

Definitions:

Ableism: A culture of mind¹ that values people according to their abilities rather than their humanity and promotes discrimination against people with physical, intellectual, or psychiatric disability²

Data: Facts & figures

Data Gap: The absence or inaccessibility of data

Data Equity: Data collection, analysis, interpretation, and distribution that ensures soundness and fairness in any decisions, predictions, or value derived from it³

Disability: A condition of the body or mind that makes it more difficult for the person with the condition to function and interact with the world around them⁴

Equity: The quality of being fair and impartial⁵

Health Disparity: Preventable poorer health and fewer opportunities to achieve health experienced by one population relative to another⁶

Health Equity: When everyone has a fair and just opportunity to attain their highest level of health⁷

Statistics: Calculated outcomes from manipulation of data

Policymaking: Decision-making about laws, rules, and guidelines by governments and organizations

Practices: Implemented procedures to achieve objectives

Programs: Organized practices to achieve goals

Research: Evidence-gathering

Resources: Assets like people, time & dollars

Policy Brief

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

Why Does This Matter?

- Up to 26% of adults⁸ and 4.3% of children⁹ (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 14th 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 others^{26,27,28,29,30} 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 adults³² and almost 20%³³ of children (**305,218** people)³⁴ in **Maine** have at least one disability.
- 26%⁸ of adults and 4.3%⁹ of children (nearly **70.6 million** people¹⁰) 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.^{15,16,17,18}
- **Health equity is less costly than health disparities.**^{13,14,15}

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.³¹
- **Maine and many other states still have disability data gaps.**³¹

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.**³¹

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.**²³

... And change mindsets:

- **Incorporate a focus on the ADA and disability health equity** when reviewing equity for other underserved groups.²³
- **Address ableism** by enforcing the ADA and incorporating training into professional programs.^{19,20,21,23,35}
- **Review and revise federal data privacy laws and provide regular training.**^{16,18,24,36,37}
- **Harmonize disability definitions, data systems, and language and collect disability data alongside demographics** in all federal health & community surveys.^{25,36}
- **Designate PWD as a Special Medically Underserved Population** under the Public Health Services Act or at least **fund research on health challenges for PWD.**^{22,38}

Drafted by Michelle Fong, a trainee in NH-ME LEND, and MPH student at the University of New England

The Center for Community Inclusion and Disability Studies at the University of Maine is a University Center for Excellence in Developmental Disabilities. NH-ME LEND is a collaboration of the University of New Hampshire, the University of Maine, & Dartmouth Geisel School of Medicine. Find this brief at: <https://ccids.umaine.edu/resource/policy-brief-advancing-data-equity-to-improve-health-equity-for-people-with-disabilities/>

REFERENCES:

