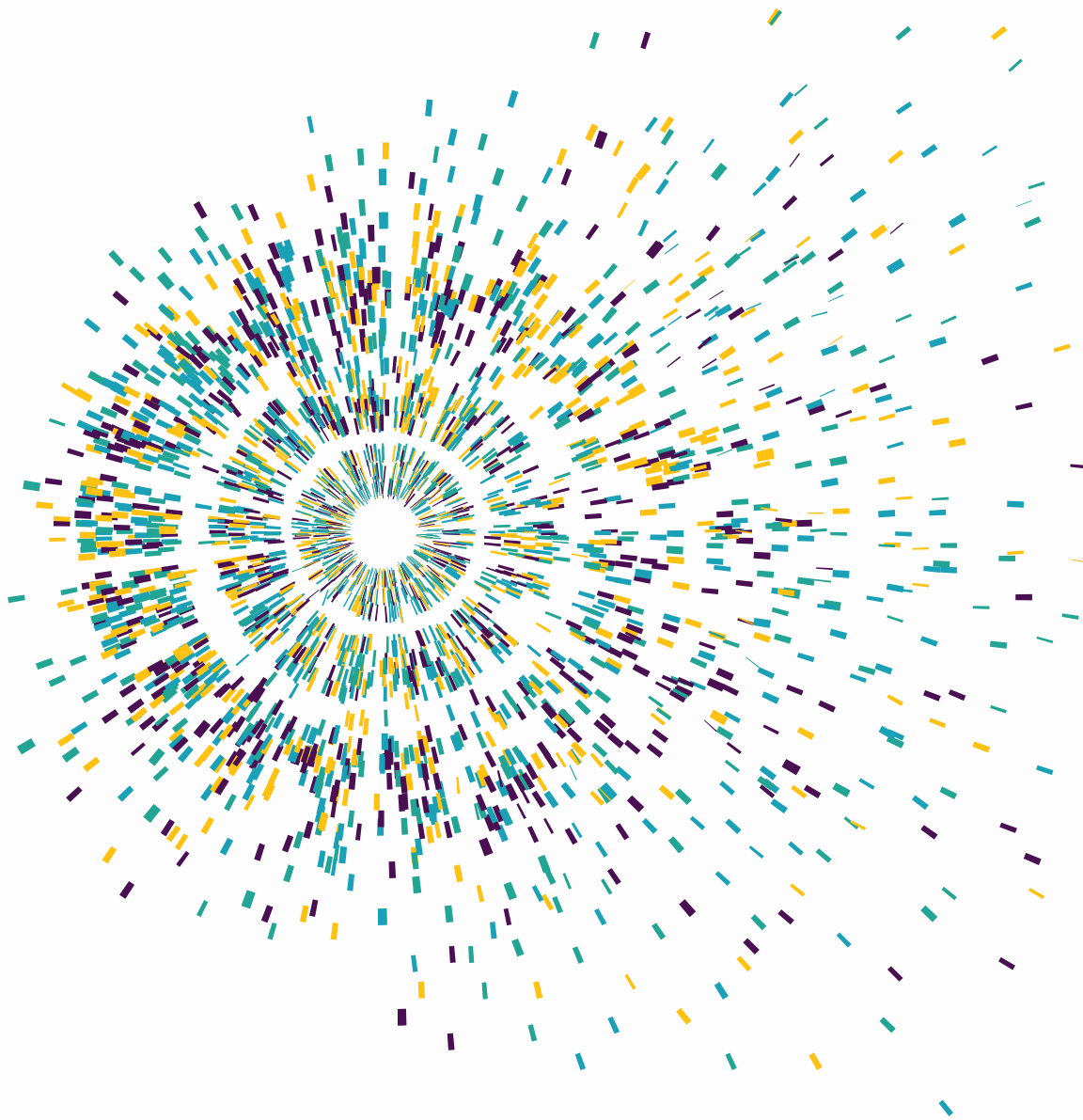


Interim guidelines for the collection of data on disability and call to action



A tool to support data-informed decisions
and improve service quality



Utah Department of
Health & Human Services
Health Equity

Contents

Section 1: Purpose	Page 3
Section 2: Background • Why collect disability status data? • What do we mean by demographic and SDOH data? • What are health disparities and health equity?	Page 4
Section 3: Disability terminology and definitions	Page 6
Section 4: Data standard development process • Limitations to current data collection standards	Page 7
Section 5: Interim standards for the collection of data on disability status	Page 9
Section 6: Data collection principles and considerations	Page 11
Section 7: Call to action and recommendations	Page 12
Acknowledgments	Page 13
References	Page 14
Appendix A: Disability status data collection limitations and recommendations	Page 16

Note: The [Standards for the collection of data on disability status reference guide](#) provides a quick reference guide to the disability status data collection standard.

1 | Purpose

The Utah Department of Health and Human Services (DHHS) vision is to ensure all Utahns have fair and equitable opportunities to live safe and healthy lives. DHHS will advocate for, support, and serve all individuals and communities in Utah. The goal of these data collection standards is to increase availability, quality, and comparability of demographic and social drivers of health (SDOH) data to identify and address health disparities, improve health outcomes, and advance health equity in Utah.

High-quality data on demographics and SDOH is crucial to address health disparities and advance health equity in Utah. The DHHS Office of Health Equity (OHE) developed standards for collecting demographics and SDOH to promote consistent and comparable data collection across the state of Utah. Uniform data collection improves quality, comparability, and effectiveness of health data to make data-informed decisions to improve health outcomes for all Utahns.

This guide is designed to help organizations in Utah collect meaningful and actionable data on disability status in a standardized way. In order to enhance data collection on disability status and address limitations in current standards, this document also outlines a call to action for key subject matter experts in Utah to develop updated data collection standards for disability status.

