

Report to Congress on Medicaid and CHIP

JUNE 2024



MACPAC

Medicaid and CHIP Payment
and Access Commission

About MACPAC

The Medicaid and CHIP Payment and Access Commission (MACPAC) is a non-partisan legislative branch agency that provides policy and data analysis and makes recommendations to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states on a wide array of issues affecting Medicaid and the State Children's Health Insurance Program (CHIP). The U.S. Comptroller General appoints MACPAC's 17 commissioners, who come from diverse regions across the United States and bring broad expertise and a wide range of perspectives on Medicaid and CHIP.

MACPAC serves as an independent source of information on Medicaid and CHIP, publishing issue briefs and data reports throughout the year to support policy analysis and program accountability. The Commission's authorizing statute, Section 1900 of the Social Security Act, outlines a number of areas for analysis, including:

- payment;
- eligibility;
- enrollment and retention;
- coverage;
- access to care;
- quality of care; and
- the programs' interaction with Medicare and the health care system generally.

MACPAC's authorizing statute also requires the Commission to submit reports to Congress by March 15 and June 15 of each year. In carrying out its work, the Commission holds public meetings and regularly consults with state officials, congressional and executive branch staff, beneficiaries, health care providers, researchers, and policy experts.

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Medicaid and CHIP Payment
and Access Commission

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June 11, 2024

The Honorable Kamala Harris
President of the Senate
The Capitol
Washington, DC 20510

The Honorable Mike Johnson
Speaker of the House
The Capitol
Washington, DC 20515

Dear Madam Vice President and Mr. Speaker:

On behalf of the Medicaid and CHIP Payment and Access Commission (MACPAC), I am pleased to submit the June 2024 *Report to Congress on Medicaid and CHIP*. This report includes recommendations for increased transparency in Medicaid and the State Children's Health Insurance Program (CHIP) financing, tools that states can use to optimize state Medicaid agency contracts (SMACs), enrollment trends in Medicare Savings Programs (MSPs), and improvements to demographic data collection in Medicaid.

Chapter 1 makes recommendations to Congress on improving the transparency of financing the non-federal share of Medicaid and CHIP. In the Commission's view, the primary goal of improving transparency of Medicaid and CHIP financing is to better understand how much providers are paid today under currently permissible financing mechanisms. Understanding payment amounts is the first component of MACPAC's provider payment framework for assessing whether payments are consistent with the statutory goals of efficiency, economy, quality, and access.

Financing of Medicaid and CHIP is a shared responsibility between states and the federal government. The federal government matches allowable state expenditures according to the federal medical assistance percentage (FMAP). The statute permits states to raise the non-federal share of Medicaid and CHIP expenditures through multiple sources. The extent to which states rely on funding sources other than state general revenue varies considerably by state and type of service. The Commission makes two recommendations to Congress to require states to collect and publicly report information on the sources of non-federal share of Medicaid spending, including financing methods, state-level financing amounts, and provider-level financing amounts.

Chapter 2 focuses on steps toward better coordination of care for people who are dually eligible for Medicaid and Medicare and makes recommendations for how states can optimize and oversee SMACs with Medicare Advantage dual eligible special needs plans (D-SNPs). Dually eligible beneficiaries who are eligible for both Medicaid and Medicare may experience fragmented care and poor health outcomes when their benefits are not coordinated. The chapter highlights the role of care coordination data in assisting state efforts to evaluate integrated care and to oversee and monitor D-SNPs. The Commission makes two recommendations, one to states and one to the Centers for Medicare & Medicaid Services, that are intended to support states



by providing a starting point for optimizing and overseeing SMACs and to explain how integrated care may benefit beneficiaries residing in their states.