1. Miller MR, Castrucci BC, Locke R, Haskins J, Castillo GA. *Talking Health: A New Way to Communicate About Public Health*. De Beaumont Foundation, Oxford University Press; 2022.
2. Smith L. #Ableism. Center for Disability Rights. Accessed March 26, 2023. <https://cdnys.org/blog/uncategorized/ableism/>
3. Civic Hacker. Data equity means protecting people and their data. Accessed March 24, 2023. <https://civichacker.com/blog/data-equity-means-protecting-people/>
4. Disability and health overview. US Centers for Disease Control and Prevention. Reviewed September 16, 2020. Accessed March 26, 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>
5. Oxford Language Dictionary. Equity. Google. Accessed March 24, 2023. https://www.google.com/search?q=define+equity&rlz=1C1CHBF_enUS937US937&toq=define+equity&aqs=chrome..69i57j0i512l2j0i67j0i512l6.3400j1j7&sourceid=chrome&ie=UTF-8
6. Health disparities. US Centers for Disease Control and Prevention. Reviewed November 24, 2020. Accessed March 24, 2023. <https://www.cdc.gov/healthyyouth/disparities/index.htm>
7. What is health equity? US Centers for Disease Control and Prevention. Reviewed December 16, 2022. Accessed March 7, 2023. <https://www.cdc.gov/nchhstp/healthequity/index.html>
8. Disability Impacts All of Us. US Centers for Disease Control and Prevention. Reviewed January 5, 2023. Accessed March 7, 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>
9. Young NAE. Childhood disability in the United States: 2019. United States Census Bureau. Published March 25, 2021. Reviewed August 22, 2022. Accessed March 7, 2023. <https://www.census.gov/library/publications/2021/acs/acsbr-006.html>
10. QuickFacts, United States. United States Census Bureau. Accessed March 26, 2023. <https://www.census.gov/quickfacts/fact/table/US/PST045221>
11. Sabatello M, Landes SD, McDonald KE. People with disabilities in COVID-19: fixing our priorities. *Am J Bioethics*. 2020;20(7):187-190. doi: 10.1080/15265161.2020.1779396
12. Public Health National Center for Innovation. The 10 Essential public health services. Published 2020. Accessed March 15, 2023. <https://phnci.org/uploads/resource-files/EPHS-English.pdf>
13. Engelgau MM, Zhang P, Jan S, Mahal A. Economic dimensions of health inequities: the role of implementation research. *Ethnic Dis*. 2019;29(Suppl 1):103-112. doi: 10.18865/ed.29.S1.103

14. LaVeist TA, Gaskin D, Richard P. Estimating the economic burden of racial health inequalities in the United States. *Int J Health Serv.* 201;41(2):231-238. doi: 10.2190/HS.41.2.c. Cited by Engelgau MM, Zhang P, Jan S, Mahal A. Economic dimensions of health inequities: the role of implementation research. *Ethn & Dis.* 2019;29(Suppl 1):103-112. doi: 10.18865/ed.29.S1.103
15. Nwando Olayiwola J, Rastetter M. Aiming for health equity: the bullseye of the quadruple aim. *J Hosp Manag Health Policy.* 2020;101:1-6. doi: 10.21037/jhmhp-20-101
16. Sapat A, Lofaro RJ, Trautman B. Policy responsiveness and institutions in a federal system: analyzing variations in state-level data transparency and equity issues during the Covid-19 pandemic. *Int J Disast Risk Re.* 2022;77:1-16. doi: 10.1016/j.ijdr.2022.103066
17. Lau DT, Sosa, P. Disparate impact of the COVID-19 pandemic and health equity data gaps. *Am J Public Health.* 2022;112(10):1404-1406. doi: 10.2105/AJPH.2022.307052
18. Hodge JG (Jr.), Wetter S, Piatt JL, Reinke H. Post-COVID U.S. legal reforms promoting public health and equity. *J Law Med Ethics.* 2020;48:784-788. doi: 10.1177/1073110520979390
19. Guide to disability rights laws: Americans with Disabilities Act (ADA). ADA.gov US Department of Justice Civil Rights Division. Updated February 28, 2020. Accessed March 8, 2023. <https://www.ada.gov/resources/disability-rights-guide/#americans-with-disabilities-act-ada>
20. Section 504, Rehabilitation Act of 1973. US Department of Labor. Accessed March 8, 2023. <https://www.dol.gov/agencies/oasam/centers-offices/civil-rights-center/statutes/section-504-rehabilitation-act-of-1973>
21. Mayerson A. The history of the Americans with Disabilities Act: a movement perspective. Disability Rights Education & Defense. Published 1992. Accessed March 8, 2023. <https://dredf.org/about-us/publications/the-history-of-the-ada/>
22. Akobirshoev I, Vetter M, Iezzoni LI, Rao SR, Mitra M. Delayed medical care and unmet care needs due to the COVID-19 pandemic among adults with disabilities in the US. *Health Affair.* 2022;41(10):1505-1511. doi: 10.1377/hlthaff.2022.00509
23. National Council on Disability. NCD Letter to HHS Secretary Becerra concerning health equity. Published June 8, 2021. Accessed January 20, 2023. <https://ncd.gov/publications/2021/ncd-letter-hhs-secretary-becerra-concerning-health-equity>
24. The path forward: improving data to advance health equity solutions. Centers for Medicare & Medicaid Services. Published November, 2022. Accessed March 8, 2023. <https://www.cms.gov/files/document/path-forwardhe-data-paper.pdf>
25. Institute of Medicine. The future of disability in America. Published 2007. Accessed March 15, 2023. <https://ebookcentral.proquest.com/lib/uneedu/reader.action?docID=3378298&query=>