Standards outlined in Section 5 are recommended for use as appropriate during demographic and SDOH data collection including, but not limited to, health surveys, healthcare and program registration, vital records, and health systems user feedback conducted by, sponsored by, or reportable to DHHS as specified by the Utah Health and Human Services Code (Title 26B of the Utah Code). Additional public health, healthcare, social services, and community-based organizations in Utah are encouraged to use these standards as appropriate to promote uniform and consistent disability data collection throughout the state.

Note: This document aligns with Utah Code 26B-7-114, Office of Health Equity duties.

2 | Background

Why collect disability status data?

According to the Behavioral Risk Factor Surveillance System (BRFSS) data collected in 2022, it is estimated that 26% of adults have a disability in Utah.¹ Data collection on disability status is necessary to accurately understand the health disparities experienced by people with disabilities and target interventions to improve health and well-being.²

Data standards allow for communication across disciplines, accurate surveillance and monitoring of population health, and the ability to determine the impacts and outcomes of interventions.³ The standardized collection of disability status was mandated in 2011 under the Affordable Care Act (ACA) in all national population health surveys.⁴ At a minimum, this requires the use of the American Community Survey (ACS-6) questions or the Washington Group on Disability Statistics Short Set on Functioning (WG-SS) in all federal surveys.^{4, 5}

The purpose of a standardized question set such as the ACS-6 or WG-SS is to identify who has a disability using survey questions in order to ascertain the prevalence of disability in a population. Both the ACS-6 and WG-SS use six questions that cover six domains and are outlined below in Figures 1 and 2.

What are health disparities and health equity?

What are health disparities?

Health disparities are differences in health outcomes closely linked to economic, socio-cultural, environmental, and geographic disadvantage.⁹

What is health equity?

Health equity is the principle underlying the commitment to reduce and, ultimately, eliminate health disparities by addressing its drivers. Pursuit of health equity means striving for the highest possible standard of health for all people with special attention to the needs of those communities at greatest risk for health disparities.⁹

What do we mean by demographic and SDOH data?

