

Health Disparities in Individuals with Intellectual and Developmental Disabilities

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This Presentation Will Cover

- Health Disparities Experienced by People with ID/DD
- Barriers Leading/Relating to These Disparities
- Strategies to Reduce Health Disparities

Developmental Disabilities

- A developmental disability (DD) is a severe, long term disability beginning prior to age 22 that affects cognitive functioning, physical functioning, development of adaptive skills or some combination of these impairments.
- Approximately 4.5 million people in the US have a developmental disability.⁸
- People with DD have the same healthcare needs as any other person, including access to culturally competent medical, dental and mental health care, access to wellness and preventative services, care coordination and accessible healthcare facilities.⁸
- People with DD are at increased risk of some medical or psychiatric conditions related to their disability, including seizure and other neurological disorders, dementia and psychiatric/behavioral disorders.³

Health Disparities Experienced by People with DD

- More likely to report being in poor health.^{5, 8}
- Shorter average life expectancy than the general population.⁶
- Less likely to receive preventative screenings and vaccinations.^{2, 7, 8}
- Higher rates of undiagnosed hearing and vision impairments.^{3, 6}
- Higher rates of obesity.^{3, 6, 8}
- Higher rates of poor dental health.^{2, 8}
- Higher rates of diabetes, arthritis and cardiovascular diseases, including asthma.³
- Most common causes of death differ from the general population and show higher rates of mortality due to illnesses/conditions less likely to lead to death in the general population.^{2, 6}
- More likely to have poorly managed chronic health conditions.^{2, 3, 6}
- Higher rates of prescribed psychotropic medication.^{1, 6, 8}
- People needing behavior support show higher rates of many disparities than others in the DD population.⁷

Identified Barriers to Health Equity

- People with developmental disabilities lack access to quality health care.
- Quality health care has a variety of components, so there are a multitude of individual barriers that contribute to a lack of access to quality health care for people with DD.
- Barriers to quality health care fall into several categories:
 - Systemic barriers
 - Societal/attitudinal barriers
 - Barriers due to a person's functional limitations related to his/her disability
 - Barriers influenced by factors other than a person's developmental disability

Systemic Barriers

- The US health care system was not designed to accommodate the specific needs of people with developmental disabilities, especially as the life expectancy for people with DD increases.^{2, 8}
- There is a lack of research into health disparities experienced by people with disabilities, including developmental disabilities.^{6, 8}
- Public campaigns for health promotion are typically not inclusive of people with DD. ^{2, 4, 8}
- There are no curriculum requirements for undergraduate pre-med programs or medical schools to provide education that prepares medical professionals to understand and accommodate the specific needs of people with developmental disabilities. ^{2, 8}

Societal/Attitudinal Barriers

- Societally, there are many stereotypes, misconceptions and prejudices towards people with DD. Medical professionals who have had little exposure to people with DD and little education specific to developmental disabilities often carry these attitudes.^{4, 8}
- Societal lack of understanding related to the human and civil rights of people with DD continues to be a barrier to progress in many areas.⁴
- Societal stigmas surrounding receiving psychiatric care or having psychiatric diagnoses may cause people with DD to avoid seeking specialty health care when they need it.
- People with DD and their families/advocates report that negative experiences with health care providers have made them less likely to seek medical care when they need it.⁸

Barriers Related to Disability

- People with developmental disabilities often have functional limitations to their communication skills which create difficulty in communicating their needs to medical providers and understanding recommendations or instructions from their medical providers.
- People with developmental disabilities are three to five times more likely to demonstrate challenging behavior. Challenging behavior may make it difficult to provide treatment to participants and impact a person's compliance with treatment plans.⁷
- Cognitive limitations can be a barrier to understanding when it is important or necessary to seek medical care and to understanding or following treatment plans.
- People with developmental disabilities may have physical disabilities, sensory processing issues and other needs. For example, medical centers, exam rooms and other physical environments where health care is provided are often not fully accessible to people who use wheelchairs or need to avoid bright lighting.⁷
- Medical providers often do not have access to specific equipment that may be needed to provide treatment to a person with a disability.²

