2016

Autism

Tara Crapnell
UCLA Center for Healthier Children, Families, and Communities

Lynette Lau
UCLA Center for Healthier Children, Families, and Communities

Christopher D. Hanks
The Ohio State University Wexner Medical Center

Christina Nicolaidis
Portland State University, christina.nicolaidis@pdx.edu

Alice Kuo
UCLA Center for Healthier Children, Families, and Communities

AUTISM

Tara Crapnell, OTD, OTR/L
Health Care Transitions Research Network for Autism and Other Developmental Disorders (HCT-RN)
UCLA Center for Healthier Children, Families, and Communities
Crapnellt@outlook.com

Lynette Lau, PhD
Health Care Transitions Research Network for Autism and Other Developmental Disorders (HCT-RN)
UCLA Center for Healthier Children, Families, and Communities
lynette@ucla.edu
310-206-1585

Christopher D. Hanks, MD
Ohio State University Wexner Medical Center
Center for Autism Services and Transition (CAST)
christopher.hanks@osumc.edu
614-688-9220

Christina Nicolaidis, MD, MPH
School of Social Work at Portland State University
General Internal Medicine and Geriatrics at Oregon Health & Science University
Academic Autistic Spectrum Partnership In Research and Education (AASPIRE)
christina.nicolaidis@pdx.edu
503-725 9603

Alice Kuo, MD, PhD
UCLA Medicine-Pediatrics Comprehensive Care Center
UCLA Center for Healthier Children, Families, and Communities
Health Care Transitions Research Network for Autism and Other Developmental Disorders (HCT-RN)
akuo@mednet.ucla.edu
310-825-5797

Abstract

Autism spectrum disorder (ASD) is a complex, lifelong neurodevelopmental condition that is marked by deficits in social communication and interaction and repetitive or restrictive patterns of behavior, interests, or activities. These symptoms can create challenges for individuals on the autism spectrum and their parents during the transition to adulthood, which may interfere with their ability to access and receive adequate and appropriate health care. Awareness of how the challenges associated with ASD may translate to health care barriers can help primary care providers address the complex needs of individuals who are on the autism spectrum and mitigate the risks of additional health disparities. This chapter starts with a case presentation to illustrate key considerations for serving a patient population with ASD and the differences between a medical versus social model of disability, then provides an overview of ASD and its common co-morbidities and risk factors, discussion about special issues that arise during the transition to adulthood, common interventions for individuals on the autism spectrum, as well as practical tips to facilitate healthcare.

Keywords: Autism, Adults with Autism, Autism in Primary Care, Transition to Adulthood

Allen is a 21-year-old male with autism spectrum disorder (ASD) and mild intellectual disability who presents to establish care. He is accompanied by his mother who says he refused to return to his previous Internal Medicine physician because the physician “did not know what to do with him.” One year ago, his pediatrician had suggested that they find an adult doctor but they have had difficulty finding the right physician. Allen graduated high school with a diploma and spent some time in a vocational training program. After completing that, he struggled to find work and spent about one year at home with no regular daily activities. He recently obtained some support through his local Board of Developmental Disabilities and he is now working part-time at a local grocery store bagging groceries and retrieving shopping carts with a job coach for support. They feel he is capable of more than this but have not been able to find the right fit for him.

Allen appears well-groomed, quiet, and avoids eye contact. He answers questions with short responses and at times takes longer than expected to answer. He is unable to answer some of the questions about his medical history. His mother at times needs to re-word the questions asked so that he can understand them. His mother reports he had ADHD and was on a stimulant through high school, but he has not taken it for several years. He is also on an atypical antipsychotic which was started eight years ago due to explosive outbursts. He has not had any outbursts for years and they are not sure if he should continue this medication or not. They also wonder if restarting his stimulant would help him focus at work. He exhibits some intermittent rocking in his chair and several episodes of hand-flapping that become more prominent as the visit progresses.

Exam is only remarkable for being overweight, ticklish during the abdominal exam, and refusal of the genital exam.

Allen reports that when he is not at work he spends most of his day playing video games or watching videos online. His mother expresses concern about his weight, which has been steadily increasing since he graduated from high school. Additionally, he resists brushing his teeth and bathing himself because he does not like how the toothpaste and soap feel. She also notes that he is struggling to develop relationships with friends and has seemed more withdrawn recently. When asked about these things, he is reluctant to discuss it.

CASE DISCUSSION

This case illustrates some of the challenges that both individuals on the autism spectrum and their parents face when they reach adulthood. Many people with ASD struggle to maintain close relationships with others once they leave the structured environment of high school. Several studies indicate that youth with ASD tend to be "disconnected" for up to five years after aging out of school, meaning that they are not in any employment or post-secondary education setting (Shattuck et al., 2015). Additionally, parents of young adults on the autism spectrum struggle to find the balance of allowing autonomy and independence while ensuring safety and support for their children.

In Allen's case, he is struggling to express himself and communicate with his physician. This can occur due to several causes, including anxiety, challenges with communicating feelings and needs, or sensory processing difficulties that may inhibit him from performing at his highest level of ability. His physician should explore how he best

communicates and seek accommodations to help him remain engaged in the encounter. The provider should try to use precise, literal language to help improve the effectiveness of his or her communication. Encouraging him to come prepared with questions that are pre-planned or written down may be beneficial. Additionally, Allen is demonstrating challenges that could benefit from services such as occupational therapy (OT) to improve his self-care skills and address possible sensory processing challenges associated with bathing and brushing his teeth. This would help improve his level of independence as well as functional and meaningful participation in other activities of interest.

