Chapter 4:

Medicaid Demographic Data Collection

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Key Points

- A critical step in advancing health equity is expanding and improving self-reported language, sexual orientation and gender identity (SOGI), and disability data collection to measure and address health disparities and to provide meaningful insights into the health care experiences of Medicaid-covered populations.
- Research demonstrates that individuals with language service needs, sexual and gender minorities, and individuals with disabilities experience disparities in health care access and use, health outcomes, and quality of care when compared to their counterparts. However, due to limited data, less is known about the disparities that these groups experience, including those with multiple marginalized identities.
- Although some demographic data are already collected, this information is not gathered consistently. Most states collect language, and some collect self-reported disability on the application, but few collect SOGI. Federal surveys typically collect functional disability, but data on other types of disabilities, language, and SOGI are less common. Additionally, the questions and categories used to identify these populations vary, and the responses may not be self-reported or updated over time, reinforcing that these data may not be comparable or reflective of an individual's self-identity.
- The inconsistent collection of comparable demographic data across sources can limit their usefulness to federal and state agencies, stakeholders, and researchers. Specifically, data can be incomplete, lack representativeness of specific populations, and be inaccurate.
- Improving the collection and use of demographic data is a federal and state priority, and there are numerous ongoing efforts to address the existing limitations. Beyond redesigning survey questions to enhance current data collection, states are expanding the type of information collected on the Medicaid application and developing approaches to integrate data from other sources, such as electronic health records, with Medicaid data.
- As this work continues, the Centers for Medicare & Medicaid Services, state Medicaid programs, and researchers should consider the purpose of collecting the information, which may affect the approach. Additionally, the state and beneficiary burden associated with additional questions may influence how data are best collected. Finally, the quality of the data can affect their usability for analyses.
- Despite the current limitations, the use of existing data to measure and address health disparities experienced by these demographic populations should not be delayed.

CHAPTER 4: Medicaid Demographic Data Collection

The Commission has committed to prioritizing and embedding health equity in all its work to inform policy and advance health equity. Medicaid plays an important role in providing health insurance coverage to historically marginalized populations, and disparities in health care access and outcomes persist among these populations. Medicaid data are necessary to understand beneficiary access to and experiences with receiving care. However, gaps in demographic data collection can prevent key stakeholders from measuring and addressing health disparities based on many factors, including their race, ethnicity, language, sex, gender identity, sexual orientation, and disability (MACPAC 2023, 2022a, 2022b).

The Commission's most recent work focuses on expanding and improving Medicaid demographic data collection, emphasizing this as an important step in addressing disparities and supporting federal and state efforts to advance health equity (CMS 2023a; HHS 2023a; MACPAC 2023, 2022a). MACPAC's June 2022 report to Congress highlighted how Medicaid can take an active role in advancing health equity and identified areas for future MACPAC equity-focused work, including improving the collection and reporting of race and ethnicity data as well as the need to monitor access among marginalized demographic groups (MACPAC 2022a, 2022b). In the March 2023 report, the Commission recommended updating the race and ethnicity questions on the model application and developing training materials to encourage responses and improve the usability of data. In addition to these recommendations, the Commission identified a need for additional work related to the collection and reporting of other demographic data (MACPAC 2023).

As a continuation of this work, MACPAC evaluated the availability of primary language, limited English proficiency (LEP), sexual orientation and gender identity (SOGI), and disability data for measuring and addressing health disparities in access to care and outcomes among the Medicaid population. To inform this work, we conducted a literature review and federal survey assessment, fielded an online survey of all state Medicaid programs, and conducted stakeholder interviews. Interviewees included federal officials from the U.S. Department of Health and Human Services (HHS), the Centers for Medicare & Medicaid Services (CMS), state Medicaid programs, research experts, and beneficiary advocates representing individuals with language service needs, sexual and gender minorities (SGMs), and individuals with disabilities (Appendix 4A). This work identified existing data limitations, which can impede using these data for analytical purposes, and challenges with improving the collection of demographic data. When feasible, research methods, such as pooling multiple years of data to increase sample size and using clinical information to identify individuals with disabilities, could be used to compensate for these constraints. In the Commission's view, efforts to use the currently available data to address health disparities should not be delayed. CMS, state Medicaid programs, and researchers should use the data that are currently available to measure health outcomes and inform policy to advance health equity. Although there are limitations with Medicaid demographic data, especially SOGI and disability data, the Commission is encouraged by the ongoing work at the federal and state levels to address them (Santos 2024; CMS 2023a, 2023b; NSTC 2023; USCB 2023a; EOP 2021a). CMS should continue to support collecting demographic data and reporting these data to the Transformed Medicaid Statistical Information System (T-MSIS).

This chapter begins by describing the importance of collecting demographic data to understand and address health disparities and summarizing the federal and state priorities for collecting and using these data. The chapter goes on to describe the primary modes for Medicaid demographic data collection and existing data limitations. The chapter concludes with key considerations for collecting these data, including the data collection purpose, state and beneficiary burden, and factors affecting data quality, which are similar to those presented in prior MACPAC work (MACPAC 2023, 2022a).

The Need to Improve the Collection of Medicaid Demographic Data

Demographic data, including language, SOGI, and disability, can provide meaningful insights into the experiences of historically marginalized populations. Health services researchers and advocates we interviewed, as well as published literature, recommend including questions about these characteristics as part of all demographic data collection efforts, as the collection of these data is a key step toward measuring and addressing health disparities. These data are important in supporting independent research and state monitoring efforts, informing policy decisions, enforcing civil rights, and improving stakeholder knowledge about the health service needs of the many populations covered by Medicaid (Goldberg 2023, NSTC 2023, MACPAC 2022a, Swenor 2022, NDRN 2021). For example, information about language and disability are needed to ensure that state Medicaid programs can identify individuals who need translation services and accommodations when accessing and using services. SOGI data can be used to identify SGM populations and measure what kind of care they are receiving. Additionally, these data can be used to understand the experiences of those who identify with multiple demographic characteristics and identities, including race and ethnicity, language, SOGI, and disability.

Limitations with the currently collected Medicaid demographic data prevent these populations from being counted and included in research and analysis that is needed to better understand the health care and service needs, quality of care, and health outcomes of these beneficiary populations. There are gaps due to the data not being collected using consistent measures or as part of data collection efforts (Yee and Breslin 2023, Baker et al. 2021, NDRN 2021, Ortman and Parker 2021). Some types of demographic data are collected on federal and state administrative forms and surveys, but others are not included as part of these collection efforts. Additionally, even when these data are collected, multiple definitions and validated measures are used to identify individuals with these characteristics, which can lead to challenges with comparability (Box 4-1). Furthermore, in federal surveys, small sample sizes limit the ability to report on individuals covered by Medicaid and to assess particular measures of health care access (SHADAC 2023).

BOX 4-1. Demographic Data Definitions

Many definitions are used to identify individuals with language service needs, sexual and gender minorities, and individuals with disabilities, and they may vary depending on the data collection purposes.

Language. Primary language and limited English proficiency (LEP) are two distinct components for understanding the preferred spoken and written language and English comprehension:

- Primary language identifies the language that is most often used in the home or in someone’s everyday life. When these data are self-reported, individuals can identify their primary or preferred language for written and spoken communication. This information is often used as a proxy for determining whether someone may have language service needs, such as translation.
- LEP identifies the level of English language comprehension of individuals who report having a primary or preferred language that is not English. It can provide more specific information about the types of language services they may need (Liou 2018, Youdelman 2008).

BOX 4-1. (continued)

Sexual orientation and gender identity. Including sexual orientation and gender identity questions in data collection efforts allows individuals to self-identify as lesbian, gay, bisexual, transgender, queer, asexual, agender, and other terms that align with their identity.

- Sexual orientation encompasses multiple dimensions of identity, attraction, and behavior. This information can be used to understand the experiences of individuals who do not identify as straight or heterosexual with the health care system, including the quality of and satisfaction with care.
- Sex assigned at birth identifies the binary sex (e.g., what is listed on someone's original birth certificate), which can be used for verification with other data sources.
- Gender identity is defined by one's sense of self, identity, and expression through behavior and appearance and by the social and cultural expectations that are associated with the sex assigned at birth. When collected with sex assigned at birth, this information can be used to identify whether an individual's sex assigned at birth and gender identity align (cisgender) or do not align (transgender or gender diverse). Additionally, gender identity can be used to understand the experiences of individuals who do not identify as cisgender with accessing health care services, quality of care, and satisfaction with care (NASEM 2022).

