

# Collection of Self-Reported Disability Data in Medicaid Applications: A Fifty-State Review of the Current Landscape

Prepared by SHADAC

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## Introduction

States are likely undercounting the number of people with disabilities in their Medicaid programs. Very little is known about people who self-identify as having a disability within the Medicaid program who are not a part of the group that qualifies for benefits through a disability-related eligibility category. Collecting better demographic data about the types of disabilities Medicaid enrollees experience is vitally important so that inequities can be identified, and resources and programs can be tailored appropriately.

The objective of this brief is to provide an overview of current disability data collection standards and to document how states are collecting self-reported disability information on their Medicaid applications. The brief focuses on self-reported disability, which is separate and distinct from the disability evaluation conducted by the Social Security Administration to determine categorical eligibility for Medicaid. The information presented here draws from the [State Health Access Data Assistance Center's](#) (SHADAC's) review of paper Medicaid applications for all 50 states and the District of Columbia alongside online applications for 36 states and the District of Columbia.<sup>a</sup> We encourage state Medicaid programs to start thinking now about what changes can be made to improve the collection of self-reported disability data on their applications and to better align with the federal disability data collection standard.

## Background

Over 44.5 million Americans, more than 16.4% of the entire population, reported having a disability in 2021 ([SHADAC](#) analysis of the 2021 American Community Survey)<sup>b</sup>, but the average disability prevalence for individuals covered by Medicaid is 33%. While the specific percentage of Medicaid enrollees who report a disability varies by state, in no state is it less than 20%. Medicaid is an important source of coverage for many of those individuals.

**Figure 1: Disability Prevalence for Individuals Reporting Medicaid Coverage, 2021**

| States with the highest prevalence |       | States with the lowest prevalence |       |
|------------------------------------|-------|-----------------------------------|-------|
| U.S. average: 33.3%                |       |                                   |       |
| Mississippi                        | 48.2% | Arizona                           | 29.0% |
| South Dakota                       | 46.9% | New Jersey                        | 28.7% |
| Maine                              | 46.6% | New York                          | 27.8% |
| Missouri                           | 45.6% | California                        | 25.5% |
| Kansas & Wyoming                   | 45.4% | Hawaii                            | 23.9% |

Data for all 50 states can be found in Appendix A. Data broken down by type of functional disability (Hearing, Vision, Memory or Cognitive, Mobility, Motility, Self-Care, and Independent Living) for all 50 states is available in Appendix B.

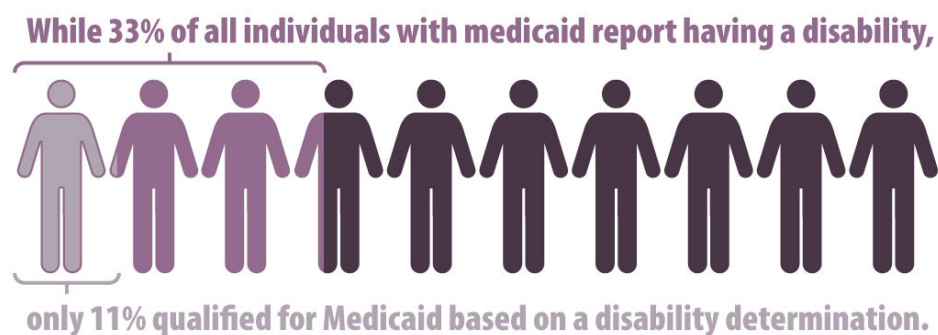
Source: [SHADAC](#) analysis of the 2021 American Community Survey (ACS) Public Use Microdata Sample (PUMS) file.

a Applications were reviewed in September and October 2023. For State-Based Marketplace (SBM) states, online applications can be either exclusive to Medicaid or integrated with the Marketplace. For Federally Facilitated Marketplace (FFM) states and states with SBMs using the federal platform (SBM-FP) we retrieved Medicaid paper and online applications from state (include the District of Columbia) Medicaid websites. For this review, we examined the online application available through the state's Medicaid agency portal. Remote identity proofing (RIDP) processes prevented us from reviewing 14 states' online Medicaid applications. RIDP requires that an applicant answer a series of personal questions (drawn from credit files and other sources) in order to verify an applicant's identity. Some states require this information before an individual can complete an application, therefore we were not able to review these states' online Medicaid application questions.

b Defined based on a self-report of any of the following ACS-6 Disability Measures discussed in detail below: Hearing, Vision, Memory or Cognitive, Mobility, Motility or self-care.

In spite of the fact that one-third of Medicaid enrollees report having a disability, only 11% of the Medicaid population<sup>1</sup> (9.6 million people) qualified for Medicaid based on a disability determination in 2021 (Figure 2). According to MACPAC<sup>2</sup>, in order to qualify for Medicaid through the disability pathway, most individuals must meet the stringent definition of disability used by the Supplemental Security Income (SSI) program. This definition is narrow, and based on a medical model of disability (see sidebar). To be eligible for SSI<sup>3</sup>, individuals must have low incomes, limited assets, and an impaired ability to work either because of age or a significant disability. Under these rules, individuals with multiple chronic conditions may not be eligible. In addition, individuals who qualify for Medicaid via a different eligibility requirement often don't seek a disability determination. Other eligibility categories, like low-income child or parent, for example, require less documentation compared to the disability pathway. For these reasons, the total number of Medicaid enrollees with a disability is significantly higher than the number of enrollees who qualify for benefits based on disability.

**Figure 2: Gap Between Medicaid Enrollees Reporting a Disability and Qualifying Based on a Disability Determination**



Source: SHADAC analysis of the 2021 American Community Survey (ACS) Public Use Microdata Sample (PUMS) file.

Considering a broad definition of individuals with disabilities is important to better understand the often significant disparities in their health, healthcare, and health outcomes<sup>4</sup> compared to their non-disabled peers. Individuals with disabilities who have additional minoritized identities, such as members of racial or ethnic groups or LGBTQ+ people, fare even worse<sup>5</sup>. In spite of the growing body of literature documenting disability-related health disparities, these differences are often poorly understood and rarely addressed<sup>6</sup>.

