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Parallel tracks: reflections on the need for collaborative health disparities research on race/ethnicity and disability

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The latest definition of health disparities used by Healthy People 2020—the national disease prevention and health promotion agenda for the United States—has now expanded to specifically include people with disabilities as a health disparities population (see Table 1). However, in the past, policymakers interested in health disparities have primarily focused their attention on disparities experienced by racial and ethnic groups other than non-Hispanic whites. Disability disparities research remains little recognized within the broader health disparities field. The two bodies of research relevant to this supplement – research on racial and ethnic disparities and research on disability-related disparities – have evolved along separate tracks, in part due to the legacy of public health policy that funded health disparities research primarily based on race and ethnicity. This commentary reflects on the history, foci, and current status of these two separate tracks of health disparities research. That historical lens offers valuable insight as to why very little of the extant literature focuses on the intersection of race, ethnicity, and disability. We end with suggestions for future research that addresses both disability and race and ethnicity.

Current state of research on racial and ethnic disparities in health and healthcare

Although public health in the United States uses the term “disparity” widely, there are different opinions of what is meant.^{8,9} In general, the term refers to differences in health status or healthcare which are considered both avoidable and unfair. For more than three decades, multiple reports have found disparities to exist across all aspects of healthcare access and quality, for many clinical conditions and many subpopulations including but not limited to those defined by race, ethnicity, gender, socio-economic status, geographic locale and, most recently, sexual orientation. e.g.^{10–14} However, public policy gave scant attention to these disparities until 1985 when a seminal report that examined racial differences in healthcare was issued to the Secretary of the U.S. Department of Health and Human Services.¹³ Among the report’s conclusions was that health care in the U.S. was “a national paradox of phenomenal scientific achievement and steady improvement in overall health status, while at the same time, persistent, significant health inequities exist for minority Americans.” (p. 2).¹³ It is regrettable to note that this conclusion has not changed appreciably in nearly 30 years as evidenced by the most recent National Healthcare

Disparities Report.¹⁴ For example, African-Americans as a whole continue to experience an infant mortality rate that is more than twice that of whites, and Hispanics continue to experience disparities in access to care.

The Office of Minority Health (OMH) was subsequently established in 1986 in the Office of the Secretary to lead public health efforts designed to address the nation's racial and ethnic disparities. OMH however was not charged with implementing a research agenda; its mission was primarily focused on improving health of African Americans, American Indians/Alaska Natives, Hispanics/Latinos, and Asian American and Pacific Islander populations. It was not until 2000 and the passage of Public Law 106–525, the Minority Health and Health Disparities Research and Education Act, that United States' public policy fully focused on the critical need for a national research agenda and infrastructure to address racial and ethnic disparities.¹⁵ This statute authorized the National Institutes of Health (NIH) to establish the National Center on Minority Health and Health Disparities (NCMHD) in 2000. With the passage of the Patient Protection and Affordable Care Act in 2010, the NCMHD was subsequently granted recognition as an NIH Institute.

Public health researchers interested in health disparities have used surveillance to raise awareness of issues to be addressed, conducted measurement research to refine exposure and outcome measures, identified causal relationships in natural settings through etiologic research, piloted potential actions through intervention research, and considered the impact of policies through evaluation research.¹⁶ Data have been used effectively to help prioritize issues; tell the story; provide a base for developing strong, long-term, multidisciplinary team approaches; and develop consensus with stakeholders around the importance of needed change.¹⁷

Specific examples of how epidemiologists and other researchers have impacted on policies to reduce/eliminate health disparities have included development and evaluation of housing interventions to reduce asthma exacerbations, data development (e.g., health equity index), establishing the need for and evaluating moratoriums on new fast food restaurants in communities, and documenting the need for a diverse workforce.¹⁶ Recognition that the process of policy development, implementation, and evaluation is cyclical and requires ongoing data collection and analysis to be effective, has led to success in reductions in disparities in key areas (e.g., closing gaps in childhood immunization; reducing black/white gap in gonorrhea from 60:1 to 20:1).

