

# The Double Burden: Health Disparities among People of Color Living with Disabilities



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## Introduction

Public health and health policy experts agree on the need to assess health disparities and healthcare inequities experienced by historically disadvantaged groups and subpopulations of interest. However, these assessments often fail to consider the significance of collecting data on members of historically disadvantaged groups and subpopulations *with disabilities*. This evidence-based policy brief discusses the need to collect disability data and/or identifiers, together with racial and ethnic data, based on the “enormous health disparity amplifying phenomenon” and “double burden” of disability on racial and ethnic minority status to improve the health of *all* people of color.<sup>1</sup>

## Background

The inclusion of disability as a personal identifier in the evaluation of population health benefits many. Disability constitutes the largest underserved group in America (1 in 5 individuals) and intersects with all historically-disadvantaged and underrepresented racial and ethnic groups.<sup>1</sup> Prevalence of disability varies across racial and ethnic groups and is widespread: The 2010 U.S. Census reported that 22.2% of African Americans, 14.5% of Asians, 17.8% of Hispanics, and 17.6% of non-Hispanic whites have a disability.<sup>2</sup> However, these numbers fail to show the enormous health disparity amplifying phenomenon that individuals from minority racial/ethnic groups who also have disabilities confront.<sup>1</sup> In fact, the HHS Advisory Committee on Minority Health has described living as a member of a racial or ethnic minority group with a disability as a “double burden” due to the added sociopolitical challenges encountered.<sup>3</sup> As powerfully stated by researchers, the “omission of disability as a critical category in discussions of intersectionality [with race and ethnicity] has disastrous and sometimes deadly consequences for disabled people of color caught at the violent interstices of multiple differences.”<sup>4</sup>

Disability is often misunderstood and under-recognized as a disenfranchised subpopulation. The World Health Organization (WHO) defines disability as any health condition resulting in impairments (i.e. problem in body function or structure), activity limitations (i.e. difficulty executing tasks), and participation restrictions (i.e., limitations in the ability to participate in life situations).<sup>5</sup> Disabilities can be identified at birth or acquired throughout the lifespan. Historically, disability has been mistakenly described by many as an adverse health outcome, rather than a lifestyle for millions of Americans. More accurately, people with disabilities should be viewed as a community of individuals who share a unique culture and collective lived experiences. Unfortunately, these experiences often include instances of institutionalized discrimination. Public health experts often innocuously exclude disability from discussions of social determinants of health due to misinformation or misunderstanding surrounding disability and health.<sup>6</sup> Knowledge barriers may prompt erroneous assumptions that people with disabilities cannot achieve a state of health and wellness. The WHO makes the distinction between health and disability in its International Classification of Functioning (ICF).<sup>5</sup> Accordingly, individuals with disabilities are not destined for a life of poor health status by virtue of their disability; rather it is the lack of institutional support for this underserved population that contributes to their poor health outcomes, a phenomenon seen among all historically underserved populations.

## Health Disparities at the Intersection of Race and Ethnicity *and* Disability

Recent efforts, including the Patient Protection and Affordable Care Act, have driven the availability of data on disparate social determinants of health and health outcomes for people with disabilities. As this data unfolds, it reveals startling information showing that members of racial and ethnic minority groups who have a disability face greater health disparities and inequalities than do their peers without a disability. Data from the 2012 Behavioral Risk Factor Surveillance System (BRFSS) show that approximately 50% of Hispanic and African American individuals with a disability

rated their health status as fair or poor, compared to 41.5% of non-Hispanic, white individuals with a disability.<sup>7</sup> This data is of particular concern, considering only 9.7% of people *without* a disability rated their health status as fair or poor.<sup>7</sup> BRFSS data from 2011 indicated that people of color with a disability are more likely to report fair or poor health, be obese, have a chronic health condition, and have greater difficulty accessing care than do racial and ethnic minorities without a disability.<sup>1</sup> In 2013, BRFSS included items related to functional types of disability (i.e. vision, cognition, mobility, self-care, and independent living) in its survey and discovered that African American, non-Hispanic adults reported the highest prevalence of each type of disability.<sup>8</sup> Data from the National Health Interview Survey (NHIS) show that people with both mobility limitations *and* minority status experienced *greater* health disparities than adults with *minority status or mobility limitations alone*. These individuals with both mobility limitations and minority status experienced worsening health, more difficulty with activities of daily living, depressive symptoms, diabetes, stroke, visual impairment, obesity, low participation in physical activity, and low workforce participation.<sup>9</sup>