Since Allen is on the autism spectrum and has an intellectual disability, you should consider referring him for genetic testing because the genes which have been linked to autism can also be associated with cancers, leading to a need to adjust the cancer screening timeline. Genetics programs at major academic centers will often have a cancer-screening clinic for individuals who are at risk for early cancers.

Allen's mother coached and supported him through this encounter, which allowed Allen to stay more involved in the discussion. However, many parents or caregivers struggle to find the right balance in supporting independence while also ensuring essential information is conveyed. Providers may need to coach parents to allow the individual to interact with the provider at their highest potential. Parents and caregivers can perform important roles in helping patients learn their medical needs and learn to self-advocate. Depending on patient preference, effort should be made to allow the patient some time with the physician without a parent or caregiver present to allow development of comfort with the medical provider as well as allow discussion of topics that may be difficult to discuss with parents present.

Several important medical and social issues were raised in this case. Obesity is common in adults with ASD. His “disconnectedness” over the past several years may be contributing to this, as he has limited opportunity to get out of the home, be active, interact with others, and develop friendships. Assisting Allen and his parents in identifying opportunities for work that fit his strengths, interests, and needs will be important for him to maintain a healthy lifestyle. While helping patients in this dilemma is beyond the purview of a typical primary care office, making recommendations to parents to connect with the Department of Vocational Rehabilitation, a local Family Resource Center, or the public Department of Developmental Services in the area is a good place to help them get started.

Finally, many individuals on the autism spectrum are treated with medication for behavioral issues. Commonly used medications include selective serotonin reuptake inhibitors (SSRIs), antipsychotics, stimulants, as well as antiepileptic medications. Many of these medications have significant adverse effects and need monitoring with labs or other clinical assessments. Additionally, polypharmacy concerns are common in patients on multiple psychotropic medications. In this case, the provider should consider a trial discontinuation of the atypical antipsychotic, as the risks associated with antipsychotics may outweigh the benefit in this patient who has not had an aggressive outburst in many years. In many cases, primary care providers may not feel comfortable managing these medications, and patients should be referred to a psychiatric or neurologist who has more experience managing these medications in with people on the autism spectrum.

Medical model versus social model of disability

Of relevance to this case study and discussion is the concept of the medical model versus the social model of disability. For several decades, approaches and interventions for individuals on the autism spectrum have largely focused on the individual, their impairment, and remediation of skills so that individuals can progress along the typical developmental pathway of their peers. The medical model has defined how we see and describe individuals on the autism spectrum, the interventions that have been developed over the past several decades, and the treatments that we often refer individuals and families to. While it is known that individuals on the autism spectrum experience significant challenges in areas such as social and communication skills and sensory processing, and various interventions have proven to be effective in improving these areas, we should also have an understanding of ASD through the lens of the social model. The social model views disability as a result of societal and environmental barriers. As physicians, we should consider the individual within their context, and the social and environmental factors that may be influencing our interactions with individuals and exacerbating their symptoms during office visits or in their day-to-day life. Examples of this include our own personal biases and assumptions, as well environmental factors, such as lights or sounds in the waiting room. Many of the tips provided in this chapter focus on low cost accommodations that could be implemented in practice. These accommodations can help create a more supportive environment and increase the chances of a successful checkup or office visit for those on the autism spectrum.

While it is important to understand the individual challenges experienced by those on the autism spectrum and the impact of social and environmental factors, it is also important to acknowledge the individual strengths of our patients. Examples of strengths

unique to individuals with ASD include detailed thinking, good long-term memory, and the ability to analyze information (1). Identifying and focusing on the strengths of your patients with ASD can assist individuals in seeing their own strengths. While this can positively affect the attitudes and beliefs of the individuals and parents, it can also help providers identify and make proper referrals to services and community programs, and can assist individuals and families realize the different opportunities one could pursue in adulthood with the proper supports in place.

The following sections provide information on the phenomenology and etiology of ASD, comorbidities and risk factors associated with ASD, and special issues arising during the transition to adulthood that may be important for primary care providers to be aware of, as well as brief descriptions of the interventions and treatments that individuals on the autism spectrum may receive or benefit from and practical tips for facilitating health care.

BACKGROUND

Definition

Autism spectrum disorder (ASD) is a complex, lifelong neurodevelopmental condition that is marked by deficits in social communication and interaction and repetitive or restrictive patterns of behavior, interests, or activities (2). Signs and symptoms are present in early childhood, but may not become obvious until later childhood or adulthood, when demands increase (2). Individuals on the autism spectrum may also experience a lack of coordination, motor planning, and atypical sensory processing, such as oversensitivity to auditory, tactile, and visual input (3, 4). Furthermore, an intellectual disability may or may not be present (5). Symptoms and behaviors associated with autism

often result in decreased social participation, occupational, and other areas of functional participation and may change over time with development and life stages (2, 6, 7)

Prevalence

Over the past several years, the prevalence of ASD has increased 123% from 2002 and 2008 (5). The reasons for the increasing prevalence of ASD remains unclear, however, it is suspected that it is related to factors such as increased awareness and diagnostic practices (8, 9). The current estimated prevalence of ASD in the United States is 14.7 per 1,000 (one in 68) children aged 8 years (5). In addition, it has been found that prevalence does not change with age (10). While ASD is reported to occur in all racial/ethnic and socioeconomic groups, prevalence estimates vary between these groups, as there are reported gender (11, 12), ethnic, and racial disparities in the identification of ASD (13, 14).

