



NATIONAL
GOVERNORS
ASSOCIATION



Promising Practices for State and Territory Disability Data Collection and Usage

Over 28% of adults in the United States have a disability,^{1,2} yet people with disabilities are often overlooked or ignored when collecting and using data, creating a challenge for evidence-based policy making. There is considerable literature indicating that people with disabilities face barriers to healthcare access and experience unaddressed health inequities.¹⁻¹⁰ It is therefore important that states and territories address disparities faced by disabled people in efforts to advance health equity. Disability data allows states and territories to better allocate resources, plan social services and benefits, improve accessibility of public spaces and digital resources, and increase inclusivity of education, employment, and healthcare-related programs.¹⁻¹¹ This brief outlines promising practices that states and territories can implement to collect disability data to advance health equity.

Current State of Disability Data Collection and Utilization

States and territories vary in how they collect and use data on disability. For example, some states utilize the six disability data questions used in the Census Bureau’s American Community Survey (ACS)² and are also used in the Centers for Disease Control and Prevention (CDC) Behavioral Risk Surveillance System (BRFSS),¹² while others use the Washington Group Short Set of disability questions.¹³ Within state programs and departments, disability data is also collected using combinations of questions from the ACS, Washington Group, or unique questions developed by the state or territory. The lack of definitive guidelines and methods for disability data collection within and across states and territories, and limitations with current disability data measures,¹⁴ create challenges when comparing and analyzing disability data. While it is clear that standards for disability data are necessary to advance health equity, an in-person roundtable discussion hosted by the National Governors Association with state and territory policymakers confirmed the need for more guidance on state disability data collection and use.

Strategies For Using Disability Data to Advance Health Equity

Key strategies that states and territories use to gather data include crafting legislative mandates for disability data collection, shifting the focus of disability from a medical health outcome to a demographic group and health disparity population, and increasing inter-departmental collaboration and data sharing.

Colorado & Oregon: Legislative Mandates

Colorado¹⁵ and Oregon¹⁶ have passed legislation (Table 1) requiring state health departments and agencies to collect disability data. A key reason for passing this legislation was to standardize disability data collection across state health departments and organizations, ensuring consistent data to tackle health inequities, which is an approach outlined in the Affordable Care Act.¹¹ Additionally, in Oregon, during the COVID-19 pandemic, all healthcare providers were required to collect and report race, ethnicity, preferred language and disability status data in all COVID-19 health encounters.¹⁵ Likewise, Colorado required collecting and reporting disability, race, ethnicity, sexual orientation, and gender identity data by all state and county, district, and municipal public health agencies (Table 1) specifically to address health inequities.¹⁶ As part of the Workforce Innovation and Opportunity Act (WIOA), Colorado requires the tracking of disability employment data.¹⁷ Both Colorado and Oregon require the tracking of Individualized Education Program (IEP) and 504 Plans through the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act.^{18,19} IEPs are designed to provide students access through specific education plans, whereas 504 plans provide students accommodations to access general curriculums.²⁰ Collecting disability education and early intervention data allows states to identify and track these important components of disability throughout the lifespan. By including disability as one of the main categories of data collection, states can better analyze their impact on health equity.

Table 1: Legislation that Support Disability Data Collection

Name	Year	Purpose
Oregon HB 2134	2013	Requires the Oregon Health Authority and Department of Human Services to implement standards for collecting data on race, ethnicity, preferred language and disability status (REALD).
Colorado HB 22-1157	2022	Requires Colorado Department of Public Health and Environment to collect and report disability, race, ethnicity, sexual orientation and gender identity data.