Disability. Definitions of disability and how individuals with disabilities are identified in data collection efforts can vary. Some definitions are narrow, such as those based on specific types of disabilities or used to determine eligibility for benefits, while others are broader and more inclusive of individuals with different types of disabilities (Mitra et al. 2022). Many categories are used to group individuals with disabilities based on type of disability or dimensions related to impairment, activity limitation, and participation restrictions. There is some overlap between these categories as individuals may have more than one disability or multidimensional disabilities (CDC 2020, Larson et al. 2001). Additionally, individuals with disabilities may be identified using clinical diagnosis codes and eligibility criteria, such as those used for Supplemental Security Income, or they may self-identify through survey measures.

- Functional disability is often defined as individuals who have difficulties or limitations with core activities, including hearing, seeing, walking, cognition, and communication (Mont et al. 2022).
- Developmental disability is a broad term that includes individuals with intellectual disabilities. A developmental disability is often defined as a severe, chronic disability that is attributable to a mental or physical impairment, is manifested before the individual attains age 22, is likely to continue indefinitely, and results in substantial functional limitations in three or more areas of major life activity. An intellectual disability is characterized by substantial limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18 (Havercamp et al. 2019).
- Serious mental illness is a broad category that can be defined using many methods, including eligibility criteria for benefits programs or screening tools developed for surveys. The definition often includes individuals who are diagnosed as having a mental, behavioral, or emotional disorder resulting in serious functional impairment, which substantially interferes with or limits one or more major life activities (NIMH 2023).

Health disparities

Current health research on underserved communities, including those with language service needs, SGMs, and individuals with disabilities, often focuses on these populations more broadly rather than on those specifically covered by Medicaid, so less is known about Medicaid beneficiaries and those with multiple demographic or marginalized identities. Findings indicate that generally these underserved groups experience disparities in health care access and use, health outcomes, and quality of care when compared to their counterparts (CMS 2023a; ED Working Group 2022; EOP 2022, 2021b).

Language. Research findings about individuals with language service needs indicate that these individuals experience disparities with accessing and using care and challenges with enrolling and remaining covered by Medicaid (Haldar et al. 2022, Berdahl and Kirby 2019, Proctor et al. 2018). For example, individuals with LEP may experience language access barriers that can lead to challenges with scheduling appointments, understanding written health care materials, and communicating with providers, which can contribute to poor health outcomes (Terui 2017). Poor patient communication with providers can result in a provider having an incomplete medical history, misunderstanding patients’ symptoms, misdiagnosing patients, and other potential medical errors as well as patient misunderstanding of their diagnosis and treatment plan (Berdahl and Kirby 2019, Proctor 2018, Terui 2017, Gershon et al. 2016, Youdelman 2008). Additionally, findings indicate that individuals with LEP have greater difficulty enrolling in and maintaining Medicaid coverage than those without LEP (Mirza et al. 2022, Gee and Guintella 2011, Feinberg et al. 2002). For example, a recent case study in Illinois found that of Medicaid beneficiaries with a primary language other than English, individuals with LEP were more than five times more likely than those who were English proficient to lose their benefits (Mirza et al. 2022).

SGMs. Research shows that SGM populations experience disparate access to and use of health care services and health outcomes compared to their straight and cisgender counterparts, and many factors can contribute to these outcomes (Stanton et al. 2021, Ruprecht et al. 2020). For example, lesbian, gay, and bisexual individuals, including those covered by Medicaid, have a higher prevalence of chronic conditions and report a higher need for mental health services than heterosexual individuals (MACPAC 2022c, Heslin and Hall 2021, Frimpong et al. 2020). Additionally, transgender and gender diverse individuals are more likely to report one or more disabilities and to experience depression, anxiety, and substance abuse compared to cisgender individuals (Stanton et al. 2021, Tabaac et al. 2018, Toomey et al. 2018). Factors contributing to reported lower rates of access and poorer health outcomes among these populations can include fear of or experienced discrimination, lack of culturally competent providers, provider refusal to provide care, cost of health care, and a lack of or gap in coverage (Stanton et al. 2021, Kates et al. 2018).

Disability. Individuals with disabilities experience disparities in health outcomes and access to care compared to those without disabilities. Many barriers may contribute to these disparities. For example, individuals with disabilities are much more likely to report having poor health and chronic conditions and unmet medical and dental care needs than those without disabilities (Gonzalez et al. 2023, Yee and Breslin 2023, Mitra et al. 2022, Krahn et al. 2015). Additionally, compared to those without disabilities, adults with disabilities are more likely to experience discrimination and unfair treatment when accessing and using health care services and to report having poor provider experiences (Gonzalez et al. 2023, Mahmoudi and Meade 2015). Access to appropriate care can be inhibited by poor provider communication and training and perceptions about individuals with disabilities. For example, a survey of physicians found that fewer than half felt confident in providing equal care to individuals with disabilities and about half reported they would welcome individuals with disabilities into their practice (Iezzoni et al. 2021). Additionally, patients who need accommodations to communicate with their providers, such as sign language interpreters, do not always receive them (Iezzoni et al. 2022, Yee et al. 2017).

Demographic Data Collection Priorities and Uses

In recent years, health equity has become a greater priority for federal and state governments, and improving and expanding the collection and use of demographic data is a key area of focus (CMS 2023a, EOP 2021a). Federal and state agencies use demographic data for multiple purposes, including to support program administrative functions, measure and address health disparities, and assess compliance with civil rights requirements.[1] Without data to identify individuals with language service needs, SGM populations, and individuals with disabilities, state Medicaid programs and CMS cannot ensure they are providing equitable access to care and make informed policy decisions about how to address disparities and achieve health equity (Iezzoni et al. 2022).

Federal health equity actions

The Biden Administration has launched several efforts focused on improving the measurement of health disparities experienced by underserved communities (CMS 2023a; ED Working Group 2022; EOP 2022, 2021a, 2021b). The Equitable Data Working Group identified challenges with current federal demographic data collection, including difficulties with measuring small populations and disaggregating data for individuals with multiple identities. The Equitable Data Working Group recommended federal strategies to improve the collection and disaggregation of demographic data and leverage underused data sources to conduct meaningful disparities research (ED Working Group 2022, EOP 2021a).

The Biden Administration also issued an executive order to specifically advance equality for lesbian, gay, bisexual, transgender, and intersex individuals. This order required the development of the *Federal Evidence Agenda on LGBTQI+ Equity*, federal agency SOGI Data Action Plans, and best practices for collecting SOGI data on federal statistical surveys.[2] The goal of these efforts is to increase evidence for how to address systemic discrimination and barriers faced by SGMs, implement policy changes to advance health equity, and establish standardized questions to identify SGMs. The *Federal Evidence Agenda on LGBTQI+ Equity* highlights that federal surveys alone are not sufficient for measuring disparities, and expanding the collection of SOGI data using consistent, evidence-based methods on administrative forms may address some of the data gaps (NSTC 2023, OCS 2023, EOP 2022).[3]

In addition to improving data collection efforts, the federal government has also focused on improving civil rights protections for historically marginalized populations. For example, in 2024, HHS finalized a rule to update provisions under Section 504 of the Rehabilitation Act of 1973 that prohibit discrimination on the basis of disability in health and human services programs. The rule clarifies that medical decisions should not be biased and based on beliefs about individuals with disabilities and their quality of life and establishes enforceable standards for accessible medical equipment (HHS 2024a). Additionally, HHS finalized a rule related to discrimination on the basis of SOGI, which reaffirms the prohibition on discrimination on the basis of SOGI and explicitly protects LGBTQ+ individuals from discrimination in health and human services programs (HHS 2024b).[4]

CMS actions. In response to the Biden Administration's executive orders, CMS released a framework for health equity prioritizing demographic data collection, language access, accessibility to health care services and coverage, and improvement of the enforcement of accessibility requirements. As part of this work, CMS is focusing on the collection of comparable demographic data across the agency to measure and address disparities experienced by underserved communities (CMS 2023a).[5] Consistent with these priorities, CMS has proposed and implemented several improvements to demographic data collection and analysis. For example, CMS has published a new series of Medicaid data issue briefs, stratifying data by race, ethnicity, primary language, geography, and eligibility on the basis of disability (CMS 2023d, Proctor 2023).

In November 2023, CMS released a new model application and updated assister trainings by adding SOGI questions. These questions allow individuals to self-identify and will support the identification of health disparities and access to equitable health care for SGMs. CMS also provided guidance for including these questions on state Medicaid and State Children's Health Insurance Program (CHIP) applications, although states are not required to add the new questions.[6] Beginning in calendar year 2025, states that choose to collect these data should be able to report these data elements to T-MSIS. The guidance also specifies protections for these data, reinforcing that Medicaid and CHIP agencies are prohibited from using or disclosing applicant or beneficiary demographic information, including SOGI, for any purposes other than those directly related to the administration of the state plan (CMS 2023b, 2023e, 2023f).

