

## Communication and Interaction Challenges for Autistic Adults

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. While autism is typically diagnosed in children, approximately one percent of adults meet the criteria for autism.<sup>1</sup> Communicating and interacting with autistic adults<sup>2</sup> can be challenging for care coordinators and other health care professionals. Autistic adults experience different behavioral symptoms and communication patterns, which may make it hard to understand the preferences and needs they are trying to communicate.

It is important for care coordinators and other health care professionals to understand that while autistic adults may communicate differently than other adults, they are still communicating important messages about their symptoms, needs, and experiences. This resource addresses possible barriers that care coordinators and other health care professionals may face when communicating and interacting with autistic adults and offers potential strategies to mitigate these challenges.<sup>3</sup>

### Components of Communication and Interaction

To understand how best to communicate with autistic adults, it is important to first understand how autism affects communication and interpersonal interactions. There are essentially five components of communication and interaction with autistic adults.

- 1) Verbal
- 2) Non-verbal
- 3) Comprehension
- 4) Visual and sensory
- 5) Executive skills

Each participant will vary in their communication skills related to these five components and will often require accommodations from care coordinators and other health professionals. It is important to note that anxiety, stress, and pain commonly affect autistic adults' communication and cognition, and that their abilities can vary from day to day; therefore, it is important to be flexible with accommodations. The responsibility lies with the professionals who work with autistic adults to understand, document, and accommodate the unique experiences and needs of each participant. The remainder of this resource provides specific strategies and other tips on how care coordinators and other health care professionals can achieve this.

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<sup>1</sup> Brugha T MS, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J. 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>2</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>3</sup> For more information on the unique care management needs of adults with disabilities who are on the autism spectrum, please view the recording of the Serving Adults With Disabilities On The Autism Spectrum webinar at: [https://resourcesforintegratedcare.com/DisabilityCompetentCare/2018\\_DCC\\_Webinar\\_Series/Autism\\_Spectrum](https://resourcesforintegratedcare.com/DisabilityCompetentCare/2018_DCC_Webinar_Series/Autism_Spectrum)

## Gathering Information during Initial Assessment

The autistic adult's care team, including their care coordinator, primary care provider, and other health care professionals, should use the participant's initial assessment as an opportunity to identify and gather baseline information on the participant's communication and interaction style and preferences. It is best to include this information on an easily accessible summary document (commonly referred to as a "facesheet") in the participant's health record. This allows all care coordination and other care team members to access the information to guide and adapt their ongoing interactions with the participant based on their particular way of communicating.

According to the Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE), the following items are important to understand and document in the participant's health record following the initial assessment<sup>4</sup>:

- Ability to understand spoken language.
- Ability to speak and voice concerns/opinions, including challenges they may experience based on the social contexts and situations in which they interact with others. For example, autistic people may have difficulty generating speech while upset or anxious.
- Ability to read and write, including their preferred method of reading and writing. For example, an autistic person may have no difficulty sending emails, but may have trouble filling out a medical intake form or HIPAA form, and returning it.
- Use of augmentative and alternative communication (AAC), such as visually-based systems (e.g., picture boards), text-based systems (e.g., text-to-speech programs), or sign language. These may be stand-alone devices, programs on computers, tablets, smartphones, or informal systems (e.g., notes on paper).
- Ability to use the telephone for between-visit communications and alternatives that are more effective if telephone communication is not effective.
- Ability to use preferred online modes of communication such as email and social media (Facebook, Twitter, etc.).

Care coordinators should remember that autistic adults will commonly have another person with them (e.g., a family member or care partner) during assessments, appointments, and other interactions. This person is there to assist both the participant and the health care professional and can be a helpful resource during assessments. However, even though the participant may not always understand or be able to respond to questions, it is important to speak with the participant directly, not just to their care partner.

## Communication Strategies

The information below identifies common communication challenges in working with autistic adults, along with several strategies to mitigate each challenge.

