

# US Disparities in Life Expectancy: Not One “Population Health Iceberg” But Two

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## ABOUT THE AUTHOR

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 See also Farina et al., p. 708.

Using data from the 2013–2017 American Community Survey and the 2017 United States Mortality Database, Farina et al. (p. 708) explored state-specific total life expectancy (TLE), disability-free life expectancy (DFLE), and disabled life expectancy (DLE) by gender for US adults and hypothetical worst- and best-case scenarios.

Their finding is that “stark variation in DFLE and DLE across states highlights the large health inequalities present today across the United States” (p. 708). As the authors argue clearly and thoughtfully, these findings have profound implications not only for individuals’ well-being but also for the US financial costs and medical care burden.

Moreover, this study invites a body of further research. The data sets used for this study do not contain covariates at the individual level (such as education, income, or housing) or state policy level (e.g. tobacco taxes, opting out of Medicaid expansion, weak antipoverty laws, or actively implementing preemption laws) that could add important insights into understanding state and regional

variations. But data to further explore these factors are readily available.

An additional issue that the authors also could not explore given the limitations of their data is that the significant variation by state and by gender may, in fact, be even more striking because for millions of poorer Americans lacking access to affordable health care, identification of disabling conditions may occur long after onset of initial injury or signs of ill health.

The authors labeled the current invisibility of these striking state and regional differences in DFLE and DLE a “population health iceberg.” This is an excellent analogy. The issue of course, is not just finding that there are differences between states. The issue is also what these statistics say about national health inequalities. It asks us what we, both at state and national levels, owe to our fellow citizens—and what we should expect of ourselves as a nation. For my part, I would add that it raises other significant issues, such the United States’ standing as the only high-income country without some type of universal health care and how such a system

could help address these striking disparities.

## AN ADDITIONAL “ICEBERG”

In these findings, I would also argue that the authors raise an additional “iceberg”—routinely overlooked by our public health community. It pertains to the concept of DLE—years of life lived with a disability.

As someone who has long worked on disability research, I am always struck by the facility with which the concept of DLE is invoked and then remains largely unquestioned. Too often, the diagnosis of “disabled” is the clinical and administrative equivalent of crossing the Rubicon—a sudden transformation from a full participant in and contributor to society to epidemiological invisibility.

Living with a disability is complex. There are different types of disabilities—physical, sensory, intellectual, and mental health—and varying degrees of severity. Age of onset<sup>1</sup>—when one becomes disabled—also has significant implications. The life of a newborn with significant intellectual disabilities will be very different than that of a 45-year-old with a newly acquired spinal cord injury. A young man or woman born with a visual impairment may be otherwise perfectly healthy.

Over the past several decades, a large and growing body of research globally shows how much the lives of people with disability are defined and too often limited not by their disability but by a range of socially determined factors linked to a lack of equal access to medical, social, community, and economic support as well as limited educational, employment, and civic engagement.<sup>2,3</sup> People with disabilities are disproportionately poorer, more socially isolated, and less likely to receive

equal access to both general health care and disability-specific health care. All of these are compounding factors that, across the life span, have clearly been shown to increase short- and long-term risks for mortality and morbidity.

Research from the United States clearly reflects these global data. In all too many communities, especially in poorer urban and rural areas, there are limited or nonexistent social services, community nursing, rehabilitation, and mental health services; there is a lack of public transportation; there are ineffective nutrition programs; and there is an absence of a range of other programs and services that we know have direct impacts on the morbidity and mortality of people with disabilities. In addition, restrictive social policies force millions of Americans with disabilities to have to decide to forgo paid full- or part-time employment to be entitled to what benefits are available. Restrictive insurance policies—often arbitrarily administered—prove difficult or impossible to navigate. And a whole new group of studies show that there are always additional expenses when living with a disability.<sup>5</sup>

In addition, too often in terms of community support and legislative decisions, people with disabilities are conceptualized as living in isolation or dependent on others for care and support. It is important to underscore the fact that people with disabilities are also members of families and households. Often they are husbands and wives, mothers and fathers, not only struggling to cope with issues related their own disability but also responsible for their own children, a sick spouse, or elderly parents. The implications at the household level for both immediate and multigenerational poverty are significant.

Moreover, asking that we, in public health, more critically think about what

we mean when we discuss DLE is not just the right thing to do. It is the law. The Americans With Disabilities Act must be a factor in discussions of DLE, related to both services and legislation at state and national levels.<sup>6</sup> Globally, comparable attention to ensuring that people with disabilities have a right to a range of covariates such as health, housing, and income is a cornerstone of the United Nations Convention on the Rights of Persons With Disabilities, now ratified by 182 countries, although, regrettably, not yet by the United States.<sup>7</sup> This legislation has been driven by an international Disability Rights Movement, which over the past four decades has been led for and by people with disabilities themselves.<sup>8</sup> To consign the 1 billion people—15% of the world's population—who according to the United Nations live with a disability solely to discussions of DLE is a missed opportunity to improve population health and well-being.

## IN CONCLUSION

The authors of this important article label the unequal distribution of DFLE and DLE as “the tip of the population health iceberg” (p. 710). They could not be more correct. Their findings have profound implications not only for local and national public health policy but also for questions of equality between states and regions. This study provides a lens for all of us—as a nation—to see what we need to do to ensure equity on a national scale.

And I argue that this study also provides a space for the US public health community to pause and think more broadly and far more critically of what we mean by “DLE.” The authors state “disability is part of a health ‘trajectory’ ending in death” (p. 709). This is certainly true for people with many types of

disabling conditions—but it might also be good to keep in mind that, by this definition, disability is also part of life itself. *AJPH*

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## CONFLICTS OF INTEREST

The author does not have any conflicts of interest to declare.

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