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Medicaid Sexual Orientation and Gender Identity Data Collection

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Overview

- Definitions
- Health disparities
- Federal priorities
- Medicaid sexual orientation and gender identity (SOGI) data collection
- Considerations for data collection
- Next steps

Definitions

- **Sex assigned at birth**: identifies the binary sex listed on someone's birth certificate
- **Sexual orientation:** identifies individuals who do not identify as straight or heterosexual
- **Gender identity:** identifies individuals who do not identify as cisgender (sex assigned at birth aligns with gender identity)
- **Sexual and gender minorities (SGM):** identifies individuals who identify as part of the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) community

Health Disparities

Compared to straight and cisgender individuals, SGM are more likely to have:

- a chronic condition or a disability and to report a need for mental health services;
- poor provider experiences, including facing discrimination, lack of culturally competent care, and provider refusal of care; and
- difficulties with accessing care due to cost of health care and gaps in coverage.

Federal Priorities

- In 2022, the Biden Administration issued Executive Order 14075 to advance equality for lesbian, gay, bisexual, transgender, and intersex individuals. This led to the development of:
  - a roadmap for federal agencies to develop agency specific SOGI Data Action Plans
  - best practices for the collection of SOGI data on federal statistical surveys
- In November 2023, the Centers for Medicare & Medicaid Services (CMS) added SOGI questions to the model single, streamlined application and released guidance on adding them to state Medicaid and State Children's Health Insurance Program (CHIP) applications

Medicaid SOGI Data Collection

Medicaid application

- Beneficiary-level SOGI information can provide information about Medicaid populations and be used to measure differences in service use
- Few Medicaid programs collect SOGI information on the application or on optional state demographic surveys
  - There is little consistency in how states ask these questions

Medicaid SOGI Data Collection, cont.

Federal surveys

- Population-level information can be disaggregated to assess the experiences of Medicaid-covered SGM with accessing and using health services, satisfaction with providers, and quality of care
- In a review of 13 population health surveys, five ask about sexual orientation and two ask about gender identity
- Analyses can be limited by comparability of specific questions and a small sample size of SGM individuals

KEY CONSIDERATIONS FOR SOGI DATA COLLECTION

Data collection purposes

- Programmatic
- Research

State and beneficiary burden

- Data collection updates
- Data system updates

Data quality

- Self-reported
- Change over time
- Question standardization
- Representative of Medicaid population
- Data privacy

SOGI Data Collection Purposes

- **Programmatic:** assess and ensure the program is inclusive of SGM and meets the needs of these populations
- **Research:** inform the development of targeted interventions to address barriers to accessing health care services and health inequities experienced by SGM
- States are early in the process of adding SOGI questions to state data collection efforts, and the data are insufficient for research purposes

State and Beneficiary Burden

Data collection updates

- **Lack of standards:** there are no federal standards for collecting SOGI data on administrative forms, although the newly released CMS guidance may address this challenge
- **Language translation:** translated terminology and constructs should be consistent with the terminology used by SGM that speak languages other than English
- **Applicant assister training:** training may be needed so assisters feel comfortable asking these questions and explaining the rationale for their inclusion, although the CMS training materials may help address this challenge
- **Application length:** applications can be long, and additional questions may increase individual burden

State and Beneficiary Burden

Data system updates

- Resource and time intensive to update and test changes to the data systems used to store Medicaid eligibility and enrollment data
- Currently, T-MSIS does not include SOGI data elements for data reporting, so there are no reporting requirements or guidelines for states on how to store these data
  - The new CMS guidance indicates that beginning in calendar year 2025, states will be able to report these data elements

Data Quality Considerations

- **Self-reported:** considered the best method for collecting information that reflects an individual’s identity
- **Change over time:** an individual’s sexual orientation and gender identity and the terms used to describe them can change over time
- **Question standardization:** lack of SOGI data standards can limit data accuracy and comparability
- **Representative of Medicaid population:** data collection methods should allow for generalizability to the Medicaid population
- **Data privacy:** providing individuals with assurance that their data are secure and will not be used inappropriately or to harm them can improve response rates

Next Steps

- January presentation on Medicaid self-reported disability collection
- It would be most informative to receive Commissioner feedback on the considerations presented and if there are additional factors that should be included

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