Demographics refer to personal and social characteristics of a population. These characteristics may influence patterns of disease occurrence, risk factors, health outcomes, and health disparities in populations.

SDOH are the nonmedical factors that influence health. They are the conditions in which people are born, grow, live, work, and age and the wider set of forces and systems that shape the conditions of daily life.^{6, 7, 8} Demographics and SDOH can be more important than individual behaviors in affecting health outcomes and contribute to a wide range of health disparities.⁸

Some data can be understood as either demographics, or SDOH, or both. These two concepts can be regarded collectively in the context of collecting this information about populations in Utah to better understand health outcomes.

3 | Disability terminology and definitions

Disability status is an important demographic variable to understand the health status and health disparities experienced by people who have disabilities. Defining and understanding disability is complex. Many models of disability have been developed to define and operationalize disability, with the most common being the medical and social models. The medical model views disability as a condition to be treated within an individual. The social model views disability as a societal issue and focuses on barrier reduction and protections against discrimination. Under the social model, disability occurs when environmental and societal barriers prevent or limit a person's activities or participation.

The way we define and conceptualize disability affects how we approach it. The Americans with Disabilities Act (ADA) defines disability as “a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.”¹⁰ The World Health Organization shaped the definition of disability through the development of the International Classification of Functioning, Disability, and Health which defines disability as “any condition of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions).¹¹ These definitions influence how disability is operationalized in data collection. The World Health Organization defines disability from a functional perspective and has shaped the standard disability questions currently included in national surveys.¹¹ The functional limitations captured in these questions include cognitive, mobility, self-care, independent living, communication, hearing, and vision.

4 | Data standard development process

The development process began with a literature review of the history of disability within Utah and the U.S. to understand the various definitions, models, and theories surrounding disability. The literature review revealed two sets of standards that are commonly used for disability status, the ACS-6 and the WG-SS.

The use of the ACS-6 or the WG-SS question sets is required in all federal surveys.⁴ Both question sets contain six questions and use the World Health Organization International Classification of Functioning, Disability, and Health as the conceptual model to ask about difficulty in core domains of functioning.¹² The question sets have five overlapping functional domains which include vision, hearing, walking, cognition, and self-care. The sixth domain in the ACS-6 is independent living while the sixth domain in the WG-SS is communication.

Another difference between the two question sets is the structure of response options. The ACS-6 questions use a dichotomous yes/no response structure. A response of “yes” to any of the six questions in the ACS-6 is considered as having a disability (see Figure 1). The WG-SS uses a four-category scaled response structure, including “no difficulty,” “some difficulty,” “a lot of difficulty,” and “unable or cannot do at all.” A response of “a lot of difficulty” or “unable or cannot do at all” to at least one of the questions in the WG-SS constitutes as having a disability (see Figure 2).¹²

OHE wanted to understand how well the ACS-6 and WG-SS met the needs of people working in the disability field, as well as limitations to these standards. A survey was sent to members of the Utah Disability Advisory Council (UDAC) for feedback on current disability data collection practices and needs. Major limitations identified from the survey are outlined below and in Appendix A.

Throughout this process, OHE gained insight into the various challenges and limitations of the current ACS-6 and WG-SS question standards. Outside of the requirement to use the ACS-6 or WG-SS in federal surveys, there is a lack of accurate and appropriate data standardization. Efforts are underway to address these issues at the national level. Based on these findings, OHE determined that more needs to be done both locally and nationally to develop a more comprehensive and inclusive data collection standard for disability status.