Ohio: Disability as a Health Population

The Ohio Department of Health (ODH) emphasizes the importance of conceptualizing people with disabilities as a population that faces health disparities when reviewing state grants and proposals. Using this framing, the ODH has established the Ohio Disability and Health Partnership (ODHP), which is a partnership between the ODH, the Ohio State University, the University of Cincinnati, and a statewide Disability and Health Partnership advisory committee that is supported by grant funding from the Centers for Disease Control and Prevention (CDC).²¹ The ODHP focuses on advancing health equity for disabled people through societal and structural change, rather than the individual level. This collaboration is an example of how states can leverage federal funding and partner with academic institutions and community organizations to advance health equity for people with disabilities.²¹⁻²³

Massachusetts: Inter-Departmental Collaboration and Data Sharing

Massachusetts coordinates efforts to increase collaboration and data sharing within different state departments and agencies. The Executive Office of Health and Human Services (EOHHS) established the Advancing Health Equity in Massachusetts (AHEM) Initiative (Box 1) to target health disparities for people of color, low-income people and disabled people.²⁴ Representatives from all Massachusetts EOHHS agencies and several quasi-governmental offices including the Department of Public Health, Center for Health Information and Analysis, the Health Policy Commission, the Medicaid Office (MassHealth), MassAbility,²⁵ Department of Developmental Services, Department of Mental Health and many more are part of this AHEM workgroup which aims to increase standardization and collaboration to advance health equity in Massachusetts.²⁴

Box 1: Examples of Advancing Health Equity in Massachusetts Initiatives

1. In recognition of the challenges in defining, classifying and standardizing disability data collection, AHEM's Actionable Data Interoperability Subgroup prioritizes establishing a minimum data collection standard across the Executive Office of Health and Human Services (EOHHS) agencies. This effort is taking place in collaboration with all payers and providers, aiming to improve granular demographic data collection across the healthcare system in the Commonwealth.
2. The AHEM Operations team is preparing to implement the Race, Ethnicity, Language, and Disability data standards (RELD) as a first step to improve data collection and completeness, before expanding to additional health equity data standards. The team will provide technical assistance to EOHHS agencies and improve their data sharing capacity. The Department of Public Health is creating a Disability Data Standard & Training Module to improve standardization and data integration across the health care system.

Challenges in Disability Data Collection

Lack of Federal Standardization & Guidance

Federal requirements and definitions of disability differ between federal, state, and territory programs and agencies, making it difficult to integrate and compare information. Discussions with stakeholders identified the variation in how disability is defined, measured and collected as primary challenges to advancing health equity for disabled people. In 2022, the Centers for Medicare and Medicaid Services (CMS) released a Framework for Health Equity with a focus on improving the collection, use, and standardization of demographic information and social determinant of health data, which includes disability data. CMS additionally outlined their intent to “work with states to improve measurement of health disparities across a core set of stratified metrics,” elevating the importance for standardized disability data.²⁶

Legislative Requirements, Prioritization, and Funding

Legislative requirements or guidelines can be used to prioritize the collection and use of data on disability. Governors can issue executive orders establishing working groups, offices, and centers that specify responsibilities on disability inclusion and equity. Furthermore, revising current laws to incorporate the collection of disability data can assist states and territories with integration into existing demographic data collection processes. Allocating funding to support disability data collection and utilization in the Governor’s Executive Budget is one way to ensure successful implementation of these legislative requirements.

Accessibility

Ensuring accessibility is a major reason states are focused on gathering accurate and comprehensive state and territory data. For example, surveys with limited language options and technology without accessible features can lead to underreporting and imprecise statistics. To address this, data collection can be conducted in culturally relevant formats and languages, including with individuals whose primary language is American Sign Language (ASL). Understanding internet and phone access for various groups, as well as providing physical assistance for individuals can improve data collection processes. Such changes would also help states and territories comply with recent revisions to Title II of the Americans with Disabilities Act (ADA), which focuses on services, programs, and activities offered by state and local governments.^{27,28}

Recommendations

Federal and State Standardization

Standardizing disability definitions and data collection requirements for federal, state and territory programs is vital in collecting accurate, comprehensive and comparable information. Consistent disability data standards and definitions across state and territory agencies and programs can support using various data sources to create accurate and effective policies and programs to advance disability health equity.

Training & Accessibility

To collect accurate and inclusive disability data, data collection methods must be accessible and inclusive. Accessibility must be prioritized across all phases and aspects of data collection. This requires appropriate logistical resources, funding, training and implementation. Instead of building these resources from scratch, states and territories can consider partnering with trusted community-based organizations, hiring consultants or collaborating with disability-led organizations. These partnering organizations should have the specialized skills and trust from the community to develop and implement accessible data collection methods and improve the inclusion of people with disabilities in all data sources used to advance health equity, not just datasets specific to disabled people.

