization of their needs. At least 3 informal groupings of autistic adults have been described that integrate cognitive ability and independence⁸:

- Those with low cognitive and social abilities, who need lifelong support
- Those with midrange cognitive and social limitations but who can complete their work in special education classes; they often find employment in supervised workshops or other work with repetitive tasks
- Those who have greater cognitive ability and some social skills; they may proceed to college and employment and live independently.

■ UNCERTAIN PROGNOSIS

Prognostication for people with ASD remains an area of research. Some adults experience a reduction in symptoms as they age, with significant improvements in speech and, sometimes, modest improvements in restrictive and repetitive behaviors.^{9,10}

Nevertheless, autism remains a lifelong disorder for many. Adults may still require significant support and may experience impairment, particularly in social interaction.¹⁰ In longitudinal studies, only 15% to 27% of patients with ASD are characterized as having a positive outcome (often defined as variables related to independent function, near-normal relationships, employment, or a quantified reduction in core symptoms), and many experience significant dependency into adulthood.¹⁰⁻¹³

IQ has been cited as a possible prognostic factor,^{10,13} with an IQ below 70 associated with poorer outcome, although an IQ above 70 does not necessarily confer a positive outcome. Less-severe impairment in speech at

baseline in early childhood also suggests better outcomes in adulthood.¹⁰

As we see more adults with autism, studies that include both children and adults, such as the Longitudinal European Autism Cohort, will be important to characterize the natural history, comorbidities, and genetics of ASD and may help provide more specific predictors of disease course into adulthood.¹⁴

■ ACHIEVING A DIAGNOSIS FOR ADULT PATIENTS WITH SUSPECTED AUTISM

While many patients are recognized as having autism in early to mid-childhood, some adults may not receive a formal diagnosis until much later in life. Those with fluent language and normal-range IQ are likely to be overlooked.¹⁵ People with ASD may have had mild symptoms during childhood that did not impair their functioning until demands of daily life exceeded their capacities in adulthood. Alternatively, parents of a child with newly diagnosed ASD may realize that they themselves or another adult family member also show signs of it.

The UK National Institute of Health and Care Excellence suggests that assessment should be considered if the patient meets psychiatric diagnostic criteria and one of the following:

- Difficulty obtaining or sustaining employment or education
- Difficulty initiating or sustaining social relationships
- Past or current contact with mental health or learning disability services
- History of a neurodevelopmental or mental health disorder.^{15,16}

Currently, diagnosis typically involves a multidisciplinary approach, with psychiatric assessment, neuropsychological testing, and speech and language evaluation.¹⁷ Providers may need to refer patients for these services, sometimes at the patient's request, if previous mental health misdiagnoses are suspected, if patients report symptoms or impairment consistent with ASD, or if benefits, services, or accommodations, such as a coach in the workplace, are needed.

Diagnosing ASD in adults can be difficult, given that the gold-standard diagnostic tests

A parent of a child with newly diagnosed ASD may realize that he or she also shows signs of it

such as the Autism Diagnostic Observation Schedule-2 (ADOS-2)¹⁸ and the Autism Diagnostic Interview-Revised (ADI-R)¹⁹ are typically used to diagnose autism in children. However, Module 4 in the ADOS-2 was developed for adolescents and older patients with fluent language and has shown at least moderate power to distinguish adults with ASD from those without ASD.^{18,20}

An initial psychiatric assessment should include a thorough history taken from the patient and, if applicable, the patient's caregiver, as well as a psychiatric interview of the patient. Neuropsychological testing should include evaluation of cognitive function, social functioning (using the ADOS-2 for adults without intellectual disability, the ADI-R, or both), and adaptive functioning (using the Vineland Adaptive Behavior Scales, second edition²¹).

Evaluation of speech and language is particularly important in patients with limited language ability and should include both expressive and receptive language abilities. Serial testing every few years, as is often recommended in childhood, may help establish the pattern of impairment over time.

