

▶ Ensuring effective communication with patients who have developmental disabilities

Do you remember the details of interactions with every Too often, people with developmental disabilities (DDs) such as Down syndrome or autism spectrum disorder (ASD) don't receive adequate healthcare, and one reason is inadequate communication. Possible events range from failure to take medication as prescribed to failure to receive proper routine health screening. In addition to harming the patient and creating emotional distress in families and caregivers, PAs can find themselves the target of legal action in these situations.

Patients at risk

Patients with DDs are at risk for healthcare disparities. Disparities are particularly concerning given that these patients are more likely to have health problems, including multiple comorbidities.

Unfortunately, patients with DDs may find that screenings and preventive services are neglected, and chronic diseases aren't managed effectively. Those experiences are not in line with healthcare providers' legal and ethical responsibilities.

Fulfilling legal and ethical responsibilities

The Americans with Disabilities Act requires healthcare providers to ensure effective communication with patients who have disabilities, which includes providing services (such as translation) or assistive devices. If the patient's caregiver has a disability that affects communication, healthcare providers also must provide services or assistive devices.

The informed consent process can be of concern for patients with DDs. Do not assume that a DD means the patient can't provide consent. It may be simply a matter of the provider communicating clearly and in terms the patients will understand.

If, however, the patient is not capable of giving consent, determine the surrogate decisionmaker. Although you are not responsible to obtaining consent, as a patient advocate, you want to protect your patient. Retain signed consent forms in the patient's health record.

Assessing communication skills

Not every patient with a DD has communication challenges. Start by determining if the patient has speech, hearing, or vision impairments that will make communication challenges more likely.

An assessment strategy for patients with ASD is to suggest they complete the Autism Healthcare Accommodations Tool. This tool generates a report for healthcare providers that gives specific ideas for how to communicate better with the individual. An excerpt from a sample report notes that to help the patient better understand what is being said, "use very precise language, even if it means using longer sentences or advanced vocabulary." There are also suggestions for how to provide information and how to help with shared decision-making. Access the tool, along with other communication resources for providers and patients, at <https://autismandhealth.org>.

Based on your assessment, establish the patient's communication strengths and challenges and tailor your approach. Be sure to document preferences in the patient's health record so that they are accessible to all members of the team.

In addition to assessing communication, obtain a complete health history, including determining if preventive measures, such as vaccines, are current, and if needed screening, such as colorectal screening, has been completed.

Communication basics

The Health Care for Adults with Intellectual and Developmental Disabilities Toolkit for Primary Providers identifies several goals for communicating effectively and provides tips for achieving each one. Below are the goals, along with sample tips. Access the complete list at <https://vkc.mc.vanderbilt.edu/etoolkit/general-issues/communicating-effectively>.

- Establish rapport. Speak directly to the patient; avoid talking to an adult as if he or she were a child.
- Choose appropriate language. Use concrete words and avoid jargon.
- Listen. Allow enough time to listen and understand that interactions will likely take longer; know that differences in muscle tone for some individuals may complicate reading their facial expressions or body language, so validate your perceptions.
- Explain clearly. Tell and show what you are going to do and why; pause frequently so you aren't overloading the patient.
- Communicate without words. Use visual aids; demonstrate what will occur.

Caring communication

People with DDs deserve the best possible care from healthcare providers, including preventive health measures and appropriate management of health conditions. Through thoughtful communication and collaboration with caregivers, family, and the interprofessional team, PAs can help achieve the goal of optimal care—and optimal outcomes.

RESOURCES

CAASPIRE Healthcare Toolkit. 2018. <https://autismandhealth.org>.

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