The enormous health disparity amplifying phenomenon and double burden of people of color who are also individuals with disabilities presents more startling data. For example, African Americans and Hispanics with peripheral arterial disease and diabetes experience a greater incidence and odds of non-traumatic amputation – between 1.5 and 4 times higher – and at a higher amputation level when compared with non-Hispanic whites.<sup>10</sup> This is especially troubling when one considers the disparities in the rate of diagnosis of diabetes – itself a disability – by race and ethnicity. According to the 2014 National Diabetes Statistics Report, the rate of diagnosed diabetes by race and ethnic background are 15.9% of American Indians/Alaska Natives, 13.2% of non-Hispanic African Americans, 12.8% of Hispanics, 9.0% of Asian Americans, and only 7.6% of non-Hispanic whites.<sup>11</sup>

Other significant health disparities exist at the intersection of race and ethnicity and disability. For example, white people with Down syndrome in the U.S. had a median death age of 50 in 1997, while the median age was 25 for African Americans with Down syndrome, and only 11 for people of other races with Down syndrome.<sup>12</sup> Additionally, health care providers prescribe fewer pain medications to African American patients than white patients, a disparity which is likely to disproportionately affect African American patients who also have disability.<sup>13</sup>

Health disparities affect the ability of older adults to live independently. Based on the national survey data from “Assets in Health Dynamics of the Oldest Old,” one study found that during a two-year period, nearly 20% of African American individuals age 70 and older lost the ability to perform personal tasks such as eating, dressing and bathing compared to 17% of Hispanics and 15% of whites. Older African Americans (23%) and Hispanics (23%) were more likely than whites (19%) to have difficulty performing household tasks that help them live independently, such as shopping, preparing meals and managing money.<sup>14</sup>

Health disparities at the intersection of race and ethnicity and disabilities are even more profound in the area of mental health. African Americans are diagnosed more frequently with schizophrenia and less frequently with affective disorders, compared with whites who exhibit the same symptoms.<sup>15</sup> Health care providers are more likely to diagnose Asians with schizophrenia than whites, African Americans, or Hispanics.<sup>16</sup> Only 27% of African Americans received antidepressants when first diagnosed with depression, compared with 44% of whites.<sup>15</sup> The 2001 Surgeon General’s report on mental health cited striking disparities in access, quality, and availability of mental health services for Americans who are from racial and ethnic minority backgrounds.<sup>15</sup>

Disability health inequities are currently addressed within the scope of public health planning: Healthy People 2020 prioritizes the wellbeing of people with disabilities in their most recent initiative.<sup>17</sup> People with disabilities were prioritized due to their alarming rate of high-risk health behaviors (e.g. smoking, physical inactivity, etc.) and inequitable allocation of resources.<sup>17</sup> In 2009, the Centers for Disease Control and Prevention (CDC) Report on Health Equity first began to recognize disability status as a significant social determinant of health and included disability status as a personal identifying marker during this time. The addition of disability status as a personal marker yielded rich research incorporated throughout this report.<sup>18</sup> The Institute of Medicine suggests that the federal government, politicians, and health care systems have yet to sufficiently address the growing health issues of the expansive disability community. However, The Patient Protection and Affordable Care Act now includes language and specific provisions calling for the “standards for measurement of disability status and collection of data on disability status for all federally funded health care or public health program, activity, or survey.”<sup>19</sup>

Finally, let us not forget the deleterious effects of barring disenfranchised groups from equitable representation in health research; disability groups do not currently benefit from participation in health research.<sup>20</sup> No regulations are in place to encourage inclusion of people with disabilities in research as currently exist for women, children, and members of minority groups.<sup>21,22</sup>

In light of the impact of the enormous health disparity amplifying phenomenon seen at the intersection of race and ethnicity and disability with the above examples, it is critical that attempts to measure health determinants and health equity among people of color include collection of disability data and/or identifiers. Without this information, policy makers, researchers, and others cannot attempt to address these issues with a goal to improve the health of *all* people of color.