Chapter 3 examines MSPs. People who are eligible for both Medicare and Medicaid may be eligible to receive Medicaid assistance with their Medicare premiums and cost sharing through MSPs. The Commission has had a longstanding interest in MSPs because of their potential to improve access to care for low-income Medicare beneficiaries. The chapter describes MSPs and their role in providing Medicaid assistance with Medicare premiums and cost sharing to individuals who are dually eligible for Medicaid and Medicare. The chapter then discusses MACPAC's prior work analyzing participation rates in the programs, including prior Commission recommendations aimed at improving participation in the MSPs. The chapter concludes with our new analysis of enrollment trends, including comparisons across MSPs and comparisons of enrollment trends by demographic characteristics including age, sex, and urban or rural residence.

The final chapter of the June report looks at the collection of demographic data in Medicaid. 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. However, gaps in demographic data collection can impede efforts to measure and address these health disparities. As a continuation of MACPAC's work in this area, we evaluated the availability of primary language, limited English proficiency, sexual orientation and gender identity, and disability data to help measure and address health disparities among the Medicaid population. This chapter describes the importance of collecting demographic data and federal and state priorities for collecting and using these data. We conclude with key considerations for collecting these data and factors affecting data quality.

MACPAC is committed to providing in-depth, non-partisan analyses of Medicaid and CHIP policy, and we hope this report will prove useful to Congress as it considers future policy development affecting these programs. This document fulfills our statutory mandate to report each year by June 15.

Sincerely,



Verlon Johnson

Chair



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and Access Commission

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Executive Summary: June 2024 Report to Congress on Medicaid and CHIP

MACPAC's June 2024 *Report to Congress on Medicaid and CHIP* contains four chapters of interest to Congress: (1) improving the transparency of financing in Medicaid and the State Children's Health Insurance Program (CHIP), (2) optimizing state Medicaid agency contracts (SMACs), (3) analyzing enrollment trends in Medicare Savings Programs (MSPs), and (4) improving demographic data collection in Medicaid.

CHAPTER 1: Improving the Transparency of Medicaid and CHIP Financing

Chapter 1 makes recommendations to Congress on improving the transparency of financing the non-federal share of Medicaid and CHIP. In the Commission's view, the primary goal of improving transparency of Medicaid and CHIP financing is to better understand how much providers are paid today under currently permissible financing mechanisms. Identifying payment amounts is the first component of MACPAC's provider payment framework for assessing whether payments are consistent with the statutory goals of efficiency, economy, quality, and access.

Financing of Medicaid and CHIP is a shared responsibility between states and the federal government. The federal government matches allowable state expenditures according to the federal medical assistance percentage. The statute permits states to raise the non-federal share of Medicaid and CHIP expenditures through multiple sources. The extent to which states rely on funding sources other than state general revenue varies considerably by state and type of service.

MACPAC has previously recommended that the Centers for Medicare & Medicaid Services (CMS) collect data on provider costs of contributing to the non-federal share so that we can account for these costs when assessing net payments to hospitals and nursing facilities. This work expands on earlier

research by including all providers, not just hospitals and nursing facilities, including all financing methods, not just provider contributions, and including both state- and provider-level financing amounts.

In this chapter, we make the following recommendations:

- 1.1 In order to improve transparency and enable analyses of net Medicaid payments, Congress should amend Section 1903(d)(6) of the Social Security Act to require states to submit an annual, comprehensive report on their Medicaid financing methods and the amounts of the non-federal share of Medicaid spending derived from specific providers. The report should include:
 - a description of the methods used to finance the non-federal share of Medicaid payments, including the parameters of any health care-related taxes;
 - a state-level summary of the amounts of Medicaid spending derived from each source of non-federal share, including state general funds, health care-related taxes, intergovernmental transfers, and certified public expenditures; and,
 - a provider-level database of the costs of financing the non-federal share of Medicaid spending, including administrative fees and other costs that are not used to finance payments to the provider contributing the non-federal share.

This report should be made publicly available in a format that enables analysis.

- 1.2 In order to provide complete and consistent information on the financing of Medicaid and the State Children's Health Insurance Program (CHIP), Congress should amend Section 2107(e) of the Social Security Act (the Act) to apply the Medicaid financing transparency requirements of Section 1903(d)(6) of the Act to CHIP.