Barriers Related to Other Disparity Groups

- When people with DD also fall into racial and other minority groups that experience health disparities, the disparities they experience are compounded.⁶
- There are numerous social determinants of health that contribute to health disparities that are very common in the DD population, including:⁸
 - Low income/socioeconomic status
 - Inadequate or inaccessible housing
 - Unemployment
 - Lack of reliable transportation
 - Lack of social connectedness
- Issues in these areas compound the already significant disparities experienced by people with DD related to their disability.^{6, 8}

Strategies to Address Disparities

- In the same way that there are a multitude of barriers to people with DD receiving quality health care, there are also many recommendations and strategies to improve access to health care for people with DD, in order to reduce the health disparities they experience.
- To fully address the identified barriers to quality health care for people with DD, change is needed on multiple levels of our healthcare system, including:
 - Systemic changes at a federal or nationwide organizational level
 - Systemic changes at a state or local level
 - Individual changes that can be made by medical providers and healthcare practices/organizations

Systemic Changes to Reduce Health Disparities

At a national level:

- Health care reform to reduce funding complexity and fragmentation of health care systems.⁸
- Recognition of people with disabilities, including developmental disabilities, as a demographic group that experiences health disparities by government agencies tasked with studying and making recommendations to reduce health disparities.^{6, 8}
- Efforts to make public health initiatives more inclusive and accessible to people with disabilities.^{2, 4, 8}
- Creation and standardization of curriculum requirements for undergraduate medical programs and medical schools to ensure medical professionals receive education on the specific needs and human rights of people with disabilities.^{2, 8}

At a state or local level:

- Continued efforts to address issues of poverty, inadequate housing and accessible transportation.⁸
- Efforts to make statewide or local public health initiatives more inclusive and accessible to people with disabilities.^{2, 4, 8}
- Improve data collection on demographic information related to disabilities.



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Changes at the Provider or Health Care Organization Level

- Medical providers may benefit from continuing education to increase understanding of the specific medical needs of people with developmental disabilities.⁸
- Medical providers may benefit from continuing education on the human rights issues and societal stigmas and stereotypes faced by people with developmental disabilities.⁴
- See each patient as a whole person, not just their disability.^{4, 11}
- Encourage self-advocacy and self-determination for patients with DD.¹¹
- Ensure that the physical environment in which health care is provided is accessible to people with all types of disabilities and that specialized medical equipment needed to treat people with disabilities is available.
- Maintain awareness of programs and resources available to support people with developmental disabilities in various aspects of daily life and refer patients to resources that may benefit them.
- Encourage patients with DD to seek treatment from specialists if a provider feels like he/she is not well equipped to manage the specific needs of the patient.
- Offer patients with developmental disabilities the same preventative health care that is offered to all other patients.

Changes at the Provider or Health Care Organization Level

The following strategies may be helpful in facilitating effective communication with a patient with DD:¹¹

- Communicate with the patient in a respectful manner.
- Be patient and be aware a person with DD may need extra time to speak or act.
- Provide instruction/resources in writing and/or in formats that are accessible to the patient.
- Give patients resources that may help them better understand their medical conditions, even when they don't request it.
- Encourage patients who struggle with communication to write down their questions and concerns before each visit.
- Give clear instruction when a patient needs to return or see another medical provider (e.g. for follow-up, for specific symptoms, for specialized health care, etc.)
- Be proactive in asking for additional information when treating a person with DD to help manage barriers that may arise related to challenging behavior, communication limitations and physical accessibility concerns.

In Conclusion...

- People with developmental disabilities face many obstacles in their lives. Lack of access to quality, culturally competent health care and the resulting poorer medical outcomes should not be an obstacle they face.
- Systemic changes are complex and take time, but there are things that each of us can do today to begin working towards a health care system that is inclusive and supportive of people with DD.
- Everyone in the health care field has the opportunity each day to be an advocate for people with DD, with our colleagues and employers, and in our society.

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