## Social Determinants of Health

Disability-related inequities occur across all determinants of health. Evidence of each health determinants' impact on people of color with disabilities highlights the critical need for the inclusion of disability as a subpopulation of interest when researching people of color. Disability data in the context of social determinants of health impacting racial and ethnic minorities is vital to establish the foundation to improve the health of *all* people of color.

### 1. Access Quality Health Care

As shown above, people of color with disabilities experience an enormous health disparity amplifying phenomenon as they experience racial and ethnic health disparities compounded exponentially by the effects of disability health disparities. Disability-related health disparities are associated with compromised care, preventable morbidity, institutionalization, and premature death.<sup>4</sup> The mental health of people with disabilities is significantly compromised compared to people without disabilities: people with disabilities reported approximately five times more mentally unhealthy days than those in the general population.<sup>23</sup> People with disabilities struggle to obtain access to quality healthcare services due to structural, financial, and cultural barriers.<sup>24</sup> For instance, 27% of people with disabilities in 2010 needed to see a doctor, but did not because of cost. This rate was more than twice the estimated 12.1% of people without disabilities who faced a similar financial barrier.<sup>25</sup>

Despite the passage of the Americans with Disabilities Act (ADA) in 1990, many healthcare facilities still maintain structurally inaccessible waiting areas and examination rooms. Health care providers and health care systems often fail to provide patients with resources to facilitate communication, such as American Sign Language interpreters, even if patients request them. Quality of care is further compromised by biases harbored by health care providers who admit a preference for treating patients without a disability and with private health insurance, as the majority of people with disabilities rely on Medicare and/or Medicaid for health coverage.<sup>26,27</sup> Delay of treatment, especially in preventative care, can result in the development of secondary health conditions or unnecessary hospitalizations, morbidity, and mortality for members of the disability community.<sup>28</sup> This disparate treatment of people with disabilities in the health care system is more readily apparent among racial minorities. As referred to above, African Americans are 50% more likely to undergo an amputation that leads to limitations in functional abilities, which may contribute to higher disability prevalence rates.<sup>10</sup> An Institute of Medicine report suggested that medical service utilization rates among members of racial minority groups with disabilities are unrelated to socioeconomic variables and are likely the result of disability discrimination.<sup>29</sup> Inclusion of disability data as part of research into access to quality health care as a social determinant of health for people of color will shed light on the enormous health disparity amplifying phenomenon experienced by people of color who also have disabilities and will provide data to improve the health of *all* people of color, including people of color who have disabilities.

### 2. Education

In spite of the Individuals with Disabilities Education Act (IDEA), and the ADA, people with disabilities receive an education limited in content by school personnel who often do not expect them to graduate.<sup>30</sup> Well-educated Americans tend to acquire more desirable job positions, earn higher wages, and use more readily available health-conducive resources, such as fresh produce and gym memberships, compared to individuals without a postsecondary education.<sup>31</sup> The lucrative career opportunities afforded to those who attain higher levels of education are of particular importance with regards to health equity. Research has demonstrated that higher socioeconomic status generally leads to better health outcomes.<sup>32</sup> People with disabilities often receive subpar education or fail to obtain a high school diploma. According to data from 2009-2011 published in the CDC Report on Health Equity, 23.3% of people aged 25 or over with a

disability did not complete high school, nearly twice that of people without a disability (11.9%).<sup>33</sup> The rate of high school graduation for students with a disability varies by state, but disparities in high school completion rates are as high as 40% in Georgia and Louisiana.<sup>34</sup>