The Commission will continue to examine Medicaid payment policies guided by MACPAC's provider payment framework as well as monitor larger trends in federal Medicaid spending, including the share

of Medicaid spending financed by states, providers, and the federal government. The Commission has previously examined alternative approaches to federal Medicaid financing that are intended to alter the trajectory of federal spending but cannot examine the full effects of these policies until more state- and provider-level financing data are available.

CHAPTER 2: Optimizing State Medicaid Agency Contracts

Chapter 2 focuses on steps toward better coordination of care for people who are dually eligible for Medicaid and Medicare. Dually eligible beneficiaries may experience fragmented care and poor health outcomes when their benefits are not coordinated. The most widely available tool for integrating Medicaid and Medicare benefits are Medicare Advantage dual eligible special needs plans (D-SNPs), which operated in 45 states and the District of Columbia in 2023. To operate, D-SNPs must sign a SMAC with the state Medicaid agency that details the federal minimum requirements describing how the D-SNP must coordinate Medicaid services for beneficiaries as well as additional requirements the state chooses to include.

In the Commission's previous reports to Congress, we highlighted the benefits of integrated care and the barriers that states face in developing these models and described the strategies available to states to integrate care through their contracts with D-SNPs. Building on that work, we set out to better understand the degree to which states use their contracting authority to provide care coordination and integrate care for their dually eligible beneficiaries as well as to understand how states consider, oversee, and enforce their contracts.

The chapter describes findings from this work, in addition to highlighting how states face barriers to overseeing their SMACs. The Commission makes two recommendations, one to states and one to CMS, that are intended to support states by providing a starting point for optimizing and overseeing SMACs and to explain how integrated care may benefit beneficiaries residing in their states.

In this chapter, we make the following recommendations:

- 2.1 State Medicaid agencies should use their contracting authority at 42 CFR 422.107 to require that Medicare Advantage dual eligible special needs plans (D-SNPs) operating in their state regularly submit data on care coordination and Medicare Advantage encounters to the state for purposes of monitoring, oversight, and assurance that plans are coordinating care according to state requirements. If states were required by Congress (as previously recommended by the Commission) to develop a strategy to integrate Medicaid and Medicare coverage for their dually eligible beneficiaries, states that include D-SNPs in their integration approach should describe how they will incorporate care coordination and utilization data and how these elements can advance state goals.
- 2.2 The Centers for Medicare & Medicaid Services should issue guidance that supports states in their development of a strategy to integrate care that is tailored to each state's health coverage landscape. The guidance should also emphasize how states that contract with Medicare Advantage dual eligible special needs plans can use their state Medicaid agency contracts to advance state policy goals.

CHAPTER 3: Medicare Savings Programs: Enrollment Trends

Chapter 3 examines MSPs, in which the Commission has had a long-standing interest because of the potential to improve access to care for low-income Medicare beneficiaries. People who are eligible for both Medicare and Medicaid may be eligible to receive Medicaid assistance with their Medicare premiums and cost sharing through MSPs.

The chapter describes MSPs and their role in providing Medicaid assistance with Medicare premiums and cost sharing to individuals who are dually eligible for Medicaid and Medicare. It begins by providing an overview of the MSPs and then discusses MACPAC's prior work analyzing participation rates in the programs, including prior Commission

recommendations aimed at improving participation in the MSPs. The chapter concludes with our new analysis of enrollment trends, including comparisons across MSPs and comparisons of enrollment trends by demographic characteristics, including age, sex, and urban or rural residence.

We found that MSP enrollment trends increased from 2010 to 2021 across all MSP categories of dual eligibility, with the majority of dually eligible beneficiaries enrolled in an MSP. In 2021, around 80 percent of dually eligible beneficiaries, or about 10 million people, were enrolled in an MSP. These findings indicate that state and federal efforts over the last decade to increase awareness of the MSPs among eligible low-income Medicare beneficiaries may have achieved their intended goals.