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<sup>4</sup> [https://autismandhealth.org/?a=pv&p=main&theme=ltlc&size=small&s=fac\\_fac&t=pv\\_fac](https://autismandhealth.org/?a=pv&p=main&theme=ltlc&size=small&s=fac_fac&t=pv_fac)

## Verbal Challenges

**Autistic adults may struggle to verbally communicate during interpersonal conversations.**

- Attempt to use the most effective communication mode for the participant, even if it means altering your usual assessment style. For example:
  - Avoid broad questions; instead, ask “yes/no” questions or those with a limited number of answer choices.
  - If necessary, use multiple-choice options instead of open-ended questions.
  - Use examples or other non-leading questions if they have trouble describing their feelings.
- Provide lists of symptoms or common experiences from which to choose.

## Non-Verbal Challenges

**Autistic adults may vary in their understanding and expression of tone of voice, facial expressions, or body language.**

- Do not force the participant to make eye contact; they may find it uncomfortable or it may hinder their communication.
- Do not assume that a participant is distracted or inattentive just because they are fidgeting, making repetitive movements, avoiding eye contact or making non-communicative sounds or vocalizations while you speak. Try not to dissuade these repetitive motions or sounds, which are often used to help the participant compensate or focus.
- Don't assume how the participant feels based on their appearance (i.e., facial expressions or body language).

## Comprehension Challenges

**Autistic adults may experience slow processing speed, commonly resulting in trouble responding to questions or making quick decisions.**

- Be concrete and specific regarding health conditions and treatment options to minimize the opportunity for misunderstanding; provide examples and avoid expressions and figures of speech.
- Give the participant time to process what has been said and to pull together their response. After giving the participant new information, check to see if they are ready to move on.
- Schedule longer appointments.
- Encourage the participant to prepare notes in advance about what they want to discuss and suggest that the participant review information or resources about their health condition(s) prior to the appointment.
- At the conclusion of the appointment, write down important information or instructions.
- Allow the participant time to process treatment options and to ask questions and communicate final decisions following the appointment.

## Visual and Sensory Challenges

**Autistic adults may experience varying reactions to visual and sensory stimulants that may be present in the immediate environment.**

- Ask about the participant's lighting preferences. For example, participants may prefer natural light, turning off fluorescent lights, or dimming lights.
- Reduce stimulation, such as noise and visual distractions.
- Avoid unnecessarily touching the participant, and warn the participant before you touch them.

- Encourage the participant or their care partner to bring objects to reduce or increase sensory stimuli. For example, headphones to block noise, sensory toys, or fidgets.
- Body awareness may be affecting how the participant recognizes or describes a symptom, or how they respond to an illness; clarify by rephrasing or asking additional questions.
- Offer to use diagrams, visual representations, or models for your recommendations. For example, use visual schedules to show when a participant should take their medications.

### Executive Skill Challenges

**Autistic adults may experience difficulty with planning, organizing, and sequencing, making it difficult to navigate health care services and recommendations.**

- Autistic participants can have difficulty comprehending or communicating timeframes. It may be helpful to associate timeframes to important dates, such as holidays or life events. Repeating timeframes to confirm accuracy can also be helpful.
- Work with the participant to best explain time-based recommendations. For example, propose setting an alarm to remind the participant when to perform an activity like taking medication, or link the act to a specific part of their daily routine.
- Show the participant what you want them to do while the participant is still in your office.
- Contact the participant or their care partner after the visit to make sure that the participant has been able to follow your instructions. Autistic participants may be sensitive to the perception of not being trusted to perform a task. To prevent this, plan ahead of time and practice the conversation to avoid perceived instances of condescending comments or innuendos.
- Provide worksheets or diaries to the participant or their care partner to keep track of symptoms.

### Additional Communication Resource

In addition to the strategies described above, another helpful resource is the [AASPIRE Healthcare Toolkit for Healthcare Providers](#). The Toolkit provides strategies for providers on communicating with autistic participants<sup>5</sup> and also includes materials, resources, and practical information to help providers offer high-quality primary care to autistic adults. Researchers, autistic adults, and people who support individuals on the autism spectrum all worked together as equal partners throughout every phase of the research process to design the toolkit. Care coordinators and other health care professionals can use this Toolkit to improve communication between providers and autistic adults during visits. The AASPIRE website has additional information and worksheets for providers, adults on the autism spectrum, and those who support autistic individuals.

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

<sup>5</sup> AASPIRE uses the term “patient” to refer to autistic adults being seen by a medical professional. The DCC model commonly refers to the “patient” as the “participant,” which implies person-centered language.