

Date of Council: September 2022

Title of Initiative: *Health Disparities Experienced Among Persons Living with Disabilities*

Program Officers: Sundania Wonnum, Ph.D., LCSW; Larissa Aviles-Santa, M.D., MPH; Michelle Doose, Ph.D., MPH; Priscah Mujuru DrPH, RN; Vanessa Marshall, Ph.D.; Crystal Barksdale, Ph.D.; Yewande Oladeinde, Ph.D.; Olga Herren, Ph.D., Deborah Linares, Ph.D., Michael Banyas, MPA; Simrann Sidhu, MPH

Reviewers: Kimberly S. Johnson, M.D. (Rush University); Lisa L. Barnes, Ph.D. (Duke University)

Objective: The objective of this concept is to support novel and innovative research that applies an intersectional lens to examining and addressing disability health care and outcomes among health disparity populations—i.e., racial and ethnic minority groups, sexual and gender minority (SGM) groups, and people with lower socioeconomic status (SES) or in underserved rural areas. Resulting initiatives will support science that advances our understanding of and efforts to mitigate the underlying causes and pathways adversely impacting the health and well-being of adults and children living with disabilities among populations with health disparities.

Background: The population of persons living with disabilities in the United States is heterogeneous, comprising 24-26% of adults and 4.3% of children of diverse backgrounds, life circumstances, and health conditions. The Americans with Disabilities Act (ADA) broadly defines a disability as a “physical or mental impairment that substantially limits one or more major life activities” (mobility, cognition, independent living, hearing, vision, and self-care). Impairments of mobility (13.7%), cognition (10.8%), and independent living (6.8%) are most common among adults, and impairments of cognition (4.4%) are most common among children. For purposes of this concept, NIMHD operationalizes disabilities as physical impairments present at birth or resultant of an injury, serious mental illnesses (SMI), and intellectual developmental disorders (IDD) and that indefinitely limit functioning.

In general, individuals living with disabilities experience poorer overall quality of life (QoL) and health, shorter lifespans, and more barriers to timely and comprehensive health care. Health care challenges include greater likelihood than other groups of not having a usual or primary health care provider; experiencing avoidable hospitalizations; having unmet medical, dental, and behavioral health needs; and lacking resources needed to perform instrumental activities of daily living. Consequently, there is a higher prevalence of preventable and chronic, complicating comorbidities among persons living with disabilities compared to the overall adult population, including obesity (38.2% versus 26.2%), nicotine dependence (28.2% versus 13.4%), diabetes (16.3% versus 7.2%), and heart disease (11.5% versus 3.8%). Furthermore, the objective signs and subjective experiences of disabilities are often dynamic, changing in nature, quality, and severity over time. Disabilities are further contextualized based upon social determinants of health (SDoH) with multidirectional influence on one’s ability to thrive, such as limited access to

health care, resources, and supports. This concept highlights SDoH experienced among adults and children living with disabilities among health disparity populations and some important scientific gaps. However, the paucity of intersectional research in this area, which spans levels and domains of influence across the lifespan, underscores NIMHD's call for more focused study.

Health disparities are greater among persons living with disabilities, and even more so among those who also belong to populations that already experience health disparities, such as racial and ethnic minority groups, underserved rural communities, people with lower socioeconomic status (SES), and sexual and gender minority (SGM) groups.

- Among racial and ethnic minorities, disability rates are markedly higher (Black, non-Hispanic 27.1%, Hispanic 30.4%, Native Hawaiian or other Pacific Islander 29.4%, American Indian or Alaska Native (AI/AN) 39.1%, multiracial 32.8%) compared to their White, non-Hispanic counterparts (23.5%).¹
- Adults living in rural communities are 9% more likely to have any disability and 24% more likely to report having three or more disabilities compared to adults in urban areas. Such individuals may also face barriers to health care access, including inadequate economic resources, transportation, education, and vocational or rehabilitation services.
- Adults with lower SES living with disabilities experience higher rates of unemployment and poverty correlated with diminished capacity for independent living (e.g., adverse living conditions, housing instability, food insecurity, transportation limitations, social isolation, and disaster unpreparedness).
- SGM adults commonly experience multilevel challenges to accessing SGM-specific physical and mental health care; however, barriers are compounded for SGM persons also living with disabilities.
- Adults living with SMI account for approximately 5.6% of the U.S. population; experience higher rates of obesity, diabetes, and hypertension; and consequently have up to three times higher mortality rates. SMI and associated disparities are more prevalent among racial minorities, particularly among multiracial (9.9%) and AI/AN adults (6.6%).
- Common health disparities experienced by African American, Hispanic, and AI/AN adults are greater use of crisis-based care (e.g., emergency or psychiatric emergency services) instead of community-based services, sometimes or often resultant of interactions with law enforcement; a higher rate of involuntary hospitalization upon help-seeking; overdiagnosis of schizophrenia; higher dosing of antipsychotic medications; and lower treatment rates for co-occurring depression.
- Among persons of childbearing age, 12% live with at least one disability and are at a higher risk for maternal morbidities including preeclampsia and eclampsia, gestational diabetes, placenta previa, postpartum hemorrhage, fever, infection, and death.
- Pregnant persons living with IDD among racial and ethnic minority groups are more likely to experience preterm birth or stillbirth and to deliver babies with low birth weight than their non-minority counterparts.

