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STATE HEALTH ACCESS DATA ASSISTANCE CENTER

Improving Health Equity Through Better Demographic Data Collection in Medicaid

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AHIP Medicare, Medicaid, Duals & Commercial Markets Forum

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About SHADAC

- Health policy research center located at the University of Minnesota School of Public Health
- Provide technical assistance to state officials and policy makers in the collection and use of data
- Passionate about the importance of using sound data to inform policy decisions
- Nonpartisan – commitment to producing unbiased results

Demographic Data Collection in Medicaid

- Medicaid serves people who have historically faced disparities in health and health care
- Through its policy, financial, and programmatic levers, Medicaid is uniquely situated to address health inequities experienced by the program's diverse enrollees
- All states collect demographic data through their Medicaid application
  - Race, ethnicity, language (written and spoken), disability, sexual orientation and gender identity
- These administrative data are used internally, reported to Centers for Medicare & Medicaid Services (CMS), and widely used by researchers to examine health care access, use, and inequities
- High quality demographic data are critical to improve health equity

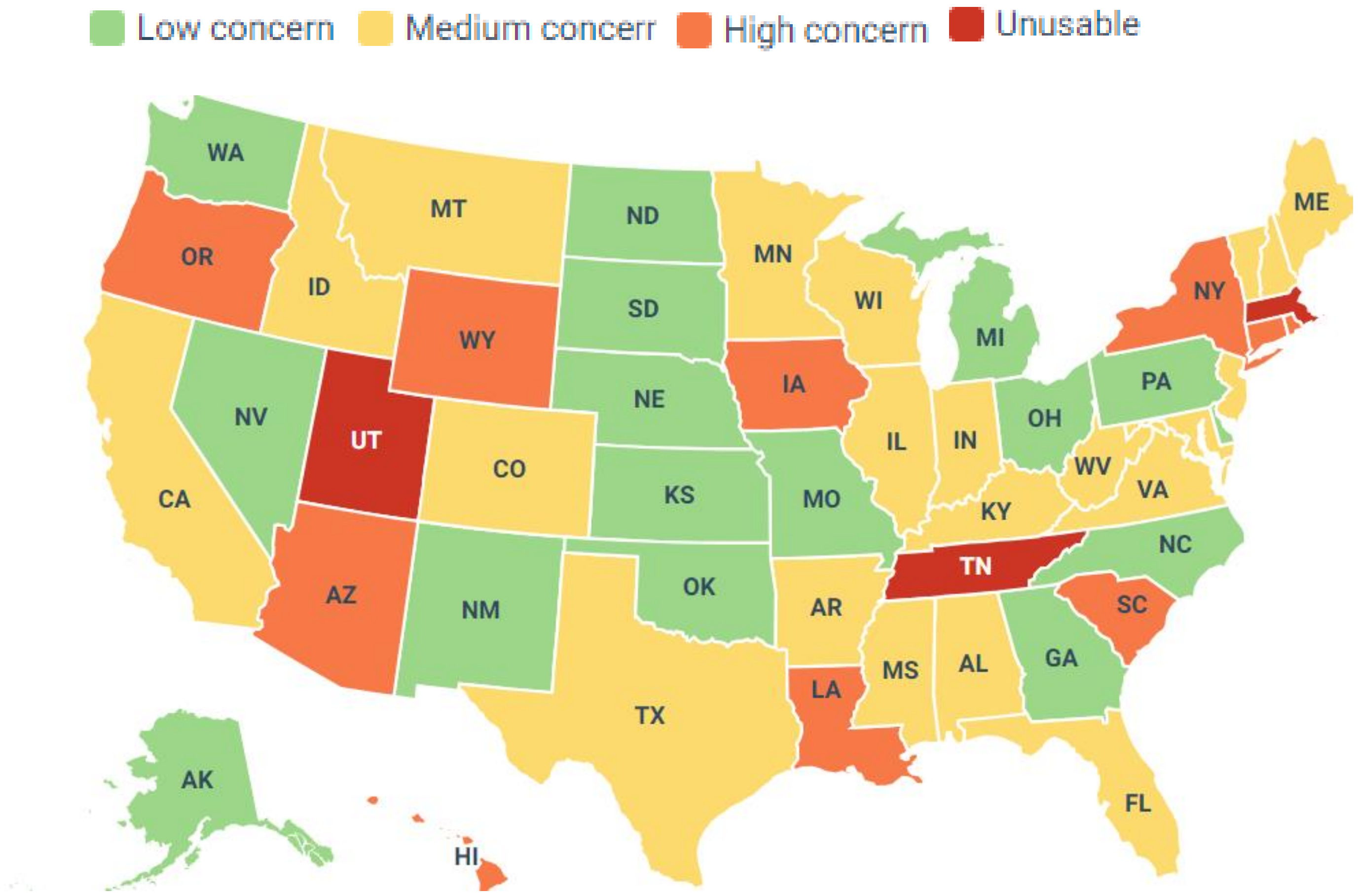
Reasons for Missing/Poor Quality Demographic Data in Medicaid