Centralized Data Hubs

Organizing disability data sources into a centralized data hub allows for greater access and collaboration within and between states and territory agencies and organizations. This could be via dashboards, data registries or an internal archive shared by departments and agencies. By consolidating data sources, states and territories will have a greater understanding of which data has already been collected, how disability requirements and categories have been defined, and potential gaps in data.

Community Integration

Including people with disabilities in leadership roles and designing, planning, and implementing data collection and utilization is crucial. Historically, the disability community has not been involved in developing policy solutions to improve access to healthcare and advance health equity. States and territories should find ways to partner with the disability community in planning and implementing data collection, ensuring a diversity of perspectives is represented. Including disabled people in leadership roles and creating advisory boards are ways to build partnerships with the disability community. One example is West Virginia's Commission for the Deaf and Hard of Hearing which is responsible for advocating, promoting, and coordinating implementation of public policies, regulations and programs impacting individuals who are deaf or hard of hearing.²⁹ It is a statutory requirement for the Governor to appoint no less than five of the seventeen members of the commission to be people who are deaf or hard of hearing.³⁰ In addition, to the extent possible, the Executive Director of the Commission is expected to be also be a person who is deaf or hard of hearing themselves.³¹ By including people with disabilities in leadership and advisory roles, West Virginia's Governor's Office and Department of Health can center the perspectives and networks of this community in the policymaking process.

Transparency

Transparency is vital in building trust. Making disability data publicly available can advance transparency and allow states and territories access to information needed to compare and analyze disability data and programs. However, recognizing the importance of individual privacy rights and acknowledging the potential negative consequences from releasing this data make it important to ensure members of the disability community are part of the decision-making process from start to finish.

Legislation & Increased Funding

Legislation and funding are often necessary to ensure comprehensive disability data collection. Executive orders supporting disability data collection and utilization, passing new legislation and revising current legislation to include disability status in state and territory data collection are actions which governors can support to ensure effective use of disability data. This includes prioritizing and earmarking funds specifically towards collecting and analyzing disability data. While mandates can be useful, without sufficient funding it may be impossible to implement accessible, comprehensive and accurate data collection. Given this, states and territories may want to work with the federal government to help support the implementation of disability data collection.

Conclusion

With more than one in four adults in the United States having a disability,¹ it is crucial for states and territories to include individuals with disabilities in their efforts to advance health equity. While further research and federal guidance is necessary to continue addressing disability health inequities, this brief provides initial guidance. Promising practices for using disability data to advance health equity across states and territories include:

- Developing standards for disability data collection,
- Increasing training on disability data collection among agencies,
- Maximizing accessibility of data collection processes,
- Organizing centralized data hubs that include and report data on people with disabilities,
- Partnering with the disability community to design, plan, and implement disability data collection,
- Increasing transparency in sharing and implementing disability data and
- Establishing legislation to support the collection of disability data across agencies.

Acknowledgements

The NGA Center would like to thank the Robert Wood Johnson Foundation (RWJF) for their generous support for the development of this publication. The contents of this publication are solely the responsibility of the authors and do not necessarily represent the views of RWJF.

This brief was developed by Bonnielin Swenor, Director; Varshini Varadaraj, Director of Research; Franz Castro, Director of Data Analytics; Caroline Cerilli, Research Program Coordinator; and Grace Jo, Research Assistant at the Johns Hopkins Disability Health Research Center with guidance from the National Governors Association Center for Best Practices (NGA Center).