26. Office for State, Tribal, Local, and Territorial Support, Centers for Disease Control and Prevention. Federal public health laws supporting data use and sharing. Published March 19, 2015. Accessed March 8, 2023. <https://www.cdc.gov/phlp/docs/datasharing-laws.pdf>
27. HIPAA for Professionals. HHS.gov Health Information Privacy. Reviewed May 17, 2021. Accessed March 9, 2023. <https://www.hhs.gov/hipaa/for-professionals/index.html>
28. The Network for Public Health Law and Data Across Sectors for Health. Pathways to yes: a legal framework for achieving data sharing for health, well-being, and equity. Published October 18, 2022. Accessed March 8, 2023. <https://www.networkforphl.org/resources/pathways-to-yes-a-legal-framework-for-achieving-data-sharing-for-health-well-being-and-equity/>
29. Disclosures for Public Health Activities. HHS.gov Health Information Privacy. Published December 3, 2002. Revised April 3, 2003. Reviewed July 26, 2013. Accessed March 8, 2023. <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/disclosures-public-health-activities/index.html>
30. Robert Wood Johnson Foundation. Charting a course for an equity-centered data system. Published October 1, 2021. Accessed March 9, 2023. <https://www.rwjf.org/en/insights/our-research/2021/10/charting-a-course-for-an-equity-centered-data-system.html>
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)
32. Disability & health U.S. state profile data for Maine (adults 18+ years of age). US Centers for Disease Control and Prevention. Reviewed May 18, 2022. Accessed March 7, 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/maine.html>
33. Students with disabilities in Maine. The Annie E. Casey Foundation Kids Count Data Center. Updated June 2022. Accessed March 7, 2023. <https://datacenter.kidscount.org/data/tables/8863-students-with-disabilities?loc=21&loct=2#detailed/2/any/false/2048,574,1729,37,871,870,573,869,36,868/any/17748,17749>
34. QuickFacts Maine, United States. United States Census Bureau. Accessed March 7, 2023. <https://www.census.gov/quickfacts/fact/table/ME,US/HSD410221>
35. Jesus TS, Kamalakannan S, Bhattacharjya S, Bogdanova Y, Arango-Lasprilla JC, Bentley J, et al. PREparedness, Response and SySTemic transformation (PRE-RE-SyST): a model for disability-inclusive pandemic responses and systemic disparities reduction derived from a scoping review and thematic analysis. *Int J Equity Health*. 2021;20:204-220. doi: 10.1186/s12939-021-01526-y
36. Waggoner C, Murphy S. Collecting and disseminating public health data disaggregated by race and ethnicity to advance health equity: navigating the legal issues. January 19, 2023. Accessed live January 19, 2023. Recording:

<https://www.networkforphl.org/resources/collecting-and-disseminating-public-health-data-disaggregated-by-race-and-ethnicity-to-advance-health-equity-navigating-the-legal-issues/>

37. Sadarangani TR, Gaugler JE, Dabelko-Schoeny H, Marx KA. Adult day services, health equity for older adults with complex needs, and the COVID-19 pandemic. *Am J Public Health*. 2022;112(10):1421-1428. doi: 10.2105/AJPH.2022.306968
38. National Archives. Code of Federal Regulations, Title 42. Updated February 24, 2023. Reviewed March 7, 2023. Accessed March 9, 2023. <https://www.ecfr.gov/current/title-42>