

SERVING ADULTS ON THE AUTISM SPECTRUM: RESOURCE GUIDE

This is a supplemental resource guide to the webinar hosted on February 28, 2018, *Serving Adults on the Autism Spectrum*. This guide is intended for providers and health plans who are interested in enhancing their capacity to integrate care for adults with disabilities. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care website:

https://www.resourcesforintegratedcare.com/DisabilityCompetentCare/2018_DCC_Webinar_Series/Autism_Spectrum.

GENERAL RESOURCES FOR PROVIDERS

The **Diagnostic and Statistical Manual of Mental Disorders (DSM-5)** defines and classifies mental disorders in order to improve diagnoses, treatment, and research.

<https://www.psychiatry.org/psychiatrists/practice/dsm>

The Center for Disease Control and Prevention (CDC) published a press release in March 2014 titled **CDC estimates 1 in 68 children has been identified with autism spectrum disorder**. The press release gives updated statistics on autism and provides advice for parents that suspect their child may have ASD.

<https://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>

Springer International Publishers published **Epidemiology of Autism Spectrum Disorders** in January 2015. The article reviews existing prevalence estimates for autism spectrum disorders (ASDs) since 2000 and discusses methodological factors impacting the estimation of prevalence and the interpretation of changes in prevalence estimates over time. Possible explanations for an increase in the prevalence of ASD within and across populations are considered.

<https://tinyurl.com/y7nrxsgm>

The **Academic-Autism Spectrum Partnership in Research and Education (AASPIRE)** has information and worksheets for adults on the autism spectrum, supporters, and healthcare providers. It focuses on healthcare with a primary care physician.

www.autismandhealth.org

The **Autism Society** provides resources and tools for autism advocacy related issues. The organization also provides education, information, and referral support at the national, state and local levels through their strong nationwide network of affiliates.

<http://www.autism-society.org/>

The **Autism Speaks Organization** website provides resources and opportunities for promoting solutions across the spectrum and throughout the lifespan for the needs of individuals with autism and their families through advocacy and support; increasing understanding and acceptance of people with autism spectrum disorder; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

🔗 <https://www.autismspeaks.org/family-services/adults>

Is It Autism and If So, What Next? A Guide for Adults is a tool designed to help assist adults who suspect they may have autism, as well as those who have been recently diagnosed with the disorder.

🔗 https://www.autismspeaks.org/sites/default/files/docs/is_it_autism- tool_kit_complete.pdf

AASPIRE developed a **Healthcare Toolkit for Patients and Supporters** and a **Healthcare Toolkit for Providers**. The toolkit is designed for adults new to an autism diagnosis. It includes information about autism spectrum disorder, adult diagnosis, therapy and assistive technology, disability rights laws, and Autistic culture and meeting others on the spectrum.

🔗 **Patients and Supporters:** <https://autismandhealth.org/?a=pt&p=main&theme=ltlc&size=small>

🔗 **Providers:**

https://www.autismandhealth.org/?a=pv&p=main&t=pv_fac&s=fac_fac&theme=ltlc&size=small

AASPIRE's website brings together the academic community and the autistic community to develop and perform research projects relevant to the needs of adults on the autism spectrum.

🔗 <https://aaspire.org/>

'Gently does it,' caring for older adults with autism provides a physician perspective of the challenges and techniques to provide primary care to adults with autism.

🔗 <https://acpinternist.org/archives/2008/11/autism.htm>

Participants with autism and advocates for participants with autism often prefer using identity-first language to describe the condition, which is a departure from the standard person-centered language used in the Disability-Competent Care model. For more information, please refer to the following resources:

Autistic Self Advocacy Network

🔗 <http://autisticadvocacy.org/>

Identity-First Autistic: Effecting Social Change through Language

🔗 <https://www.identityfirstautistic.org/>

ISSUE BRIEFS AND REPORTS

CMS produced a data snapshot in April 2016 on **Health Disparities in the Medicare Population: Autism Spectrum Disorders**. The brief report highlights 2014 prevalence statistics of Autism Spectrum Disorders.

🔗 https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH_Dwnld-DataSnapshot-Autism.pdf

ACADEMIC JOURNAL ARTICLES

The journal, Medical Clinics of North America, published an article in June 2014, on **Primary care for older adults on the autism spectrum**. This focuses on the identification of ASD in adults, referrals for services, the recognition of associated conditions, strategies and accommodations to facilitate effective primary care services, and ethical issues related to caring for autistic adults.

🔗 <https://www.ncbi.nlm.nih.gov/pubmed/25134878>

Sage Journals published **The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder** in November 2016. The study examines the extent to which gender-related social behaviors help girls with autism spectrum disorder to seemingly mask their symptoms.

🔗 <http://journals.sagepub.com/doi/abs/10.1177/1362361316671845>

The Journal of Autism and Developmental Disorders published **Emergency Department Use among Adults with Autism Spectrum Disorders (ASD)** in April 2016. The study conducted a cross-sectional analyses using Nationwide Emergency Department Sample (2006-2011) to examine the trends, type of ED visits, and mean total ED charges for adults aged 22-64 years with and without ASD.