State priorities and data uses

States primarily use Medicaid demographic data for programmatic purposes, and their research efforts are nascent. Currently, many states are focusing on efforts to improve the collection and reporting of race, ethnicity, and language data and less so on SOGI or self-reported disability (SHADAC 2024a, 2024b, 2023; MACPAC 2023; Hinton et al. 2022). For example, states are working to develop clarified explanations to share with beneficiaries on the reasons for collecting race and ethnicity data and improve response rates. Furthermore, in response to requirements enacted by their state legislatures, the state Medicaid agencies in New Mexico and Oregon are collecting additional demographic data (NMHSD 2022, Oregon 2021).[7] These efforts have primarily focused on updating the Medicaid application, but a few states are also considering opportunities to link Medicaid data with electronic health records and other external data sources.

Programmatic purpose. State Medicaid programs primarily collect disability and language data to support program administrative functions. States reported using disability data to conduct eligibility determinations, identify the characteristics of the populations the program serves, and determine what services a person is already using and additional service needs. States reported primarily using language data to identify beneficiaries needing translated and accessible materials, including braille, and the language to be used for ongoing communication with individuals. A few others also reported using language data to support state compliance with language and accessibility requirements and to identify whether additional accommodations and assistance may be needed during the application process (MACPAC 2023, 2022b).[8]

Although few states collect SOGI data, some state Medicaid programs reported considering collecting these data to assess and ensure the state Medicaid program is inclusive of SGM populations and their needs. For example, one state shared that collecting information about chosen names and pronouns would allow them to provide inclusive customer service to individuals during the enrollment and redetermination processes.

State demographic data can also be used to comply with civil rights protections. For example, Medicaid agencies are required to ensure that individuals with disabilities are protected against discrimination in health care services and have equitable access to programs and services (Section 1557 of the Patient Protection and Affordable Care Act (P.L. 111-148, as amended), Section 504 of the Rehabilitation Act of 1973 (P.L. 93-112), the Americans with Disabilities Act of 1990 (P.L. 101-336), and the ADA Amendments Act of 2008 (P.L. 110-325)). Providing beneficiaries with accessible written materials, including braille, interpreter services for those who use sign language, and physical accommodations, such as accessible buildings and diagnostic equipment, can help make care more available to them (CMS 2023a, DREDF 2012).

Research purpose. Demographic data could also be used to support research into beneficiary service needs and experiences and to measure and address health disparities. However, in general, states did not report using language, SOGI, or disability data for such purposes. Additionally, most states were unsure of how these data could be used for non-programmatic purposes, and in many cases, collecting additional demographic data was not a state priority. Some states reported being early in the process of considering how to collect and use these types of demographic data to measure health disparities. A few states indicated an interest in using SOGI data to measure access to effective and inclusive care. Others reported an interest in collecting self-reported disability data for quality improvement purposes, such as identifying specialized services that may improve quality of life and health outcomes. For example, South Carolina reported using Medicaid administrative data to identify individuals with intellectual disabilities or development disabilities (ID/DD) and measure the number of ambulatory care sensitive conditions and emergency department visits, length of stay, and inpatient hospitalization (McDermott, Royer, Mann, et al. 2018).[9] Demographic data could also be used to inform state efforts to ensure provider network adequacy for populations with specific needs, and, if provider demographic data are also available, better understand provider concordance, which has been shown to be important for trust and communication between patients and providers (Ku and Vichare 2022, Ghabowen and Bhandari 2021).

Medicaid Demographic Data Collection Modes and Limitations

Medicaid demographic data are most often collected on the Medicaid application and in federal surveys using validated measures and approaches for identifying individuals with language service needs, SGMs, and individuals with disabilities. A few states are investigating options to use demographic information from other data sources to supplement the data collected on the application. The type of demographic data collected also varies, with some sources collecting information about several demographic characteristics and others collecting even fewer.

Medicaid application

Although state Medicaid programs are not required to collect demographic data, most states collect such information on the application and report it to T-MSIS, when possible. Among states, there is variability in the questions and categories included on the application and in the completeness and accuracy of the demographic data reported to T-MSIS.

Data collection. One recent review of state applications found that almost all Medicaid programs collect primary or preferred language on their application, but few programs collect SOGI and self-reported disability information on the application (SHADAC 2024a, 2024b, 2022). For example, the review identified four states that ask about sex and include more than the binary female and male response options and two states that ask about sex and gender identity separately. The review did not identify any states that collect sexual orientation data (SHADAC 2024b). Regarding questions about self-reported disability, the review identified 28 state paper applications and 8 state online applications that include a single binary-response screening question about functional limitations. A number of states also ask questions about whether the applicant has a disability or is blind, and three states ask a question about the specific type or nature of the disability. Additionally, the review identified that Oregon is collecting self-reported disability, mental health, gender identity, need for spoken or sign language interpreter, and English proficiency through a separate application section (SHADAC 2024a, OHA 2020).

Many states use the model application or develop an alternative application with CMS approval (CMS 2023f, 2013a, 2013b). State applications must include screening questions related to disability and long-term care needs to identify individuals who are potentially eligible on a basis other than modified adjusted gross income. Furthermore, they are required to develop either a supplemental or separate application for non–modified adjusted gross income populations to collect additional information which may include further details on disability necessary to determine eligibility (42 CFR 435.907(c)).

The model application includes questions about sex and optional questions about the preferred spoken or written language, race and ethnicity, and, beginning in November 2023, SOGI. It does not include questions about LEP and self-reported disability (Table 4B-1) (CMS 2013a). States can choose to add other demographic questions to or modify questions on the model application as long as these questions are optional, as they are not a requirement of Medicaid eligibility (CMS 2023b, 2023f, 2013a, 2013b; HHS 2011).[10]

Data reporting. Most demographic data that are collected on the state Medicaid application can be reported as part of the eligibility and enrollment file to T-MSIS.[11] Specifically, T-MSIS includes data elements for sex, primary language, LEP, and disability type.[12]

As of December 2023, states are required to report disability type to T-MSIS but not primary language and LEP data (CMS 2023c, 2023g). CMS has indicated that states should be able to report SOGI data as early as calendar year 2025 (CMS 2023b).

CMS assesses the quality of primary language data but not disability information submitted to T-MSIS as part of the Data Quality Atlas. The most recent quality assessment of primary language data indicates that of the 53 Medicaid programs included in the assessment, 37 report primary language data and 6 report LEP data that are useable for analyses.[13,14] CMS does not assess the quality of the self-reported disability type data elements or the quality of other disability information, such as eligibility on the basis of disability or diagnoses codes from claims data (CMS 2023a, 2023h, 2021a, 2021b). A MACPAC analysis of fiscal year 2021 T-MSIS disability type data (before the T-MSIS disability type reporting requirement) indicates that 28 states reported missing or invalid data for more than 90 percent of all beneficiaries enrolled in Medicaid, including those eligible on the basis of disability. Of those states that are reporting valid data for some of their beneficiaries, the majority of states report "other" and do not report specific disability types.[15]

Federal and state surveys

Federal population surveys are another tool for understanding the demographic characteristics and use of services by Medicaid beneficiaries. These data can also provide insight into beneficiary experiences with accessing services, satisfaction with and quality of care, and health outcomes across many demographic groups that may not be available in administrative data. Furthermore, these data can be used to measure differences in experiences between individuals covered by Medicaid, those covered by private insurance, and the uninsured (MACPAC 2022c, 2022d).