Recently, though, there has been some increasing attention to the unmet health needs of people with disabilities. At the federal level, President Biden's Executive Order 13985<sup>7</sup> explicitly includes people with disabilities as an underserved group in its requirement that all federal agencies assess "whether, and to what extent, its programs and policies perpetuate systemic barriers to opportunities and benefits for people of color and other underserved groups." In July 2022, the Office of the National Coordinator for Health Information Technology took the first steps toward setting a national standard for collecting disability status in Electronic Health Record (EHR) systems through the United States Core Data for Interoperability (USCDI) Version 3 standards<sup>8</sup>. And in September 2023, the National Institutes of Health (NIH) formally designated people with disabilities as a population experiencing health disparities<sup>9</sup>. The hope is that this designation will encourage research, funding, and attention specific to the unmet health needs of this population.

### Medical Versus Social Model of Disability

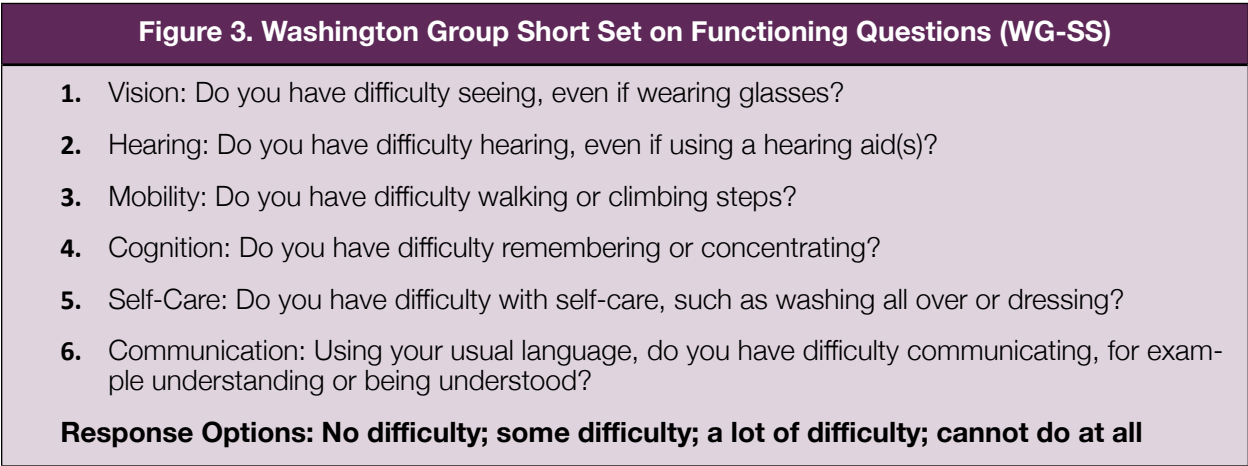
Two of the most common models for thinking about disability are the medical and social models. The medical model views disability as a result of an individual's physical or mental limitations. The social model views disability as a product of societal and environmental structures that limit people from fully participating in society. Not surprisingly, their goals for addressing barriers differ. The medical model focuses on addressing the person – normalizing or "fixing" their condition – while the social model focuses on addressing the environmental and social barriers.

Source: Barnes, Colin. 2019. "Understanding the Social Model of Disability." In Routledge eBooks, 14–31. <https://doi.org/10.4324/9780429430817-2>.

Standards for Defining & Measuring Disability

There are multiple ways to define the concept of disability. According to the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF)<sup>10</sup>, the concept of disability relates to the interaction of many factors, including: a person’s body functions and structures, activity limitations they experience, participation restrictions they experience, and environmental factors that affect these experiences. In addition to these factors there is increasing evidence of the impact of the social determinants of health, including racism, on disability identity. Due to its multidimensional nature, disability can be a difficult concept to measure. As ICF notes, “A decision about where to draw a line between ‘no disability’ and ‘disability’ can depend on the purposes for doing so.” This poses a challenge for quantifying disability in a numerical way. In response to these measurement difficulties, most common methods for collecting information on disability include asking multiple questions across a range of functional areas.

There are two widely used approaches for the collection of disability data: the Washington Group Short Set on Functioning Questions (WG-SS) and the American Community Survey 6-Item Set of Questions (ACS-6). Most international surveys use the WG-SS<sup>11</sup> (Figure 3). This set measures an individual’s difficulty functioning in six basic capabilities that often limit an individual and result in participation restrictions. It uses a graded response set (i.e., no difficulty, some difficulty, a lot of difficulty, or cannot do at all) to identify the degree of functional limitations a person experiences. This approach allows people to identify themselves along the continuum of functioning. But for the purposes of defining those with a disability and creating a summary statistic, the WG-SS indicates a cut off<sup>12</sup> – only individuals who respond with “a lot of difficulty” or “cannot do at all” to at least one of the six questions are defined as having a disability.



Unlike most international surveys that use the WG-SS, many U.S. federal surveys instead use six questions developed by the American Community Survey (ACS) and the U.S. Census to identify people with disabilities. Like the WG-SS, though, the ACS-6 set of questions was designed to capture information about basic functioning and identify the population at risk of disability (Figure 4). The ACS-6 differs from the WG-SS in that it does not include a communication difficulty question, and it uses binary ‘yes/no’ response options rather than graded response categories. Typically, if an individual answers “yes” to any one of the six ACS-6 questions, then they are considered to have a disability. See Appendix C for additional detail on which question structure is used in various federal surveys.

**Figure 4. American Community Survey 6-Item Set of Question (ACS-6)**

1. Hearing: Are you deaf or do you have serious difficulty hearing? (all ages)
2. Vision: Are you blind or do you have serious difficulty seeing, even when wearing glasses? (all ages)
3. Memory or Cognitive: Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)
4. Mobility: Do you have serious difficulty walking or climbing stairs? (5 years old or older)
5. Motility: Do you have difficulty dressing or bathing? (5 years old or older)
6. Self-Care and Independent Living: 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)

**Response Options: Yes/No**

Both the WG-SS and the ACS-6 have important limitations. Research has found<sup>13</sup> that both question sets often undercount certain subgroups, such as people with intellectual or developmental disabilities, psychiatric disabilities, and chronic illness due to the focus on function-based questions. One analysis found that both the WG-SS and ACS-6 failed to identify 43% and 20%, respectively, of respondents with disabilities. The researchers noted why this is problematic: “Even if people with disabilities report no functional limitations because they have adequate services and supports, it is still essential that they be counted and their disabilities known so that those services and supports continue to be funded and the disparities continue to be documented.”