CHAPTER 4: Medicaid Demographic Data Collection

The final chapter of the June report looks at the collection of demographic data in Medicaid. 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. However, gaps in demographic data collection can impede efforts to measure and address these health disparities.

MACPAC's June 2022 report to Congress highlighted how Medicaid can take an active role in advancing health equity. 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. As a continuation of this work, we evaluated the availability of primary language, limited English proficiency, sexual orientation and gender identity (SOGI), and disability data to help measure and address health disparities among the Medicaid population.

Chapter 4 describes the importance of collecting demographic data and federal and state priorities for collecting and using these data. These data are important in supporting independent research and state monitoring efforts, informing policy decisions,

informing civil rights enforcement, and improving stakeholder knowledge about the health service needs of the many populations covered by Medicaid. We conclude with key considerations for collecting these data and factors affecting data quality.

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. MACPAC will continue to capitalize on existing Medicaid demographic data to measure health disparities in access to care and health outcomes and encourages CMS, states, researchers, and other stakeholders to do the same.

Chapter 1:

Improving the Transparency of Medicaid and CHIP Financing

Improving the Transparency of Medicaid and CHIP Financing

Recommendations

- 1.1** In order to improve transparency and enable analyses of net Medicaid payments, Congress should amend Section 1903(d)(6) of the Social Security Act to require states to submit an annual, comprehensive report on their Medicaid financing methods and the amounts of the non-federal share of Medicaid spending derived from specific providers. The report should include:
- a description of the methods used to finance the non-federal share of Medicaid payments, including the parameters of any health care-related taxes;
 - a state-level summary of the amounts of Medicaid spending derived from each source of non-federal share, including state general funds, health care-related taxes, intergovernmental transfers, and certified public expenditures; and,
 - a provider-level database of the costs of financing the non-federal share of Medicaid spending, including administrative fees and other costs that are not used to finance payments to the provider contributing the non-federal share.

This report should be made publicly available in a format that enables analysis.

- 1.2** In order to provide complete and consistent information on the financing of Medicaid and the State Children’s Health Insurance Program (CHIP), Congress should amend Section 2107(e) of the Social Security Act (the Act) to apply the Medicaid financing transparency requirements of Section 1903(d)(6) of the Act to CHIP.

Key Points

- Financing of Medicaid and the State Children’s Health Insurance Program (CHIP) is a shared responsibility between states and the federal government. Statute permits states to raise the non-federal share of Medicaid and CHIP expenditures through multiple sources. States are increasingly relying on health care–related taxes, intergovernmental transfers (IGTs), and certified public expenditures (CPEs) as ways to fund the non-federal share of Medicaid expenditures.
- The amount providers pay in health care–related taxes, IGTs, and CPEs can be seen as additional costs that effectively reduce gross payments. As such, the net payment that providers can use to cover the cost of providing services is lower than the gross amount initially received. Stakeholders have stressed the importance of analyzing both gross and net payment amounts when developing payment policy and assessing how these payments are linked to goals of access and quality.
- The Centers for Medicare & Medicaid Services (CMS) does not collect information on the sources of non-federal share in a comprehensive manner, resulting in data that are fragmented, incomplete, and not always publicly available.
- The Commission has long held that analyses of Medicaid payment policy require complete data on all Medicaid payments that providers receive as well as data on the costs of financing the non-federal share necessary to calculate net Medicaid payments at the provider level. The recommendations made in this chapter expand on prior Commission recommendations by including reporting of all types of Medicaid financing for all types of providers, not just hospitals and nursing facilities.
- CMS should make any new financing data publicly available to enable analyses by all stakeholders. In addition, CMS should seek ways to reduce the administrative burden by consolidating reporting when possible and establishing procedures to ensure accuracy and consistency across data sources.

