Office of Developmental Primary Care

Improving health outcomes for people with developmental disabilities

Supporting People with Disabilities in Health Care Settings

Communication

“When I have brought others, especially my parents, the providers tend to direct their questions to them and not me. They take them more seriously. It’s frustrating.”

- People with disabilities express frustration when medical providers direct questions and comments about their health to caregivers or family members. Support their communication by:
  - Presuming competence.
  - Always addressing the disabled person.
  - Exploring different communication options, such as visual aids, slowing down the conversation, and using plain language.

Disabled & Beyond: Intersecting Identities

“My primary nurse practitioner sees me as a whole person, including my disability, sexuality, social life, and other medical needs unrelated to my disability.”

- Acknowledge and respect people with disabilities as whole people when considering the impact of potential treatment.
- Recognize that for many, disability is a cultural identity.

Assumptions

“I wish medical students had to work in the community so they could see for themselves what our lives can be. I would like them to see ‘life’. That it’s not all medical – we have fun!”

- People with disabilities want clinicians to avoid basing treatment options on assumptions about their quality of life. Ask patients what brings value to their lives.
- Negative messages regarding disability can be found everywhere, including in medical literature. Refer patients to peer-led groups and/or websites that promote positive disability identity.
- Do not confuse a patient’s health status in a hospital setting with their typical baseline. Ask patients (or their caregivers) to describe their baseline.
- Respect privacy and personal boundaries, regardless of cognitive or communication skills. Tell patients what they can expect to happen before starting an exam or procedure.

Decision-Making

“I brought in her communication device and they were shocked that she could do anything like that. They had assumed that she was a little lump.”

- In medical decision-making, disabled patients need as much autonomy over their bodies as possible.
- Disabled patients should be able to choose trusted supporters to help them make medical decisions.
- Rather than assuming that disabled people cannot make decisions, consider what supports or accommodations can optimize a patient’s capacity to participate in decision-making.

Cultural Humility & Respecting Patient Experiences

“Believe me. I may not have medical training, but I know a lot about my disability. Don’t give up on me.”

- Recognize people with disabilities and their caregivers as experts in their care and abilities.
- Trust the information and history they provide and correct errors that may exist in the medical chart.
- Everyone has unconscious bias – look at your patient as an individual and don’t make assumptions based on appearance or diagnosis.

Adapting to Change in Function

“About 10 years ago, I became spinal cord injured. It’s common with CP (cerebral palsy), but no one spoke to me about it. I had to relearn things. It was heavy.”

- All people have the capacity to adapt to change and evolving circumstances – people with disabilities and their families are used to adapting to new circumstances. Trust them when they tell you they know what they can handle.
- Aging with a significant developmental disability can be full of unknowns. Clinicians can help patients by educating them on any disability-specific progressions based on literature and clinical experience.

Visits to the Emergency Department

“People I see more than once are almost always okay. The problem is the ED or people who work in the hospital. They don’t know who we are. They only see us for our problems and that’s a real problem.”

- Emergency visits pose unique challenges to disabled patients:
    - Physicians and medical personnel may be unfamiliar with a patient’s disability, medical history, baseline, or communication style.
    - Sensory overload due to bright lights and loud noises can impair a disabled person’s capacity to communicate.
    - Some disabled people are survivors of medical trauma.

- Accommodations to consider:
    - Reduce wait time.
    - Better coordinate between departments.
    - Streamline discharge.

Advanced Care Planning

“Afterward, they kept talking about it, when I was doing well. A social worker came to my house and her first question was, “Do you want a DNR?” This is when I was doing fine. All I wanted to do was move away from that conversation.”

- Parents and caregivers want to know that their options are based on neutral medical advice.
- Patients want to know that their lives are valued. Learn what your patients value, what’s important in their lives, and how to support their goals in the context of their environment.
- Disabled people need opportunities to make decisions about what happens to them during a medical emergency and at the end of their lives.

End of Life

“I really appreciated how hard they tried to save her. They gave value to her life.”

- All lives have value and all deaths will be grieved, regardless of one’s level of functioning at the time of death.
- Disabled people are concerned that their wishes would not be followed at the end of their lives. Clinicians can discuss these fears with patients and identify themselves as advocates in ensuring that their wishes are followed.
- Along with disability status, many factors impact patients’ relationship to the death and dying process, e.g. religion, family structure and legacy of access to medical care.