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A Year of Disability Health Equity Milestones: Why Disability Data is Still Needed

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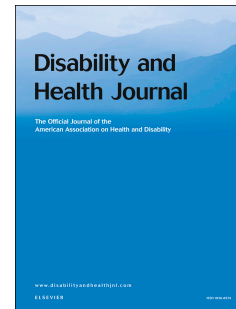
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1 Title: **A Year of Disability Health Equity Milestones: Why Disability Data is Still Needed**

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16 **A Year of Disability Health Equity Milestones: Why Disability Data are Still Needed**

17

18 Three milestone disability health equity related decisions occurred between September 2023 and
19 May 2024: 1) designation of disabled people as a health disparities population; 2) the halting of
20 plans to switch to questions that would underestimate the disabled population in the American
21 Community Survey; and 3) the announcement of a Final Rule tightening regulations under
22 Section 504 of the Rehabilitation Act of 1973. While each milestone represents progress in the
23 path towards disability health equity and highlights the strength of the US disability community,
24 the lack of comprehensive and equitable disability data collection remains a critical barrier to
25 achieving full disability health equity. In this invited commentary, we summarize these
26 milestones and offer three recommendations essential improving disability data collection in the
27 US.

28

29 *National Institute on Minority Health and Health Disparities (NIMHD) Designation of Disabled*
30 *People as Population with Health Disparities*

31 The first milestone was marked by the Director of the National Institute on Minority Health and
32 Health Disparities (NIMHD). In September of 2023, the National Advisory Council on Minority
33 Health and Health Disparities (NACMHD) Working Group on Persons Living With Disability, a
34 working group of the National Institute on Minority Health and Health Disparities (NIMHD),
35 provided an oral report (September 1, 2023)¹ and final report (September 20, 2023)² regarding
36 whether disabled people should be designated as a population experiencing health disparities.
37 The oral report recommended that disabled people NOT be designated as a health disparities
38 population.¹

39 After the September 1, 2023 meeting, there was an immediate outcry from the US
40 disability community led by disabled researchers.^{3,4} Though causality is not clear, the final report
41 of the Working Group did not make a recommendation regarding designation and admitted that
42 no disabled people work members of the Working Group.² Then, on September 26, 2023,
43 pursuant to 42 U.S.C. Section 285t(d)(1),⁵ the Director of the NIMHD designated disabled
44 people as a population with health disparities.⁶ As the NIMHD is the institute authorized to
45 coordinate, review, and evaluate all of the National Institutes of Health's (NIH) health disparities
46 research,^{7,8} this decision will likely expand opportunities for disability health equity research.

47

48 *US Census Bureau Halts Plans to Change Disability Questions in American Community Survey*

49 The second milestone was marked by the US Census Bureau. Based on a request from the
50 National Center for Health Statistics (NCHS), the Census Bureau intended to change the
51 disability measures used in the American Community Survey (ACS) from the ACS-6 questions
52 to the Washington Group questions.⁹ However, these changes moved forward without
53 engagement with the disability community and without considering the societal implications of
54 moving to questions that, per the results of the Census Bureau's own content testing of these
55 questions, would underestimate disabled people by at least 40%.¹⁰⁻¹³ In response to
56 overwhelmingly negative feedback from the disability community and allies,¹⁴ on February 6,
57 2024 the Census Bureau halted its plan to change the ACS disability questions and engage with
58 the disability community to chart a path towards improving disability questions in the ACS.¹⁵
59 Importantly, this discourse elevated a need to reassess how disability data are collected and used
60 across the entire federal government and lead to the creation of the Disability Data Interagency
61 Working Group (DDIWG) tasked with developing a "Federal Evidence Agenda on Disability

62 Equity, in order to improve the Federal government's ability to make data-informed policy
63 decisions that advance equity for the disability community.”¹⁶ At the time of the writing of this
64 commentary, the DDIWG is reviewing feedback garnered via the Federal Register process, with
65 a report anticipated before November 2024.