### Current Federal Standard

In 2010, Section 4302(a) of the Affordable Care Act (ACA) directed the Secretary of the U.S. Department of Health and Human Services (HHS) to implement standards for the collection of race, ethnicity, sex, primary language, and disability status data in federal surveys and federally supported healthcare or public health activities, including Medicaid and the Children's Health Insurance Program (CHIP). In October 2011, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) published guidance on uniform data collection standards for race, ethnicity, sex, primary language, and disability status<sup>14</sup>. **This current standard for disability includes the ACS-6 questions.** This standard is intended to be the minimum standard—additional questions on disability may be added as long as the minimum standard is included.

In October 2023, the Census Bureau proposed changes to questions assessing disability status in the 2025 American Community Survey<sup>15</sup> to align with the Washington Group Short Set and the ICF disability framework. Most notable is the proposed shift from binary response options to graded response options. However, at the time of publication of this brief it is unclear if those changes will move forward as proposed. Many organizations, researchers, and disability advocates have voiced concerns with the proposed changes<sup>16</sup> and lack of input from the disability community. In November, the National Advisory Committee to the Census Bureau recommended against making any changes to the ACS disability questions<sup>17</sup> until a diverse group of stakeholders, including disability researchers and members of the disability community, could be engaged to further assess, revise, and make recommendations on how to conceptualize and measure disability status. The HHS 2011 guidance does note that if the ACS changes the disability questions in the future, HHS will revisit and modify the disability data collection standard as needed.

## Collection of Self-Reported Disability Data in Medicaid

SHADAC reviewed paper Medicaid applications for 50 states and D.C. along with online Medicaid applications for 36 states and D.C. The review examined whether, and how, a state collected data about disability status as part of the enrollment process for all Medicaid applicants (regardless of whether an individual was applying for a disability-related eligibility category). The review found that 49 of the 50 states' and D.C.'s paper applications collect some type of data about disability as part of the enrollment process. Of the 37 states' online applications we reviewed, SHADAC was able to identify 30 states that asked about disability status. Although most states are asking about disability, there is significant variation in what specific disability information is collected. **Despite the HHS recommended data standard, only one state (Oregon) was identified that is currently collecting self-reported disability data in alignment with the ACS-6 on their Medicaid application. (Figure 5)**

**Figure 5: Oregon's Paper Application Questions Example**



**4. Is this person deaf or do they have serious difficulty hearing?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**5. Is this person blind or do they have serious difficulty seeing, even when wearing glasses?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**6. If this person is age 5 or older, do they have serious difficulty concentrating, remembering, understanding, or making decisions because of a physical, mental, or emotional condition?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**7. If this person is age 5 or older, do they have serious difficulty walking or climbing stairs?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**8. If this person is age 5 or older, do they have difficulty dressing or bathing?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**9. If this person is age 15 or older, do they have difficulty doing errands alone? Examples are visiting a doctor's office or shopping. Is this because of a physical, mental, or emotional condition?**

☐ YES, what age did it begin? \_\_\_\_\_ ☐ NO ☐ Don't know ☐ Decline to answer

**10. Is this person limited in any way in any activities because of physical, mental or emotional problems?**

☐ YES ☐ NO ☐ Don't know ☐ Decline to answer

The disability questions Oregon uses on its paper Medicaid application align with the state's required standard. In 2021, the Oregon Legislature passed [House Bill 3159](#)<sup>18</sup>, which requires routine collection of data on race, ethnicity, preferred spoken and written languages, disability status, and sexual orientation and gender identity according to statewide data standards. As Oregon explains in its [Race, Ethnicity, Language, & Disability \(REALD\) Implementation Guide](#)<sup>19</sup>, the state uses the six questions from the American Community Survey followed by an additional question from the Behavioral Risk Factor Surveillance System (BRFSS) that reads as follows: *Does a physical, mental, or emotional condition limit your activities in any way?* Oregon recommends asking this additional question after the previous six ACS questions



because, “this question may be perceived by some people as offensive. This is particularly true from the viewpoint of the social model of disability, in which it is the inaccessible and discriminating society that is disabling, not the individual.”

**Most Common Disability Question Structure**

Most states (28 states’ paper application and 8 states’ online applications) ask Medicaid applicants to respond ‘yes’ or ‘no’ to a single combined question that addresses physical, mental, or emotional conditions that limit daily activities, or whether the applicant lives in a medical facility or nursing home – similar to the structure of the healthcare.gov model application (Figure 6).

**Figure 6: Healthcare.gov Model Application Disability Question**


10. Do you have a physical, mental, or emotional health condition that causes limitations in activities (like bathing, dressing, daily chores, etc.), a special health care need, or live in a medical facility or nursing home? .....

☐ Yes ☐ No

**Are You Blind or Disabled?**

The second most common question structure states used on their Medicaid applications asks respondents to indicate if they are blind or disabled. Many states then prompt individuals to consider applying for disability eligibility programs if they endorse one of the answers. Some states asked this as one combined question (e.g., New Hampshire - Figure 7); other states ask this information as two questions (e.g., Indiana - Figure 8).

**Figure 7: New Hampshire’s Paper Application Disability Question**

NEW HAMPSHIRE  
DHHS  
DEPARTMENT OF  
HEALTH & HUMAN SERVICES

4. Is anyone in your household blind or disabled? ☐ Yes ☐ No

**Figure 8: Indiana’s Paper Application Disability Question**

INDIANA FAMILY & SOCIAL SERVICES  
ADMINISTRATION  
INDIANA  
MEDICAID  
for Members

Are you blind? ☐ Yes ☐ No

Are you disabled? ☐ Yes ☐ No

**More Detailed Disability Questions**

Only three states ask applicants to provide more detailed disability information: Georgia, Ohio, and Minnesota. Georgia’s online application asks applicants to indicate the specific nature of each type of disability from a dropdown menu of choices (Figure 9). Ohio’s online application asks applicants to endorse whether they have one of five specific limitations or needs (Figure 10). Minnesota asks applicants to endorse several disability-related questions, including one about whether the applicant is in a residential treatment program for mental illness or drug or alcohol dependency (Figure 11).

