



Improving Communication with Patients who have Intellectual and Developmental Disabilities

Physician's

FACT SHEET

Patients with Intellectual and Developmental Disabilities (IDD) are recognized as an underserved population that experience significant disparities in healthcare.¹⁻³ As medicine continues to advance, patients with IDD are living longer, experiencing more secondary and chronic illnesses, apart from their disability, and are seeking treatment from primary care providers to manage these conditions.³⁻⁶ Individuals with IDD experience poorer health outcomes, and are at greater risk of disparity and poorer social health determinants including:^{1,5}

- Complex health conditions
- Decreased cancer screenings and preventive services
- Poorly managed chronic diseases
- Undetected vision problems
- Additional mental health problems
- Limited access to health care services
- Being unemployed
- Under educated
- Lower income

Individuals with IDD have a greater need for healthcare; however, disability has been found to be a risk factor for dissatisfaction and disappointment with provider encounters.⁷ One way in which medical encounters can be improved is through better communication practices. Effective doctor-patient communication is essential for establishing strong patient relationships and working to eliminate health disparities faced by individuals with disabilities. However, communicating with patients with IDD can present various challenges to the physician. Patients can have dysarthria, low literacy, or be non-verbal. It is important to remember that there is significant diversity within diagnoses, e.g., people with cerebral palsy may or may not have intellectual disability. Regardless of the patient, or their diagnosis, it is important to remember that the basis of communication with patients with IDD, or any patient, is to treat them with dignity and respect.

Building Rapport:

- Always address the patient first, and orient yourself in a way that allows you to maintain eye contact with the patient.
- Irrespective of IDD, it is always important to use age appropriate tone and language (be careful not to allow your communication to be misconstrued as patronizing).
- Always begin your interview by explaining the purpose of the encounter and establish communication preferences. The patient may require the use of assistive communication devices or interpreters.
- Practice triadic communication – always speak to the patient first. Use their caregiver to help facilitate communication, not as a surrogate for communication.

** Remember, appointments for patients with IDD will most likely take more time. It may be helpful to schedule appointments at the beginning or end of the day when your schedule has more flexibility.

History Taking:

- Explain the purpose of your questions.
- Be sure to focus on the patient's chief complaint – do not focus solely on their disability.
- Ask questions directly to the patient.
- Allow the caregiver to fill in information or provide additional details that the patient may not be able to give.
- Take advantage of the knowledge/insight that the individual/caregiver can provide about their health and disability.

** Prompt patient and caregiver to come to the appointment prepared. Ask them to bring copies medical records, their medication list and a list of questions they may have. This will speed up the history taking process and allow you more time to speak with the patient about their concerns.



During the Physical Exam:

- In some cases it may be necessary to adapt specific physical exam maneuvers. Do not avoid any component of the physical exam that you think may be difficult to complete or hard for the patient to comply with – patients and caregivers expect the same kind of treatment and attention. For instance, you may need to adapt the positioning of some maneuvers to accommodate patients who are wheelchair users.
- Offer assistance when you feel it is needed; wait until that offer is accepted before stepping in.
- Explain, and demonstrate when possible, during each step of the physical exam. It may be helpful to use a model, or demonstrate what you will be doing on yourself before starting (i.e. where you will be placing the stethoscope, or how you will be palpating the patient's stomach during an abdominal exam).
- Do not avoid questions/screening for sexual health issues. Many people with IDD do have intimate sexual relationships.



Assessment and Diagnosis:

- Do not assume that there is a correlation between symptoms and disability – patients with IDD have many of the same secondary and chronic conditions as the general population.
- Beware of ‘diagnostic overshadowing’. Often, symptoms are automatically attributed to the patient’s disability. This is especially true of behavioral and developmental problems.⁸

Treatment and Plan:

- Explain your findings in appropriate terms.
- Ensure understanding of both the patient and the caregiver. Avoid medical jargon and attempt to use clear, concise medical language.
- Provide patients and caregivers with appropriate materials to take home with them. Try to use adapted literature that uses visual aids and is in “easy read” format.
- Easy read materials are written at an elementary or middle school reading level, include visual aids and are written in clear and concise language.

Quality Patient Care

Quality patient care begins with you; as this patient’s physician you will play a large role in ensuring they receive appropriate care in all aspects of life – not just for their disability. With such diversity within patients with IDD, it is impossible to be an expert on every syndrome and symptom. Allow the patient and caregiver to share their knowledge about their condition with you. Good doctor-patient communication is essential to providing quality care to every patient. Remember, effective communication begins with dignity and respect, regardless of the patients’ cultural background or abilities.

For more information, and to further build your knowledge about IDD and providing quality care to patients with disabilities, seek out CME courses focused on these topics. Organizations including the American Academy of Developmental Medicine and Dentistry (www.aadmd.org), and the American Association on Intellectual and Developmental Disabilities (www.aaid.org) offer useful information. For a range of free materials for patients with IDD, visit FCIC health resources website (<http://fffcic.fmhi.usf.edu/program-areas/health.html?tab=2>).

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