

Intellectual & Developmental Disabilities: A Narrative Review of Racial/Ethnic Disparities in Healthcare Outcomes

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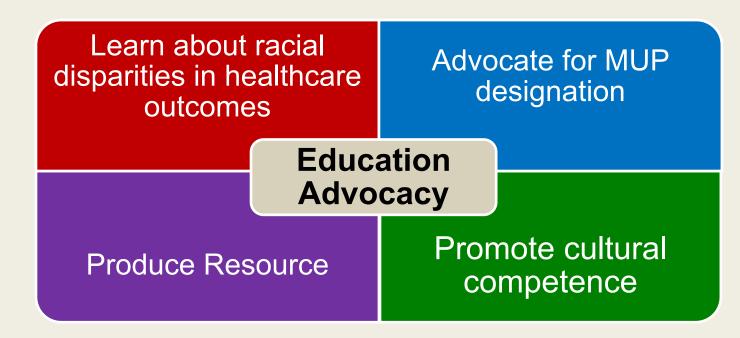
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Introduction

- Racial and ethnic minorities in the U.S. consistently experience worse outcomes and greater morbidity and mortality rates compared to non-minorities¹
- The Institute of Medicine states that disparities in healthcare do exist across providers and health systems and may present in forms such as stereotyping, prejudice, and clinical uncertainty²
- People with intellectual and developmental disabilities (IDDs) are a minority group that has also had worse health outcomes compared to people with disabilities³
- 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 needs⁴
- Factors like race/ethnicity, poverty, and low education can compound the disability's impact and lead to a much poorer quality of life⁵

Objectives



Method

Using the databases and keywords identified in the next column, we identified 65 articles. The articles for this study were deliberately limited to the U.S. population. We purposely chose to search the broad category of IDD as well as specific disabilities that are most encountered. The 30-year period since 1990, including the pandemic period, was used to be comprehensive and inclusive of trends over the last three decades. After completing the literature review, the reference lists of each article were further searched.

•PubMed •Google Scholar •Web of Science •CINAHL •APA PsycInfo

Keywords
Intellectual developmental disabilities
Race/ethnicity
Racial disparities
Healthcare outcomes
Autism spectrum disorder
Down syndrome
Cerebral palsy
Fragile X syndrome
Spina bifida
COVID-19

Results

General Findings

- Black people with IDDs have higher childhood mortality rates⁶
- All minority groups have less access to disability benefits, community services, and routine care⁷
- Many tools used to evaluate children with IDD are not validated for use with non-English speaking children⁸

Autism Spectrum Disorder (ASD)

- Black and Latino children with ASD were found to receive lower quality of healthcare⁹ and less access to services^{10,11}
- The median age for ASD diagnosis was 6 months later in black children than white children¹²
- Black children with ASD were 3 times more likely to receive another diagnosis first, mainly conduct or adjustment disorder¹³

Down Syndrome (DS)

• The life expectancy for black people with DS is much lower than for white people with DS, potentially due to factors including socioeconomic status, community support, and access to preventative care^{10,14}

Cerebral Palsy (CP)

- Asian and Black infants are more likely to get CP compared to white infants 10.15
- The difference in prevalence for Black infants may be due to racial disparities in prenatal care or poverty and increased rates of low birth weight and prematurity¹⁵

Fragile X Syndrome (FXS)

 Patients who utilize FXS clinics are more likely to be white, non-Hispanic, and come from families with incomes of greater than \$100,000¹⁶

Spina Bifida

- The prevalence of spina bifida is higher among Black populations¹⁷
- Black and Hispanic children with spina bifida were found to have a lower probability of survival compared to children born to white mothers¹⁷

COVID-19 Findings

Black and Hispanic populations have greater mortality and prevalence rates of COVID-19 compared to white populations, potentially due to crowded living conditions and preventable underlying comorbidities^{18,19}

COVID-19 Findings (continued)

- Black, Asian, Hispanic, and Native Americans with IDDs were found to have higher COVID-19 rates than their white counterparts²⁰
- Study in New York found that people with IDDs living in group homes had a case fatality rate of 15% whereas the risk for their counterparts without IDDs was 7.9%²¹

Discussion and Conclusion

The intersection of racial/ethnic minority status with IDDs is associated with worse health outcomes than non-minorities. Studies highlighted Blacks and other minorities with IDDs have delayed diagnoses, less access to healthcare and social services, higher rates of mortality, and lower adherence to prescribed treatments. The COVID-19 pandemic has also much higher prevalence and mortality rates among racial/ethnic minorities and people with IDDs. The reasons for these disparities are likely multifactorial, including barriers to care and systemic factors that can affect the quality of care.

Recommendations

- Recommend the federal government to give this population a medically underserved population (MUP) designation
 - Incentives for physicians, community grants, more training on caring for people with IDDs²²
- Healthcare workers should enter every interaction with a knowledge of cultural competence
- Meet the patient in their cultural context and make sure they understand the information presented
- Take into account family dynamics, social barriers, and local resources when creating treatment plans
- Have open communication with others and learn to recognize personal biases.

Resource Development

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

A Primer on Health Disparities in People with Intellectual and Developmental Disabilities from Racial/Ethnic Minorities Background In the United States, racial and erhoic minorities compared in the United States, racial and erhoic minorities are compared in the United States, racial and erhoic minorities are compared in the United States, racial and erhoic minorities (IOAM) has been disparated in mortality states compared to non-eminorities. The Institute of Medicine (IOAM) has been disparated in the United States, racial and erhors and a surveying clinical management of the United States and the Institute of the United States, racial and erhors and an acreeying clinical management of the United States and the Institute of the United States and the Institute of the United States and the Institute of the United States and Institute of United States and I

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