



Lightspring

The role of the NP in primary care of adults with autism spectrum disorder

Abstract: Adults with autism spectrum disorder have poorer physical and psychological health outcomes compared with individuals who are neurotypical and benefit from exceptional primary care. NPs are uniquely positioned to reform primary care and eliminate inequities, and can help influence practice standards and optimize care for these patients through education, advocacy, and health promotion.

By Jacqueline Robert, BN, RN, MN GNP and Elsie Duff, PhD, NP

Autism spectrum disorder (ASD) is a neurodevelopmental disorder involving variations in socialization, communication, and relationship formation.^{1,2} Persons with ASD may have limited interests, dependence on routine, and/or repetitive behaviors.^{1,2} According to the CDC, approximately 1

in every 54 children in the US is diagnosed with ASD.¹ When compared with neurotypical individuals, adults with ASD have poorer physical and psychological health outcomes, greater difficulty obtaining an appropriate primary care provider, higher rates of acute care visits, and lower rates of health prevention screenings during

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routine visits.^{3,4} NPs are uniquely situated to adapt their primary care practices and bridge gaps in care to better meet the complex needs of this growing population. The purpose of this article is to examine the role of the NP in improving the primary care experiences and chronic disease outcomes of adults with ASD.

In the US, millions of dollars are invested into ASD research every year; unfortunately, few projects focus on the unmet physical and psychological health needs of adults with this disorder.^{3,4} Adults with ASD tend to experience poorer health outcomes, including earlier morbidity and mortality, when compared with neurotypical individuals.^{3,5} There are several ASD-specific risk factors associated with the development of chronic disease (see *ASD and health outcome risks*), including difficulty deviating from routine, restrictive dietary preferences, and challenges participating in physical activities that require socialization.^{4,5} Adults with ASD face significant barriers when trying to access healthcare, even though many physical and psychological health disorders associated with ASD require prompt access to healthcare services.^{4,6}

■ Terminology in the ASD community

The use of person-first language (PFL) versus identity-first language (IFL) has been an ongoing topic of debate within the ASD community. As practitioners, we are educated on the importance of determining our patients' names and gender pronouns to establish a therapeutic relationship and welcoming environment. We must understand that this practice needs to extend to adults with ASD when determining whether our patients prefer PFL ("person with autism") or IFL ("autistic person"). Studies show that those with ASD prefer IFL as they view ASD as innate and something that cannot be separated from their personhood.^{7,8} Greater adoption of IFL by adults with ASD has been attributed to the neurodiversity movement, which emphasizes that ASD is a condition that should be accepted and accommodated, rather than a disorder to be prevented or cured.⁷⁻⁹ The neurodiversity movement and IFL focuses on the unique characteristics and strengths that each person with ASD brings to society and works toward abolishing harmful terminology such as "high and low functioning" that can be highly detrimental to the progress the ASD community has made.⁷⁻⁹ Although PFL is the preferred terminology of the literature, it is our responsibility as NPs to establish our patients' chosen identifying language and make

ASD and health outcome risks^{4,5,14,16-18}

- Early morbidity and mortality
- Potential late cancer diagnosis due to lack of preventive care
- Obesity
- Diabetes
- Hypertension
- Anxiety and depression
- ADHD
- Suicidal ideation
- Overprescription of pharmacologic agents, such as antipsychotics

a point of using those terms and advocate that other healthcare practitioners do the same.

■ Diagnosis of ASD in adulthood

Diagnosing ASD in the adult population has become increasingly common due to the expansion of diagnostic criteria and spectrum language that emphasizes viewing ASD as a spectrum rather than a binary disorder.^{10,11} However, making a formal diagnosis of ASD in adulthood can be challenging as the expanded diagnostic criteria have resulted in a wider range of deficits and presentations being subsumed under ASD. For instance, patients who may have previously met criteria for Asperger syndrome may be overlooked due to their good language skills and high-level intelligence even though they may struggle with communication and relationship building.¹¹ Although identifying ASD in adulthood has its challenges, literature has noted that characteristics such as trouble socializing or building relationships, gaining employment, and/or history of mental health or neurodevelopmental disorders in adult patients should prompt a referral to a psychiatric specialist or multidisciplinary team for further evaluation and diagnosis.^{10,11} Currently, males are four times more likely to be diagnosed with ASD than females possibly due to the current diagnostic criteria being potentially biased toward male diagnosis.^{12,13} For example, females tend to display more "socially acceptable" characteristics than males, including engaging in imaginative play, better use of verbal language, and a tendency to copy others to mask their difficulties.^{12,13} Restricted interests and behaviors may also differ between females and males. Research suggests that females may display greater interest in animals or people, whereas males may be more interested in

