



Improving Health Equity Through Better Demographic Data Collection in Medicaid

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AHIP Medicare, Medicaid, Duals & Commercial Markets Forum

March 12, 2024 ● Baltimore, MD

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**

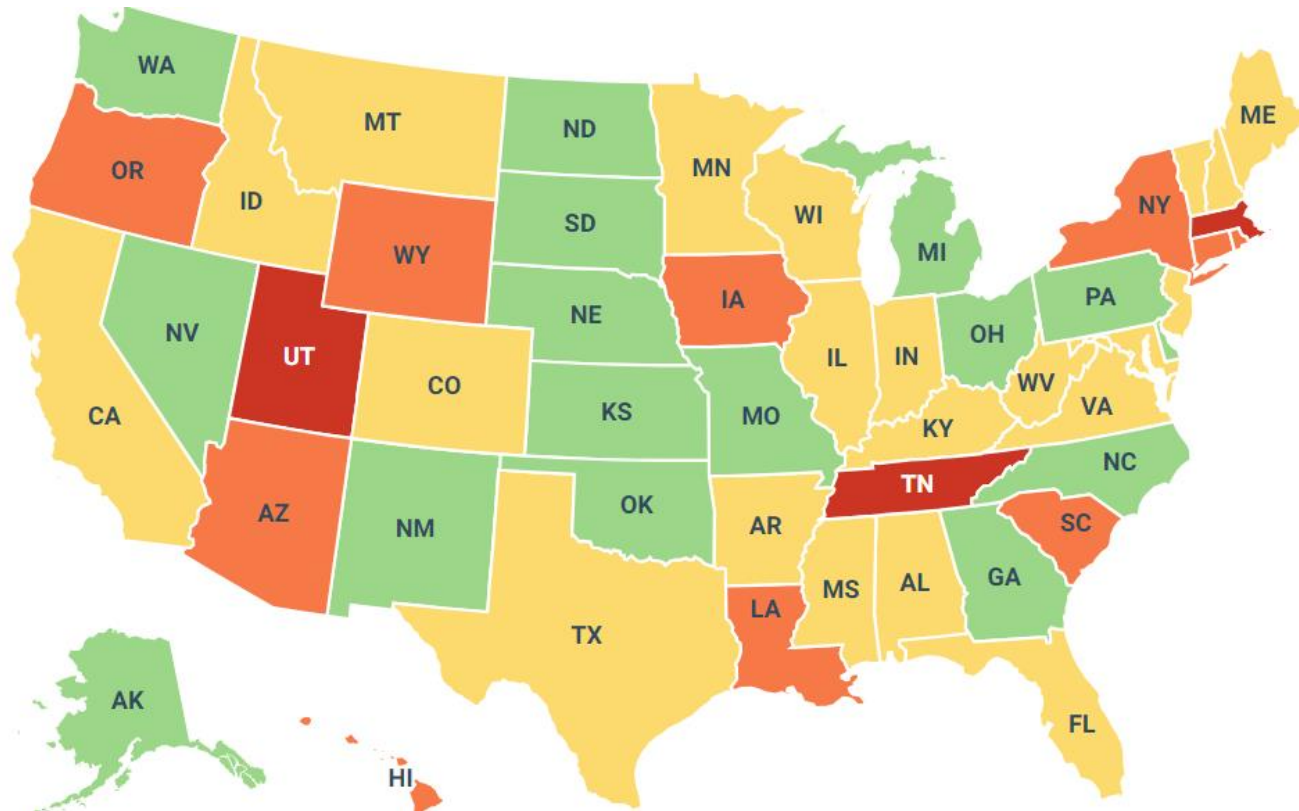
There are concerns about how data collection might be used to discriminate