Thomas et al.¹⁸ have argued that much more needs to be done to effect change in policies and practice. There is a need for health disparities researchers to move aggressively beyond first generation (detection), second generation (understanding), and third generation (provide solutions) research, to fourth generation (take action) research. We would argue that there are still gaps in our knowledge of the nature and extent of disparities experienced by racial and ethnic groups. For example, the Institute of Medicine's Committee on Advancing Pain Research, Care, and Education noted that data weaknesses regarding pain prevalence and care "are particularly important when one is examining racial and ethnic disparities, and only limited data are available on the prevalence of pain in certain population subgroups."¹⁹ Funders such as the National Institutes of Health have also expressed interest in related

topics such as genetics and molecular epidemiology, acculturation and the Hispanic paradox, the intersection between healthcare disparities and the quality chasm, measures of racism and discrimination, health literacy, impact of policy changes on healthcare access and quality (e.g., impact of the Affordable Care Act); and the application of interdisciplinary, community-based participatory research, qualitative and mixed methods, and translational research approaches. Due to ethical, financial and other concerns, alternatives to clinical trials (often cited as the “gold standard”) are being considered for future research studies, such as meta-analysis, outcomes research, post-marketing surveillance, comparative effectiveness studies, and analysis of large multipurpose databases of patient information.

Even when we have some understanding of why health disparities occur, we still need further work in developing and evaluating interventions. For example, the Institute of Medicine’s Unequal Treatment report¹¹ noted that healthcare disparities occur due to multiple factors such as pressures of time and cost-containment, access barriers (e.g., language), health system financial and institutional arrangements and environments, and uncertainty, biases and stereotyping by health care providers. Although cultural competency education and training has been recommended to partially address these concerns, little research has been conducted on the impact of such training on health outcomes.²⁰ Related questions include²¹: what are the best practices, effective teaching methods, and faculty development in health literacy and cultural competency training? Can communication training focused on underserved populations change behavior and enhance patient comprehension? Is there a different impact of programs that aim to change attitudes versus focusing primarily on behavior change? How can we involve patients and community stakeholders in health professional training? These are just a few examples of common research questions that could be better addressed by involving researchers from multiple disciplines.

Current state of research on disability-related disparities in health and healthcare

From its inception, public policy driving health disparities research in the United States has centered on the disease burden affecting populations defined broadly by demographic characteristics of race, ethnicity, and to some extent gender and socioeconomic status. Disability within the body of research on health disparities has primarily been treated as a negative health outcome or as a consequence of aging.²² This interpretation is consistent with a medical model of disability, in which disability is considered a problem (i.e. diagnosis) within the individual. In the medical model, disability is viewed as a negative health outcome, and health professionals are tasked with preventing and curing such outcomes.²³ However, other common approaches for conceptualizing disability include social and integrated models. Social models of disability emphasize the role of environmental barriers (e.g. negative attitudes, physical structures) in limiting full societal participation. Correspondingly, social models stress the importance of social change and modification of environments to maximize access and inclusion.²³ Integrated models, most notably the *International Classification of Functioning, Disability and Health* (ICF),²⁴ incorporate aspects of both medical and social models.²³ In the ICF, disability is an umbrella

term that encompasses impairments (problems in body structure or function), activity limitations, and restrictions in participating in work and social roles. Importantly, the ICF model also includes environmental factors that may interact with impairments to impede or facilitate participation.²⁴

Building on newer models of disability, examination of health disparities affecting people with disabilities is an emerging area of focus in which researchers have only recently begun to document: (1) differences in health status that cannot be solely attributed to the presence of disability, and (2) the provision of disparate health care that is solely attributed to the presence of disability.^{25,26} The field of disability and health research in the United States began to emerge in the late 1980s, with the creation of state disability and health programs funded by the Centers for Disease Control and Prevention (CDC).²⁷ Development of the field was further spurred by the 1990 passage of the Americans with Disabilities Act (ADA), which included requirements pertaining to healthcare settings as well as access to recreation, fitness, and other health-related resources.²⁷ Also in 1990, health targets for people with disabilities were included in *Healthy People 2000*,²⁸ and later expanded in *Healthy People 2010*²⁹ and *Healthy People 2020*⁶(see Table 1). Reports from the Institute of Medicine^{30–32} and from the Office of the Surgeon General^{33,34} highlighting issues, gaps, and research needs related to the health of people with disabilities provided additional impetus for a rapidly expanding body of research on disability and health. McDermott³⁵ noted that 88% of the extant disability and health literature was published after 1990, with an upward trajectory culminating in over 500 articles in the first two months of 2013 alone. Much of the literature in the field of disability and health is grounded in the ICF framework of acknowledging individual impairments while seeking opportunities to reduce barriers to optimal health and full participation.

