

## Serving Adults with Disabilities on the Autism Spectrum

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Autism and autism spectrum disorder (ASD) are terms for a group of complex neurodevelopmental disabilities that affect social communication, sensory processing, and scope of interests. The skills and challenges of autistic adults<sup>1</sup> fall across multiple spectra and can change depending on the individual's environment and over time as the individual matures. While autism is typically diagnosed in children, approximately one percent of adults meet the criteria for autism.<sup>2</sup> The number of autistic adults is expected to increase as the large cohort of children diagnosed in the 1990's and early 2000's reach adulthood.

Several health care disparities exist between autistic adults and adults without autism. Compared to adults without autism, those on the autism spectrum experience greater unmet health care needs, greater emergency department use, lower use of preventative care services, lower satisfaction with participant-provider communication and health care self-efficacy.<sup>3</sup> Autistic adults may also experience fear and anxiety, sensory issues, and difficulty communicating with providers, which can result in additional barriers to accessing health care services.<sup>4</sup> Additionally, provider-level factors, such as the provider's knowledge and assumptions about autism, as well as their understanding of the importance of incorporating care partners such as caregivers or specialists, may contribute to the quality of care an autistic participant receives.

Autistic participants may require certain accommodations during appointments to address environmental and sensory sensitivities, such as lighting preferences and noise and visual distractions. Providers can assess their care delivery processes prior to appointments and identify accommodations that will improve care for autistic participants. For example, providers can inquire about a participant's lighting preferences (e.g., natural light, turning off fluorescent lights, or dimming lights) before the appointment and ensure that the preferred lighting is set up in the participant's room. Providers also can encourage the participant or their care partner to bring objects to the appointment to reduce or increase sensory stimuli (e.g., headphones to block noise, sensory toys, or fidgets). Additional accommodations may also be made during the visit itself, such as showing any equipment to the participant before using it and warning the participant before touching them.

Providers and health plans can use a variety of tools to help improve health care for autistic adults. One such tool is the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE) Health Care Toolkit.<sup>5</sup> This toolkit offers materials, resources, and practical information to help providers offer high-quality primary care to autistic participants. Information and instructions are also available within the toolkit to help participants and their care partners navigate the health system and become advocates for their own care. An especially helpful aspect of the AASPIRE toolkit is the Autism Health Care Accommodations Tool (AHAT), which generates personalized reports that can be used to inform health care providers of needed accommodations to effectively care for autistic participants. Accommodations could include changing the physical environment, such as lighting or ambient noises, or changing communication methods, such as

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<sup>1</sup> Participants with autism and their advocates often prefer using identity-first language to describe the condition; thus, you will see the term "autistic adult" used in this document. Visit the [Resources for Integrated Care website](#) for additional details.

<sup>2</sup> Brugha T MS, et al. Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007. Information Centre for Health and Social Care; 2009.

<sup>3</sup> Nicolaidis, C, et al. (2013) 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.* Jun; 28(6):7610769.

<sup>4</sup> Raymaker, DM, et al. (2016) Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities. *Autism* 21:8 972-984

<sup>5</sup> The AASPIRE toolkit is available for use free of charge, and can be accessed at [www.autismandhealth.org](http://www.autismandhealth.org).

writing down important information or instructions.

***For more information and resources on Disability-Competent Care, please visit***  
***<https://www.resourcesforintegratedcare.com/concepts/disability-competent-care>***

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***[https://resourcesforintegratedcare.com/DisabilityCompetentCare/2018\\_DCC\\_Webinar\\_Series/Building Partnerships](https://resourcesforintegratedcare.com/DisabilityCompetentCare/2018_DCC_Webinar_Series/Building_Partnerships)***

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