Figure 9: Georgia's Online Application Disability Question

Figure 10: Ohio's Online Application Disability Question



Figure 11: Minnesota's Online Application Disability Question



## Disability Definition

Only two states explicitly define disability on their paper applications. California's application directs applicants to a frequently asked questions section that cites the six dimensions of the ACS-6 (Figure 12). Colorado directs applicants to a glossary at the end of the application that defines disability (Figure 13).

**Figure 12: California's Paper Application Disability Question and Definition**



Do you have a physical, mental, emotional, or developmental disability?  
☐ Yes ☐ No *See FAQ #27 for more information on what it means to have a disability.*

### 27. What do you mean by "disability"?

You may have a disability and qualify for Medi-Cal if:

- You are deaf or have a serious hearing loss.
- You are blind or have a serious vision loss, even when wearing glasses.
- You have an intellectual or cognitive disability and have difficulty remembering, concentrating, or making decisions.
- You have an ambulatory condition and have difficulty walking or climbing the stairs.
- You have difficulty bathing or dressing or doing similar daily activities.
- You have a physical, mental, or emotional condition and have difficulty doing errands (such as shopping or visiting a doctor's office) without help.

You do **not** have to be receiving special assistance services in your home or living in any kind of nursing facility or assisted living facility.

**Figure 13: Colorado's Paper Application Disability Question and Definition**



20. \*Do you have a medical, physical, mental, or developmental condition that has lasted, or is expected to last, more than 12 months, including blindness? ☐ Yes ☐ No

21. \*Do you have a medical, physical, mental, or developmental condition that causes you to regularly need help with some or all of your self-care activities (such as bathing, dressing, eating, using the bathroom)? ☐ Yes ☐ No

|  |                   |   |
|--|-------------------|---|
|  | <b>Disability</b> | Having a disability means you cannot do any substantial gainful activity or major activity to receive pay (or, in the case of a child, having marked and severe functional limitations or have an easily recognized and extreme lack of ability to do everyday activities). |
|--|-------------------|---|



There are also only two states that explicitly define the term disability on their online application forms. Maine uses a hover box to display the definition of disability in a pop-up box, which includes any physical or mental impairment that limits major life activities (Figure 14). The second state is Florida; they define disability as a condition that prevents someone from working and is expected to last at least 12 months (Figure 15).

Figure 14: Maine’s Online Application Disability Question and Definition

Note: Not all household members may be disabled, either does not apply to them or we do not need more information.

A disability is any sort of physical or mental impairment that substantially limits one or more major life activities.

Is any applicant blind or disabled? ⓘ

Yes

No

Figure 15: Florida’s Online Application Disability Question and Definition

FLORIDA DEPARTMENT OF  
HUMAN SERVICES  
MyACCESS

Personal Information

\* Is this person a resident of Florida?

☒ Yes ☐ No

\* Is this person disabled or blind?

☐ Yes ☐ No

Disability Details

A disability is a condition that may prevent a person from working and be expected to last for a continuous period of at least 12 months.

When Disability Began

Only five states collect information about when someone became disabled. Oregon (see Figure 5 above) and New Jersey do so on their paper applications. Alaska (Figure 16) and North Dakota do so on their online applications, and Nevada asks respondents to provide a date that the disability began both on its paper and online applications.

Figure 16: Alaska’s Online Application Disability Question

STATE OF ALASKA  
DEPARTMENT OF HEALTH

More About Jane's Disability or Blindness

You've told us that Jane is disabled or blind. Please tell us a little more about this.

Jane's Disability Status

\* What is Jane's disability status?

☐ Blind ☒ Disabled

Jane's Disability or Blindness


When did Jane become blind or disabled?

Ex: mm/dd/yyyy

### Disability Free Write-in Text

Six states give applicants a free write-in option to allow individuals to describe their disability in their own words on the application. Five states do so on their paper application, including Connecticut (Figure 17), and one state (Mississippi) does so on its online application.

**Figure 17: Connecticut's Paper Application Disability Write-In Option**



Do you have a disability or impairment?  
☐ Yes ☐ No If yes, explain.

### Conclusions and Looking Ahead

Overall, few states collect detailed self-reported disability data on their Medicaid applications, and some that do collect data continue to use outdated or inaccurate language. Our review of state Medicaid applications reveals that only one state, Oregon, is collecting disability data in alignment with the current HHS recommended ACS-6 data standard. However, other states are considering making changes to how they collect disability data. Massachusetts, for example, has endorsed the ACS-6 for use in the state's new [Health Equity Data Standards that were approved in March 2023](#)<sup>20</sup>. The state plans to implement these standards by January 1, 2025.

Other design factors such as an application's overall length, readability, or layout constraints sometimes make it challenging for states to add questions to their Medicaid applications. But because many states need to revise their data collection tools in response to the Office of Management and Budget's [\(OMB's\) proposed updates to the federal standard for collecting race and ethnicity data](#)<sup>21</sup> (expected to be completed by summer 2024), now is an especially opportune time to assess additional changes that could be made to improve disability data. There is also a [new opportunity to add sexual orientation and gender identity data questions](#)<sup>22</sup> to Medicaid applications.

Although there are unresolved methodological and conceptual issues related to collection of disability data, the ACS-6 continues to be an excellent starting point that states should consider. In addition to aligning with the current 2011 HHS data standard, using the ACS-6 has two other distinct benefits: 1) it serves as a common standard that would allow states to compare their enrollees' data with data from other states across the nation, and 2) it would allow states to examine data quality by comparing rates of disability reported on their Medicaid applications to rates of disability reported using the same questions on the U.S. Census Bureau's American Community survey by those who report having Medicaid. (SHADAC can provide technical assistance to states seeking to conduct this type of external validation.)