The concept of “optimal health” for people with disabilities may require some explanation for those accustomed to thinking of disability as equivalent to poor health. Contemporary views separate the concept of disability as “functional limitation” from that of health.³⁶ There are strong associations between chronic disease and disability,^{37,38} and poor health is much more common among people with disabilities than those without disabilities.³⁹ Yet more than half of people with disabilities describe their health as good, very good, or excellent^{39,40} so it is clearly possible to have a disability and enjoy positive health. When disability and health are understood as two separate constructs, an individual can be at any point along either continuum.³⁶ For example, a Paralympic athlete, despite having certain functional limitations, may have better general health and cardiovascular fitness than a sedentary individual with no disability.⁴¹ One goal of disability and health researchers is to determine how much of the poor health experienced by people with disabilities is attributable to modifiable factors (e.g. health behaviors; access to and quality of healthcare) and therefore preventable.⁴²

Disability research has been complicated by the heterogeneity of the population (encompassing multiple types of disabilities of varying severity and duration) and the lack of a clear consensus about how to operationalize measurement of disability in various data sources.⁴³ Those challenges notwithstanding, a body of research has been built over the past two decades examining healthcare disparities impacting people with disabilities. For

example, numerous studies have found that women with disabilities are less likely than women without disabilities to receive timely screening for breast and cervical cancer.^{e.g.44}

Another important area of study has identified specific barriers people with disabilities experience when attempting to obtain healthcare. Barriers include economic and systemic factors (e.g. insufficient insurance coverage for specialized or ongoing services; inability to afford needed care; poor coordination of care) along with lack of knowledge, negative attitudes, and discrimination on the part of healthcare providers.⁴⁵ Further, the ADA is enforced only in response to patient-driven complaints or lawsuits filed with the federal government or the courts.⁴⁶ Healthcare facilities do not have to demonstrate ADA compliance in order to be accredited.⁴⁷ The lack of ADA enforcement has allowed structural and communication barriers (e.g. offices and exam tables that are not wheelchair accessible; failure to provide sign-language interpretation services) to remain substantial impediments for people with disabilities.^{45,48} Indeed, the observed disparities in cervical cancer screening are likely attributable in part to particularly poor accessibility of gynecology practices.⁴⁹

Disability disparity research has largely focused on the initial stage of detecting disparities.¹⁸ Research on healthcare barriers has elucidated some potential causes of disparities, and more recent multivariate analyses of population-based survey data have begun to delve more deeply into understanding a range of factors associated with disparities.^{50,51} Yet much of the research to date consists of overall comparisons between people with and without disabilities, with little attention to subgroup differences within the population. Some studies have conducted comparisons for subgroups with different types of disabilities,^{e.g.52,53} but prior to this supplement, only a few studies have examined intersections with other marginalized characteristics, including racial and ethnic disparities among adults with disabilities.^{54–56} Of particular concern is the fact that disability and health research has been of little interest to other health services researchers⁴³ and is poorly integrated into overall health disparities research.^{26,47} A complex array of factors may contribute to the lack of interest and poor integration, including public policy and funding that has not prioritized disability research, the still common view of disability as a medical condition rather than a population group, and the lower value placed on the lives of people with disabilities relative to those without disabilities.

In a 2009 report on the state of healthcare for people with disabilities,⁴⁷ the National Council on Disability (NCD) catalogued evidence of substantial health and healthcare disparities for people with disabilities, noted a number of important research and policy gaps, and issued a series of recommendations. Some of these recommendations were addressed, at least in part, in the Patient Protection and Affordable Care Act of 2010 (ACA). The ACA has been an important development for the disability and health field because it contains several provisions with significant potential for improving access to healthcare for people with disabilities. These include standard-setting for accessibility of diagnostic equipment, disability awareness training for medical professionals, and data collection to document disability-related disparities. Other focal elements are expansion of Medicaid coverage (in participating states); expanded coverage for clinical preventive services, prescription drugs, mental health and substance abuse services, rehabilitative and habilitative services and devices, chronic disease management, wellness services, and home

and community-based services for people with disabilities; and an emphasis on care coordination. Importantly, insurers are now prohibited from denying insurance coverage based on pre-existing conditions, and annual and lifetime caps on benefits have been removed. Passage of the ACA has spurred new research efforts to predict and/or document outcomes for people with disabilities.^{e.g.57}