- **Federal rules and guidance**
  Guidance is often not consistent with best evidence about how to best ask these questions
- **Voluntary reporting**
  States cannot require people to provide things like race/ethnicity or sexual orientation as part of the application process
- **Operational/Technical**
  Systems that collect and house this information are old and often difficult and expensive to modify
- **Mistrust about how data will be used**
  There are concerns about how data collection might be used to discriminate

Race and Ethnicity Data in Medicaid

- All states collect race/ethnicity on their Medicaid applications
- SHADAC identified 64 variations of option choices across applications (paper and online)
- Number of response options varies from 5 (the minimum federal standard - American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian/Other Pacific Islander, White) to 37
- Majority of states follow federal guidelines, which are inconsistent with best practices

CMS Race/Ethnicity Data Quality Assessment, 2021



Sources: CMS TMSIS DQ Atlas background and methods and SHADAC REL Data in Medicaid .

Sexual Orientation and Gender Identity (SOGI) in Medicaid

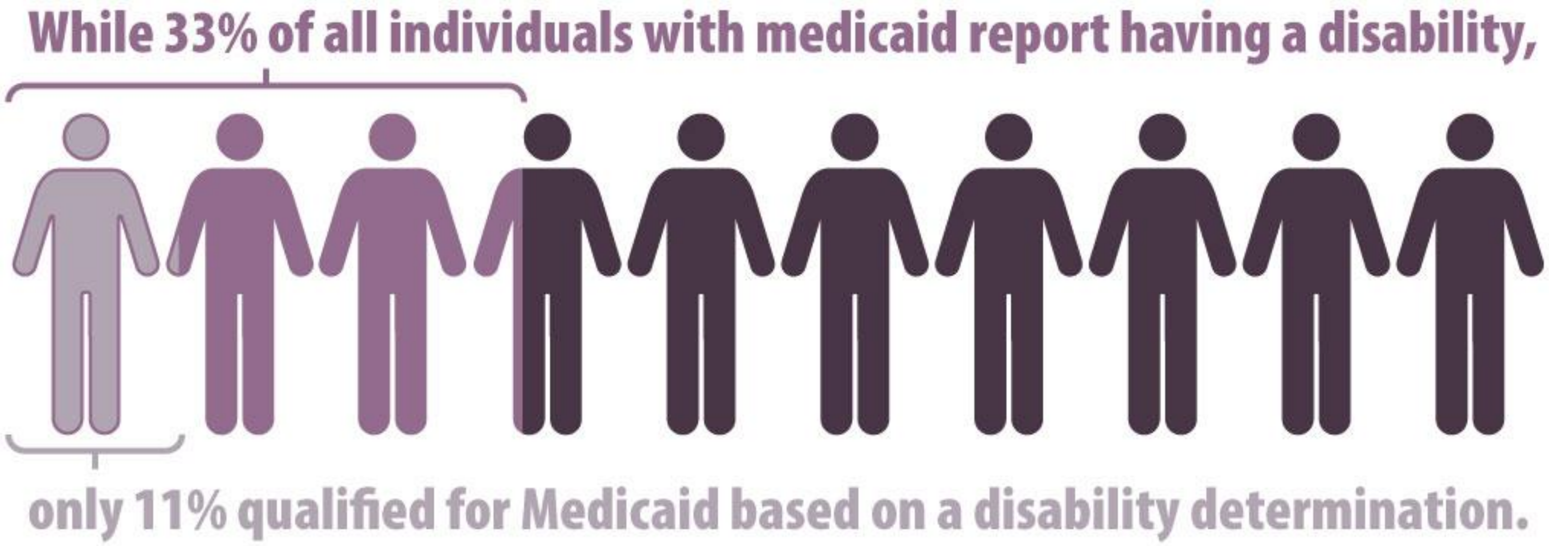
- An estimated 1.2 million LGBTQ+ adults have Medicaid
- Overall, LGB Medicaid beneficiaries reported higher rates of mental illness and substance use disorder than heterosexual counterparts
- The vast majority of states provide only binary "male" and "female" response options to either their sex or gender questions
- In fall 2023, CMS added three new SOGI questions to the single streamlined model application used by HealthCare.gov and Medicaid
  - While this will increase data collection, it is imperfect
    - Questions don't address pronouns
    - Responses don't align with recommended best practices

New CMS SOGI Questions

Category	Question	Responses
Sex	Sex (existing question, required, single select)	• Male (does not trigger pregnancy question) • Female (triggers pregnancy question)
Sex Assigned at Birth	What was [First Name]'s sex assigned at birth? You can find this on an original birth certificate or similar document. (new question, optional, single select)	• Female • Male • A sex that's not listed: [free text] • Not sure • Prefer not to answer
Gender Identity	What's [First Name]'s gender identity? (new question, optional, single select)	• Female • Male • Transgender female • Transgender male • A gender identity that's not listed: [free text] • Not sure • Prefer not to answer
Sexual Orientation	What's [First Name]'s sexual orientation? (new question, optional, single select)	• Lesbian or gay • Straight • Bisexual • A sexual orientation that's not listed: [free text] • Not sure • Prefer not to answer

Sources: The Williams Institute LGBT FAQs, MACPAC Access in Brief Experiences of LGBT and SHADAC SOGI in Medicaid.