Federal survey inclusion of demographic data. In a review of 13 federal population health surveys, the majority of the surveys include functional disability questions, and fewer than half include questions about serious mental illness (SMI), ID/DD, primary language, LEP, or SOGI (Figure 4-1).[16,17] Of those that include these questions, the majority have a sufficient sample for reporting about individuals covered by Medicaid, although the ability to assess particular measures of access may be limited (SHADAC 2023).[18]

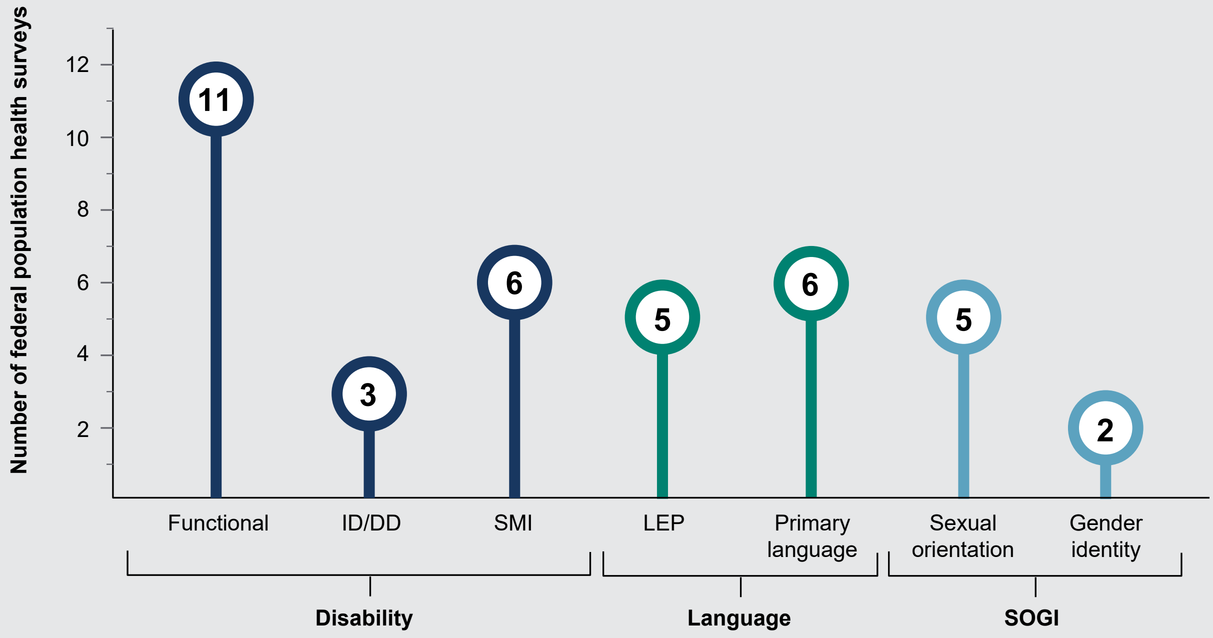
Although many of these surveys collect some of these types of data, there are no federal standards, so the questions and categorical responses vary among surveys (Table 4B-2). For primary language and LEP, many federal surveys ask questions that closely align with those included in the 2011 HHS guidance for demographic data collection (HHS 2011). For SOGI data, many have adopted the recommended standards developed by either federal agencies or non-federal research institutes (NASEM 2022, Ortman and Parker 2021).[19] Many validated measures are used to identify adults and children with different types of disabilities, but there is no consensus among researchers regarding which data collection method should be used (Hall et al. 2022, Mitra et al. 2022, Mont et al. 2022).

Federal survey disability categories. Surveys use many categories to group individuals with disabilities based on the type of disability or dimensions related to level of impairment, activity limitation, and participation restrictions, and there also may be some overlap between these categories as individuals may have more than one disability or have multidimensional disabilities (CDC 2020, Larson et al. 2001). This survey review assessed three categories of disability, and the majority of surveys include questions to identify individuals with a functional disability, but many surveys do not include questions to identify individuals with ID/DD or SMI (Figure 4-1).

- **Functional disability:** Two of the most commonly used measures of functional disability are the American Community Survey (ACS) and the Washington Group Short Set (WG-SS) on Functioning (Yee and Breslin 2023, Mont et al. 2022).[20] In 2011, HHS recommended using the ACS question set for collecting disability data in federal survey data collection (HHS 2011).[21] The WG-SS is similar to the ACS questions in that it identifies many of the same functional limitation domains.[22] However, rather than having binary (yes or no) responses about the limitation, there are four response options: no difficulty, some difficulty, a lot of difficulty, and cannot do at all (Mont et al. 2022). Findings from our literature review and interviews with disability research experts indicate that there are concerns about the validity of the ACS and WG-SS measures given that these measures are often limited in their ability to identify children and adolescents and individuals with long-term disabilities, chronic illnesses, neurological disabilities, psychiatric disabilities, and SMI. Additional concerns with these measures are that individuals may not identify their limitations as functional limitations or as a disability if accommodations, such as a wheelchair or hearing aid, address them. Furthermore, stigma and self-perceptions about limitations may prevent someone from answering the question accurately. More research is needed to develop disability measures that address the limitations with existing approaches (Hermans et al. 2024, Hall et al. 2022).[23]

- **Intellectual disabilities or developmental disabilities:** There are no established standards for administering surveys to ID/DD populations or for identifying them in national surveys (Fox et al. 2015). Additionally, national population health surveys are limited in their ability to measure access to care for individuals with ID/DD, including use of services, provider availability, and beneficiary perceptions of and experiences with care. There are some state level data collection efforts that can support the measurement of these populations, including the state-administered National Core Indicators surveys, which are used to monitor the performance of state programs, identify gaps in care, and ensure the program is performing as intended. However, these data can be limited in their generalizability. Findings suggest that consistent definitions of ID/DD and data collection methods may be needed across federal and state data sources (Bonardi et al. 2019, Havercamp et al. 2019).[24]

FIGURE 4-1. Summary of Demographic Questions Included in 13 Federal Population Health Surveys



Notes: ID/DD is intellectual disability or developmental disability. 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. Functional disability includes surveys that ask the six questions used in the American Community Survey. SMI questions included the Kessler-6 screener, Patient Health Questionnaire (PHQ)-9 screener, and PHQ-2 screener and reported diagnosis of depression or poor mental health.

Source: SHADAC 2023.

- **Serious mental illness:** Some of the most common SMI screening questions used in federal population surveys include the Kessler-6 scale and the Patient Health Questionnaire (PHQ)-9 assessment (MACPAC 2021, Kessler et al. 2010). The Kessler-6 scale is a broad screener that can identify individuals with SMI but cannot screen for specific types of mental illness. Given the broad scope of the scale and the limited number of questions included, up to 15 percent of individuals with SMI may not be identified. The PHQ-9 is a validated screening tool for major depression and is an example of a screener used to identify individuals with a specific type of mental illness (Kessler et al. 2010).[25]

State surveys. Some state Medicaid programs also administer state surveys to collect additional demographic information, but there are reported challenges with response rates. For example, in MACPAC's survey of Medicaid programs, a couple of states reported asking SOGI questions on an optional survey provided to applicants after the online application is completed. One state shared that these data are stored only at the aggregate level, so they are not linked to individual applicants or beneficiaries. Due to a low response rate, the state has not used these data for any research purposes.

Other data sources

A few states reported using other data sources to identify these demographic populations, but these efforts are early in development given the challenges with integrating these data with Medicaid reporting systems. Some researchers suggested states could use Medicaid claims data to identify individuals with disabilities. Medicaid claims include many types of data, such as *International Classification of Diseases, Tenth Revision*, codes, which can be used as a proxy for disability and identify individuals with ID/DD, physical disabilities, and SMI. However, using claims data and disability-related codes may not identify all individuals with disabilities if the disability is not the primary reason for the service or the health care visit or if someone with functional limitations does not have a specific diagnosis (Palsbo et al. 2008, Iezzoni 2002). For example, at least one state noted plans to link disability data from its accountable care organizations with its new Medicaid Management Information System. Additionally, a few researchers noted that administrative data collected through home- and community-based services assessments and health care plans are often not integrated with T-MSIS. However, these data could be an important source for collecting and improving demographic information about these beneficiaries.

A few states reported considering how to collect SOGI data from other sources, including using electronic health record data, which researchers noted can be more accurate and reflective of current identity than data collected at one point in time on the application because the electronic health record can be updated during each care visit. However, there are challenges with linking and reconciling data that are collected outside the Medicaid eligibility and enrollment process. For example, one state is trying to address this challenge by developing a database with a hierarchy that will reconcile data from multiple sources, including information from accountable care organizations and acute care hospitals.