Unfortunately, many of the NCD's recommendations have yet to be met. Key among them is broadening the definition of "health disparity population" in the Minority Health and Health Disparities Research and Education Act (MHHDRREA) so that people with disabilities can be better integrated into the health and healthcare disparities research supported by the National Institute on Minority Health and Health Disparities and other Federal agencies.⁴⁷ Although the ACA recognizes people with disabilities as a health disparity population, most health disparities research funding is allocated through the MHHDRREA.⁵⁸ Historically, the primary focus of that research has been on race and ethnicity. Yet race and ethnicity intersect with disability in important ways. For example, African Americans, Latinos, and American Indians have increased risk of severe disability resulting from chronic disease (e.g. vision loss and amputation as sequelae of diabetes).^{59,60} Ironically, the health and self-care information that these individuals especially need is very rarely available in alternate formats (e.g. large print for people with limited vision). We argue that attention to additional disparities associated with disability is particularly relevant for constituency groups concerned with racial and ethnic health disparities. Indeed, racial and ethnic minorities with disabilities have been identified as an especially underserved and vulnerable group whose needs are important to address as the ACA is implemented.⁶¹

Merging the tracks: Where do we go from here?

Research in both tracks frequently fails to address the multiple cultural identities⁶² within population groups. We hope this supplement encourages racial and ethnic disparity researchers to think about the additional impact of disability, which spans all racial and ethnic groups. Similarly, we encourage disability researchers to consider the high degree of diversity within the disability population, and the ways in which racial and ethnic disparities operate in that population. The opportunity is ripe for researchers from both fields to collaborate on a research agenda to address health disparities at the intersection of disability, race, and ethnicity. Last but not least, we urge funders to promote research portfolios that are inclusive of individuals with disabilities from diverse racial, ethnic, and cultural groups.

Both quantitative and qualitative studies are needed to understand the experiences of people "at the intersection" and determine if the barriers they face are multiplied because of their unique status. Further, there is a need to create and study health disparity interventions that are culturally and linguistically competent for the diverse population of people with disabilities "at the intersection."⁶³ This will require approaches to research that acknowledge and measure myriad cultural differences among people with disabilities effectively, rather than simply using race and ethnicity as proxies for culture. Diversity includes factors beyond disability and race and ethnicity. For example, researchers must also be able to elicit the "experiences of someone who self identifies as African American, female, lesbian, with a disability, who is married to a woman and has children."⁶⁴ Research will prove more

valuable if the culturally diverse populations that are studied have an investment and are active participants in all aspects and phases of the research process. Community-based participatory research approaches should include people with disabilities and the accommodations necessary to ensure their meaningful involvement.

We hope current definitions of health disparities – along with recognition that people with disabilities can be healthy and that many of the causes of their poor health are preventable – will facilitate better integration of people with disabilities into broader health disparities research and prevention efforts. As the diversity of our population continues to increase, and as people with disabilities continue to live longer and fuller lives, we look forward to an era of expanded consideration of disability-related disparities and the ways in which they intersect with race, ethnicity, and other characteristics associated with cultural identity and social determinants of health.

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Table 1

Healthy People Disparities Goals and Inclusion of Disability

Healthy People Year	Disparities Goal	Inclusion of Disability Targets and Data
2000	“Reduce disparities in health status among different populations.” ¹	Disability included in “Diabetes and Chronic Disabling Conditions” focus area (focus area 17). ² “Separate targets have been established to improve the risk and health profile of population groups (e.g., minorities, persons with low incomes, and persons in certain age groups) who have a disproportionate share of illness, injury, disability, and premature death.” ¹
2010	“Eliminate health disparities among different segments of the population.” ³	Separate focus area for disability and secondary conditions (focus area 6). Disability data not available for all objectives. ⁴ Final report lists 13 disability and secondary conditions objectives (focus area 6) with follow-up data; of those, 8 were not tested for statistical significance. ⁵ Four objectives remained developmental (data not yet available) and seven had no follow-up data to measure progress.
2020	“Achieve health equity, eliminate disparities, and improve the health of all groups.” ⁶	Disability is specifically mentioned in the definition of health disparities. ⁷ There are 27 objectives in disability and health focus area, but several are developmental.

[Superscript numbers refer to references in the manuscript’s reference list.]