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Medicaid Demographic Data Collection

Review of draft chapter for the June report

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Overview

- Need to improve Medicaid demographic data
  - Primary language and limited English proficiency (LEP)
  - Sexual orientation and gender identity (SOGI)
  - Disability
- Data collection priorities and uses
- Medicaid administrative and federal survey data collection
- Data limitations
- Demographic data collection considerations
- Looking ahead

Need to Improve Medicaid Demographic Data

- Demographic data can provide meaningful insights about historically marginalized populations

- Research shows that individuals with language service needs, sexual and gender minorities, and individuals with disabilities experience disparate access to care and health outcomes compared to their counterparts

- Current data limitations can prevent stakeholders from measuring the experiences of these populations, including those covered by Medicaid

Data Collection Priorities and Uses

- The Biden Administration has launched several efforts focused on improving the measurement of health disparities for underserved communities

- The Centers for Medicare & Medicaid Services (CMS) framework for health equity, prioritizes demographic data collection, language access, and accessibility to health care services and coverage
  - In November 2023, CMS added SOGI questions to the model application and released guidance to states

- Some states are taking steps to update data collection and reporting to include new demographic data

- Interviewed researchers and advocates emphasized collecting these data with other demographic data to ensure inclusion in research

Medicaid Administrative Data

- Demographic data are most often collected on the Medicaid application, with variation across states
  - Almost all state Medicaid programs collect primary language
  - More than half ask at least one question about self-reported disability
  - Few collect LEP or SOGI
- States can report primary language, LEP, and self-reported disability to the Transformed Medicaid Statistical Information System (T-MSIS)
  - CMS has indicated that states should be able to report SOGI data as early as calendar year 2025

Federal Population Survey Data
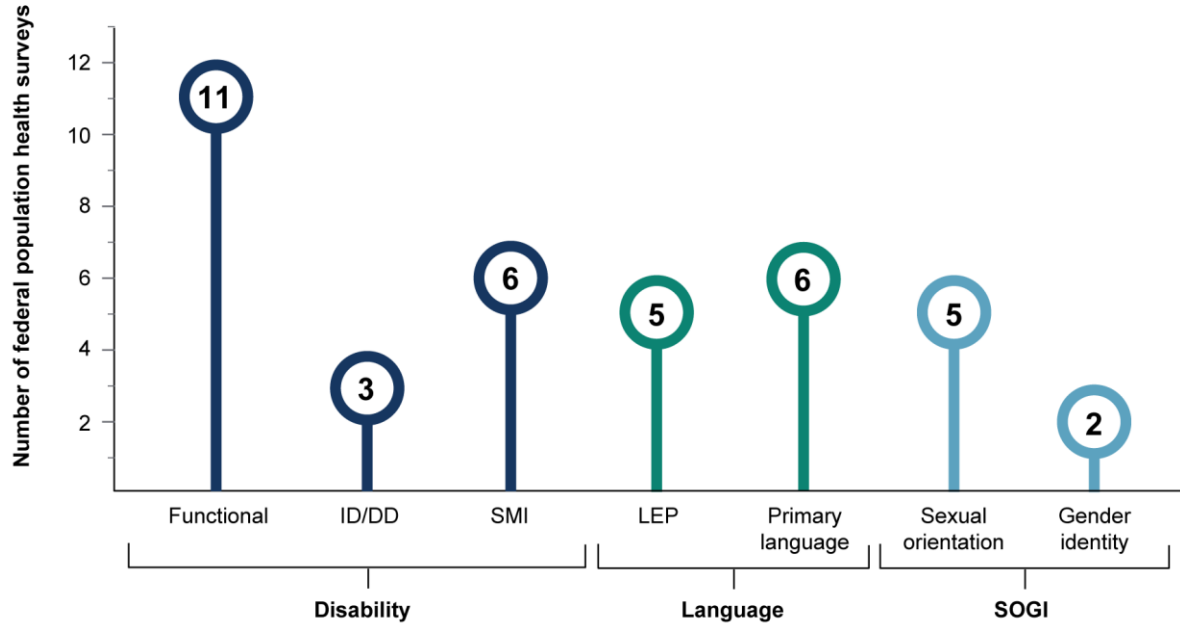
Notes: ID/DD is intellectual disabilities and developmental disabilities. SMI is serious mental illness. LEP is limited English proficiency. SOGI is sexual orientation and gender identity. Thirteen federal population health surveys were included in the survey review. SMI questions included the Kessler-6 screener, PHQ-2 screener, and PHQ-9 screener, and reported diagnosis of depression or poor mental health. Functional disability includes surveys that ask the 6 questions used in the American Community Survey or the Washington Disability Group instruments.
Source: State Health Access Data Assistance Center analysis of federal survey data, 2023. https://www.macpac.gov/publication/federal-survey-sample-size-analysis-disability-language-and-sexual-orientation-and-gender-identity/

Data Limitations

- Absence of data collection in federal surveys and incomplete collection on applications and reporting to T-MSIS

- Lack of representativeness due to small sample sizes and differences in population definitions

- Issues with data accuracy due to collection methods and inconsistencies with who responds to the questions (e.g., self-report, head of household, proxy, etc.)

Demographic Data Collection Purposes

- **Programmatic:** collect language and disability information to determine eligibility, service needs, or accommodations
- **Research:** very few states reported considering collecting LEP and self-reported disability information and many were unsure of how these data could be used to support state-level research
  - A few states indicated interest in collecting and using SOGI data to assess access to effective and inclusive care

State and Beneficiary Burden

- Changes to the application can be administratively intensive, requiring updates to written and oral translations, explanatory text about how the information will be used, and applicant assister training

- Applications can be long, and additional questions may increase applicant burden

- Modifications to the data systems used to store and report Medicaid eligibility and enrollment data and testing of these changes can be resource and time intensive

Data Quality Considerations

- **Self-reported:** considered the best method for collecting information that reflects an individual's identity
- **Change over time:** providing individuals opportunities to update their information can help ensure that their demographic information aligns with their current identity
- **Question standardization:** inconsistent use of measures across data sources can limit comparability
- **Representative of Medicaid population:** data collection methods should allow for generalizability to the Medicaid population
- **Data privacy:** federal and state privacy policies protect sensitive data and specify how the data can and cannot be used

Looking Ahead

- The findings from this work identify challenges with collecting complete and comparable demographic data
  - There is ongoing work by the federal government, state Medicaid programs, and researchers to address limitations by expanding and improving demographic data collection
- The findings also indicate that many of these data are currently available from some sources
  - Research can capitalize on existing data to measure and address health disparities

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