Some [researchers](#)<sup>23</sup> have also [advocated](#)<sup>24</sup> for the inclusion of additional questions to improve the ACS-6, including:

- Asking respondents to indicate their specific condition or conditions (and identify which is the main or primary condition) via an open-ended or self-categorization question.
- Asking either age of onset, duration, or expected duration of the condition (which Oregon does—see Figure 4 above).
- Asking the Washington Group's question about communication disability since the most frequent American

with Disabilities Act complaint in healthcare settings is the lack of effective communication for patients with communication-related disabilities.

To facilitate the collection of self-reported disability data it will also be important for states to provide eligibility workers, call center staff, and navigators with education on the importance of collecting this data, as well as training and resources on how to ask these questions and how to respond to questions from individuals. States should also communicate with enrollees about why this data is being collected, with whom and how it will be shared, and how the data will be used and protected.

Given ongoing discussion around the best way to collect data on self-reported disability, states interested in collecting these data are strongly encouraged to engage in a thoughtful community stakeholder process. Collecting feedback from disability advocates, enrollees, and other stakeholders can inform efforts to establish new data collection on a topic that is both complex and vitally important for the health of Medicaid populations.

The review conducted for this issue brief found that despite the existence of a federal disability data collection standard, there is still wide variation in application of those standards and ample opportunities for improvement in how almost all state Medicaid agencies collect this information. This was summed up in a paper released by the Centers for Medicare & Medicaid Services (CMS) in November 2022 titled, *The Path Forward: Improving Data to Advance Health Equity Solutions*<sup>25</sup>, detailing the current state of enrollee-focused health equity data across CMS programs. The report concludes that “Although Medicaid and CHIP disability status data collection aligns to standards [referring to the fact that the 2011 HHS data standard for disability includes the ACS 6-item question set], completeness issues persist.”

The collection of self-reported disability demographic data is a necessary first step in efforts to understand and monitor where health disparities are occurring for people with disabilities. It is also an important step away from the outdated medical model of disability in Medicaid. Documenting the number of Medicaid enrollees with various disabilities is essential for allocating sufficient resources and developing and maintaining programs to meet their needs. It is also vital for understanding the impact of intersectionality on multiple communities, and the impacts that has on equity. Collecting this information using the federal standard of the ACS-6 questions on Medicaid applications provides states with an excellent opportunity to do this in a consistent manner for everyone applying for the program.

Support for this issue brief was provided by the Robert Wood Johnson Foundation. The views expressed here do not necessarily reflect the views of the Foundation.

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The Robert Wood Johnson Foundation (RWJF) is committed to improving health and health equity in the United States. In partnership with others, we are working to develop a Culture of Health rooted in equity that provides every individual with a fair and just opportunity to thrive, no matter who they are, where they live, or how much money they have.

Health is more than an absence of disease. It is a state of physical, mental, and emotional wellbeing. It reflects what takes place in our communities, where we live and work, where our children learn and play, and where we gather to worship. That is why RWJF focuses on identifying, illuminating, and addressing the barriers to health caused by structural racism and other forms of discrimination, including sexism, ableism, and prejudice based on sexual orientation.

We lean on evidence to advance health equity. We cultivate leaders who work individually and collectively across sectors to address health equity. We promote policies, practices, and systems-change to dismantle the structural barriers to wellbeing created by racism. And we work to amplify voices to shift national conversations and attitudes about health and health equity.

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For more information, visit [www.rwjf.org](http://www.rwjf.org).

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State Health and Value Strategies (SHVS) assists states in their efforts to transform health and healthcare by providing targeted technical assistance to state officials and agencies. The program is a grantee of the Robert Wood Johnson Foundation, led by staff at Princeton University's School of Public and International Affairs. The program connects states with experts and peers to undertake healthcare transformation initiatives. By engaging state officials, the program provides lessons learned, highlights successful strategies and brings together states with experts in the field. Learn more at [www.shvs.org](http://www.shvs.org).

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#### ABOUT SHADAC

This issue brief was prepared by Emily Zylla and Elizabeth Lukanen. The State Health Access Data Assistance Center (SHADAC) is an independent, multidisciplinary health policy research center housed in the School of Public Health at the University of Minnesota with a focus on state policy. SHADAC produces rigorous, policy-driven analyses and translates its complex research findings into actionable information for states.

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## Appendix A:

### Disability Prevalence in Total Population and in Individuals with Medicaid



| State                | Any Disability - Total Population |                   | Any Disability - Individuals with Medicaid |                   |
|----------------------|-----------------------------------|-------------------|--|-------------------|
|                      | %                                 | Count             | %  | Count             |
| U.S.                 | <b>16.3%</b>                      | <b>44,550,122</b> | <b>33.3%</b>                               | <b>15,859,969</b> |
| Alabama              | 20.2%                             | 838,078           | 44.6%                                      | 255,970           |
| Alaska               | 17.2%                             | 101,773           | 34.4%                                      | 43,019            |
| Arizona              | 16.5%                             | 993,277           | 29.0%                                      | 315,263           |
| Arkansas             | 21.7%                             | 538,122           | 40.5%                                      | 214,534           |
| California           | 14.0%                             | 4,516,082         | 25.5%                                      | 1,911,911         |
| Colorado             | 13.9%                             | 671,703           | 30.5%                                      | 223,859           |
| Connecticut          | 14.9%                             | 452,728           | 29.3%                                      | 180,531           |
| Delaware             | 16.0%                             | 134,980           | 32.8%                                      | 47,448            |
| District of Columbia | 14.6%                             | 82,140            | 32.9%                                      | 40,248            |
| Florida              | 16.4%                             | 3,024,679         | 37.2%                                      | 924,194           |
| Georgia              | 16.2%                             | 1,426,160         | 39.1%                                      | 442,036           |
| Hawaii               | 14.9%                             | 177,550           | 23.9%                                      | 47,338            |
| Idaho                | 17.6%                             | 270,213           | 35.4%                                      | 89,503            |
| Illinois             | 15.2%                             | 1,585,603         | 30.6%                                      | 530,828           |
| Indiana              | 17.4%                             | 968,147           | 36.7%                                      | 338,372           |
| Iowa                 | 16.2%                             | 422,905           | 37.2%                                      | 161,156           |
| Kansas               | 17.2%                             | 409,377           | 45.4%                                      | 126,600           |
| Kentucky             | 22.0%                             | 817,956           | 37.7%                                      | 354,511           |
| Louisiana            | 20.1%                             | 757,075           | 34.0%                                      | 349,464           |
| Maine                | 18.8%                             | 220,918           | 46.6%                                      | 98,560            |
| Maryland             | 14.2%                             | 722,810           | 29.6%                                      | 255,972           |
| Massachusetts        | 14.5%                             | 856,064           | 30.4%                                      | 383,647           |
| Michigan             | 17.4%                             | 1,452,084         | 33.8%                                      | 582,867           |
| Minnesota            | 15.3%                             | 713,086           | 32.0%                                      | 238,497           |
| Mississippi          | 22.4%                             | 542,355           | 48.2%                                      | 211,829           |
| Missouri             | 18.4%                             | 933,624           | 45.6%                                      | 258,749           |
| Montana              | 18.1%                             | 165,983           | 36.6%                                      | 59,021            |
| Nebraska             | 16.6%                             | 262,117           | 41.1%                                      | 77,899            |
| Nevada               | 16.0%                             | 414,323           | 29.7%                                      | 131,962           |
| New Hampshire        | 14.7%                             | 175,019           | 37.0%                                      | 51,187            |
| New Jersey           | 13.2%                             | 1,011,373         | 28.7%                                      | 339,549           |
| New Mexico           | 20.0%                             | 348,526           | 30.6%                                      | 156,102           |
| New York             | 15.0%                             | 2,492,067         | 27.8%                                      | 1,154,136         |