The NGA Center and Johns Hopkins Disability Health Research Center (DHRC) would like to thank the state officials from Colorado, Massachusetts, Ohio, Oregon, the U.S. Virgin Islands and Wyoming for participating in stakeholder discussions on state and territory disability health equity. NGA and DHRC also thank Andrew Myers (University of Montana Research and Training Center on Disability in Rural Communities), Javier Robles (Rutgers University Center for Disability Sports, Health and Wellness), Poorna Kushalnagar (Gallaudet University Center for Deaf Health Equity), Jean Hall (University of Kansas Institute for Health and Disability Policy Studies), Scott Landes (Syracuse University), Silvia Yee (Disability Rights Education & Defense Fund), Zaineb Alkebsi (National Association of the Deaf), Bob Williams and Tauna Szymanski (CommunicationFirst) and Rachita Singh (American Association for People with Disabilities (AAPD)).

Recommended Citation

Swenor, Bonnielin, Varshini Varadaraj, Franz Castro, Caroline Cerilli, and Grace Jo. "Promising Practices for State and Territory Disability Data Collection and Usage." National Governors Association. December 9, 2024.

Endnotes

1. Centers for Disease Control and Prevention. 2023. "Disability Impacts All of Us." Centers for Disease Control and Prevention. May 15, 2023. <https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html>.
2. CDC. 2019. "Disability and Health - Disability Data." Centers for Disease Control and Prevention. April 24, 2019. <https://www.cdc.gov/ncbddd/disabilityandhealth/datasets.html>.
3. Scott, Haleigh M, and Susan M Havercamp. 2014. "Race and Health Disparities in Adults with Intellectual and Developmental Disabilities Living in the United States." *Intellectual and Developmental Disabilities* 52 (6): 409–18. <https://doi.org/10.1352/1934-9556-52.6.409>.
4. Mitra, Monika, Linda Long-Bellil, Ian Moura, Angel Miles, and H. Stephen Kaye. 2022. "Advancing Health Equity and Reducing Health Disparities for People with Disabilities in the United States." *Health Affairs* 41 (10): 1379–86. <https://doi.org/10.1377/hlthaff.2022.00499>.
5. National Institute of Health. 2023. "NIH Designates People with Disabilities as a Population with Health Disparities." National Institutes of Health (NIH). September 25, 2023. <https://www.nih.gov/news-events/news-releases/nih-designates-people-disabilities-population-health-disparities>.
6. Anderson, K., Esquenazi, A., Hall, J., Havercamp, S., Moore, C., Zazove, P., Barnett, S., Iezzoni, L., Swenor, B., Le Fauve, C., Shin, J., Lang, N., Cruz, T., Mann Koepke, K., Politis, A., & Rice, D. *Advisory Committee to the Director Working Group on Diversity Subgroup on Individuals with Disabilities* (pp. 1–66). National Institutes of Health (NIH) December 1, 2022.
7. Epstein, Sabrina, Kara Ayers, and Bonnielin K. Swenor. COVID-19 vaccine prioritisation for people with disabilities. *The Lancet Public Health*. 2021;6(6):e361.
8. Doebrich, Adrienne, Marion Quirici, and Christopher Lunsford. 2020. "COVID-19 and the Need for Disability Conscious Medical Education, Training, and Practice." *Journal of Pediatric Rehabilitation Medicine* 13 (3): 393–404. <https://doi.org/10.3233/PRM-200763>.
9. Lund, Emily M., Anjali J. Forber-Pratt, Catherine Wilson, and Linda R. Mona. 2020. "The COVID-19 Pandemic, Stress, and Trauma in the Disability Community: A Call to Action." *Rehabilitation Psychology* 65 (4). <https://doi.org/10.1037/rep0000368>.
10. Deal, Jennifer A., Kening Jiang, Joshua F. Betz, Gwendolyn D. Clemens, Jiafeng Zhu, Nicholas S. Reed, Brian T. Garibaldi, and Bonnielin K. Swenor. 2023. "COVID-19 Clinical Outcomes by Patient Disability Status: A Retrospective Cohort Study." *Disability and Health Journal* 16 (2): 101441–41. <https://doi.org/10.1016/j.dhjo.2023.101441>.
11. McGee, M.G. (2020). Race, ethnicity, language and disability (REALD) implementation guide. Portland, Oregon: Oregon Health Authority, Equity and Inclusion Division.
12. CDC. 2019. "Behavioral Risk Factor Surveillance System." www.cdc.gov/brfss/. November 5, 2019.
13. "WG Short Set on Functioning (WG-SS)." n.d. The Washington Group. <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>.