Completing secondary education can be more challenging for people of color with a disability, lending support for what the HHS Advisory Committee on Minority Health calls the double burden faced by people of color who also have disabilities.<sup>3</sup> Furthermore, while in school, African American children seem to be disproportionately placed in special education classrooms. An estimated 14.8% of the general school-aged population is African-American and yet they comprise 20% of the special education population.<sup>35</sup> Not only do these students receive a poorer education than students without disabilities, African-American students in special education experience additional disparate treatment; African American students who participate in special education services are punished more harshly by teachers than their white counterparts, increasing the likelihood of involvement in the juvenile justice system.<sup>35</sup> Inclusion of disability data collection as part of research into education as a social determinant of health for people of color, will likely shed light on the double burden experienced by people of color who also have disabilities and will provide data to improve the health of *all* people of color, including people of color who have disabilities.

### 3. Income

Poverty is one of the most significant and most commonly cited social determinant of health.<sup>36</sup> Race, ethnicity, and disability are all associated with poverty. In 2012, 27.2% of African Americans lived in poverty, compared with 25.6% of Hispanics, 11.7% of Asians, and 9.7% of whites.<sup>37</sup> However, the poverty rate for people with disabilities is greater than any other demographic group. The poverty rate for people aged 18-64 with disabilities in 2012 was 28.4% - more than twice the poverty rate of 12.5% for people in the same age category without a disability.<sup>37</sup> People with disabilities make up 7.7% of all people in the 18-64 age group, compared with 16.1% of all people in poverty.<sup>37</sup> People with disabilities are oftentimes financially under-resourced: those with disabilities who earn a high school diploma earn on average 37% less than their peers without disabilities.<sup>38</sup> Moreover, 33% of people with disabilities experience economic insecurity, earning less than \$25,000 per year.<sup>1</sup> In general, research indicates that low socioeconomic status impedes quality of and access to health care.<sup>1</sup> Over 4 million Americans with disability rely on Supplemental Security Income (SSI).<sup>39</sup> In 2014, a single beneficiary received \$8,995 of SSI payments, equal to only about 20% of the national median income for one-person households and approximately 23% below the federal poverty level.<sup>40</sup> This despite the fact that it is very expensive to have a disability.<sup>30</sup> People with disabilities experience increased financial burden from significant disability-related expenses, such as unreimbursed medical expenses and therapy costs, catheters, diabetic test strips, hearing aids and batteries, and wheelchair cushions, as well as adaptive clothing, and other adaptive equipment and aids for daily living.<sup>30</sup> These expenses, plus many other factors including barriers to employment, inadequate education, and minimal benefit programs that limit the ability to save money keep people with disabilities in poverty, including people of color with disabilities. People of color with disabilities experience the compound effect of race and ethnicity and disability with an increased poverty rate, plus the many additional barriers to climbing out of poverty. Collection of disability data within the context of gathering data on income and poverty as a social determinant of health for people of color will provide data that can benefit the health of *all* people of color, including people of color with disabilities.

### 4. Environment

Both children of color and children with disabilities experience adversities from the environments in which they live. Children with disabilities are more likely to be exposed to environmental adversities due to living in poverty, disability-related discrimination, and social exclusion.<sup>27,30</sup> This is pertinent because environmental adversities in childhood have been shown to have immediate and long-term negative effects on health and wellness.<sup>41,42</sup> For example, living in poverty exposes all children to environmental contaminants, such as lead paint and toxic waste dumps, and exposure to violence in the communities in which they live, which can lead to physical and psychological trauma, injury, and death.<sup>43</sup> Adults with disabilities face another environmental issue. A significant environmental difficulty for people with disabilities is use of and access to reliable transportation.<sup>30</sup> While the Americans with Disabilities Act of 1990 prohibited discrimination on the basis of disability in public transportation services, these services vary in their level of compliance with the ADA.<sup>44</sup> People with disabilities still struggle to obtain reliable transportation to and from health care