Etiology and Risk Factors

The etiology of ASD is not fully understood, however, several studies have identified various risk factors associated with ASD. Genetic factors have long been thought to influence autism and are one of the most extensively studied factors in epidemiologic research. Studies have found a 40 to 90 percent heritability rate (15, 16) and associations with fragile X syndrome, 15q11-13 duplications, genetic variants, and de novo mutations (17, 18). Over 100 mutated genes have been found to be associated with ASD (19). Gene mutations in ASD are believed to be a result of spontaneous mutations, suggesting gene-gene interaction (20), gene-environment (21), and epigenetic programming early in life (22-25) as well as windows of vulnerability that may influence ASD (26) during fetal development and in early childhood. While studies indicate there is a neurogenetic

component to ASD, some studies suggest there are associations between ASD and prenatal exposures and perinatal factors (27-32). However, it should be noted that there are limitations associated with these studies.

Associated Morbidity

Autism spectrum disorders have been commonly researched within the disciplines of psychiatry and neurology. However, evidence has shown that individuals on the autism spectrum experience high rates of co-occurring mental and physical conditions, shifting the focus from solely neurodevelopmental and behavioral to a more complex process. Research indicates that specific medical conditions are more prevalent in individuals with autism compared to the neurotypical population. Medical conditions that are reported to occur at higher rates in people on the autism spectrum include: eczema, allergies, asthma, ear and respiratory infections, gastrointestinal problems, severe headaches and migraines, sleep disorders, and epilepsy (33). People on the autism spectrum are also at heightened risk for chronic health conditions in adulthood, such as diabetes, coronary heart disease, cancer (34), and mental health conditions (33, 35, 36). These co-occurring conditions have been found to negatively impact functional ability of individuals on the autism spectrum within the areas of behavior, communication, cognition, and sensory processing.

Genetics and Cancer Screening

Recent studies have suggested that ASD has a strong genetic component with potential links to cancer (37-40). Findings have indicated associations between ASD and up regulation of the PI3k (phosphatidylinositol 3-kinase) – Akt-mTOR (mammalian target of rapamycin) growth-signaling pathway (41-45), which has been associated with the

development of cancers (46, 47). Individuals with autism have been found to have similar mutations in the gene, PTEN, as seen in various forms of cancer (39). PTEN is a tumor suppressor gene that helps prevent cells from becoming cancerous and is a negative regulator of PI3K-Akt-mTOR signaling. Mutations in PTEN have been associated with cognitive impairments and abnormalities in brain structure and various forms of cancer, including cancers of the breasts, kidney, prostate, and brain. In addition, the neurofibromatosis gene NF1, which is also a tumor suppressor and negative regulator of the PI3K-Akt-mTOR pathway, has been associated with ASD (48). Because recent evidence suggests individuals with ASD are at heightened risk for cancer, a referral for genetic testing and cancer screening is recommended (see **Box 1**).

Box 1: Genetics and Cancer Screening

- The American Academy of Neurology and the Child Neurology Society recommend referring individuals with ASD for high-resolution chromosome studies (karyotype) and DNA analysis for Fragile X, particularly if:
    - intellectual disability is present (or cannot be excluded)
    - there is a family history of Fragile X or undiagnosed intellectual disability
    - dysmorphic features are present.

  Note, however, there is little likelihood of positive karyotype or Fragile X testing in the presence of autism without intellectual disability.
- Genetic counseling for individuals with ASD (and their families) should always accompany genetic evaluation.
- Routinely include age-appropriate cancer screening procedures during health maintenance visits.

Seizure Disorder

Individuals on the autism spectrum are reported to experience higher rates of epilepsy than the general population with a prevalence rate of 12.5% in children with ASD, which increases to 26% by adolescence (49, 50). Seizure disorder has been associated with increased age, lower intellectual functioning, and decreased adaptive behavior. Epilepsy can be easily misdiagnosed in individuals with intellectual disabilities as a result of misinterpretation of behavioral, physiological, and psychological events (51). Undiagnosed or misdiagnosis can potentially have fatal implications. Therefore, further evaluation, such as EEG, and/or referral to a specialist should be considered when patients present with changes in behavior that could be related to seizures (52).

Gastrointestinal Disorder

Individuals on the autism spectrum are reported to experience higher rates of gastrointestinal problems, including diarrhea, constipation, vomiting, and abdominal pain. These symptoms can have negative implications on behavior. Evaluation and management of gastrointestinal problems in individuals on the autism spectrum is not yet fully understood (53), however, it is recommended that individuals should receive the same thoroughness and standard of care as patients without ASD. Furthermore, gastrointestinal workup should be considered with change in behavior.

Sleep Disturbances

Sleep disturbances are commonly reported in individuals on the autism spectrum across the lifespan (54-57). Sleep disturbances can negatively impact daily functioning and quality of life (58, 59). Sleep problems may be a result of obstructive sleep apnea and

gastrointestinal reflux, and have been associated with emotional and behavioral problems as well as psychiatric conditions (60). Melatonin and other behavioral interventions have been found to be effective in improving sleep (54, 61).

Mental Health Conditions

Individuals on the autism spectrum are reported to experience high rates of mental health conditions (33, 35, 36), with anxiety and depression being the most commonly reported co-occurring conditions. In addition, reports suggest around 30% of individuals on the autism spectrum meet the criteria for attention deficit hyperactivity disorder (ADHD) (62).While anxiety is reported to occur in children with ASD, studies have indicated that anxiety often increases in adolescence and adulthood. Assessment and diagnosis of anxiety and depression can be challenging as individuals may have difficulties with communicating feelings and symptoms. While various interventions including using components of cognitive behavioral therapy (CBT) have been proven to be effective in improving anxiety symptoms in ASD (63, 64), there is often a lack of mental health providers trained to serve adults with ASD. Effort should be made to identify mental health providers with experience treating those with ASD, if possible.