|                |       |           |       |           |
|----------------|-------|-----------|-------|-----------|
| North Carolina | 16.8% | 1,472,825 | 37.6% | 459,797   |
| North Dakota   | 15.8% | 99,408    | 38.9% | 21,131    |
| Ohio           | 18.0% | 1,752,176 | 35.7% | 645,294   |
| Oklahoma       | 21.6% | 701,157   | 40.6% | 182,208   |
| Oregon         | 18.4% | 658,035   | 33.2% | 246,996   |
| Pennsylvania   | 17.2% | 1,872,499 | 38.0% | 744,965   |
| Rhode Island   | 17.1% | 159,579   | 32.9% | 66,037    |
| South Carolina | 17.5% | 755,928   | 36.4% | 232,602   |
| South Dakota   | 16.7% | 120,781   | 46.9% | 34,981    |
| Tennessee      | 18.6% | 1,070,597 | 40.5% | 358,990   |
| Texas          | 15.6% | 3,680,662 | 38.6% | 1,035,602 |
| Utah           | 13.8% | 356,401   | 39.2% | 96,761    |
| Vermont        | 16.2% | 89,701    | 35.7% | 40,937    |
| Virginia       | 15.2% | 1,089,926 | 33.7% | 307,888   |
| Washington     | 16.0% | 1,026,898 | 32.2% | 356,732   |
| West Virginia  | 22.7% | 341,899   | 38.5% | 142,671   |
| Wisconsin      | 14.8% | 722,381   | 36.0% | 269,906   |
| Wyoming        | 16.9% | 80,372    | 45.4% | 19,709    |


Source: SHADAC analysis of the 2021 American Community Survey (ACS) Public Use Microdata Sample (PUMS) file.

## Appendix B:

Disability Prevalence in Individuals with  
Medicaid, by Type of Functional Limitation in  
Total Population, by State, 2021