Limitations to current data collection standards

There are many limitations to the use of the ACS-6 and WG-SS that have been shared in the literature by leaders in this field and practitioners of data collection. Neither question sets captures neurological, developmental, psychiatric (including mental health), and chronic conditions. These exclusions may mean people who have disabilities are undercounted and underrepresented. This also limits the ability to identify the types of services people need. The question sets also do not include environmental barriers or age of onset of the disability. Although some of these limitations may not affect the count of people with disabilities, they may impact resource allocation and informed interventions. Although there are advantages of using a scaled response, the current definition of disability under the WG-SS significantly undercounts people with disabilities. It also leads respondents to question “how disabled is disabled enough?”

Subject matter experts have shared concerns about the limitations to the current standards and use of the current question sets. In February 2024, OHE conducted a survey with UDAC to understand if the ACS-6 and WG-SS questions met the needs of organizations. Of the 13 respondents, two responded that the ACS-6 questions met their needs, and three responded that the WG-SS met their needs. The gap in organizations reporting the current ACS-6 and WG-SS standards met their needs, as well as other survey findings, indicates a need for appropriate and inclusive disability data collection standards that can encompass all disability types.

Another limitation is that sampling frames and data collection methods may exclude certain populations from participating, which may lead to underreporting the prevalence of disability in a population. Therefore, it is important to understand what groups might be missing from the dataset. For example, the BRFSS sampling frame excludes people who live in institutions or group homes which can lead to an undercounting of disability in a population. Additionally, the ACS-6 and WG-SS questions are only asked of certain ages as it is not appropriate for children younger than age 5 to be asked these questions. Some data may be able to be supplemented through other databases, however there are various considerations and limitations to consider with each database.

Additional limitations identified from literature reviews and survey results, as well as recommendations, are outlined in Appendix A: Disability status data collection limitations and recommendations.

5 | Interim standards for the collection of data on disability status

Given the limitations to the current data collection standards for disability status, DHHS recommends action be taken to develop a more comprehensive and inclusive standardized question set given the limitations to the current data collection standards for disability status. However, until additional questions have been developed, DHHS recommends you use the current federal standard and ask either the ACS-6 questions (see Figure 1) and/or the WG-SS questions (see Figure 2) for disability data collection purposes. The ACS-6 and WG-SS questions are used nationally, so data collected will be comparable to other agencies, departments, or organizations across Utah and the U.S.

Figure 1: DHHS interim disability status data collection standard, ACS-6⁴

1. Are you deaf, or do you have serious difficulty hearing?

☐ Yes

☐ No

2. Are you blind, or do you have serious difficulty seeing, even when wearing glasses?

☐ Yes

☐ No

3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)

☐ Yes

☐ No

4. Do you have serious difficulty walking or climbing stairs? (5 years old or older)

☐ Yes

☐ No

5. Do you have difficulty dressing or bathing? (5 years old or older)

☐ Yes

☐ No

6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

☐ Yes

☐ No

Figure 2: DHHS interim disability status data collection standard, WG-SS¹³**1. Do you have difficulty seeing, even if wearing glasses?**

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

2. Do you have difficulty hearing, even if using a hearing aid?

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

3. Do you have difficulty walking or climbing steps?

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

4. Do you have difficulty remembering or concentrating?

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

5. Do you have difficulty with self-care (such as washing all over or dressing)?

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

6. Do you have difficulty communicating?

- ☐ No difficulty
- ☐ Some difficulty
- ☐ A lot of difficulty
- ☐ Cannot do entirely

Note: The WG-SS questions are designed to collect information on the population aged 5 years and above, with a knowledgeable proxy respondent providing information for children. The WG-SS was not specifically designed for use among children, as it does not include key aspects of child development important for identifying disability in children and the wording of certain domains may not be relevant (or suitable) for children and adolescents.¹³

6 | Data collection principles and considerations

These principles outline key concepts that enhance quality in data collection practices.

Use self-reporting

Self-identification is the preferred way to get information about an individual's demographics and SDOH. Whenever possible, demographic and SDOH information should be collected through self-report.¹³ The surveyor should not tell a respondent how they should classify themselves.