Special Issues that Arise in the Transition to Adulthood

It is estimated that approximately 500, 000 individuals on the autism spectrum will transition into young adulthood each year in the United States. Youth on the autism spectrum are especially vulnerable during the transition to adulthood due to the inherit characteristics of ASD, such as challenges with communication and social interaction, (2), co-morbid physical and mental health problems (36), and societal biases and discrimination (65). These pervasive challenges often result in complex service needs that

cut across sectors and require high levels of care coordination, further complicating this transitional period (66-69).

Based on Part B of the Individuals Disability Education Act (IDEA), children and youth are eligible to receive special education related services from 3 to 22 years of age (70). The IDEA ensures that while children are in school and of eligible age (3-22 years of age), they are entitled to services that will help them function within their current educational setting and prepare them for adulthood within the areas of education, employment, and independent living (70). However, upon reaching their 22nd birthday, individuals essentially experience a "services cliff" where they go from receiving several hours of services to no services, despite the need for continued supports and services to assist them during and after the transition to community-based settings.

Although this is a time of much needed support, the gap between service needs and receipt increases as many individuals on the spectrum exit the special education system and attempt to access adult systems of care. Evidence has shown less optimal outcomes for young adults on the autism spectrum with high rates of disconnectedness upon leaving high school (71, 72). It is reported that one-third of young adults are disconnected after high school (never had a job or continued education after high school) and approximately 26% receive no services that would help them become employed, continue their education, or live more independently (72). In addition, only 36% ever attend postsecondary education and 58% work for pay outside of the home between high school and their early 20s (72).

Evidence suggest that many individuals on the autism spectrum continue to lack skills, such as self-care and daily living skills that are foundational and necessary for

achieving functional and meaningful participation in adulthood (73-75). In addition, marked social deficits may become increasingly problematic in adolescence when social expectation demands increase and social network heightens (76). Symptoms of autism do not disappear when an individual becomes an adult (77) and many could benefit from continued support and services throughout life (75, 78). Educating and assisting individuals on the autism spectrum and families connect to services within their community, such as the Department of Vocational Rehabilitation, Department of Developmental Services, and community centers can help reduce disconnectedness and improve outcomes in adulthood for those on the autism spectrum.

Interventions and Treatment

There is a wide range of severity of symptoms in autism. Families may pursue treatments including behavioral, psychological, educational, and alternative treatments. Interventions are generally targeted at improving social communication and interaction, increasing and maintaining adaptive behaviors, functional skills, and increasing meaningful participation. Below are common interventions provided to individuals on the autism spectrum.

Applied Behavioral Analysis

Applied behavioral analysis (ABA) is an evidence-based intervention for children on the autism spectrum that uses principles of learning theory to try to bring about meaningful and positive change in behavior. The goal of ABA is to increase and maintain functional and adaptive behaviors, decrease maladaptive behaviors, teach new skills, and generalize skills to other environments. Functional behavioral assessments include identifying antecedents, behaviors, and consequences of behavior and developing individualized

treatment plans that will increase the frequency of a targeted behavior and adaptive behavior. It is important to note that although ABA is commonly used in children on the autism spectrum, autistic rights advocates have raised significant concerns about ABA (Jones, 2014) and there is very limited evidence to support this intervention for adults on the autism spectrum.

Cognitive Behavioral Therapy

Cognitive behavioral therapy (CBT) is used to help individuals on the autism spectrum improve behaviors and self-regulation. Cognitive behavioral therapy is an approach that aims to change perceptions of thoughts. It is an approach that has been proven to help reduce anxiety and depressive symptoms. While CBT can help reduce symptoms and challenging behaviors, such as obsessive thoughts, it teaches individuals how to cope, manage, and reduce unwanted feelings.

Speech and Language Therapy

Speech and language therapy aims to improve social communication and interaction, self-advocacy, and other language impairments in individuals on the autism spectrum. Intervention includes a variety of modalities to help support and improve social interaction and verbal and nonverbal communication, including activity schedules/visual supports and/or augmentative and alternative communication (AAC). Augmentative and alternative communication includes supplementing or replacing natural speech with aided or unaided symbols. Examples of these devices, include, but are not limited to Picture Exchange Communication System (PECS), speech generative devices, and manual signs or gestures. These approaches have been proven to be effective in improving

communication skills, social skills and interactions, and self-advocacy and self-determination in individuals on the autism spectrum.

Occupational Therapy

Occupational therapy (OT) is a client-centered profession that assists individuals to achieve the highest degree of independence. Occupational therapy aims to improve performance and participation in daily occupations, such as self-care routines, leisure activities, and school or work-related tasks. Occupational therapy works on developing and maintaining individual skills and modifying the environment to create a person-environment fit. Occupational therapy also uses sensory integration (SI) alone or as part of therapy. The goal of SI is to remediate processing and integration of sensory information to allow the individual to adapt and interact with their environment.

Practical Tips to Facilitate Healthcare

Limited communication and social interactions as well as sensory processing challenges experienced by individuals on the autism spectrum can make it challenging for medical providers to identify health complications in individuals on the autism spectrum. Adults on the autism spectrum report greater unmet healthcare needs, lower use of preventive services, and greater use of the emergency department than adults without ASD (79), placing them at risk for less optimal health outcomes. A recent qualitative study indicated that poor provider and patient level interactions contribute to negative healthcare experiences . Individuals on the autism spectrum have a significant need for services and supports to help increase quality of life and function and to treat co-occurring medical conditions. Timely, accurate information with care coordination can help improve outcomes in adulthood.