Proposed changes to primary care practices to enhance the care of patients with ASD^{14,17,18,20,21}

- Accessible panel of interdisciplinary experts
- Increased frequency of health promotion discussions such as diet, exercise, and sedentary behaviors
- Increased frequency of preventive health visits to address cancer screening, immunizations, and chronic disease prevention and screening
- Additional funding for office enhancements and time for complex patient appointments
- Improvements to formal education such as implementation of ASD content
- Opportunities to attend ASD-specific workshops and conferences

inanimate objects (wheels on a toy car).^{12,13} As delays in the diagnosis of ASD are associated with many barriers and challenges, it is important to focus on the person's behavior rather than the examples that display the behavior described above in order to identify the need for prompt referral and subsequent diagnosis.^{12,13}

Physical health risks

Compared with neurotypical individuals, adults with ASD are up to 3.4 times more likely to be diagnosed with obesity or diabetes.^{2,14} Obesity is a significant risk factor for physical and psychological comorbid disease.^{2,4} Adults with ASD, especially men, are also at increased risk of hypertension compared with neurotypical individuals.^{2,14} Patients with ASD may also have a higher risk of developing complications related to infectious diseases, such as COVID-19, due to the impact of common comorbid disorders—including gastrointestinal disorders, epilepsy, and psychiatric conditions—on their immune function and inflammatory response.¹⁵ Although the risks of some chronic diseases can be modified with diet and exercise, adults with ASD may have difficulties understanding these correlations and making lifestyle modifications.¹⁴ Addressing chronic conditions for adults with ASD is beyond the scope of this article but it is important for NPs to be cognizant of the increased incidence of chronic disease in individuals with ASD and provide education and/or screening during routine visits. It may be helpful for NPs to encourage family or other support persons to attend routine appointments, if the patient is agreeable, to improve adherence to lifestyle modifications.

Psychological health risks

Adults with ASD also have a higher incidence of comorbid psychiatric disorders, such as anxiety, depression, attention-deficit hyperactivity disorder (ADHD), and suicidal ideation.^{11,16} Individuals with ASD may experience continued psychological stress over time, potentially increasing their risk of developing psychiatric disorders.^{3,16} Moreover, existing inequities within the healthcare system reduce access to preventive mental health care for patients with ASD. This is because, similar to the pediatric population, lifelong consistent access to behavior specialists, specialists and generalists to facilitate diagnosis, and treating and monitoring of psychiatric and medical comorbidities are needed for this population.¹⁰ Therefore, NPs must be vigilant in screening patients with ASD for comorbid psychiatric disorders and associated risk factors, including behavioral changes, sleep disturbances, and signs of abuse.¹⁶

Risk of overprescribing

Overprescribing of psychotropic or atypical antipsychotic medication is another risk factor associated with poor health outcomes among adults with ASD.^{4,17} Psychotropic medications are known to increase risk of obesity, cardiovascular disease such as hypertension, hyperlipidemia, and diabetes.¹⁷ Alarming, psychotropic medications are often prescribed to patients with ASD in the absence of an appropriate diagnosis that warrants their usage.¹⁷ Furthermore, it is estimated that prescription drugs, specifically psychotropics or antipsychotics, are prescribed twice as often to patients with ASD compared with neurotypical individuals and may contribute to premature mortality among the ASD population.^{4,18} Using pharmacotherapy that accompanies increased physical and psychological health risks to control behaviors that society views as unacceptable is becoming far too common in the ASD community. It is critical that NPs weigh the risks and benefits of pharmacotherapeutic agents when working with adults with ASD and ensure that prescribed treatments are justified and appropriate. If the risks are not justified, then steps should be taken to deprescribe any inappropriate pharmacotherapy.