66

67 *Final Rule Implementing Section 504 of the Rehabilitation Act of 1973*

68 The third milestone was when the US Department of Health and Human Services (HHS)
69 announced a Final Rule tightening regulations under Section 504 of the Rehabilitation Act of
70 1973 on May 9, 2024.¹⁷ The Rehabilitation Act of 1973 is a landmark civil rights law that
71 prohibits discrimination on the basis of disability in settings receiving federal funds. However,
72 this law had not been updated in over 50 years and lacked needed clarity and details to support
73 enforcement. As acknowledged by HHS, the passage of the Final Rule was largely in response to
74 community advocacy informed by data and evidence.¹⁷ The Final Rule prohibits discrimination
75 based upon disability status regarding access to and receipt of medical treatment from federally
76 funded health and human services program inclusive of hospitals, health care providers, nursing
77 homes, and state and local human services agencies. Specifically, the Final Rule prohibits
78 medical treatment decisions that are based on value-of-life assessments or discriminatory views
79 of disabled people, outlines standards for accessibility of websites, mobile applications, and
80 medical equipment in these settings, and clarifies how 504 applies to child welfare programs and
81 home and community based services.

82 Though definite milestones, these wins for the disability community must be considered
83 against the backdrop of larger efforts to advance health equity. A true celebration of disability
84 health equity would be marked with empirical evidence demonstrating that disabled people are

85 experiencing fewer health disparities and improved access to and receipt of quality health care.
86 But we are far from that possibility. Data are necessary to fully comprehend health equity
87 patterns for all minoritized populations, including disabled people.¹⁸⁻²⁴ The limited data available
88 on disability and the health outcomes for disabled people will prevent the full realization of
89 disability health equity possible due to these milestones. Therefore, we suggest three data-related
90 actions that can be taken to ensure that these remarkable milestones result in increased disability
91 health equity.

92

93 **Recommendations**

94 *Recommendation 1: Fund the Development of Improved Disability Measures*

95 In order to have a more accurate estimate of disabled people in US population health surveys, as
96 well as to allow disability data collection for federal agencies such as HHS, it is imperative to
97 create more inclusive disability questions that accurately estimate all disabled people in the US.²⁵
98 Developing improved measures of disability will require moving away from solely using medical
99 diagnoses and/or functional limitations to define disability (e.g., limiting the definition of
100 disability to only include those with a medical diagnosis or functional limitations, or to only
101 those with a select group of functional limitations) to understanding disability as a demographic
102 characteristic.²⁵⁻²⁹ As explained by Breslin and Yee,²⁷ defining and collecting disability
103 demographic information requires accounting for the fact that disabled people may understand
104 and report their disability via multiple descriptors inclusive of conditions, diagnoses, functional
105 limitations, and accommodation/accessibility needs. In addition, for some disabled people,
106 understanding and reporting of disability may involve disability identity,³⁰ while others may do

107 so via administrative categories set by agencies such as the Social Security Administration or
108 Department of Veterans Affairs.^{31,32}

109 While a challenging task, it is imperative to robustly engage with disabled people in the
110 US in order to understand the multiple ways they describe their disability status and ensure that
111 disability measures are inclusive of any variation in reporting. It was a positive sign that the
112 National Institutes of Health released a Notice of Funding Opportunity on addressing disability
113 health disparities caused by ableism in health.³³ But, our ability to assess the impact of root
114 causes of health inequities, such as ableism, on disability health equity is limited if the measures
115 of disability are not accurate.^{10,25,29} As the primary funder of biomedical and health equity
116 research, NIH could create funding opportunities to pursue the development of more inclusive
117 and equitable measures based on understanding disability as a demographic to advance health
118 equity. Implementing this recommendation would lead to more accurate representation of the
119 disabled population in research and policy-making, ultimately enabling more targeted and
120 effective health equity interventions.