Below are a list of practical tips from the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) for healthcare providers when managing and providing care of individuals with ASD (see **Box 2 through 5**). The complete list of helpful tips can be found on their website at: www.autismandhealth.org.

Communication and Interaction

Individuals on the autism spectrum are reported to have various strengths and challenges in verbal and non-verbal communication, receptive and expressive skills, and ability to process information. In addition, individuals on the autism spectrum commonly take language literally and require information to be provided to them in a way that is precise, concrete, and specific. Understanding a patient's communication needs is very important to providing quality care.

Box 2: Tips on Communication and Interaction

- Do not assume that a patient cannot understand healthcare information or communicate when he/she does not speak fluently. In addition, do not assume that a patient who speaks fluently does not have significant communication challenges.
- Obtain individualized information on communication needs and preferences.
- Be precise, concrete, and specific.
- Do not assume a patient is distracted or inattentive because he/she is fidgeting, making repetitive movements, or avoiding eye contact.
- Give adequate time for individuals to process information they need to see, hear, or feel before they respond.

Sensory Challenges

Individuals on the autism spectrum commonly have atypical sensory processing. Individuals may be hyper-responsive or hypo-responsive to sounds, lights, smells, touch, or taste. As a result, some environments can be over stimulating for some individuals. Environments that are not sensitive to their sensory need can have a negative impact on their healthcare experience and social interactions. In addition, individuals may have difficulties with body awareness, making it difficult for them to discriminate between different tactile inputs and location of symptoms. Therefore understanding these sensory challenges and creating a sensory friendly environment can create more positive experiences for the patient on the spectrum.

Box 3: Tips on Sensory Challenges

- Use natural light or make the lighting dim.
- See the patient in a quiet room.
- Avoid unnecessarily touching the patient and warn him/her if you will be use touch for a physical examination.
- Suggest that the patient bring manipulatives or other physical supports to help reduce or increase sensory stimuli.

Planning and Organizing

Some individuals on the autism spectrum experience difficulties with executive functioning within the areas of planning, organizing, and sequencing information. Individuals on the autism spectrum also commonly have difficulties adapting to new environments and situations, creating a need for routine and consistency. Below are tips

on the types of supports that can assist individuals in making decisions, following through with information, and decreasing the stress of attending a healthcare appointment.

Box 4: Tips on Planning and Organizing

- Identify patient needs and necessary accommodations prior to the visit by having patients complete a pre-visit assessment or complete a Personalized Accommodations Report by going to www.autismhealth.org/AHAT.
- Let the patient and/or his/her supporter know what will occur at the appointment.
- Provide visual supports to help the patient through the healthcare routine.
- Write up step-by-step instructions.
- Have staff assist the patient in scheduling follow-up visits, referrals, or tests.
- Contact and follow-up with the patient and/or supporter after the visit.

Exams and Procedures

Tolerating examinations, tests, and procedures may be challenging for individuals on the autism spectrum due to reasons mentioned above. Below are tips to help people on the autism spectrum in better tolerating these medical procedures (see **Box 5**).

Box 5: Tips on Exams and Procedures

- Explain to the patient what is going to be done before doing it.
- Slowly expose individuals to different equipment and perform a “trial run” if possible.
- Give patients extra time to process information he/she sees, hears, or feels before they respond.

- Order blood tests only when absolutely necessary.
- Use a numbing spray, cream, or provide the patient with anti-anxiety medication, if necessary, before a blood draw.

SUMMARY

Having an understanding of the challenges that individuals on the autism spectrum experience, and the how social and environmental factors can allow for better provider-patient interactions, successful checkups, and can assist providers in making proper referrals to services and community resources. Utilizing the tips discussed above and creating a supportive environment can help improve your practice and delivery of care to adults on the autism spectrum and their families.

References

1. Robertson SM. Neurodiversity, quality of life, and autistic adults: Shifting research and professional focuses onto real-life challenges. Disability Studies Quarterly. 2009;30(1).
2. Association AP. Diagnostic and Statistical Manual of Mental Disorders, 5th ed.2013.
3. Kern JK, Trivedi MH, Garver CR, Grannemann BD, Andrews AA, Savla JS, et al. The pattern of sensory processing abnormalities in autism. Autism. 2006;10(5):480-94.
4. Fournier KA, Hass CJ, Naik SK, Lodha N, Cauraugh JH. Motor coordination in autism spectrum disorders: A synthesis and meta-analysis. J Autism Dev Disord. 2010;40(10):1227-40.
5. Investigators DDMNSYP, (CDC) CfDCaP. Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. MMWR Surveill Summ. 2014;63(2):1-21.
6. Sukhodolsky DG, Scahill L, Gadow KD, Arnold LE, Aman MG, McDougle CJ, et al. Parent-rated anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core autism symptoms and cognitive functioning. J Abnorm Child Psychol. 2008;36(1):117-28.
7. Cheely CA, Carpenter LA, Letourneau EJ, Nicholas JS, Charles J, King LB. The prevalence of youth with autism spectrum disorders in the criminal justice system. J Autism Dev Disord. 2012;42(9):1856-62.
8. Blumberg SJ, Bramlett MD, Kogan MD, Schieve LA, Jones JR, Lu MC. Changes in prevalence of parent-reported autism spectrum disorder in school-aged U.S. children: 2007 to 2011-2012. Natl Health Stat Report. 2013(65):1-11, 1 p following
9. Schieve LA, Rice C, Devine O, Maenner MJ, Lee L-C, Fitzgerald R, et al. Have secular changes in perinatal risk factors contributed to the recent autism prevalence increase? Development and application of a mathematical assessment model. Annals of Epidemiology. 2011;21(12):930-45.
10. Brugha TS, McManus S, Bankart J, Scott F, Purdon S, Smith J, et al. Epidemiology of autism spectrum disorders in adults in the community in England. Arch Gen Psychiatry. 2011;68(5):459-65.
11. Giarelli E, Wiggins LD, Rice CE, Levy SE, Kirby RS, Pinto-Martin J, et al. Sex differences in the evaluation and diagnosis of autism spectrum disorders among children. Disabil Health J. 2010;3(2):107-16.
12. Rivet TT, Matson JL. Review of gender differences in core symptomatology in autism spectrum disorders. Res Autism Spect Dis. 2011;5(3):957-76.
13. Mandell DS, Wiggins LD, Carpenter LA, Daniels J, DiGuiseppi C, Durkin MS, et al. Racial/ethnic disparities in the identification of children with autism spectrum disorders. Am J Public Health. 2009;99(3):493-8.
14. Jo H, Schieve LA, Rice CE, Yeargin-Allsopp M, Tian LH, Blumberg SJ, et al. Age at Autism Spectrum Disorder (ASD) diagnosis by race, ethnicity, and primary household language among children with special health care needs, United States, 2009-2010. Matern Child Hlth J. 2015;19(8):1687-97.
15. Folstein SE, Rosen-Sheidley B. Genetics of austim: Complex aetiology for a heterogeneous disorder. Nature Reviews Genetics. 2001;2(12):943-55.