settings and to and from their jobs, if employed.<sup>30,44</sup> Of the approximately 2 million people with disabilities who do not leave their homes, about 560,000 do not leave because of transportation problems.<sup>44</sup> African Americans with disabilities tend to rely on public transit more often than non-African-Americans with disabilities providing further support for what the HHS Advisory Committee on Minority Health calls the double burden faced by people of color who are also people with disabilities.<sup>3,45</sup> Inadequate transportation is a major barrier to obtain and maintain employment, engage in community life, and participate in medical appointments and other healthy lifestyle activities (e.g., physical fitness activities, access to nutritious food, etc.).<sup>44</sup> Inclusion of disability identifiers as part of research into the impact of the environment as a social determinant of health for people of color will likely shed light on the double burden phenomenon and help improve the health of *all* people of color, including people of color with disabilities.

## 5. Employment

Unemployment is prevalent among people with disabilities and especially people of color with disabilities. According to the Bureau of Labor Statistics in 2014, 17.1% of people with disabilities *were employed* in contrast with the 64.6% employment rate of those without disabilities.<sup>46</sup> The *unemployment* rate of people with disabilities was 12.5% in 2014, while the rate for those without disabilities was 5.9%.<sup>46</sup> However, within the disability community, employment rates were lowest for African Americans.<sup>47</sup> According to U.S. Census Figures from 2008-2010, approximately 9,383,365 people with disabilities were employed. Of this population, 68.9% were identified as non-Hispanic white, 13.3% African-American, 12.1% Hispanic and 2.4% Asian.<sup>48</sup> Barriers to employment impede the opportunity to earn wages, reduce access to employer-sponsored insurance, limit opportunities to find meaning and purpose in one's life, and diminish social capital through workforce participation. These barriers for people with disabilities include but are not limited to: discrimination, harassment, stigma, insufficient vocational rehabilitative services, and restrictive Social Security policy that limits monthly earnings to maintain benefits.<sup>47</sup> Collection of disability identifiers in the context of health disparities and health inequities data collection of people of color regarding employment as a social determinant of health can only benefit the health of *all* people of color, including people of color with disabilities.

## 6. Housing

The presence or absence of adequate housing is a significant health indicator for individuals with disabilities and for people of color. Both marginalized populations experience discrimination in housing, substandard housing, and high rates of homelessness. For example, most homeless people are either white (49%) or African American (40%), with an equal number of African Americans and white people found in shelters.<sup>49</sup> Hispanics or Latinos make up 20% of the homeless population.<sup>49</sup> However, in 2015, almost 23% of all homeless individuals on a single night were people with disabilities.<sup>49</sup> Further, two-thirds of these individuals with disabilities were staying in unsheltered locations (e.g., under bridges, in cars, or in abandoned buildings) – more than twice the national rate for all homeless people.<sup>49</sup> The deinstitutionalization of people with disabilities in the 1970's facilitated the movement of people with disabilities into the community and afforded them many psychosocial opportunities and benefits. Still, people with disabilities have difficulties accessing community housing. For example, people with disabilities in Chicago faced discrimination in the housing market on par with that faced by African Americans or Hispanics.<sup>40</sup> Affordability is also a barrier to obtain quality housing – the average monthly Social Security payment could not cover the average rent expenses for a modest one-bedroom apartment in 2014.<sup>40</sup> Even when one controls for income, people with disabilities are more likely to report living in substandard housing than those without disabilities. This includes living in smaller, lower-rated housing units that offer fewer amenities (e.g., air conditioning, dishwasher, and garage) and have more present hazards (e.g., pest or rodent infestations, leaks, physical damage).<sup>50</sup> Unsafe housing can lead to injury or mortality. People with physical disabilities find their housing choices even further restricted by their absolute need for *accessible* housing.<sup>30</sup> While people *without* disabilities face long waits for Section 8 or subsidized housing, people *with* disabilities can wait years for accessible housing through Section 8 programs.<sup>30</sup> Accessible housing may be more costly because it is often newer than inaccessible housing.<sup>30</sup> People with disabilities may incur additional costs and expenses just to make the housing accessible.<sup>30</sup> Further, people who require accessible housing often find themselves isolated because they are unable to visit the homes of friends and family that are not accessible, or their accessible housing is not located near accessible transportation.<sup>30</sup> Research into health equity, health disparities, and housing as a social determinant of health among

people of color must include the collection of disability data and/or identifiers to better equip researchers to assess these systemic problems and the compounding impact of race and ethnicity and disability to improve the health of *all* people of color.