- There is a lack of research to develop appropriate or adaptable clinical practice guidelines for pregnant persons with disabilities, and to better understand the effects of health risk behaviors, such illicit substance use and opioid abuse, on this population.

While the challenges that persons living with disabilities among health disparity populations experience are generally known, the discrete differences, layers of overlap, types of and relationships among factors, and severity outcomes across and within multiply marginalized groups warrant much more study.

Experiences of health and QoL for persons with disabilities among health disparity populations may be adversely intensified by structural and implicit biases and/or discrimination (e.g., ableism and clinical misperceptions) within health care systems and medical education. Non-adaptive clinical facilities, equipment, and communication mechanisms, as well as non-inclusive clinical care guidelines and procedures impede equitable access to appropriate, full-scope health care when needed, or lead to erroneous attribution of symptoms related to the primary disability rather than a new or co-occurring diagnosis or health crisis. Thus, when aggregating and examining individuals’ disability condition(s) and functional impairment throughout the lifespan and their interface across levels and domains of influence, health and QoL can be grossly complicated among health disparity populations.

Scientific Gaps: Existing research largely focuses on a specific disability, age group, or demographic rather than representative samples showing between or within groups group characteristics across the lifespan. This is in part due to limited disability data collected by health care systems and public health entities. An analysis of recent NIH-wide grants yielded 292 funded studies, the majority of which focused on disability conditions not necessarily within the context of a health disparity population (Table 1). A focused review of the types of scientific projects funded across 6 institutes (National Eye Institute (NEI), National Institute on Aging (NIA), *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), National Institute on Deafness and Other Communication Disorders (NIDCD), National Institute on Mental Health (NIMH), and NIMHD) uncovered 118 disability-related studies, which were predominantly clinical trials (Table 2). This limited quantity and diversity of studies funded across NIH is indicative of gaps in the current research of disability health and health care among minority or health disparity populations. This underscores the need for targeted research to better understand the range of intersectional factors and mechanisms influencing unique health disparities, and to develop actionable strategies to mitigate their impact on health outcomes and QoL.

Table 1: Funded Research on Disabilities FY 2018-22

Project Focus	No. of Projects
Disability conditions (all ICs)*	292

Disability conditions (NICHD)**	37 (12.7%)
Disability & disparities (NIMHD)	9 (3.1%)
SMI & disparities***	11 (3.8%)
Disability & finances/housing/food	28 (9.6%)
IDD & finances/housing/food	1 (0.3%)

*Excludes: HIV, cancer, pain

**Co-funded w/NIMHD

***Co-funded NIMHD & NIMH

**Table 2: Focused Review of Science of Six Institutes FY 2018-22
(NEI, NIA, NICHD, NIDCD, NIMH, NIMHD)**

Types of Science	No. of Projects
Clinical trials/research	48 (40.7%)
Bioinformatics/engineering	17 (6%)
Behavioral	14 (5%)
Health Services Research	12 (4%)
Mechanisms of disease	8 (3%)
Translational	10 (3%)
Basic Research	7 (2%)
Epidemiological	2 (0.6%)
Total	118

Areas of research interest for persons living with disabilities among populations living with health disparities include but are not limited to:

- **Population-based study to understand health outcomes, which identify and address:**
 - Differences between and/or within groups, intersectional characteristics, and factor interactions or effects.
 - Population health strategies to reduce complicating health risks or to increase protective factors across domains of influence (i.e., biological, behavioral, environmental, sociocultural, and health care systems).
- **Multilevel examination or evaluation of health care systems, structure, and services influencing health outcomes, which address:**
 - Factors and mechanisms influencing health care access, delivery, quality, utilization, screening, treatment, medical specialty/surgical referrals, and emergency preparedness or disaster response.
 - Effectiveness of training models and practices focused on disability competencies and structural biases (e.g., ableism).
- **Development, testing, implementation, and/or evaluation of integrative care models and interventions, which address:**

- Factors affecting adaptation, inclusivity, and equity of comprehensive healthcare and services.
- Clinical practice guidelines or processes (e.g., decision making, communication, coordination behaviors, collaboration) for the prevention, diagnosis, care, and management of multiple and/complex conditions across domains of influence.
- **Study of behavioral health interventions and social care services influencing health outcomes, QoL, and capacity-building, which address:**
 - Clinical, community, or home-based prevention and interventions to improve instrumental activities of daily living (e.g., communication, transportation, finances, housing, food, employment, health management, safety) and self-agency.
 - Interventions to improve behavioral health, mental health, and substance abuse care access, engagement, and quality across levels of influence (i.e., individual, interpersonal, community, and societal).
- **Study of underlying determinants, causes, pathways, and progression of disability conditions and diseases, which address:**
 - Characteristics and courses of disabling physical impairments, serious mental illness, and developmental disorders.
 - Longitudinal examination of the courses of disabilities and associated comorbidities or co-occurring conditions.