Advancing Data Equity to Improve Health Equity for People With Disabilities (PWD)

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Policy Brief
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Why Does This Matter?

- Up to 26% of adults\(^8\) and 4.3% of children\(^9\) (nearly 70.6 million people)\(^10\) in the US have at least one disability. This is the largest population with consistent health disparities\(^11\) and intersects with all races, ethnicities, genders, ages, and sexual orientations.

- Equity is at the core of public health practice.\(^12\)

- Data Equity is key to health equity.

- Health equity drives cost savings and increases self-reliance and productivity of PWD and their caregivers which can lead to health and economic gains across generations.\(^13,14,15\)

- Health data linked with disability data provide accountability and a basis for trust in leaders who seek meaningful health progress for PWD.\(^16\)

- Disability data gaps hide health disparities and perspectives of PWD, perpetuating harmful biases.\(^17,18\)

- The Americans With Disabilities Act (ADA)\(^19\) is a US law that upholds civil rights protections for PWD under the 14\(^{th}\) amendment.\(^20,21\) Exclusion of PWD from benefits enjoyed by other US populations is illegal.
Implications

Improving disability data equity will inform and empower leaders at all levels with evidence to drive ethical, legal, and fiscally sound decision-making.

- For Research
  The availability of health data linked with disability status and type allows research that compares health outcomes between populations, identifying health disparities. It further enables the detection of their root causes so they can be addressed.

- For Policymakers
  Data equity enables the fair representation of PWD in any body of evidence on which decision-makers rely. Policymakers will have a fuller picture of the prevalence, severity, and distribution of PWD’s health problems and any barriers to healthcare. Further, data equity enables policymaking for future health emergencies, like Covid-19, with information from PWD that can help avoid pitfalls and strengthen the response. Finally, it enables tracking of policy effects on the health of PWD, providing feedback and engendering trust in policymakers who hold themselves accountable for progress on achieving meaningful health equity gains for PWD.16

- For Planning and Practice
  An equitable evidence base permits fairer decision-making, more effective health program planning, and more efficient resource management. Targeting treatment at root causes focuses resources where they are most needed, preventing health problems and shrinking health disparities. This saves healthcare costs, increases the productivity of PWD and their caregivers, and reduces healthcare provider burnout.15

Bridging Research, Practice, and Policy

The National Council on Disability (NCD),23 Center for Medicare and Medicaid Services (CMS),24 the National Academy of Medicine (formerly the Institute of Medicine, IOM),25 and others26,27,28,29,30 have provided both rationale and guidance on achieving data equity for PWD, but broad and consistent communication and proactive support to states will be critical to advancing the work. To promote data equity and sharing for PWD, we need to focus on three areas: 1) ensure that data privacy laws are current and support health equity work, 2) advance policies that require health data systems and practitioners from different organizations to work together, and 3) help to align states’ laws and policies toward an overall goal of data equity and health improvement.31
Facts at a Glance:
- 27% of adults and almost 20% of children (305,218 people) in Maine have at least one disability.
- 26% of adults and 4.3% of children (nearly 70.6 million people) in the US have at least one disability.
- Data biases lead to uninformed decision-making and resource allocation that create and sustain barriers to care for PWD.
- Health equity is less costly than health disparities.

And yet, despite these facts:
- Standardized disability definitions and data systems are needed.
- 3 Types of data gaps exist for PWD. They are the lack of 1) disaggregatable data, 2) granular prevalence data, and 3) data from inaccessible surveillance tools.
- Maine and many other states still have disability data gaps.

Key Takeaways:
- Data equity is vital to health equity for PWD and to powering effective and efficient agency- and community-driven action.
- PWD have a right to health equity like any other US population.
- Frameworks exist for improving data equity for PWD and for achieving equity in healthcare and health emergency planning.

**Recommendations:**
- Optimize the 3 major determinants of US data equity: 1) legal data privacy framework, 2) interoperability of systems, 3) alignment of states’ laws.

To do this, support states:
- Provide consistent rationale and guidance to states about the overarching goal of health equity determined by DHHS and support its achievement with capacity and funding.
- Tie states’ Medicaid and block grant funding to substantive evidence of health equity for PWD.

... And change mindsets:
- Incorporate a focus on the ADA and disability health equity when reviewing equity for other underserved groups.
- Address ableism by enforcing the ADA and incorporating training into professional programs.
- Review and revise federal data privacy laws and provide regular training.
- Harmonize disability definitions, data systems, and language and collect disability data alongside demographics in all federal health & community surveys.
- Designate PWD as a Special Medically Underserved Population under the Public Health Services Act or at least fund research on health challenges for PWD.
REFERENCES:


31. Fong M. Center for Community Inclusion and Disability Studies. Mind the gap: a white paper on Maine’s missing Covid-19 surveillance data, how they perpetuate health disparities for Maine citizens with disabilities, and what can be done to increase Maine’s public health data & service equity. March 30, 2023. (Companion work to this policy brief)