Demographic data limitations

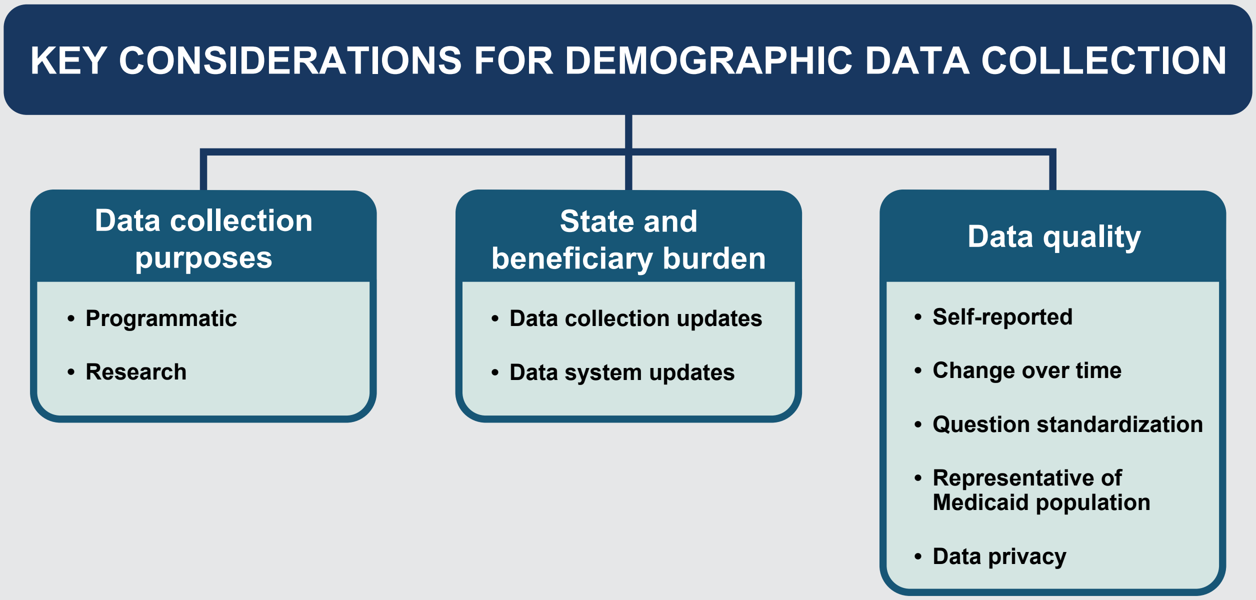
Our review of Medicaid demographic data collection identified several limitations that make it challenging to measure health disparities experienced by those with language service needs, SGMs, and individuals with different types of disabilities. The data are not always collected, resulting in gaps that can prevent stakeholders, including CMS, states, and researchers, from disaggregating the data and exclude these populations from efforts to assess and address health disparities (Baker et al. 2021, NDRN 2021). Furthermore, the use of inconsistent measures and categorical responses can lead to challenges with comparable and accurate data that are representative of the Medicaid population.

Absence of data collection and incomplete reporting. Most state Medicaid programs do not collect information about spoken and written English proficiency, SOGI, and self-reported disability data, and of the states that collect these data, inconsistency exists in the measures. The majority of states report usable primary language data to T-MSIS, but few report usable LEP and self-reported disability data, and currently, states are unable to report SOGI data (CMS 2023a, 2023b, 2021a, 2021b). Most federal surveys ask questions about functional limitations; some ask about SMI using standardized screening tools; and only a few ask questions to identify primary language, LEP, SOGI, and ID/DD.

Lack of representativeness. Disability data collected for eligibility purposes do not include beneficiaries with disabilities enrolled in other eligibility groups, which underestimates the number of Medicaid beneficiaries with disabilities. Additionally, Medicaid claims data, including for home- and community-based services, are often insufficient for determining specific service use and accommodations and may exclude certain populations due to incomplete data and lack of consistency within and across states (SHADAC 2024a, Rudowitz et al. 2023, Yee and Breslin 2023, Mitra et al. 2022).[26] Federal survey data often have small samples for populations with language service needs, SGMs, and people with different types of disabilities, including those with ID/DD and cognitive conditions such as Alzheimer's and dementia (CDC 2016a, 2016b; Altman 2014). These small population samples can limit the ability to conduct subpopulation analyses and disaggregate these data by these demographic populations and those with multiple demographic characteristics and identities.

Accuracy. Data collected on the Medicaid application may be self-reported by the individual or by the head of household, which may affect the accuracy of the responses. In the case of language, this question is asked only of the head of household. As is included on the model application, SOGI and disability screening questions are asked of all household members, but the head of household is typically responsible for completing the application for all household members (CMS 2023b, 2021c). More research is needed to assess the validity and differences between beneficiary and proxy response as well as how to ask many of these questions for younger populations (USCB 2023b, Lee et al. 2004). Additionally, these data are often collected only once, and for demographic characteristics that change over time, these data may not remain accurate (Heim Viox and Hansen 2022, NASEM 2022).

FIGURE 4-2. Key Considerations for Improving the Collection of Medicaid Demographic Data



Considerations for Demographic Data Collection

In support of the ongoing work at the federal and state levels to address demographic data limitations, MACPAC identified several key considerations, which are described below. The considerations align with prior MACPAC recommendations on race and ethnicity data collection and apply to existing and additional data collection efforts (Figure 4-2) (MACPAC 2023).[27] Additionally, the Commission previously recommended CMS field an annual federal Medicaid beneficiary survey, which could also be used to address some of the data limitations related to collection of comparable and accurate demographic data to assess health care experiences among the many populations served by Medicaid (MACPAC 2022a).

Data collection purposes

As described above, state Medicaid programs collect language and disability information for purposes of assessing language service needs and determining eligibility. In MACPAC's survey, state Medicaid programs reported that these data are sufficient to identify beneficiary language service needs and to support the eligibility determination, but they often cannot identify the specific service and accommodation needs for individuals with disabilities. However, early efforts by states to develop research uses for these data, including measuring access to care and quality of care and assessing health disparities, are limited. Although the existing data may not be collected for research purposes, stakeholder efforts to use the available data to measure health disparities, when feasible, and inform policy should not be delayed until these data limitations are addressed.

State and beneficiary burden

In state interviews, officials described the administrative burden as a factor when considering whether to collect additional demographic data on the application or through other modes. As most data are collected via the application, the application as well as the state data systems that store and report these data would need to be updated to accommodate any changes to questions or response options. Furthermore, additional questions could require more time and effort from applicants, additional resources for translating new questions, and new training for navigators assisting with the application process.

Updating state data collection. Updates to state applications require many steps, time, and resources, which can be challenging.

- **CMS approval process for application updates:** CMS requires states that choose to modify the model application or develop an alternative application to secure approval (CMS 2013b). In interviews, several states reported this requirement as a barrier to updating the application and supplemental forms with additional disability questions and new SOGI questions. However, the 2023 CMS guidance to states on collecting SOGI data permits states to add these questions as written in the guidance to the application without seeking CMS approval (CMS 2023b).
- **Lack of standards:** There are existing federal language, SOGI, and self-reported disability questions for collection in population surveys (OCS 2023, HHS 2011). CMS adopted these 2011 HHS standards for reporting to T-MSIS, but most states do not collect LEP and self-reported disability data on the application or report them to T-MSIS. Regarding SOGI, at the time of MACPAC's survey of state Medicaid programs and stakeholder interviews, states reported concerns with collecting SOGI data on applications due to the lack of standards of how to ask for this information. Specifically, a couple of states reported that developing new questions would require extensive state resources. These states noted that they prefer to wait to collect these data until CMS provided guidance and best practices for adding SOGI questions to the application and reporting these data to T-MSIS. As such, the 2023 CMS guidance for collecting SOGI data on Medicaid applications may address some of these state challenges (CMS 2023b).[28]
- **Written and oral translation:** State Medicaid applications must be accessible to individuals with disabilities and LEP (42 CFR 435.907(g),

HHS 2023d, EOP 2000). When including self-reported demographic questions on the application, the translated terminology should be consistent with the terminology used by those who speak languages other than English and be provided with all written and oral translations, including braille. Additionally, when developing translated SOGI questions, the translated terminology and constructs should be consistent with the terminology used by SGMs who speak languages other than English (Ortman and Parker 2021). CMS has provided translations for SOGI questions on the updated model application. These translations can be used as guidance for state Medicaid programs considering adding these questions to their applications (CMS 2023i).

- **Application length:** In MACPAC's survey of Medicaid programs, some states reported that additional questions lengthen the application. These states noted that a longer application may increase burden on the individuals during the enrollment process. In a 2020 review of state Medicaid applications, the average length was about 20 pages, which may contribute to the difficulty in applying for Medicaid (Longyear et al. 2020). Furthermore, new questions may be in conflict with state efforts to shorten the application. Although interviewed states did not discuss these types of efforts, in prior MACPAC work, several states were in the process of redesigning applications to streamline the enrollment process (MACPAC 2022a).

- **Applicant assister training:** Application assisters receive training to support individuals during the enrollment process, which can be particularly important given state concerns with individual burden with completing longer applications. Regarding demographic questions, some trainings include specific suggestions on asking applicants for this optional information, which is separate from required information collected for eligibility purposes (MACPAC 2023).[29] Particularly for new questions, additional training may be needed so that assisters feel comfortable asking applicants these questions and explaining the rationale for their inclusion. Although response rates are high for SOGI questions, indicating individual willingness to share this information, assisters may feel uncomfortable asking or have concerns with how to ask these questions (SHADAC 2023, Cahill et al. 2014). For example, one state that is in the process of adding a gender identity question shared that in pilot testing, the question was often skipped when the application was completed with an assister. Assisters noted concern with asking questions that they perceived to be sensitive and invasive, so they did not always ask them.