| State                | Any Disability |            | Hearing |           | Vision |           | Memory or Cognitive |           | Mobility |           | Motility |           | Self-Care and Independent Living |           |
|----------------------|----------------|------------|---------|-----------|--------|-----------|---------------------|-----------|----------|-----------|----------|-----------|----------------------------------|-----------|
|                      | %              | Count      | %       | Count     | %      | Count     | %                   | Count     | %        | Count     | %        | Count     | %                                | Count     |
| Alabama              | 44.6%          | 255,970    | 4.5%    | 43,785    | 5.3%   | 51,376    | 15.5%               | 129,658   | 16.6%    | 138,857   | 6.8%     | 56,527    | 20.6%                            | 113,099   |
| Alaska               | 34.4%          | 43,019     | 5.3%    | 9,927     | 4.2%   | 7,729     | 12.5%               | 21,011    | 10.9%    | 18,346    | 4.9%     | 8,292     | 13.3%                            | 15,677    |
| Arizona              | 29.0%          | 315,263    | 4.0%    | 63,324    | 3.6%   | 56,326    | 11.9%               | 166,453   | 10.8%    | 152,113   | 5.1%     | 71,135    | 12.0%                            | 126,233   |
| Arkansas             | 40.5%          | 214,534    | 4.6%    | 38,247    | 5.3%   | 43,407    | 16.0%               | 114,946   | 15.0%    | 107,908   | 7.6%     | 54,892    | 18.6%                            | 93,761    |
| California           | 25.5%          | 1,911,911  | 3.5%    | 372,204   | 3.6%   | 380,445   | 10.1%               | 961,487   | 10.4%    | 992,478   | 6.3%     | 599,998   | 13.1%                            | 962,022   |
| Colorado             | 30.5%          | 223,859    | 4.7%    | 51,252    | 4.0%   | 43,581    | 12.3%               | 119,035   | 10.7%    | 103,567   | 5.4%     | 52,581    | 13.9%                            | 99,841    |
| Connecticut          | 29.3%          | 180,531    | 4.0%    | 32,953    | 3.8%   | 31,786    | 12.9%               | 98,215    | 12.2%    | 92,722    | 6.7%     | 51,275    | 14.7%                            | 88,333    |
| Delaware             | 32.8%          | 47,448     | 4.5%    | 9,477     | 4.4%   | 9,285     | 13.9%               | 25,797    | 12.6%    | 23,332    | 8.0%     | 14,787    | 15.8%                            | 21,645    |
| District of Columbia | 32.9%          | 40,248     | 3.2%    | 5,201     | 3.4%   | 5,553     | 10.6%               | 16,214    | 16.4%    | 24,979    | 6.7%     | 10,190    | 13.0%                            | 15,628    |
| Florida              | 37.2%          | 924,194    | 4.6%    | 178,375   | 4.7%   | 184,876   | 14.0%               | 475,529   | 14.9%    | 506,945   | 7.6%     | 259,259   | 17.8%                            | 425,724   |
| Georgia              | 39.1%          | 442,036    | 4.1%    | 79,819    | 4.6%   | 88,943    | 13.9%               | 230,756   | 14.1%    | 233,225   | 7.2%     | 118,850   | 19.1%                            | 205,032   |
| Hawaii               | 23.9%          | 47,338     | 3.0%    | 8,795     | 2.4%   | 6,928     | 11.0%               | 28,832    | 10.0%    | 26,226    | 5.6%     | 14,606    | 12.7%                            | 24,665    |
| Idaho                | 35.4%          | 89,503     | 4.5%    | 17,675    | 4.0%   | 15,653    | 15.2%               | 52,852    | 11.6%    | 40,367    | 6.8%     | 23,741    | 16.4%                            | 40,037    |
| Illinois             | 30.6%          | 530,828    | 3.3%    | 83,899    | 3.9%   | 98,880    | 12.1%               | 276,889   | 11.9%    | 271,978   | 6.3%     | 143,748   | 14.9%                            | 252,337   |
| Indiana              | 36.7%          | 338,372    | 4.4%    | 60,782    | 4.5%   | 61,492    | 15.2%               | 184,140   | 14.0%    | 169,529   | 7.1%     | 86,233    | 17.1%                            | 150,947   |
| Iowa                 | 37.2%          | 161,156    | 4.9%    | 31,490    | 3.6%   | 23,238    | 15.9%               | 90,518    | 13.8%    | 78,335    | 7.3%     | 41,803    | 17.7%                            | 74,179    |
| Kansas               | 45.4%          | 126,600    | 5.6%    | 26,039    | 5.0%   | 22,899    | 20.0%               | 79,246    | 14.9%    | 59,318    | 9.4%     | 37,239    | 23.7%                            | 62,893    |
| Kentucky             | 37.7%          | 354,511    | 4.9%    | 64,343    | 5.9%   | 77,440    | 15.9%               | 188,465   | 15.7%    | 185,890   | 7.5%     | 88,585    | 17.4%                            | 157,720   |
| Louisiana            | 34.0%          | 349,464    | 4.6%    | 68,163    | 5.9%   | 87,057    | 13.6%               | 179,682   | 13.2%    | 173,704   | 6.4%     | 85,068    | 15.0%                            | 149,408   |
| Maine                | 46.6%          | 98,560     | 7.3%    | 20,042    | 4.9%   | 13,388    | 23.5%               | 59,125    | 19.5%    | 49,127    | 9.4%     | 23,593    | 24.5%                            | 50,678    |
| Maryland             | 29.6%          | 255,972    | 2.9%    | 37,171    | 3.6%   | 45,561    | 11.2%               | 125,889   | 11.3%    | 127,809   | 5.6%     | 63,013    | 13.6%                            | 114,536   |
| Massachusetts        | 30.4%          | 383,647    | 3.7%    | 60,690    | 3.9%   | 63,066    | 13.7%               | 207,211   | 12.6%    | 190,352   | 7.0%     | 105,844   | 14.7%                            | 180,683   |
| Michigan             | 33.8%          | 582,867    | 3.8%    | 90,626    | 3.8%   | 90,532    | 14.8%               | 319,551   | 13.7%    | 294,274   | 6.8%     | 147,353   | 16.5%                            | 275,463   |
| Minnesota            | 32.0%          | 238,497    | 3.4%    | 36,306    | 3.2%   | 34,785    | 15.2%               | 146,288   | 10.4%    | 99,570    | 7.4%     | 70,736    | 16.7%                            | 121,000   |
| Mississippi          | 48.2%          | 211,829    | 4.6%    | 32,743    | 6.8%   | 48,289    | 18.0%               | 110,055   | 19.4%    | 118,728   | 9.0%     | 54,831    | 23.0%                            | 95,667    |
| Missouri             | 45.6%          | 258,749    | 4.7%    | 44,128    | 5.0%   | 47,091    | 18.7%               | 150,704   | 16.3%    | 131,036   | 9.7%     | 78,152    | 23.6%                            | 126,996   |
| Montana              | 36.6%          | 59,021     | 5.6%    | 12,641    | 4.3%   | 9,701     | 17.5%               | 35,867    | 11.1%    | 22,710    | 6.8%     | 14,044    | 16.6%                            | 25,871    |
| Nebraska             | 41.1%          | 77,899     | 5.3%    | 15,925    | 5.0%   | 14,907    | 16.8%               | 43,462    | 14.1%    | 36,340    | 8.3%     | 21,441    | 17.6%                            | 31,508    |
| Nevada               | 29.7%          | 131,962    | 4.0%    | 26,715    | 4.3%   | 28,574    | 11.0%               | 64,852    | 12.0%    | 70,507    | 6.1%     | 35,924    | 12.3%                            | 53,423    |
| New Hampshire        | 37.0%          | 51,187     | 4.0%    | 7,774     | 4.5%   | 8,705     | 17.9%               | 31,068    | 12.5%    | 21,729    | 8.7%     | 14,995    | 20.9%                            | 27,864    |
| New Jersey           | 28.7%          | 339,549    | 3.3%    | 57,432    | 3.8%   | 66,102    | 11.2%               | 172,939   | 11.6%    | 179,156   | 7.0%     | 108,623   | 15.1%                            | 174,726   |
| New Mexico           | 30.6%          | 156,102    | 4.9%    | 35,583    | 3.7%   | 27,324    | 12.3%               | 81,087    | 11.1%    | 73,425    | 5.6%     | 36,964    | 13.5%                            | 67,347    |
| New York             | 27.8%          | 1,154,136  | 3.2%    | 180,123   | 3.5%   | 193,117   | 11.8%               | 595,960   | 12.7%    | 644,419   | 7.3%     | 369,089   | 15.3%                            | 622,306   |
| North Carolina       | 37.6%          | 459,797    | 4.1%    | 82,584    | 4.4%   | 88,602    | 14.0%               | 240,561   | 14.5%    | 249,772   | 7.3%     | 126,140   | 18.5%                            | 218,268   |
| North Dakota         | 38.9%          | 21,131     | 4.9%    | 3,939     | 5.8%   | 4,602     | 14.7%               | 10,317    | 14.0%    | 9,830     | 9.7%     | 6,816     | 19.9%                            | 10,316    |
| Ohio                 | 35.7%          | 645,294    | 3.9%    | 101,165   | 4.2%   | 109,114   | 16.0%               | 368,887   | 13.7%    | 315,668   | 7.2%     | 165,912   | 16.0%                            | 278,282   |
| Oklahoma             | 40.6%          | 182,208    | 4.2%    | 34,177    | 5.4%   | 43,857    | 14.7%               | 100,221   | 13.0%    | 88,560    | 6.2%     | 42,019    | 18.1%                            | 75,643    |
| Oregon               | 33.2%          | 246,996    | 4.2%    | 43,345    | 4.0%   | 40,990    | 15.8%               | 147,811   | 11.7%    | 109,604   | 6.9%     | 64,366    | 15.5%                            | 111,773   |
| Pennsylvania         | 38.0%          | 744,965    | 4.2%    | 115,652   | 4.9%   | 133,896   | 17.2%               | 424,470   | 14.4%    | 355,083   | 7.5%     | 184,914   | 18.5%                            | 346,234   |
| Rhode Island         | 32.9%          | 66,037     | 3.5%    | 9,265     | 4.2%   | 11,198    | 14.1%               | 34,230    | 13.6%    | 32,974    | 7.2%     | 17,348    | 16.9%                            | 32,843    |
| South Carolina       | 36.4%          | 232,602    | 3.7%    | 38,774    | 4.4%   | 45,802    | 12.6%               | 114,476   | 13.5%    | 122,611   | 6.8%     | 61,981    | 15.9%                            | 97,048    |
| South Dakota         | 46.9%          | 34,981     | 5.6%    | 7,187     | 5.3%   | 6,818     | 19.3%               | 21,167    | 16.7%    | 18,317    | 9.7%     | 10,682    | 21.9%                            | 15,520    |
| Tennessee            | 40.5%          | 358,990    | 5.0%    | 70,047    | 4.9%   | 68,143    | 15.9%               | 192,910   | 15.7%    | 190,431   | 7.5%     | 91,783    | 18.9%                            | 159,864   |
| Texas                | 38.6%          | 1,035,602  | 4.0%    | 202,499   | 4.9%   | 247,892   | 13.0%               | 545,441   | 12.8%    | 536,985   | 7.4%     | 308,471   | 18.4%                            | 465,329   |
| Utah                 | 39.2%          | 96,761     | 4.6%    | 17,147    | 4.9%   | 18,101    | 17.9%               | 58,345    | 13.2%    | 43,115    | 6.3%     | 20,658    | 19.1%                            | 45,162    |
| Vermont              | 35.7%          | 40,937     | 5.2%    | 8,176     | 3.3%   | 5,207     | 14.7%               | 21,033    | 12.9%    | 18,510    | 6.4%     | 9,137     | 16.5%                            | 18,468    |
| Virginia             | 33.7%          | 307,888    | 4.2%    | 56,763    | 4.2%   | 56,472    | 14.4%               | 173,427   | 12.8%    | 154,768   | 7.5%     | 90,025    | 15.6%                            | 136,939   |
| Washington           | 32.2%          | 356,732    | 4.1%    | 67,980    | 3.7%   | 60,796    | 14.0%               | 206,088   | 11.2%    | 164,102   | 5.9%     | 86,226    | 14.9%                            | 160,213   |
| West Virginia        | 38.5%          | 142,671    | 5.8%    | 29,596    | 5.2%   | 26,399    | 16.7%               | 76,544    | 15.8%    | 72,342    | 8.5%     | 39,016    | 18.0%                            | 64,391    |
| Wisconsin            | 36.0%          | 269,906    | 4.7%    | 51,032    | 3.2%   | 34,386    | 15.3%               | 149,055   | 13.0%    | 127,308   | 7.6%     | 73,921    | 17.4%                            | 126,461   |
| Wyoming              | 45.4%          | 19,709     | 5.9%    | 4,099     | 6.5%   | 4,506     | 17.2%               | 10,165    | 18.7%    | 11,056    | 9.5%     | 5,636     | 23.1%                            | 9,423     |
| U.S.                 | 33.3%          | 15,859,969 | 4.0%    | 2,847,076 | 4.2%   | 2,994,817 | 13.5%               | 8,478,931 | 12.9%    | 8,080,037 | 7.0%     | 4,368,462 | 16.1%                            | 7,419,426 |