16. Bailey A, Lecouteur A, Gottesman I, Bolton P, Simonoff E, Yuzda E, et al. Autism as a strongly genetic disorder - Evidence from a British twin study. Psychol Med. 1995;25(1):63-77.
17. O'Roak BJ, Vives L, Fu W, Egertson JD, Stanaway IB, Phelps IG, et al. Multiplex targeted sequencing identifies recurrently mutated genes in autism spectrum disorders. Science. 2012;338(6114):1619-22.
18. O'Roak BJ, State MW. Autism genetics: Strategies, challenges, and opportunities. Autism Res. 2008;1(1):4-17.
19. De Rubeis S, He X, Goldberg AP, Poultney CS, Samocha K, Cicek AE, et al. Synaptic, transcriptional and chromatin genes disrupted in autism. Nature. 2014;515(7526):209-15.
20. Hallmayer J, Cleveland S, Torres A, Phillips J, Cohen B, Torigoe T, et al. Genetic heritability and shared environmental factors among twin pairs with autism. Arch Gen Psychiatry. 2011;68(11):1095-102.
21. Grafodatskaya D, Chung B, Szatmari P, Weksberg R. Autism spectrum disorders and epigenetics. J Am Acad Child Adolesc Psychiatry. 2010;49(8):794-809.
22. Taylor SE, Way BM, Welch WT, Hilmert CJ, Lehman BJ, Eisenberger NI. Early family environment, current adversity, the serotonin transporter promoter polymorphism, and depressive symptomatology. Biol Psychiatry. 2006;60(7):671-6.
23. Wadhwa PD, Buss C, Entringer S, Swanson JM, editors. Developmental origins of health and disease: Brief history of the approach and current focus on epigenetic mechanisms. Seminars in reproductive medicine; 2009: NIH Public Access.
24. Kuzawa CW, Thayer ZM. Timescales of human adaptation: The role of epigenetic processes. Epigenomics. 2011;3(2):221-34.
25. Borghol N, Suderman M, McArdle W, Racine A, Hallett M, Pembrey M, et al. Associations with early-life socio-economic position in adult DNA methylation. Int J Epidemiol. 2012;41(1):62-74.
26. Dietert RR, Dietert JM. Potential for early-life immune insult including developmental immunotoxicity in autism and autism spectrum disorders: Focus on critical windows of immune vulnerability. J Toxicol Environ Health B Crit Rev. 2008;11(8):660-80.
27. Gardener H, Spiegelman D, Buka SL. Prenatal risk factors for autism: Comprehensive meta-analysis. Br J Psychiatry. 2009;195(1):7-14.
28. Suren P, Roth C, Bresnahan M, Haugen M, Hornig M, Hirtz D, et al. Association between maternal use of folic acid supplements and risk of autism spectrum disorders in children. JAMA-J Am Med Assoc. 2013;309(6):570-7.
29. Rogers EJ. Has enhanced folate status during pregnancy altered natural selection and possibly autism prevalence? A closer look at a possible link. Medical Hypotheses. 2008;71(3):406-10.
30. Lyall K, Schmidt RJ, Hertz-Picciotto I. Maternal lifestyle and environmental risk factors for autism spectrum disorders. Int J Epidemiol. 2014;43(2):443-64.
31. Leeming R, Lucock M. Autism: Is there a folate connection? Journal of Inherited Metabolic Disease. 2009;32(3):400-2.
32. Gardener H, Spiegelman D, Buka SL. Perinatal and neonatal risk factors for autism: A comprehensive meta-analysis. Pediatrics. 2011;128(2):344-55.