## 7. Safety

Evidence supports the double burden faced by people of color who are also people with disabilities in the area of safety. Data released in 2014 from the Bureau of Justice Statistics' (BJS) National Crime Victimization Survey (NCVS) show that people with disabilities had higher age-adjusted violent crime victimization rates than people without disabilities, in all racial groups measured.<sup>51</sup> Due to limitations in sensory, physical, or mental functioning, people with disabilities are particularly vulnerable to abuse and exploitation.<sup>52</sup> Rates of violence against people with disabilities are staggering: 50% of adults with disabilities reported experiencing violence in the past year, while children with disabilities are more than three times as likely to experience abuse and youth aged 12-19 experience violent crime victimization at a rate nearly 3 times higher than their peers without disabilities.<sup>53,51</sup> Of utmost concern is the lack of proper identification and assessment of violence against people with disabilities. Research indicates that only 20% of women with disabilities living in the community have been asked about abuse by their healthcare provider.<sup>54</sup> Inclusion of disability identifiers in research into health equity, health disparities, and safety as a social determinant of health among people of color will provide data to monitor the safety of the vulnerable population that experience the double burden faced by people of color with disabilities, develop protective services, and improve the health of *all* people of color.

## Conclusion and Recommendations

The evidence is compelling. People with disabilities who are members of racial and ethnic minority groups experience significant health disparities with an enormous health disparities amplifying phenomenon. These individuals experience a double burden with significant inequities in numerous social determinants of health. The study of health equity and health disparities of people of color presents the opportunity to study these phenomena to improve the health of *all* people of color – including people of color with disabilities who face the double burden of disability on top of racial and ethnic minority status. Data collection regarding disability in the context of research into social determinants of health of people of color is vital to create data that can establish the foundation on which to improve the health of *all* people of color. Ignoring and/or excluding “disability status” - a critical factor with a significant impact on the health of people of color - does a disservice to the many people of color who live with this double burden. Health equity research has an opportunity to climb a precipice of inclusion and amass data inclusive of people who face this enormous health disparity amplifying phenomenon and the double burden of disability on racial and ethnic minority status. All health equity research must include disability data collection in the form of disability-related identifiers to ensure comprehensive data about and to improve the health of *all* people of color. The U.S. Department of Health and Human Services implementation guidance on minimum data collection standards for disability lists the following markers, which the U.S. Census Bureau has adopted and incorporated into the American Community Survey.<sup>55,56</sup> The six-item disability standard questions represent a minimum standard. As a standard, the questions and answers must remain unchanged. We recommend that all researchers who investigate health equity, health disparities, or social determinants of health of people of color or other historically unrepresented groups include these standard questions at a minimum in any research that seeks to collect population data. Surveys may include additional questions on disability beyond the minimum standard.

1. Are you deaf or do you have serious difficulty hearing?
2. Are you blind or do you have serious difficulty seeing, even when wearing glasses?
3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)
5. Do you have difficulty dressing or bathing? (5 years old or older)
6. Because of physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

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## Recommended Citation:

Blick R.N., Franklin M.D., Ellsworth D.W., Havercamp S.M., Kornblau, B.L. (2015). The Double Burden: Health Disparities Among People of Color Living with Disabilities. Ohio Disability and Health Program.

ODHP is a partnership between The Ohio State University Nisonger Center, the Ohio Department of Health, the University of Cincinnati University Center for Excellence in Developmental Disabilities, and the Ohio Colleges of Medicine Government Resource Center.