



A Primer on Health Disparities in People with Intellectual and Developmental Disabilities from Racial/Ethnic Minorities

Physician's

FACT SHEET

Background

In the United States, racial and ethnic minorities consistently experience worse outcomes and greater morbidity and mortality rates compared to non-minorities.¹ The Institute of Medicine (IOM) has long stated that disparities in healthcare do exist, presenting in various forms such as stereotyping, clinical uncertainty, prejudice, and across providers and health systems.² Similarly, people with intellectual and developmental disabilities (IDDs) are a minority group that has also had worse health outcomes compared to people without disabilities. An intellectual disability may affect an individual's ability to learn or adapt to social situations and a developmental disability is a broader category that can cause delays in the function of physical and/or intellectual skills.³ People with disabilities are not currently designated by the NIH as a health care disparity population, but many of them are vulnerable to co-morbid conditions and have significant unmet healthcare needs.⁴ The intersection of racial/ethnic minorities with IDDs unfortunately have been found to have worse health outcomes than non-minorities.

Findings about healthcare outcomes in racial/ethnic minorities with IDD:

- Black people with IDDs have higher mortality rates.⁵
- All minority groups have less access to disability benefits, community services, and routine care.^{6,7}
- Black and Latino children with autism spectrum disorder were found to receive lower quality of healthcare⁸, delayed diagnoses, and less access to services.⁹
- The life expectancy for black people with Down syndrome is much lower than for white people with DS, potentially due to factors including socioeconomic status, community support, and access to preventative care.⁹



Recommendations

Clinical recommendations for physicians and healthcare workers

- Enter every interaction with cultural competence in mind.
 - » This does not mean that you need to know much about a patient's culture prior to the interaction, but that you are open to learning about their experiences and how their culture may affect their care.
 - » Ask patients to explain their values to you.
 - » Have frank discussions with patients about their race/ethnicity, Socio-economic status, disabilities, and other factors that may affect their health care.
- Make sure that patients and their caregivers fully understand the information they are presented with.
- When creating a treatment plan, consider outside factors like family dynamics, social barriers, and local resources.
- We all have biases. You can help minimize the impact that has on healthcare disparities by taking the time to learn about your own biases.

- » The American Medical Association recommends the Implicit Association Test, a free online tool from Harvard University.¹⁰
- » Have honest conversations with people you trust. You can ask fellow colleagues for their feedback on how you can improve unconscious biases.



Non-clinical recommendations

The MUP (medically underserved population) designation is assigned by the federal government to populations that are unable to access necessary quality health care. We recommend the federal government to give racial minorities with IDD a MUP designation, so incentives may be created for physicians to serve this population, for community grants, and more training on caring for people with IDDs.¹¹

- You can reach out to your local or state government for petitions to sign or other ways to get involved.
- Look into community resources about access to care, subsidized medication programs, and social services that you can offer your patients if needed.
- National health and disability related organizations often feature CE/Webinars on the topic and at their annual conferences (e.g., www.AUCD.org, www.AAIDD.org, www.AADMD.org) and the CDC publishes the Health Equity Matters newsletter.¹²

Summary

The overwhelming majority of research has shown that Blacks and other minority groups with IDDs have less access to healthcare and social services, higher rates of mortality, and lower adherence to treatments. In certain subgroups of IDDs, racial/ethnic minorities have delayed diagnoses and less knowledge about their disability compared to non-minorities with IDDs. Many of these disparities may be the result of structural or systemic issues, such as socioeconomic status and access to care. However, it is important for every clinician to recognize and reduce these healthcare disparities in ways they can control – listening to your patient’s perspective, having active discussions together, and considering those structural issues when creating a plan for your patient.

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