121

122 *Recommendation 2: Collect Data to Uphold Disability Civil Rights Laws*

123 In the Section 504 Final Rule, HHS recognizes that “Developing a civil rights data collection
124 scheme can help to ensure that any civil rights data collection yields accurate data that mitigates
125 potential negative impacts and that adequately protects the privacy of individuals.”³⁴ Despite this
126 recognition, the rule states that HHS had to “forgo the imposition” of data collection due to
127 concerns that collected data could misalign with the data needs of other federal agencies.³⁴
128 Limitations in disability data collection severely hampers the scope and impact of this law as

129 well as many other disability civil rights laws, and limits our ability to monitor its
130 implementation or impact and serve as barriers on the road to disability health equity.³⁵

131 While there is ongoing debate regarding how to best measure disability across federal
132 agencies and products, the lack of consensus should not prevent the federal government from
133 collecting and using disability data currently available to ensure the Section 504 Final Rule is
134 being upheld. Further, there are opportunities to develop novel data infrastructures, develop
135 publicly available databases that include information about the availability and locations of
136 accessible medical equipment and metrics of health information website accessibility that
137 support accountability and enforcement of this Final Rule. Implementing this recommendation
138 would lead to more clarity regarding the current state of accessibility among medical providers,
139 as well as experiences of civil rights violations experienced by disabled people within medical
140 settings.

141

142 *Recommendation 3: Require Disability Data Collection in Electronic Health Records*

143 The HHS disability data standards that resulted from the ACA set an important precedent of
144 operationalizing disability as a demographic measure, similar to gender and race-ethnicity. But
145 the restricted and limited application of this policy to national health surveys means that
146 disability data are still not required to be collected in healthcare settings. In order to track
147 inequities in healthcare access and outcomes for disabled people, it is imperative that disability
148 data be collected as demographic in electronic health records (EHR).^{21,22} This would not exclude
149 continued use of diagnostic codes or functional limitation scales in this data, but would require
150 expanding beyond these descriptors to also address the reporting of disability via
151 accommodations/accessibility needs and identity. These data are also necessary to determine the

152 impact of strategies and policies on advancing disability health equity, such as the Section 504
153 Final Rule. There has been substantial research supporting the need to collect disability data as a
154 demographic in EHR to advance health equity.³⁶ While the Office of the National Coordinator on
155 Health Information Technology (ONC) recommended including disability in the US Core Data
156 for Interoperability (USCDI v3) in July 2022,³⁷ the related Final Rule³⁸ released in January 2024
157 categorized disability as a health status, not as a demographic, and lacked sufficient specificity
158 on how disability data should be measured or collected to support a standardized approach. To
159 advance disability health equity and assess the impact of policies and laws such as the 504 Final
160 Rule, EHR disability data must align with the Affordable Care Act's framing of disability as a
161 demographic.³⁹ Additionally, a standard must be adopted for disability, as has been done for other
162 demographic groups, in order to support interoperability, or comparability, across healthcare
163 settings. Implementing this recommendation would lead to more accurate representation of the
164 disabled population in EHR data, ultimately enabling more targeted and effective medical
165 interventions for disabled people.

166

167 **Conclusion**

168 Each of the three disability policy milestones that occurred between September 2023 and May
169 2024 are to be celebrated individually for advancing disability health equity. Collectively they
170 demonstrate the ever-increasing power of the disability community and its allies in helping to
171 shape disability health equity policy in the US, as well as an increased realization among US
172 federal agencies of the need to address disparities experienced by the disability community. Each
173 will require ongoing effort to realize their maximum potential to improve disability health equity.

174 We join in celebrating these milestones. Yet, we contend that until we address a
175 foundational underlying barrier – failure to collect and/or limitations with disability data – the
176 road to disability health equity will remain blocked. To address these data limitations and
177 advance disability health equity, we recommend: 1) funding the development of improved
178 disability measures, 2) collecting data to uphold disability civil rights laws, and 3) requiring
179 disability data collection in electronic health records. By implementing these recommendations,
180 we can create a more inclusive and equitable foundation for disability health research and policy.

181 The recommendations we provide in this commentary will not be easy to accomplish and
182 will require the continued work of the disability community, allies, and federal partners.
183 Improving disability data collection will have broad implications by providing policymakers,
184 healthcare providers, researchers and the disability community with the information needed to
185 better identify and address the inequities impacting disabled people. Disability health equity will
186 not become a reality until we have inclusive and equitable measures of disability as a
187 demographic, and use these measures to collect disability data across data mechanisms.

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