- **Applicant understanding of the purpose of questions:** Research from federal survey data collection demonstrates that response rates are high for questions about language, SOGI, and self-reported disability (SHADAC 2023, Cahill et al. 2014). Additionally, willingness to respond to demographic questions and provide accurate responses has been shown to increase when individuals understand why these questions are asked or are provided information about how the data will be used (MACPAC 2023, Planalp 2021, Cahill et al. 2014). This may be of particular importance when collecting demographic disability on Medicaid applications so that it is clear to applicants how the information collected from these questions will be used and how it differs from disability information collected for eligibility purposes. For example, on the Oregon Medicaid application, these questions appear in a separate demographic data section that includes clarifying language about the purpose of these questions (OHA 2020).

Updating state data systems. States reported challenges with updating the data systems used to store and report state Medicaid eligibility and enrollment data to T-MSIS. For example, when new data elements are added to the application, new fields also need to be added to the data reporting systems, and these data elements must either align with T-MSIS data elements or be transformed to be reported properly. In addition, in states that have opted to integrate their Medicaid eligibility systems with other benefit programs, updates to the application must align with the requirements for and receive approval from multiple programs. Interviewed states shared that although system updates are common, there are administrative costs with adding new measures, and the updates may be harder to implement in older systems. For example, one state shared that it prefers to make multiple changes at once, as each update requires modifying the interface from the eligibility system to the claims system and the data feed that links the claims system to the data warehouse.

Due to the challenges with modifying state data systems, some states expressed concerns about adding SOGI questions to the application before receiving federal guidance on T-MSIS SOGI reporting requirements starting in calendar year 2025. Two interviewed states are in the process of adding SOGI questions to the application and anticipated the potential for additional changes to their data systems to accommodate CMS reporting requirements.

Data quality

It is important for stakeholders, and state Medicaid programs in particular, to understand the composition of their Medicaid population and their health care experiences. High-quality, accurate, and comparable data are needed to do so (Table 4C-1). Some of the key considerations for improving demographic data quality include whether the data are self-reported, account for changes in beneficiary identity and circumstance over time, are standardized using comparable and consistent questions, are representative of the Medicaid population, and are protected to ensure the privacy of the individuals who respond.

Self-reported. Self-reported data are considered the best method for collecting information that reflects an individual's identity and experiences with the health care system (Bradley and Hiersteiner 2022, Morris et al. 2022). The Commission and interviewed experts emphasize the importance of providing individuals with the opportunity to self-identify. If demographic data are reported by someone other than beneficiaries, their identities may be unreported or misidentified. Not all identities are visible, and perceptions of identities may not align with how an individual would self-identify.[30]

Change over time. Language proficiency, SOGI, and self-reported disability can change over time, and individuals may want opportunities to update this information. As such, it is often not sufficient to collect these types of demographic data only once at the time of completing the application. Research experts reported these types of demographic data should be collected multiple times and any time other demographic data are collected to ensure accuracy and credibility of these data over time. This allows individuals more opportunities to self-report changes in language service needs; how they self-identify their SOGI, especially in the context of changes to terminology; and their disability status, including specific service needs and accommodations (CDC 2022, Harvard Medical School 2022, Heim Viox and Hansen 2022). However, researchers and advocates also noted that many disabilities and limitations are permanent and recommended considerations for how often someone is asked these questions and whether individuals can opt out of providing updates.

Question standardization. Many validated measures exist to collect demographic information on federal surveys and administrative forms, and the inconsistency in the measures used across data sources can limit the comparability. Additional research is still needed to improve disability measures and establish SOGI standards for translating terms to languages other than English, adapting measures for children and adolescents, and encouraging self-identification of the intersex population (HHS 2023e, OCS 2023, USCB 2023a, Hall et al. 2022, NASEM 2022).

Representative of the Medicaid population. To the extent possible, data collection methods should allow for the data to be representative of the Medicaid population. When questions about these demographic characteristics are not included on administrative forms and federal surveys, the data are not inclusive of all populations served by the program. Representative data collection also depends on the use of validated measures and respondents providing complete and accurate information, which can be improved by providing explanations for how these data will be used (MACPAC 2023, Planalp 2021).

Data privacy. It is important to provide individuals who voluntarily disclose demographic information reassurance that these data will not be used to harm them and, in the case of Medicaid, will not be used inappropriately for eligibility determination purposes (CMS 2023a, 2023b; NASEM 2022; Perot and Youdelman 2001). Otherwise, applicants and beneficiaries may be reluctant to answer these questions or provide accurate responses. For example, research indicates that individuals with LEP are more likely to have concerns that their survey responses will be used against them than those without LEP (McGeeney et al. 2019).

Federal protections exist to ensure data privacy and protect sensitive data and to specify how the data can and cannot be used. State Medicaid agencies are required to restrict Medicaid beneficiary and applicant information for uses that directly pertain only to the administration of the Medicaid state plan (42 CFR 457.1110(b)). In 2023, CMS reiterated these protections and provided examples of prohibited use or disclosure (CMS 2023b). State Medicaid data collection and reporting processes must also comply with the Health Insurance Portability and Accountability Act of 1996 (P.L. 104-191) and other applicable federal and state laws to ensure the privacy of medical data and records (45 CFR 95.61) (CMS 2023a, 2006). In addition, some states have enacted their own data protections. For example, in Oregon, race, ethnicity, language, disability, and SOGI data are considered confidential and can be made public only if they are presented in the aggregate (SHADAC 2024b, Oregon 2021).

Looking Ahead

Challenges with collecting consistent and comparable demographic information impede the availability of data that are representative of the many populations served by Medicaid and the ability to measure and address health disparities and advance health equity. The federal government, state Medicaid programs, and researchers are engaged in ongoing work to address these limitations by expanding and improving demographic data collection. The Commission supports this work and has identified numerous considerations that should be addressed to enhance demographic information collected in Medicaid administrative and survey data. Additionally, the Commission has previously recommended that CMS field an annual federal Medicaid beneficiary survey to address some of the data gaps (MACPAC 2022a).

Although our findings demonstrate that there is a need to improve existing data, they also illustrate that language, SOGI, and disability data are already available from a number of data sources. Additionally, applying research methods, such as pooling data across multiple years, and maximizing existing sources, such as eligibility data, may address some of the constraints. These current limitations should not prevent the use of these existing data to more fully understand the experiences and health care needs of all Medicaid-covered populations. MACPAC will continue to capitalize on existing Medicaid demographic data to measure health disparities in access to care and health outcomes experienced by historically marginalized communities and encourage CMS, states, researchers, and other stakeholders to do the same.

Endnotes

[1] CMS and state Medicaid programs need these data to identify populations protected under civil rights laws and to comply with civil rights protections, including Title IV of the Civil Rights Act of 1964, the Americans with Disabilities Act of 1990 and ADA Amendments Act of 2008, and Section 1557 of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) (Iezzoni et al. 2022). For example, Title VI of the Civil Rights Act requires all federal agencies and programs receiving federal financial assistance to ensure language access to individuals with LEP (Proctor et al. 2018; Youdelman 2009, 2008). Language access is defined as providing translated materials and interpreters so individuals can meaningfully access services and care and are not excluded from participating in benefit programs. There are also civil rights protections for SGM. The *Bostock v. Clayton County*, 140 S. Ct. 1731 (2020) decision found the plain meaning of "discrimination on the basis of sex" to include discrimination on the basis of SOGI. In 2021, the Biden Administration incorporated this definition into the interpretation of federal rules that prohibit discrimination on the basis of sex, including Title VII of the Civil Rights Act of 1964 (EOP 2021b).

[2] Executive Order 14075 specifies that all federal agencies conducting relevant programs or statistical surveys related to LGBTQI+ equity must have developed a SOGI Data Action Plan by the end of March 2023 (EOP 2022). The plan should have outlined how the agency will collect and use SOGI data (NSTC 2023, EOP 2022). Federal agencies are not required to make these plans public. As of March 2024, the Department of Housing and Urban Development, the National Science Foundation, and HHS have publicly released their data action plans (HHS 2023d, Ledger et al. 2023, NSF 2023). In conversations with HHS, they have shared that subagencies, including CMS, will develop their own workplans by June 2024 (HHS 2023g).