Source: [SHADAC](#) analysis of the 2021 American Community Survey (ACS) Public Use Microdata Sample (PUMS) file.



## Appendix C:

### Self-Reported Disability Questions Used by Federal Surveys



| Federal Survey   | ACS-6 Disability Measure | Washington Group Short Set on Functioning |
|--|--------------------------|---|
| American Community Survey (ACS)  | ✓                        |   |
| Behavioral Risk Factor Surveillance System (BRFSS)   | ✓                        |   |
| Current Population Survey (CPS)  | ✓                        |   |
| Household Pulse Survey   |                          | ✓   |
| Medicare Current Beneficiary Survey (MCBS)   | ✓                        |   |
| National Health and Nutrition Examination Survey (NHANES)                                    | ✓                        | ✓   |
| National Health Interview Survey (NHIS)  |                          | ✓   |
| National Survey on Drug Use and Health (NSDUH)   | ✓                        | ✓   |
| Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems (NAMCAHPS) | ✓                        |   |
| Pregnancy Risk Assessment Monitoring System (PRAMS) (supplement only)                        |                          | ✓   |
| Survey of Income and Program Participation (SIPP)  | ✓                        |   |

Source: [SHADAC](#) analysis of federal survey data. Supported by work done to prepare the 2023 MACPAC report: [Federal Survey Sample Size Analysis: Disability, Language, and Sexual Orientation and Gender Identity](#)<sup>26</sup>.

## ENDNOTES

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