Challenges for adults with ASD and their families

For adults with ASD, the transition from childhood to adulthood is associated with significantly diminished supports and services, meaning that caregivers have to

shoulder the burden of navigating a convoluted health system with inadequate resources.¹⁹ Adults with ASD are often left feeling ill-prepared for the transition out of public school. They may begin to navigate through government services only to discover these programs lack the resources, services, or staff training necessary to accommodate their needs.¹⁹ Transitioning from child to adult healthcare is also very challenging for people with ASD and their families, who often lack the knowledge and expertise required to navigate the health system and obtain a new adult primary care provider.²⁰ Adults with ASD commonly report less satisfaction and more negative experiences with primary care providers than neurotypical individuals.²⁰ Communication barriers may significantly hinder their ability to have trust and confidence in their primary care providers.^{3,20} This population also experiences many barriers to accessing healthcare services, including anxiety associated with waiting for appointments, overstimulation related to the clinical environment, cost of available services, and fear of not understanding the information provided.^{3,18,20} Unfortunately, lack of provider education and expertise on ASD is another significant challenge in accessing care for these patients.²⁰ It is crucial that primary care NPs advocate for enhanced ASD education and training in academic and workplace settings to ensure that patients with ASD have equitable access to high-quality healthcare services.

■ Barriers to changing primary care practices

The provision of primary care services to adults with ASD can be extraordinarily complex and overwhelming for primary care providers as such patients often require coordination of multiple supports and services that extend beyond the role of the typical primary care provider which necessitates an immense amount of knowledge, time, and effort.⁶ A recurring theme in the literature is the importance of the practitioners' self-efficacy and confidence in providing care for patients with ASD.^{6,18} Research has shown that providers with lower self-efficacy scores are less likely to adapt their services to meet the needs of these patients.^{6,18} Low levels of self-efficacy among care providers were related to inadequate formal education and experience on ASD and other developmental disorders.²¹

■ The NP's role in primary care reform

Since most family or primary care NPs are educated to deliver healthcare services to all ages, they are ideally situated to impact the care of adults with ASD.²¹ Unfortunately, many NPs admit to having limited knowledge of the complex care needs of this population, including their medical and psychological comorbidities, communication issues, sensory perceptions, and behavioral challenges.^{6,21} Primary care providers' lack of knowledge of ASD arguably undermines the quality of care provided to such patients.²⁰ Care providers must discuss and explore possible improvements in education, support services, referral opportunities, and the sensory environment within the clinic to better meet the needs of their patients.²⁰ It is also vital that providers develop a plan to overcome the challenges associated with successfully implementing these changes.²⁰

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Iannuzzi et al. developed a pilot project for graduate family NP students at the University of Massachusetts where students completed an 8-week ASD education program that included multiple methods of learning, such as online lectures, community initiatives, and educational teachings from experts in the field of ASD.²¹ Online questionnaires administered before and after the 8-week education program showed notable improvements in the students' self-efficacy and knowledge levels.²¹ When the project concluded, the students also reported feeling more prepared to care for patients with ASD. As a result, the ASD-specific curriculum was adopted into both the graduate family NP and the adult-gerontology primary care NP programs at the University of Massachusetts.²¹

The healthcare experiences of adults with ASD may be improved through several changes to current primary care practices. For instance, primary care providers could be granted access to a panel of interdisciplinary healthcare providers with expertise in ASD, which would enhance access to services, improve morbidity and mortality, and better support primary care providers and their patients.²⁰ In addition, preventive healthcare could be prioritized in primary care appointments

to prevent or slow disease progression. As part of this, primary care providers could emphasize the importance of lifestyle modifications, such as improvements in diet and exercise, preventive health screening, and immunizations.^{14,17} The allocation of additional time and funding to primary care providers could also optimize the care of these such patients with complex needs and allow providers to make necessary improvements to clinic environments.²⁰ Finally, enhanced education is pivotal to build practitioners' confidence, communication abilities, and practice skills. This could be accomplished not only through changes to master's and doctoral programs, but also by providing opportunities for primary care providers to attend workshops and conferences related to ASD. These strategies (see *Proposed changes to primary care practices to enhance the care of patients with ASD*) have the potential to significantly improve healthcare services for adults with ASD, reduce chronic disease, and improve health outcomes and mortality in this population.^{18,21}

Conclusion

People with ASD require exceptional primary care services to reduce rates of early morbidity and mortality.⁵ NPs are uniquely positioned to provide excellent primary care services while advocating for the needs of this growing population. NPs must strive to improve their knowledge and confidence related to the care of adults with ASD by lobbying for enhanced ASD education and encouraging stakeholders to implement ASD-specific education in both master's and doctoral programs. NPs can provide a high standard of care for adults with ASD by obtaining the necessary knowledge and skills to address their complex healthcare needs. Primary care NPs have an obligation to influence healthcare services for patients across the lifespan, including those with intricate needs. 

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