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

Low concern Medium concern High concern Unusable



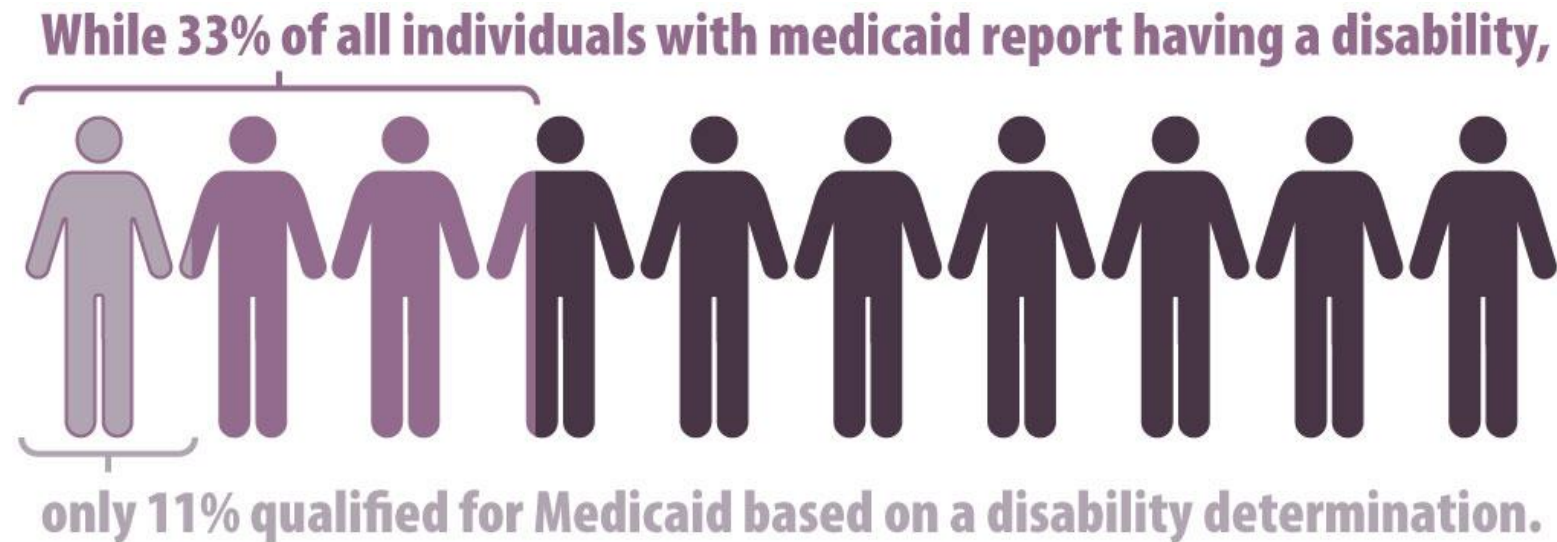
Sexual Orientation and Gender Identity (SOGI) in Medicaid

- 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)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • 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)	<ul style="list-style-type: none"> • Lesbian or gay • Straight • Bisexual • A sexual orientation that’s not listed: [free text] • Not sure • Prefer not to answer

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

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

 ▶ [OMB](#) ▶ [BRIEFING ROOM](#) ▶ [BLOGS](#)

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

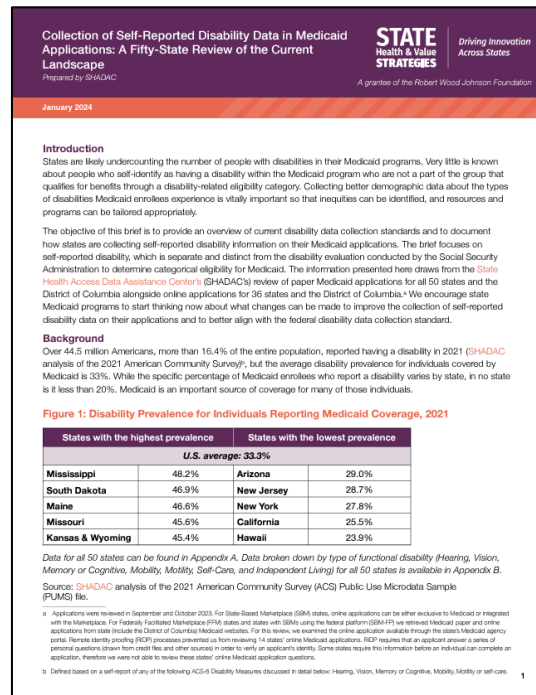
“Relationships are built at the speed of trust, and social change happens at the speed of relationships.”

- 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



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

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

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>