Self Reported Disability in Medicaid



- Very little is known about people who self-identify as having a disability within the Medicaid program who are not part of the group that qualifies for benefits through a disability-related eligibility category

- While most states collect some of data about disability, only one (Oregon) collects the information in alignment with best practices

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

Equity Initiatives In States with Improved Data

Massachusetts: Using improved demographic data, the state is developing a payment system tied to health equity, where demographic data is used both to measure improvement but also to account for differences in populations served

California: Using recent improvements in SOGI data collection, the state is tracking the impact of Medicaid unwinding for transgender enrollees

Oregon: A leader in demographic data collection, the state used data on self reported disability status to track and report COVID cases and encounters for people who reported a disability

Beyond Medicaid – Considerations for Improving Demographic Data Collection

- Make demographic data collection a **priority**
- **Improve question format**, but also look to **align collection strategy** with federal and state standards
  - Federal standards for race and ethnicity are likely to be updated this summer
- Leverage alternative data sources and **be willing to share data with others**
- Be mindful of **bias in research** and **in tools that use demographic data**, like Artificial Intelligence
- Build trust…

THE WHITE HOUSE

JANUARY 26, 2023

Initial Proposals for Revising the Federal Race and Ethnicity Standards

By Dr. Karin Orvis, Chief Statistician of the United States

Today, the Office of the Chief Statistician is taking a key step forward in its formal process to revise OMB's statistical standards for collecting and reporting race and ethnicity data across Federal agencies (Directive No. 15) by publishing an initial set of recommended revisions proposed by an Interagency Technical Working Group.

Good Data Starts with Trust

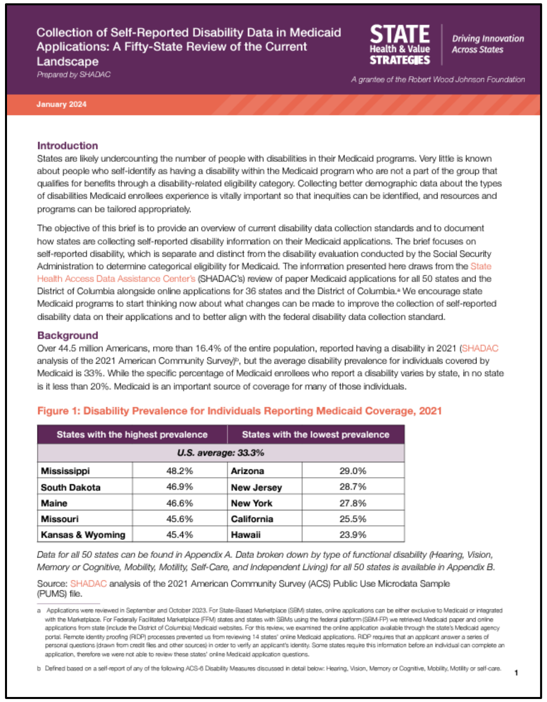
- Asking people for personal information about their history, lives, and how they identify as a person, trust requires good communication
- Privacy and confidentiality are paramount concerns
- Community input should shape questions and response options
- The staff responsible for collecting this information need education and training
- Respondents should know how their information will be used and have that output shared back with them

> "Relationships are built at the speed of trust, and social change happens at the speed of relationships."
>
> \- Reverend Jennifer Bailey

Resources

SHADAC’s understating of this issue is based on technical assistance and an ongoing convening of states focused on improving demographic data supported by State Health and Value Strategies (SHVS).

SHVS has created an accessible one-stop source of health equity information aimed at state officials



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

Prepared by SHADAC

STATE Health & Value STRATEGIES | *Driving Innovation Across States*

A grantee of the Robert Wood Johnson Foundation

January 2024

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.[a] 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)[b], 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.

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[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.

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Issue Brief: Collection of Race, Ethnicity, Language (REL) Data in Medicaid Applications: A 50-state Review of the Current Landscape

Issue Brief: Collection of Sexual Orientation and Gender Identity (SOGI) Data: Considerations for Medicaid and Spotlight on Oregon

Issue Brief: Collection of Self-Reported Disability Data in Medicaid Applications: A 50-state Review of the Current Landscape

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Thank you!

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Check out our website at www.shadac.org and follow us on LinkedIn: https://www.linkedin.com/company/shadac

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