[3] In accordance with the Executive Order, the Office of the Chief Statistician of the United States developed best practices for collecting SOGI data on federal statistical surveys. The best practices include considerations for data collection: (1) the intended uses of these data, (2) how to ensure a sufficient sample size and minimize measurement error, (3) the burden on respondents, and (4) testing terminology for understandability, including in translations to non-English languages (OCS 2023).

[4] Section 1557 of the ACA prohibits discrimination under any program or activity administered by an executive agency, including health programs and activities, on the basis of race, color, national origin, sex (including sexual orientation, gender identity, and intersex traits), age, or disability. These protections are in addition to protections specified in Section 504 of the Rehabilitation Act of 1973, Title VI of the Civil Rights Act of 1964, and Title IX of the Education Amendments of 1972 (HHS 2024c).

[5] There is not a consistent definition of health disparities or populations identified as experiencing health disparities across federal agencies. CMS uses a definition of health disparities that is adapted from the Centers for Disease Control (CDC) and defines health disparities as "occurring when an underserved group with a shared characteristic, such as race or disability, is impacted by a preventable health issue more frequently or more severely than individuals that do not share in that characteristic" (CMS 2023c). CMS uses the Executive Order 13985 definition of underserved groups and communities as members of racial and ethnic communities, people with disabilities, members of the lesbian, gay, bisexual, transgender, and queer community, individuals with LEP, members of rural communities, and persons otherwise adversely affected by persistent poverty or inequality (CMS 2023a, EOP 2021a).

[6] States that add SOGI questions exactly as they are worded in the guidance are not required to submit these changes for CMS approval. States that want to make modifications to these questions or use different questions will need to work with CMS to determine if these changes require CMS approval through a state plan amendment (CMS 2023b).

[7] The Oregon Health Authority is required to establish data collection standards to collect data on race, ethnicity, language, disability, and SOGI. The New Mexico Human Services Department is required to begin collecting SOGI data (NMHSD 2022, SNM 2021, Oregon 2021).

[8] Under current regulations, state Medicaid agencies are required to provide, at no cost to applicants and beneficiaries, program information in both paper and electronic formats that are accessible to individuals with LEP and via oral interpretation. Additionally, individuals must be informed of the availability of language services and how to access such information and services, including through the use of non-English taglines (42 CFR 435.905). Taglines are text written in non-English languages that provide

information about the availability of language services and that these services are provided free of charge (HHS 2024c).

[9] The Disability and Health Branch within the National Center on Birth Defects and Developmental Disabilities funded 10 states to examine individuals with ID/DD using state Medicaid data. Findings from five of the states receiving dedicated funding (Delaware, Iowa, Massachusetts, New York, and South Carolina) indicated they were able to identify individuals with ID/DD and their specific types of disabilities in their state's Medicaid population. Additionally, the results supported targeted interventions to reduce the risk of ambulatory care–sensitive conditions and emergency department use for individuals with ID/DD (McDermott, Royer, Mann, et al. 2018; McDermott, Royer, and Cope 2018).

[10] State Medicaid agencies are permitted to require information only on applications that are necessary for making an eligibility determination. Information that is not directly related to the administration of the program or to make an eligibility determination, such as race and ethnicity, must be marked as optional (42 CFR 435.907).

[11] For more information on the state data collection and reporting process from the eligibility and enrollment system to T-MSIS, see Chapter 1 in the March 2023 report to Congress on improving the collection and reporting of race and ethnicity data (MACPAC 2023).

[12] The sex, language, and disability T-MSIS data elements align with the 2011 HHS guidance for demographic data collection (Table 4B-2) (HHS 2011).

[13] The 53 state Medicaid programs include all 50 states, the District of Columbia, Puerto Rico, and the Virgin Islands.

[14] In March 2023, CMS released four data quality measures related to primary language. These include calculating the percentage reporting English, Spanish, other language, and missing values. There are no data quality measures related to the LEP data element (CMS 2023g).

[15] Valid T-MSIS disability type codes include: individual is deaf or has serious difficulty hearing; individual is blind or has serious difficulty seeing, even when wearing glasses; individual has serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; individual has serious difficulty walking or climbing stairs; individual has difficulty dressing or bathing; individual has difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition; other; and none (CMS 2023h).

[16] The review included 13 federal surveys that represent the most commonly used annual surveys in which individuals covered by Medicaid can be identified: (1) American Community Survey, (2) Behavioral Risk Factor Surveillance System, (3) Current Population Survey, (4) Household Pulse Survey, (5) Medical Expenditure Panel Survey, (6) Medicare Beneficiary Survey, (7) Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems, (8) National Health and Nutrition Examination Survey, (9) National Health Interview Survey, (10) National Survey of Children's Health, (11) National Survey on Drug Use and Health, (12) Pregnancy Risk Assessment Monitoring System, and (13) Survey of Income and Program Participation. The federal survey review was based on the most recent year of available data for each survey, so some questions may have been added or changed in more recent years of data collection that have not yet been made available (SHADAC 2023).

[17] The review identified only two surveys with questions about gender identity, which did not include the National Health Interview Survey. The gender identity questions are currently included as emerging content and have not yet been permanently added to the survey (NCHS 2023).

[18] The federal survey review also included a response rate and sample size analysis to measure the response rates for each type of demographic question and determine if the surveys have a sufficient sample to analyze and disaggregate the Medicaid-covered population by these demographic characteristics. The response rates for all demographic questions were more than 91 percent.

[19] Recommended and validated methods for identifying SGM are used by federal data collection efforts (NASEM 2022, Ortman and Parker 2021, Badgett et al. 2014, SMART 2009). For example, in 2022, the National Academies of Sciences, Engineering, and Medicine published guidelines and best practices for collecting SOGI information in surveys and administrative data. One best practice is to use the two-step question approach for identifying gender identity, which asks about sex assigned at birth and gender identity separately. This approach has been adopted by some state Medicaid programs that collect gender identity and is used by the Behavioral Risk Factor Surveillance System and Household Pulse Survey (SHADAC 2023, NASEM 2022).

[20] In 2023, the U.S. Census Bureau proposed updating the questions for the 2025 ACS administration to use the WG-SS (USCB 2023a). However, some researchers do not believe these updates are adequate and that the revised questions may identify fewer individuals with disabilities. In February 2024, the U.S. Census Bureau announced that in response to public comments, no changes will be made to the ACS disability questions for the 2025 collection year (Santos 2024).

[21] As required by the ACA, HHS issued guidance on the collection of race, ethnicity, language, sex, and disability in 2011 (HHS 2011). The disability standards align with the ACS set of six questions and with the domains included in the International Classification of Functioning, Disability, and Health. The ACS includes questions about six functional domains: hearing, vision, cognition, ambulation, self-care, and independent living. For some of these questions, age restrictions limit the questions to those 5 years and older or 15 years and older. The purpose of asking these questions was to standardized the data collected to identify those with and without disabilities and use the data to monitor disparities between these populations (Dorsey et al. 2014).

[22] The WG-SS assesses the same six functional domains as the ACS and an additional domain for communication (USCB 2023a).

[23] In recent years, researchers have recommended the development of new self-reported questions that are able to capture a broader definition of disability and identify the populations who are currently missed (Hall et al. 2022, Mitra et al. 2022, Mont et al. 2022).

[24] The most recent and reliable prevalence estimates for adults and children with ID/DD are from a survey fielded in 1994 and 1995. The survey estimates that about 2 percent of the U.S. population are people with ID/DD (Bonardi et al. 2019, Havercamp et al. 2019).

[25] PHQ-2 is a shortened version of the PHQ-9 instrument. It includes the first two questions from the PHQ-9, which are about depressed mood and anhedonia over the past two weeks. It is used as a screener for depression rather than a diagnostic tool (APA 2020).

[26] Results on self-reported disability from the 2021 ACS indicate that about 33 percent of the Medicaid population self-reports having a disability. This statistic is three times larger than the percentage of individuals who are eligible for Medicaid on the basis of disability (11 percent) (SHADAC 2024a).

[27] These considerations for data collection align with many of the data collection principles that are supported by federal data collection frameworks and advocacy organizations. For example, the National Academies of Sciences, Engineering, and Medicine in a recent report established principles that are consistent with many of the considerations raised in MACPAC's March 2023 report to Congress chapter on Medicaid race and ethnicity data (CMS 2023a, MACPAC 2023, NSTC 2023, NASEM 2022, NDRN 2021).

[28] In response to the model application SOGI questions, some stakeholders have published recommended changes to address question limitations (Gipson 2024). The questions may undergo revisions based on this feedback.

[29] CMS released a slide deck regarding the inclusion of new SOGI questions on the 2024 health exchange application. The deck includes information about why the questions have been added, why it is important for assisters to ask these questions and ensure they are self-reported by the applicant, and how the information will be used (CMS 2023f).