When self-reporting is not possible, demographic and SDOH data may be collected from a *knowledgeable proxy* as appropriate and in compliance with applicable policies; or by *record matching*, where existing records on an individual that contain their demographic information are used to supply the information.¹⁴

Limit data collection to the minimum necessary

All data collected should have a justified purpose. Do everything possible to make sure the demographic and SDOH information collected is limited to the minimum or reasonable amount necessary to accomplish a specified purpose.¹⁵

Consider the sensitive nature of data

When you collect demographic and SDOH information, make sure you consider the potentially sensitive nature of information collected. If you determine you need to collect potentially sensitive information to accomplish the specified purpose, consider everything possible to avoid unintended consequences.

Ensure data collection instruments are accessible

Translate data collection instruments into the language(s) spoken by those reporting the information. For data collected in an interview format, make accommodations to provide interpretation for both spoken and signed languages as applicable. Other accessible formats of data collection instruments may be necessary to ensure data quality.

7 | Call to action and recommendations

Disability data standards are crucial to understand and monitor health disparities experienced by people with disabilities. The recommendations provided in this section reflect the lessons learned through the interim disability data standard development process.

Develop data standards that represent the needs of the community

The creation of disability data collection standards is of utmost importance to ensure the accurate surveillance and reporting of health disparities experienced by people with disabilities. While this report is unable to provide a set of standards outside of the federally mandated ACS-6 or WG-SS question sets, efforts must be made to prioritize the development and implementation of appropriate disability data collection standards that encompass all areas of disability and represent the needs of the community. OHE anticipates a supportive role in this effort, specifically with regard to the monitoring and surveillance of health disparities that people with disabilities experience. This effort should be led by subject matter experts who work in the field of disability with input from OHE.

Integrate the various identities of the disability community during question development

The development of disability data standards should consider the complexity of how individuals with disabilities view themselves. Integrating this intention and understanding into the development of the disability data standards will foster a set of standards with comprehensive considerations.

Consider the development of a temporary task force in Utah

A temporary task force should be created to oversee the development process. This task force should include subject matter experts, those who have lived experiences as people with disabilities, professionals who work with people with disabilities, and other key organizations working with disability data and providing services for people with disabilities. This task force should also include those groups who are currently working on disability data such as internal DHHS programs, the Kem C. Gardner Institute, and organizations that provide services for people with disabilities to develop the disability standards.

Acknowledgments

This document was prepared by the Utah Department of Health and Human Services Office of Health Equity, with important contributions from the DHHS Disability and Health Program and the Utah Disability Advisory Council.

Published October 2024

Utah Department of Health and Human Services

Office of Health Equity

healthequity@utah.gov

healthequity.utah.gov

Suggested citation: Office of Health Equity (2024). *Interim guidelines for the collection of data on disability and call to action*. Utah Department of Health and Human Services.

Note: This document aligns with Utah Code 26B-7-114, Office of Health Equity duties.