Comorbid psychiatric disorders are common

Many people with ASD also have other psychiatric disorders,^{17,22} which clinicians should keep in mind when seeing an adult seeking evaluation for ASD.

Attention-deficit/hyperactivity disorder is present at higher rates in patients of average intellectual function with ASD than in the general population.²³

Anxiety disorders, including obsessive-compulsive disorder, were found to often coexist with autism in a sample of adults with autism without intellectual disability,^{24,25} and approximately 40% of youths with ASD have at least 1 comorbid anxiety disorder.²⁶

Mood disorders are also prevalent in adults with ASD, with a small study showing that 70% of adults with DSM-IV Asperger syndrome had at least 1 depressive episode in their lifetime.²⁷

BEHAVIORAL AND PHARMACOLOGIC THERAPIES FOR THE ADULT PATIENT

Treatment of adults with ASD should be individualized based on the challenges they are

facing. Many, including those with average or above-average intelligence, struggle with interpersonal relationships, employment, housing, other health conditions, and quality of life.²⁸ Thus, behavioral services and programs should be tailored to help the patient with current challenges (**Table 2**).

Services and medications for adults with ASD are discussed below. These will vary by individual, and services available may vary by region.

Historically, vocational and social outcomes have been poor for adults with ASD. It is estimated that most larger universities may be home to 100 to 300 students with ASD. To combat isolation, the University of California, Los Angeles, the University of Alabama, and others provide special support services, including group social activities such as board games and individual coaching.⁸ Nevertheless, half of the students with autism who attend institutions of higher learning leave without completing their intended degree.²⁹ Many still struggle to establish meaningful friendships or romantic relationships.²⁹

Planning for a transition of care

Healthcare transition planning is important but is strikingly underused.³⁰ Individual providers, including adult psychiatrists, vary in their level of training and comfort in diagnosing, treating, and monitoring adults with autism. Youths with ASD are half as likely to receive healthcare transition services as other youths with special healthcare needs.³¹

Pediatric providers, including pediatric psychiatrists, developmental behavioral specialists, and pediatric neurologists, may be best equipped to treat young adult patients or to refer patients to appropriate generalists and specialists comfortable with autism-specific transition of care. The question of eligibility for services is important to patients and families during the transition period, with many parents and professionals unaware of services available to them.³² Receiving adequate transition services is enabled by having a medical home during childhood—that is, a comprehensive, centralized medical record, culturally competent care, interaction with schools, and patient access to clear, unbiased information.³¹

Many people with ASD also have other psychiatric disorders

Ideally, in our experience, transitioning should be discussed well before the child ages out of the pediatric provider's practice. If necessary, healthcare transition services should include 4 components:

- Discussing the switch to a new physician who treats adults
- Discussing changing healthcare needs as an adult
- Planning insurance coverage as an adult
- Encouragement by the physician for the child to take age-appropriate responsibility for his or her healthcare.^{31,33}

Tools such as the Got Transition checklist from the National Health Care Transition Center can provide support during this process.³⁴

Other services

Other services provided as an extension or adjunct to the medical home in early adulthood may include customized vocational or employment training, specialized mentorship or support in a college setting, housing support, and psychological services.³⁵

Community-based programs that emphasize leisure have been shown to improve participants' independence and quality of life.³⁶ Similarly, participants in programs that emphasized supported employment, with a job coach, on-the-job support, collaboration with the participant's larger social support network, and selection of tasks to match an individual's abilities and strengths, demonstrated improved cognitive performance, particularly executive functioning,³⁷ and employment.^{38,39} These programs work best for patients who have mild to moderate symptoms.^{37,39}

Patients with symptoms that are more severe may do better in a residential program. Many of these programs maintain an emphasis on vocational and social skills development. One such long-standing program is Bittersweet Farms, a rural farming community in Ohio for adults with ASD, where individuals with moderate to low function live in a group setting, with emphasis on scheduled, meaningful work including horticulture, animal care, carpentry; and activities of daily living.⁴⁰

Studies of patients across the autism spectrum have generally found better outcomes when vocational support is given, but larger

TABLE 2

Adults with autism spectrum disorder: Advice for primary care providers

Provide "wrap-around" healthcare transitions when new patients enter the practice, addressing the need for services, insurance coverage, and the frequency and nature of anticipated future appointments.