[30] The U.S. Census Bureau has proposed to test the collection of proxy SOGI data on the ACS to better understand the reliability of proxy responses for these types of questions (USCB 2023b).

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APPENDIX 4A: Methods

To inform our work, we completed a literature review, federal survey assessment, analysis of 2021 disability type data from the Transformed Medicaid Statistical Information System (T-MSIS), and survey of all 56 state Medicaid programs and conducted 21 structured interviews.

The literature review focused on the federal and state policies related to data collection for these populations. This included the federal standards and state and federal priorities for collecting each type of data, what can be gained from these data, and what the implications are for not collecting them. We also examined research related to what is known about the health needs of these populations, including health disparities in access and outcomes, and data gaps and challenges with collecting these data.

We contracted with the State Health Access Data Assistance Center to conduct and publish a findings report of a review of 13 federal population health surveys that are most commonly used in MACPAC analyses examining access and barriers to care among Medicaid populations and individuals with various demographic characteristics.[1] The State Health Access Data Assistance Center identified which surveys ask questions about primary language, limited English proficiency, disability, and sexual orientation and gender identity and ran a sample size analysis for each measure identified. The sample size analysis measured the total population and individuals covered by Medicaid who responded to each demographic question. The results were published in a contractor report in October 2023 (SHADAC 2023).

We contracted with Acumen to conduct a state-level analysis of 2021 disability-type T-MSIS data (CMS 2023h). They assessed the completeness of the T-MSIS disability-type element, which includes six categories that align with the American Community Survey set of six disability questions, for all beneficiaries and for beneficiaries who are eligible on the basis of disability. Valid T-MSIS disability type codes include: individual is deaf or has serious difficulty hearing; individual is blind or has serious difficulty seeing, even when wearing glasses; individual has serious difficulty concentrating, remembering, or making decisions because of a physical, mental, or emotional condition; individual has serious difficulty walking or climbing stairs; individual has difficulty dressing or bathing; individual has difficulty doing errands alone such as visiting a doctor's office or shopping because of a physical, mental, or emotional condition; other; and none (CMS 2023g).

MACPAC conducted a 56-state Medicaid survey using Qualtrics (a web-based survey tool) in June and July 2023. The survey included 15 questions about state demographic data collection. The questions focused on the types of demographic data states currently collect and those they are considering collecting, how states use or would use these data, whether they report these data to T-MSIS, and challenges with collecting these types of data on their applications. The survey results from 33 states that responded were used to determine which states to include in interviews.

Interviews with the U.S. Department of Health and Human Services, the Centers for Medicare & Medicaid Services, beneficiary advocates, and research experts focused on understanding the federal requirements for collecting these data and their applicability to state Medicaid programs. The interviews also covered how these data could be used, the implications of not collecting these data, and the various approaches and challenges with collecting these data.

The 10 states interviewed represent a variation in the types of demographic data collected and reported to T-MSIS and the types of data they are considering collecting as well as population, political, and geographic diversity. State interviews focused on which types of data states currently collect and report, if they are considering collecting other data, whether there are barriers to collecting new types of demographic data, and how states use or would use additional demographic data for programmatic and research purposes. The majority of interviews were conducted on video calls, but a couple of states requested to respond in writing, which we allowed, due to time constraints and difficulties with scheduling officials across multiple departments.

Endnotes

[1] The review included 13 federal surveys that represent the most commonly used annual surveys in which individuals covered by Medicaid can be identified: (1) American Community Survey, (2) Behavioral Risk Factor Surveillance System, (3) Current Population Survey, (4) Household Pulse Survey, (5) Medical Expenditure Panel Survey, (6) Medicare Beneficiary Survey, (7) Nationwide Adult Medicaid Consumer Assessment of Healthcare Providers and Systems, (8) National Health and Nutrition Examination Survey, (9) National Health Interview Survey, (10) National Survey of Children's Health, (11) National Survey on Drug Use and Health, (12) Pregnancy Risk Assessment Monitoring System, and (13) Survey of Income and Program Participation.

APPENDIX 4B: Demographic Data Collection Guidelines

TABLE 4B-1. 2023 Centers for Medicare & Medicaid Services Sexual Orientation and Gender Identity Model, Single-Streamlined Application Questions

Questions[1]	Categories
Sex (existing question, required)	
Sex	Female
	Male
Gender identity (new question, optional)	
Sex assigned at birth (may be found on person's birth certificate)	Female
	Male
	A sex that's not listed: [free text]
	Not sure
	Prefer not to answer
Current gender	Female
	Male
	Transgender female
	Transgender male
	A gender identity that's not listed: [free text]
	Not sure
	Prefer not to answer
Sexual orientation (new question, optional)	
Sexual orientation	Lesbian or gay
	Straight
	Bisexual
	A sexual orientation that's not listed: [free text]
	Not sure
	Prefer not to answer

Notes: The 2023 Centers for Medicare & Medicaid Services (CMS) model with single-streamlined application questions about sex, sex assigned at birth, gender identity, and sexual orientation. The question about sex is required and is asked with other required questions that are related to verification and the eligibility determination. The three other questions are optional for applicants older than 12 years. They are asked in a separate section of the application with other optional questions, which include questions about race and ethnicity.

[1] The question language on the model, single-streamlined application is different from the question language provided in the CMS guidance to state Medicaid programs and CHIP, but the question categories are similar.

Sources: CMS 2023b, 2023e.

TABLE 4B-2. 2011 U.S. Department of Health and Human Services Guidelines for Demographic Data Collection

Demographic questions	Categories
Sex	
What is your sex?	Male
	Female
Primary language	
How well do you speak English?	Very well
	Well
	Not well
	Not at all
Do you speak a language other than English at home?[1]	Yes
	No
What is this language?[1]	Spanish
	Other language (identify)
Disability status	
Are you deaf or do you have serious difficulty hearing?	Yes
	No
Are you blind or do you have serious difficulty seeing, even when wearing glasses?	Yes
	No
Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?[1]	Yes
	No
Do you have serious difficulty walking or climbing stairs?[1]	Yes
	No
Do you have difficulty dressing or bathing?[1]	Yes
	No
Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?[2]	Yes
	No

Notes:
[1] Only asked of those five years and older.

[2] Only asked of those 15 years and older.

Source: HHS 2011.

APPENDIX 4C: Considerations

TABLE 4C-1. Summary of Primary Language, Limited English Proficiency, Sexual Orientation and Gender Identity, and Disability Data Collection Considerations for Each Mode of Data Collection

Demographic data collection mode	Type of demographic data	Data quality considerations				
		Self-reported	Question standardization	Representative of Medicaid population	Change over time	Data privacy
State Medicaid application	Disability information collected for eligibility purposes	Some questions may be self-reported and some information may come from medical documentation	State dependent	Data are available for all individuals determined eligible on the basis of disability and who use health care services	Eligibility group could change	Data processes must comply with federal and state laws to ensure data privacy Medicaid administrative and claims data must comply with HIPAA protections
	Language, SOGI, and disability demographic data	Head of household responds	States are not required to collect language, SOGI, or self-reported disability data on the application. However, primary language and SOGI questions are included on the HHS model application. Additionally, beginning in December 2023, states are required to report disability status aligned with the ACS questions to T-MSIS	Primary language is collected on all applications, but LEP, SOGI and self-reported disability are not currently collected on most state Medicaid applications	Demographic information is rarely updated	

TABLE 4C-1. (continued)

Demographic data collection mode	Type of demographic data	Data quality considerations				
		Self-reported	Question standardization	Representative of Medicaid population	Change over time	Data privacy
Federal population health survey	Language, SOGI, and disability demographic data	Data may be self-reported or answered by a proxy respondent Additionally, for a subset of respondents, language could be assigned based on survey administration language	Many validated measures	Typically, weighted to represent the population; however, due to small sample sizes, the data may not be usable for analyses with specific measures Surveys are not always available in multiple languages, so respondents may not be representative of individuals who do not speak English	Unless longitudinal data are collected, surveys typically collect point-in-time data	Title 13 of the U.S. Code mandates the U.S. Census Bureau ensure survey and census data remain confidential

Notes: SOGI is sexual orientation and gender identity. HHS is U.S. Department of Health and Human Services. ACS is American Community Survey. T-MSIS is Transformed Medicaid Statistical Information System. LEP is limited English proficiency. HIPAA is Health Insurance Portability and Accountability Act of 1996.

Sources: MACPAC analysis of CMS 2023e; SHADAC 2024a, 2024b, 2023; USCB 2022; and key informant interview.