33. Kohane IS, McMurry A, Weber G, MacFadden D, Rappaport L, Kunkel L, et al. The co-morbidity burden of children and young adults with autism spectrum disorders. PLoS One. 2012;7(4):e33224.
34. Tyler CV, Schramm SC, Karafa M, Tang AS, Jain AK. Chronic disease risks in young adults with Autism Spectrum Disorder: Forewarned is forearmed. Ajidd-Am J Intellect. 2011;116(5):371-80.
35. Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cunniff C, et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. J Dev Behav Pediatr. 2010;31(4):267-75.
36. Joshi G, Petty C, Wozniak J, Henin A, Fried R, Galdo M, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large comparative study of a psychiatrically referred population. J Autism Dev Disord. 2010;40(11):1361-70.
37. Kao HT, Buka SL, Kelsey KT, Gruber DF, Porton B. The correlation between rates of cancer and autism: An exploratory ecological investigation. PLoS One. 2010;5(2):e9372.
38. Chiang HL, Liu CJ, Hu YW, Chen SC, Hu LY, Shen CC, et al. Risk of cancer in children, adolescents, and young adults with autistic disorder. J Pediatr. 2015;166(2):418-23 e1.
39. Frazier TW, Embacher R, Tilot AK, Koenig K, Mester J, Eng C. Molecular and phenotypic abnormalities in individuals with germline heterozygous PTEN mutations and autism. Mol Psychiatry. 2015;20(9):1132-8.
40. McBride KL, Varga EA, Pastore MT, Prior TW, Manickam K, Atkin JF, et al. Confirmation study of PTEN mutations among individuals with autism or developmental delays/mental retardation and macrocephaly. Autism Res. 2010;3(3):137-41.
41. Belmonte MK, Bourgeron T. Fragile X syndrome and autism at the intersection of genetic and neural networks. Nat Neurosci. 2006;9(10):1221-5.
42. Kwon CH, Luikart BW, Powell CM, Zhou J, Matheny SA, Zhang W, et al. PTEN regulates neuronal arborization and social interaction in mice. Neuron. 2006;50(3):377-88.
43. Neves-Pereira M, Muller B, Massie D, Williams JH, O'Brien PC, Hughes A, et al. Deregulation of EIF4E: A novel mechanism for autism. J Med Genet. 2009;46(11):759-65.
44. Serajee FJ, Zhong H, Nabi R, Huq AHMM. The metabotropic glutamate receptor 8 gene at 7q31: Partial duplication and possible association with autism. J Med Genet. 2003;40(4):e42-e.
45. Hoeffer CA, Klann E. mTOR signaling: At the crossroads of plasticity, memory and disease. Trends Neurosci. 2010;33(2):67-75.
46. Bunney TD, Katan M. Phosphoinositide signalling in cancer: beyond PI3K and PTEN. Nat Rev Cancer. 2010;10(5):342-52.
47. Ciuffreda L, Di Sanza C, Incani UC, Milella M. The mTOR pathway: A new target in cancer therapy. Curr Cancer Drug Targets. 2010;10(5):484-95.
48. Marui T, Hashimoto O, Nanba E, Kato C, Tochigi M, Umekage T, et al. Association between the neurofibromatosis-1 (NF1) locus and autism in the Japanese population.

American Journal of Medical Genetics Part B: Neuropsychiatric Genetics. 2004;131(1):43-7.
49. Woolfenden S, Sarkozy V, Ridley G, Coory M, Williams K. A systematic review of two outcomes in autism spectrum disorder - epilepsy and mortality. Dev Med Child Neurol. 2012;54(4):306-12.
50. Viscidi EW, Triche EW, Pescosolido MF, McLean RL, Joseph RM, Spence SJ, et al. Clinical characteristics of children with autism spectrum disorder and co-occurring epilepsy. PLoS One. 2013;8(7):e67797.
51. Chapman M, Iddon P, Atkinson K, Brodie C, Mitchell D, Parvin G, et al. The misdiagnosis of epilepsy in people with intellectual disabilities: A systematic review. Seizure. 2011;20(2):101-6.
52. Stokes T, Shaw E, Juarez-Garcia A, Camosso-Stefinovic J, Baker R. Clinical guidelines and evidence review for the epilepsies: Diagnosis and management in adults and children in primary and secondary care. London: Royal College of General Practitioners. 2004;397.
53. Buie T, Campbell DB, Fuchs GJ, 3rd, Furuta GT, Levy J, Vandewater J, et al. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: A consensus report. Pediatrics. 2010;125 Suppl 1(Supplement 1):S1-18.
54. Malow BA. Sleep disorders, epilepsy, and autism. Ment Retard Dev Disabil Res Rev. 2004;10(2):122-5.
55. Øyane NM, Bjorvatn B. Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. Autism. 2005;9(1):83-94.
56. Polimeni MA, Richdale AL, Francis AJ. A survey of sleep problems in autism, Asperger's disorder and typically developing children. J Intellect Disabil Res. 2005;49(Pt 4):260-8.
57. Matson JL, Ancona MN, Wilkins J. Sleep disturbances in adults with autism spectrum disorders and severe intellectual impairments. J Ment Health Res In. 2008;1(3):129-39.
58. Patzold LM, Richdale AL, Tonge BJ. An investigation into sleep characteristics of children with autism and Asperger's Disorder. J Paediatr Child H. 1998;34(6):528-33.
59. Schreck KA, Mulick JA, Smith AF. Sleep problems as possible predictors of intensified symptoms of autism. Res Dev Disabil. 2004;25(1):57-66.
60. Sivertsen B, Posserud MB, Gillberg C, Lundervold AJ, Hysing M. Sleep problems in children with autism spectrum problems: A longitudinal population-based study. Autism. 2012;16(2):139-50.
61. Meltzer LJ, Mindell JA. Nonpharmacologic treatments for pediatric sleeplessness. Pediatr Clin North Am. 2004;51(1):135-51.
62. Leyfer OT, Folstein SE, Bacalman S, Davis NO, Dinh E, Morgan J, et al. Comorbid psychiatric disorders in children with autism: Interview development and rates of disorders. J Autism Dev Disord. 2006;36(7):849-61.
63. White SW, Schry AR, Miyazaki Y, Ollendick TH, Scahill L. Effects of verbal ability and severity of autism on anxiety in adolescents with ASD: One-year follow-up after cognitive behavioral therapy. J Clin Child Adolesc Psychol. 2015;44(5):839-45.
64. Spain D, Sin J, Chalder T, Murphy D, Happe F. Cognitive behaviour therapy for adults with autism spectrum disorders and psychiatric co-morbidity: A review. Res Autism Spect Dis. 2015;9:151-62.