Appreciate the heterogeneous nature of autism spectrum conditions and varying needs and achievements of individual patients and families.

Aim to provide a medical home for the patient and family.

Gain familiarity with the local and regional specialists, generalists, and social workers who provide care for this population to facilitate referrals for behavioral management strategies and comorbidities if needed.

Gain basic familiarity with local residential and job-training programs.

Assess the level of patient impairment due to autism spectrum disorder and any psychiatric and medical comorbidities.

Treat to reduce impairment rather than eliminate symptoms.

When initiating medications, use a low dose and a slow titration schedule to minimize adverse effects.

Wean or eliminate medications when possible.

Address sexual health needs on an individual basis, minimizing assumptions about sexual preference, gender identity, and sexual history.

Aim to provide preventive care in accordance with guidelines.

Recognize that high levels of caregiver stress and isolation are not infrequent, and encourage development of a social support network for the entire family.

and randomized studies are needed to characterize how to best support these individuals after they leave high school.⁴¹

Psychological services such as applied behavioral therapy, social cognition training, cognitive behavioral therapy, and mindfulness training may be particularly useful in adults.⁴²⁻⁴⁴

Some versions of applied behavioral therapy, such as the Early Start Denver Model,⁴⁵ have been found to be cost-effective and offset some expenses in the care of children with autism, using play-based and relationship-based interventions to promote development across domains while reducing symptoms.

In randomized controlled trials, modified cognitive behavioral therapy⁴³ and mindfulness⁴⁴ were shown to reduce symptoms of

anxiety, obsessive-compulsive disorder, and depression.

Dialectical behavior therapy, used to find a balance between accepting oneself and desiring to change, may help in some circumstances to regulate emotions and reduce reactivity and lability, although large randomized clinical trials have not been conducted in the ASD population.⁴⁶

Drug therapy

Medications may be appropriate to manage symptoms or comorbid conditions in adults with ASD. Over 75% adults with ASD have been found to use psychotropic medications.⁴⁷ However, although these drugs have been approved for treating behaviors commonly associated with ASD, none of them provide definitive treatment for this disorder, and they have not been rigorously tested or approved for use in adults with ASD.⁴⁸

Irritability and aggression associated with ASD can be treated with risperidone (approved for children over age 5), aripiprazole (approved for children ages 6–17), clozapine, or haloperidol.⁴⁹

Aberrant social behavior can be treated with risperidone.⁵⁰ Treatments under investigation include oxytocin and secretin.⁴⁹

While no approved drug has been shown to improve social communication,⁵¹ balovaptan, a vasopressin V1a agonist, has shown potential and has been granted breakthrough status by the US Food and Drug Administration for treating challenging behaviors in adults, with additional studies ongoing in children.^{52,53}

Repetitive behaviors, if the patient finds them impairing, can be managed with selective serotonin reuptake inhibitors.⁴⁹

Much more study of drug therapy in adults with ASD is needed to fully understand the best approaches to psychotropic medication use, including appropriate classes and effective dosage, in this population.

