

WHAT DOCTORS SHOULD KNOW ABOUT HEALTH CARE FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

Individuals with intellectual disabilities wrote health stories for health care and research advocacy and this is what they said.

Knowledge is Empowering

Individuals want to be agents in their own health care. They want to know about things that could make their chronic conditions worse and how to prevent them from happening.

- *"I am wondering what food and drinks I can have and what I should avoid."*
- *"I am also worried about diabetes... obesity is often a health condition that is not talked about by doctors to people with ID."*



Use Accessible Language

Individuals want doctors to explain the complexities of their medical conditions in an understandable way so that they can take proper measures to improve or stabilize their health.

- *"When I have doctor visits, I wish my doctor would ask me if I am understanding what is happening and what is being said to me."*



Provide Individualized Accommodations

People with intellectual disabilities want to be heard and respected by their doctors. This requires that doctors communicate directly with them in a manner that is both individualized and accommodating of their specific needs.



- *"I ask [doctors] to speak directly to me and not just my family members."*
- *"I wish doctors would speak slower and clearer."*
- *"It is easier for me to understand what someone is saying when they are standing in front of me instead of on the side or behind me."*

Acknowledge Health Efforts

Individuals are proactive about their health, and work hard to be happy and healthy. They want their doctors to acknowledge these efforts.

- *"I wish my doctor would ask me what I do to exercise or stay involved because I want to share all of my involvements that keep me healthy."*



Recognize Multiple Identities

Doctors should view patients with a broad lens and recognize their multiple identities.

- *"My doctor is one of the best doctors. She talks to both me and my mom. She is gentle and has good bedside manners. She is also experienced in working with people with intellectual disabilities as she also works with other Special Olympic Athletes."*



WHAT HEALTH SYSTEMS SHOULD KNOW ABOUT HEALTH CARE FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES

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Educate Doctors

Individuals want to educate current and future doctors about issues specific to individuals with intellectual disabilities.

- *"I wish doctors knew more about my health condition."*
- *"I wish my doctors would understand that people with Down syndrome are going to have different health recommendations. Health information is constantly changing, and I want my doctors to be up to date and be able to provide the best health care for people with Down syndrome."*



Consider Sensory Experience in Facility Design

Facilities should consider how to accommodate people who may be sensitive to sensory stimuli.



- *"They should make waiting rooms more friendly to people who are sensitive to light or sound or smells."*
- *"I don't like going to the emergency room when I'm in pain because it doesn't help. Even though they give me medicine, the lights and sounds and pokes can make it even worse."*

Telehealth Services

Health systems should continue to offer telehealth options to clients, in addition to in-person visits, after the COVID-19 pandemic, and insurance companies should continue to cover these visits.

- *"I would like to keep telehealth services after the pandemic. This would be very helpful so that I don't have to travel so far."*



Expand Insurance Coverage

Insurance companies and medical providers should work together to increase coverage across health care providers and include a wider range of health care services.



- *"I believe that all dentists should need to accept patients like me and patients with all types of insurance...please consider working on policies that would require all dentists in the state of Wisconsin to accept patients like me with my insurance so that I too can stay healthy."*

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