CHAPTER 1: Improving the Transparency of Medicaid and CHIP Financing

Financing of Medicaid and the State Children’s Health Insurance Program (CHIP) is a shared responsibility between states and the federal government. The federal government matches allowable state expenditures according to the federal medical assistance percentage (FMAP). The statute permits states to raise the non-federal share of Medicaid and CHIP expenditures through multiple sources, including state general revenue, health care–related taxes, and contributions from local governments (including providers owned by local governments). The extent to which states rely on funding sources other than state general revenue varies considerably by state and type of service.

MACPAC previously recommended that the Centers for Medicare & Medicaid Services (CMS) collect data on provider costs of contributing to the non-federal share so that we can account for these costs when assessing net payments to hospitals and nursing facilities (Box 1-2) (MACPAC 2023a, 2016a). The U.S. Government Accountability Office (GAO) has also recommended that CMS collect provider-level data on the costs of contributing to the non-federal share for all providers (GAO 2020). In addition, GAO has recommended that CMS collect more state-level information about financing methods to improve federal oversight of financing policies (GAO 2014). These recommendations have not yet been implemented.

This report further examines barriers to improving the transparency of Medicaid and CHIP financing based on MACPAC’s review of existing policy and interviews with multiple stakeholders. Overall, we heard that mistrust about improving financing transparency stems from concerns from states and providers about how CMS would use any new data that it collects. Stakeholders were generally not opposed to transparency that was intended to improve analyses of Medicaid payments, but they were concerned about using new data as a pretext for changing the rules

about permissible sources of non-federal share to reduce federal Medicaid spending.

In the Commission’s view, the primary goal of improving transparency of Medicaid and CHIP financing is to better understand how much providers are paid today under currently permissible financing mechanisms. Understanding payment amounts is the first component of MACPAC’s provider payment framework for assessing whether payments are consistent with the statutory goals of efficiency, economy, quality, and access (MACPAC 2015). As better financing data become available, the Commission will continue to explore whether there are opportunities to improve current financing policies to better advance these statutory goals. In doing so, it is important to weigh any potential benefits of reduced federal spending against the risk that reducing payments could jeopardize access and quality of care.

The Commission reviewed a variety of policy options that would build on MACPAC’s prior recommendations by providing more specificity about how financing data should be collected to best enable analyses of net Medicaid payments. In addition, the Commission aimed to expand MACPAC’s prior recommendations to enable analyses of all types of Medicaid financing for all types of providers, not just hospitals and nursing facilities. Finally, in designing policy recommendations, the Commission aimed to reduce administrative burden for states, providers, and CMS.

Based on this review, the Commission recommends that Congress make two complementary statutory changes:

- 1.1 In order to improve transparency and enable analyses of net Medicaid payments, Congress should amend Section 1903(d)(6) of the Social Security Act to require states to submit an annual, comprehensive report on their Medicaid financing methods and the amounts of the non-federal share of Medicaid spending derived from specific providers. The report should include:
 - a description of the methods used to finance the non-federal share of Medicaid payments, including the parameters of any health care-related taxes;

- a state-level summary of the amounts of Medicaid spending derived from each source of non-federal share, including state general funds, health care-related taxes, intergovernmental transfers, and certified public expenditures; and,
- a provider-level database of the costs of financing the non-federal share of Medicaid spending, including administrative fees and other costs that are not used to finance payments to the provider contributing the non-federal share.

This report should be made publicly available in a format that enables analysis.

- 1.2 In order to provide complete and consistent information on the financing of Medicaid and the State Children’s Health Insurance Program (CHIP), Congress should amend Section 2107(e) of the Social Security Act (the Act) to apply the Medicaid financing transparency requirements of Section 1903(d)(6) of the Act to CHIP.

To provide context for these recommendations, this chapter begins with background on Medicaid and CHIP financing and the evolution of federal policy in this area. Then we review findings from interviews with stakeholders on barriers to improving the transparency of Medicaid financing. To illustrate how provider-level financing data can inform analyses of net Medicaid payments, the chapter also includes a review of new provider-level financing data being reported in Texas. The chapter concludes with a discussion of the rationale for MACPAC’s recommendations and next steps for the Commission’s work in this area.