■ SEX: UNEXPLORED TERRITORY

The reproductive health needs of people with autism remain largely underexplored.⁵⁴ Historically, individuals with ASD were thought to have little interest in sexual activity or parenthood, owing to the nature of the core symptoms of the disorder. This has been

shown to be untrue, particularly as studies on this topic began to engage in direct interviews with people with ASD, rather than solely gathering information from caregivers or parents. The findings reinforce the importance of broaching this component of health in this population, for the following reasons:

Adults with ASD are at increased risk of sexual victimization, with nearly 4 out of 5 reporting unwanted sexual advances, coercion, or rape.⁵⁵

They have a smaller pool of knowledge with respect to sexual health. They report⁵⁶ that they learned about sex from television and from “making mistakes.” They use fewer sources. They are less likely to speak to peers and figures of authority to gain knowledge about sexually transmitted infections, sexual behaviors, and contraception. And they are more likely to use forms of nonsocial media, such as television, for information.⁵⁵

They report more concerns about the future with respect to sexual behavior, suggesting the need for targeted sexual education programs.⁵⁶

College-age young adults with ASD who misread communication may be particularly affected by Title IX, which requires schools to promptly investigate reports of sexual harassment and sexual assault, should they struggle to comport themselves appropriately.⁵⁷ Early and frank conversations about issues of consent and appropriate displays of interest and affection may better equip youth to navigate new social scenarios as they plan to leave a supervised home environment for college or the workforce.

Gender identification: Male, female, other

In one study, 77.8% of birth-sex males with ASD said they identified as men, and 67.1% of birth-sex females identified as women, compared with 93.1% of birth-sex males and 87.3% of birth-sex females without ASD. Many of the remaining individuals with ASD reported a transgender, genderqueer, or other gender identity.⁵⁸ Some studies have found females with ASD report a gay or bisexual orientation more often than males with ASD.^{59–61}

Adolescents and young adults may be exploring their changing bodies, sexual preferences, and gender roles, and as for all people at

Many struggle to establish meaningful friendships or romantic relationships

this age, these roles emerge against a backdrop of familial and societal expectations that may or may not be concordant with their own projected path regarding sexuality and reproductive health.⁶²

Having the conversation

As with non-ASD patients, a thorough sexual history should be collected via open-ended questions when possible to determine types of sexual activity and partners.

Education of the patient, alongside caregivers and parents, about healthy and safe sexual practices, screening for sexual violence, and hormonal and nonhormonal contraception options are important components of care for this population.

CAREGIVER STRESS MAY PERSIST INTO A PATIENT'S ADULTHOOD

Caregiver burden is a monumental concern for parents or others who may have lifelong primary responsibility for these neurodiverse adults.⁶³ Family members may feel isolated and may feel they have encountered many barriers to services.⁶⁴ Remaining sensitive, knowledgeable, and inquisitive about the types of support that are needed may help forge a trusting relationship between the provider and the family.

Parents of children with ASD have been reported to experience worse physical and emotional health than parents whose children do not have developmental disabilities.^{63,65} These disparities have been found to persist as their children enter adolescence and young adulthood.^{66,67} Parents of children with ASD report more anxiety, depression, and distress compared with parents of children without ASD,⁶³ and parents themselves may be affected by ASD symptoms, which has been linked to increased parenting stress.⁶⁸ Some studies have found blunted cortisol responses,^{63,69,70} and some,⁷¹ but not all,⁶³ have found elevated blood pressure in caregivers of children with developmental disabilities. Headache, backache, muscle soreness, and fatigue may also be commonly reported.⁶⁷

In our experience, caregivers are tremendously appreciative when provided connections to adult ASD services and support systems as their child ages. The school system

and other formal support systems often assist until the time of transition into adulthood. This transition can be stressful for the adolescent and family alike, and informal support systems such as friends and family may become increasingly crucial, particularly if the adolescent still lives at home.^{72,73}

The affected young adult's unmet needs, as perceived by the caregiver, have been found to be significantly associated with caregiver burden, whereas the severity of the adult patient's ASD symptoms has not.⁶⁶ Therefore, it may be helpful to ask caregivers whether they perceive any unmet needs, regardless of the clinician's perception of the severity of the patient's ASD symptoms. Providing support to address these needs, particularly those relating to the child's mood disorders, communication, social needs, safety, and daytime activities, may be the domains of support that most effectively reduce the caregiver burden in this population.⁶⁶

Caregiver positivity, lower stress levels, and increased social support, particularly in the form of friends and family members providing no-cost assistance to caregivers whose children do not live independently,⁷⁴ have been linked to better outcomes for caregivers.^{70,74,75} Rigorous studies that examine caregiver burden as individuals with ASD enter mid- and late-adulthood are limited.