65. Billawala A, Wolbring G. Analyzing the discourse surrounding autism in the New York Times using an ableism lens. Disability Studies Quarterly. 2014;34(1).
66. Brookman-Frazee LI, Taylor R, Garland AF. Characterizing community-based mental health services for children with autism spectrum disorders and disruptive behavior problems. J Autism Dev Disord. 2010;40(10):1188-201.
67. Garland AF, Hough RL, Landsverk JA, Brown SA. Multi-sector complexity of systems of care for youth with mental health needs. Children's Services: Social Policy, Research, and Practice. 2001;4(3):123-40.
68. Burns BJ, Costello EJ, Angold A, Tweed D, Stangl D, Farmer E, et al. Children's mental health service use across service sectors. Health Affairs. 1995;14(3):147-59.
69. Farmer TW, Farmer EM. Developmental science, systems of care, and prevention of emotional and behavioral problems in youth. Am J Orthopsychiatry. 2001;71(2):171-81.
70. Committee on Health E, Labor, and Pensions. Senate Report 108-185 - Individuals with Disabilities Education Act. Washington, D.C.: U.S. Government Publishing Office; 2003.
71. Wei X, Wagner M, Hudson L, Jennifer WY, Shattuck P. Transition to adulthood employment, education, and disengagement in individuals with autism spectrum disorders. Emerging Adulthood. 2014:2167696814534417.
72. Roux AM, Shattuck P, Paul T, Rast JE, Rava JA, Anderson KA. Philadelphia, PA: 2015.
73. Matthews NL, Smith CJ, Pollard E, Ober-Reynolds S, Kirwan J, Malligo A. Adaptive functioning in autism spectrum disorder during the transition to adulthood. J Autism Dev Disord. 2015;45(8):2349-60.
74. Smith LE, Maenner MJ, Seltzer MM. Developmental trajectories in adolescents and adults with autism: the case of daily living skills. J Am Acad Child Adolesc Psychiatry. 2012;51(6):622-31.
75. Bal VH, Kim SH, Cheong D, Lord C. Daily living skills in individuals with autism spectrum disorder from 2 to 21 years of age. Autism. 2015;19(7):774-84.
76. Mitchel K, Regehr K, Reaume J, Feldman M. Group social skills training for adolescents with Asperger Syndrome or high functioning autism. Journal on Developmental Disabilities. 2010.
77. Seltzer MM, Shattuck P, Abbeduto L, Greenberg JS. Trajectory of development in adolescents and adults with autism. Ment Retard Dev Disabil Res Rev. 2004;10(4):234-47.
78. Taylor JL, Seltzer MM. Changes in the autism behavioral phenotype during the transition to adulthood. J Autism Dev Disord. 2010;40(12):1431-46.
79. Nicolaidis C, Raymaker D, McDonald K, Dern S, Boisclair WC, Ashkenazy E, et al. Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership. J Gen Intern Med. 2013;28(6):761-9.
80. Kohane IS, McMurry A, Weber G, MacFadden D, Rappaport L, Kunkel L, et al. The co-morbidity burden of children and young adults with autism spectrum disorders. PloS one. 2012;7(4):e33224-e.
81. Joshi G, Petty C, Wozniak J, Henin A, Fried R, Galdo M, et al. The heavy burden of psychiatric comorbidity in youth with autism spectrum disorders: A large

comparative study of a psychiatrically referred population. J Autism Dev Disord. 2010;40(11):1361-70.

Autism Spectrum Disorders (ASD) Condition Fact Sheet	
Definition	**Autism spectrum disorders (ASD) is a lifelong neurodevelopmental condition characterized by:** o Deficits in social communication and interaction o Repetitive or restrictive patterns of behavior, interests, or activities. • Additional deficits include lack of coordination, motor planning, and abnormalities in sensory processing. • Individuals may or may not have co-occurring intellectual deficits.
Epidemiology	• In the United States, 14.7 per 1,000 (one in 68) children aged 8 years have an ASD. • ASD is five times more common in males (one in 42) than females. • Prevalence of ASD in white non-Hispanic children is 15.7 per 1000, 12.1 per 1000 black non-Hispanic children, and 10.8 per 1000 in Hispanic children. • Identical twins are at increased risk for ASD and will occur 36-95% of the time and 0-31% of the time in non-identical twins. • Parents with one child with autism have a 2-18% chance of having a second child with an ASD.
Special Considerations	**Individuals on the autism spectrum disorder have high rates of co-morbid physical and mental health conditions, including: (80, 81) (80, 81) (80, 81) (81, 82) (81, 82) (34, 37) (34, 37)** • Eczema • Allergies • Asthma • Ear and respiratory infections • Gastrointestinal problems • Severe headaches and migraines • Sleep disorders • Epilepsy • ADHD • Anxiety and depression **Individuals are at heightened risk for chronic conditions, including:** • Diabetes • Coronary heart disease • Cancer
Recommended Screening	**All individuals with a diagnosis of an autism spectrum disorder should have genetic screening, particularly:** • Females • Co-existing intellectual disability • Known sibling with an autism spectrum disorder