Promising Practices for State and Territory Disability Data Collection and Usage

14. Hall, Jean P., Noelle K. Kurth, Catherine Ipsen, Andrew Myers, and Kelsey Goddard. "Comparing Measures of Functional Difficulty with Self-Identified Disability: Implications for Health Policy." *Health Affairs* 41, no. 10 (October 1, 2022): 1433–41. <https://doi.org/10.1377/hlthaff.2022.00395>.
15. "Utilization of Demographic Data by Colorado Department Public Health and Environment." Utilization Of Demographic Data By Colorado Department Public Health And Environment | Colorado General Assembly, April 28, 2022. <https://leg.colorado.gov/bills/hb22-1157>.
16. 77th OREGON LEGISLATIVE ASSEMBLY--2013 Regular Session, House Bill 2134 § (2013).
17. "Workforce Innovation & Opportunity Act (WIOA)." Workforce Innovation & Opportunity Act (WIOA) | Department of Labor & Employment. Accessed October 22, 2024. <https://cdle.colorado.gov/wioa-js..>
18. Students on section 504 plans: Overview of a potential ... Accessed October 22, 2024. <https://www.oregon.gov/ode/students-and-family/GraduationImprovement/Documents/Students%20504%20Plans%20Overview%20of%20a%20Potential%20Focal%20Population-Published%20in%20May%202022%20by%20Isabella%20Jacoby.pdf>
19. "Special Education Rules and Regulations." CDE. Accessed October 22, 2024. <https://www.cde.state.co.us/spedlaw/rules>.
20. Schultz, Sharon. "Differences between a 504 Plan and an Individualized Education Program (IEP)." NEA. Accessed October 22, 2024. <https://www.nea.org/professional-excellence/student-engagement/tools-tips/differences-between-504-plan-and-individualized-education-program-iep>
21. "The Ohio Disability and Health Partnership." The Ohio Disability and Health Partnership | Ohio Colleges of Medicine Government Resource Center. Accessed October 1, 2024. <https://grc.osu.edu/Projects/Ohio-Disability-and-Health-Partnership>.
22. "Ohio Disability and Health Program." Nisonger Center, December 7, 2023. <https://nisonger.osu.edu/education-training/ohio-disability-health-program/>.
23. "Disability and Health State Programs." Centers for Disease Control and Prevention, August 6, 2021. <https://www.cdc.gov/ncbddd/disabilityandhealth/programs.html>.
24. "Advancing Health Equity in MA." Mass.gov. Accessed October 20, 2024. <https://www.mass.gov/advancing-health-equity-in-ma>.
25. "Governor Healey Signs Legislation Renaming Massachusetts Rehabilitation Commission to 'MassAbility.'" Mass.gov. Accessed November 4, 2024. <https://www.mass.gov/news/governor-healey-signs-legislation-renaming-massachusetts-rehabilitation-commission-to-massability>
26. Office of Minority Health, and CMS, CMS Framework for Health Equity 2022–2032 § (2022).
27. "Justice Department to Publish Final Rule to Strengthen Web and Mobile App Access for People with Disabilities." *Press Release*, April 2024. Office of Public Affairs. <https://www.justice.gov/opa/pr/justice-department-publish-final-rule-strengthen-web-and-mobile-app-access-people>.
28. "Americans with Disabilities Act Title II Regulations." ADA.gov, June 24, 2024. <https://www.ada.gov/law-and-regs/regulations/title-ii-2010-regulations/>.
29. "WV Commission for the Deaf and Hard of Hearing." Accessed October 30, 2024. <https://dhrh.wv.gov/cdhh/Pages/default.aspx>.
30. "West Virginia Code Section 5-14-3." 5-14-3. Accessed October 30, 2024. <https://code.wvlegislature.gov/5-14-3/>.
31. "West Virginia Code Section 5-14-8." 5-14-8. Accessed October 30, 2024. <https://code.wvlegislature.gov/5-14-8/>.