THE ROLE OF THE INTERNIST IN CARING FOR ADULTS WITH AUTISM

A major challenge for many adults with ASD is the transition from services provided during childhood to those provided in adulthood. While children with autism have subspecialty providers who diagnose and manage their condition, including developmental-behavioral pediatricians, pediatric neurologists, and child psychiatrists, adults with autism may have fewer options.

Autism centers are becoming more available across the nation, and many provide care across the life span. However, depending on a patient's needs, the primary care provider may need to manage residual symptoms as the patient transitions from pediatric to adult care, ultimately deciding when and where to refer the patient.

Nearly 4 of 5 report unwanted sexual advances, coercion, or rape

The patient's family should pay close attention to function and mood around the time the patient leaves the structure of high school, and they should build rapport with a primary care provider they can turn to if problems persist or arise. Referrals for behavioral therapy and for social work, job training, and vocational support can greatly benefit patients as they transition to young adulthood. Referrals and suggestions for social support can also help caregivers.

Medical care

Deciding when and how to medicate the patient for symptoms of autism and related behaviors necessitates consideration of the patient's impairment, side effects of the medication, and the impact medications may have on the patient's other conditions. Disordered eating, mood problems, anxiety, and attention-deficit/hyperactivity disorder should be considered, and, as in all patients, regular screenings of mental health status should be conducted.^{76,77}

Comorbid medical conditions may cause worsening of a patient's known behavioral symptoms or may precipitate new behaviors or aggression as a result of pain or discomfort, particularly in patients with limited speech. A change in stereotypes or increased irritability warrants a thoughtful investigation for a cause other than ASD before adding or increasing behavioral medications. Common comorbid conditions include gastrointestinal distress, most commonly constipation and diarrhea in an idiopathic ASD population, with increasing ASD symptom severity correlating with increased odds of a gastrointestinal problem.⁷⁸ Allergies, sleep disorders, seizures, and other psychiatric conditions are also frequent.⁷⁹

Preventive care, including vaccinations, should be given as scheduled. Caregivers and patients can be reminded if needed that vaccines do not cause or worsen autism, and vaccination is intended to improve the safety of the patient and those around them, protect-

ing against potentially life-threatening disease. Regular dental care visits, particularly for patients who are using medications that may affect tooth or gingival health,⁸⁰ and regular visits to an optometrist or ophthalmologist for screening of vision are also advised.

Adverse effects. Weight gain and metabolic syndrome are common adverse effects of medications used for behavioral management, and the primary care physician may uncover diabetes, cardiac disorders, and hyperlipidemia. Patients with ASD may be particularly sensitive to the effects of medications and therefore may require a lower dose or a slower titration than other patients. Working with a behavioral team, careful weaning of psychiatric medications to the minimum needed is strongly recommended whenever possible.⁸¹

■ TAKE-HOME POINTS

As more adults with autism enter society, they may require varying levels of support from the healthcare community to ensure that therapeutic gains from childhood persist, allowing them to achieve maximal functional potential.

Adults with ASD may have a high, normal, or low IQ and intellectual capability. Knowledge of this and of the patient's symptom severity and presence of comorbid psychiatric and other health conditions can help the clinician guide the patient to appropriate social services and pharmacologic treatments.

Individualized support in the workplace, as well as education regarding sexual health, can help improve outcomes for affected individuals.

Caregiver burden for individuals with autism can be high, but it can be mitigated by social support.

Further research regarding appropriate diagnostic instruments in adulthood and appropriate treatments for impairing autism-related symptoms across the life span may be particularly helpful in supporting this patient population. ■

Ask caregivers if they perceive any unmet needs, regardless of the severity of the patient's ASD symptoms

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