References

1. Utah Department of Health and Human Services. (2023, December). *Health disparities among Utah adults with disabilities in Utah*. Retrieved July 2024, from <https://healthyaging.utah.gov/wp-content/uploads/Disability-and-Health-Needs-Assessment-Report.pdf>
2. Krahn, G., Klein Walker, D., & Correa-De-Araujo, R. (2015, April). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(Suppl2): S198-S206. doi: 10.2105/AJPH.2014.302182
3. Greenberg, M. S. (2012, August 6). *Data standards in HHS Data collection* [PowerPoint slides]. 2012 National Conference on Health Statistics. Retrieved July 2024, from https://www.cdc.gov/nchs/ppt/nchs2012/SS-34_GREENBERG.pdf
4. ASPE. *HHS implementation guidance on data collection standards for race, ethnicity, sex, primary language, and disability status*. (2011, October 30). U.S. Department of Health and Human Services. Retrieved July 2024, from <https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0>
5. Washington Group on Disability Statistics. *WG short set on functioning (WG-SS)*. Retrieved July 2024, from <https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/>
6. Healthy People 2030. *Social determinants of health*. U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. Retrieved June 2024, from <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>
7. Centers for Disease Control and Prevention. (2024, January 17). *Social determinants of health (SDOH)*. Retrieved June 2024, from <https://www.cdc.gov/about/priorities/why-is-addressing-sdoh-important.html>
8. World Health Organization. *Social determinants of health*. Retrieved June 2024, from https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1
9. Office of Health Equity. *Health equity in Utah*. Utah Department of Health and Human Services. Retrieved June 2024, from <https://healthequity.utah.gov/health-equity-in-utah/>
10. ADA.gov. (2020, February 28). *Guide to disability rights laws*. U.S. Department of Justice Civil Rights Division. Retrieved July 2024, from <https://www.ada.gov/resources/disability-rights-guide/#:~:text=An%20individual%20with%20a%20disability%20is%20defined%20by%20the%20ADA,as%20having%20such%20an%20impairment>
11. Disability and Health Promotion. (2024, April 3). *Disability and health overview*. Centers for Disease Control and Prevention. Retrieved July 2024, from <https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html>

12. Miller, K., Vickers, J. B., & Scanlon, P. *Comparison of American Community Survey and Washington Group disability questions*. National Center for Health Statistics, Collaborating Center for Questionnaire Design and Evaluation Research. Retrieved July 2024, from https://wwwn.cdc.gov/qbank/report/Miller_2020_NCHS_ACS.pdf
13. Washington Group on Disability Statistics. (2022). The Washington Group Short Set on Functioning (WG-SS). Retrieved August 14, 2024, from https://www.washingtongroup-disability.com/fileadmin/uploads/wg/Washington_Group_Questionnaire_1_-_WG_Short_Set_on_Functioning_October_2022_.pdf
14. Office of Management and Budget. (2024, March 29). *Revisions to OMB's Statistical Policy Directive No. 15: Standards for maintaining, collecting, and presenting federal data on race and ethnicity*. Federal Register. Retrieved June 2024, from <https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and>
15. The HIPAA Privacy Rule and Electronic Health Information Exchange in a Networked Environment. *Collection, use, and disclosure limitation*. Office for Civil Rights. Retrieved June 2024, from <https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/special/healthit/collectionusedisclosure.pdf>

Appendix A: Disability status data collection limitations and recommendations

This table outlines limitations of the ACS-6 and WG-SS, as well as recommendations found in literature reviews, survey findings, and feedback from UDAC. Considerations should be made to determine the applicability to your project.

Note: this is not an exhaustive list.

Limitations	Recommendations / considerations
Questions do not capture neurological, developmental, psychiatric (including mental health), and chronic conditions	- Definitions of disability used to develop questions should be inclusive of all types of disability - Additional questions should capture these and other missing disability types, in addition to the existing functional domains - Considerations should also be given to conditions such as substance and opioid use disorders
Questions do not identify the types of services needed	Additional questions should capture types of services needed
Questions do not capture age of onset or [expected] duration of disability	Additional questions should capture age of onset and/or duration of disability
Questions do not capture environmental barriers	Social drivers of health (SDOH) questions should be asked in conjunction with minimum standards to understand the environmental barriers, such as accessibility of communities, services, and buildings individuals with disabilities experience
People with certain disabilities, such as intellectual and developmental disabilities, may have difficulty understanding and responding to questions	- Questions must be written in plain language and tested by people with disabilities - Interpretation and translation of plain language questions should be included for accessibility

Questions do not identify specific disability diagnosis	Consider follow-up questions on specific disability conditions or diagnoses
Questions do not align with the ADA definition of disability (Note: this only applies to the ACS-6 as the WG-SS is an international measure)	Consider whether standards should align with: 1) the ADA's definition of disability for national comparability; or 2) the international definitions of disability for international comparability (e.g., aligned with the WHO's ICF).