🔗 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4845033/>

Fifty years ago, the Journal of Applied Behavior Analysis published an article titled **Some current dimensions of applied behavior analysis**. The article described the current dimensions of applied behavior analysis as it was prescribed and practiced in 1968.

🔗 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1310980/>

The Journal of Developmental Medicine and Child Neurology published **A systematic review of two outcomes in autism spectrum disorder – epilepsy and mortality** in February 2012. The review provides comprehensive evidence for clinicians, caregivers, and people with ASD regarding these outcomes.

<http://onlinelibrary.wiley.com/doi/10.1111/j.1469-8749.2012.04223.x/full>

The British Journal of Psychiatry published a study on **Premature mortality in autism spectrum disorder** in March 2016. The study examines all-case and cause-specific mortality in ASD, as well as investigates the moderating role of gender and intellectual ability.

<https://www.ncbi.nlm.nih.gov/pubmed/26541693>

The Advances in Autism Journal published a paper on **Evidence of increased PTSD symptoms in autistics exposed to applied behavior analysis** in October 2017. The study examined the prevalence of posttraumatic stress symptoms (PTSS) in adults and children who were exposed to applied behavior analysis (ABA) autism early childhood intervention.

<http://www.emeraldinsight.com/doi/abs/10.1108/AIA-08-2017-0016>

Sage Journal published **Barriers to healthcare: Instrument development and comparison between autistic adults and adults with and without other disabilities** in September 2016. The article identified and compared barriers to healthcare experienced by autistic adults and adults with and without other disabilities.

<https://www.ncbi.nlm.nih.gov/pubmed/27663266>

The Journal of General Internal Medicine published **Comparison of healthcare experiences in autistic and non-autistic adults: a cross-sectional online survey facilitated by an academic-community partnership** in November 2012. The study compared the healthcare experiences of autistic and non-autistic adults via an online survey.

<https://www.ncbi.nlm.nih.gov/pubmed/23179969>

The Journal of Autism and Developmental Disorders published **A Study of Physician Knowledge and Experience with Autism in Adults in a Large Integrated Healthcare System** in December 2015. The study assessed providers' ability to recognize autism spectrum disorder (ASD), asked them to rate their autism knowledge, comfort level in treating affected patients, and evaluated training and resource needs.

<https://www.ncbi.nlm.nih.gov/pubmed/26334872>

The Journal of Psychiatric Services published an article titled **The Health Home: A Service Delivery Model for Autism and Intellectual Disability** in 2015. The article proposes the health home model as a new conceptual framework from which to build systems of care for persons with ASD or ID and their families. The authors describe essential elements of a health home for these populations, which would be located in a behavioral health setting.

🔗 <https://ps.psychiatryonline.org/doi/pdf/10.1176/appi.ps.201400443?code=ps-site>

The Journal of Neuropsychiatric Disease and Treatment published an article in 2016 on **Autism spectrum disorder in adults: diagnosis, management, and health services development**. The article reviews available evidence regarding the etiology, legislation, diagnosis, management, and service provision for adults with ASD and considers what is needed to support adults with ASD as they age.

🔗 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4940003/>

The Journal of Medical Clinics in North America published an article on **Primary Care for Adults on the Autism Spectrum**. The authors discuss identification of ASD in adults, potential referrals for services, the recognition of associated conditions, strategies, and accommodations to facilitate effective primary care services for autistic adults, and ethical issues related to caring for autistic adults. They also include their own patient perspectives since literature on adults with ASD is still somewhat limited.

🔗 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4851469/>

The Journal of Child Psychology and Psychiatry published an **Editorial Perspective: The use of person-first language in scholarly writing may accentuate stigma**. The author outlines arguments against the use of person-first language.

🔗 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5545113/>

The Journal of Developmental Psychology published a study on the perceived opposition between the medical model and the neurodiversity movement by assessing conceptions of autism and neurodiversity among people with different relations to autism. The study, published in April 2012, is titled **Deficit, difference, or both? Autism and neurodiversity**.

🔗 <https://www.ncbi.nlm.nih.gov/pubmed/22545843>

This systematic review on **Gender and age differences in the core triad of impairments in autism spectrum disorders: a systematic review and meta-analysis** examines gender differences in the core triad of impairments in autism.

🔗 <https://www.ncbi.nlm.nih.gov/pubmed/23989936>

Special thanks for contributions to this guide:

Christopher Duff

*Disability Practice and
Policy Consultant*

Mahsa Hesari, M.A., BCBA

*Autism Program Supervisor,
Behavioral Health Department
LA Care*

**Dr. Christina Nicolaidis,
M.D., MPH**

*Professor Portland State
University, Adjunct Associate
Professor Oregon Health
Science University, Co-
Director Academic Autism
Spectrum Partnership in
Research and Education*

The Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS) seeks to help beneficiaries dually eligible for Medicare and Medicaid have access to seamless, high-quality health care that includes the full range of covered services in both programs. This resource guide is intended to support health plans and providers in integrating and coordinating care for dually eligible beneficiaries. It does not convey current or anticipated health plan or provider requirements. For additional information, please go to <https://www.resourcesforintegratedcare.com/>.