Background

Medicaid and CHIP are jointly financed by states and the federal government. The non-federal share of spending is determined by the FMAP, which differs by state and also varies for some Medicaid services and beneficiary categories.¹ CHIP is matched at a higher enhanced FMAP rate, and unlike Medicaid, total CHIP spending is limited by federal allotments. In fiscal year (FY) 2022, federal funds accounted for 71 percent of total Medicaid benefit spending (\$792.7 billion) and 76 percent of CHIP spending (\$22.3 billion)

nationally (MACPAC 2023b, 2023c). This includes the 6.2 percentage point increase in the FMAP under the Families First Coronavirus Response Act of 2020 (FFCRA, P.L. 116-127). Historically, without this temporary FMAP increase, federal funds accounted for approximately 65 percent of total Medicaid benefit spending in FY 2019 and approximately 71 percent of CHIP spending in FY 2015.²

Permissible sources of Medicaid financing

The statute permits states to raise the non-federal share of Medicaid expenditures through multiple sources. Each permissible source of funding is subject to different rules (Box 1-1). Federal regulations in 42 CFR 457.628 apply all Medicaid financing rules to CHIP, so we did not separately examine CHIP financing rules.

State general funds are revenue collected through income taxes, sales taxes, and other sources. States can use state general funds specifically allocated to the state Medicaid agency and interagency funds allocated to other state agencies. By statute, at least 40 percent of the non-federal share of Medicaid spending must come from state sources (§1902(a)(2) of the Social Security Act (the Act)).

States or units of local government can generate state revenue from taxes on health care providers, but if they do so, they must meet certain rules. A health care–related tax is defined as a tax for which at least 85 percent of the tax burden falls on health care providers or services, or a tax that is not limited to health care items or services but treats health care providers differently than other individuals or entities. Federal regulations (42 CFR 433.56, 433.68) define the specific services that states may tax and the parameters that taxes must follow to be consistent with statutory requirements described in Section 1903(w) of the Act. CMS has the authority through rulemaking to include other health care services not currently listed in regulations, but CMS has previously established criteria that would not allow providers or services as a permissible class if the revenue for the class is predominately from Medicaid and Medicare (e.g., not more than 50 percent from Medicaid).

BOX 1-1. Glossary of Permissible Medicaid Financing Sources

State general funds are revenue collected through income taxes, sales taxes, and other sources.

Health care-related taxes (often referred to as provider taxes, fees, or assessments) are defined as taxes for which at least 85 percent of the tax burden falls on health care providers or services. Federal regulations also consider a tax that is not limited to health care items or services to be health care related if it treats health care providers differently than other individuals or entities.

Provider donations are voluntary contributions made directly or indirectly to a state or a local government by or on behalf of a health care provider or entity related to a health care provider. Provider-related donations are permissible if they are bona fide donations, which means there is no direct or indirect relationship to the payments made to the provider under a hold harmless provision. Donations of up to \$5,000 per year for individual providers and up to \$50,000 per year for health care organizations are presumed to be bona fide donations so long as there is no hold harmless provision.

Intergovernmental transfers are funds transferred to the state from other public agencies in the state or local governments. Public agencies include providers owned by local governments and state-owned providers, such as state university hospitals and state psychiatric hospitals.

Certified public expenditures (CPEs) are costs certified by state or local governments, including government-owned providers, as expenditures eligible for federal Medicaid or CHIP matching funds. Under a CPE arrangement, the non-federal share amount is not transferred to the state. States are not required to pay the federal share associated with CPEs to providers.

In general, taxes must be broadly applied to all non-governmental providers throughout the jurisdiction of the taxing authority, and the tax amount must be uniformly applied. However, states can apply for waivers of these federal requirements if the tax meets certain statistical tests that are intended to ensure that the net costs and benefits of the tax are generally redistributive and the amount of the tax is not an undue burden on Medicaid providers.

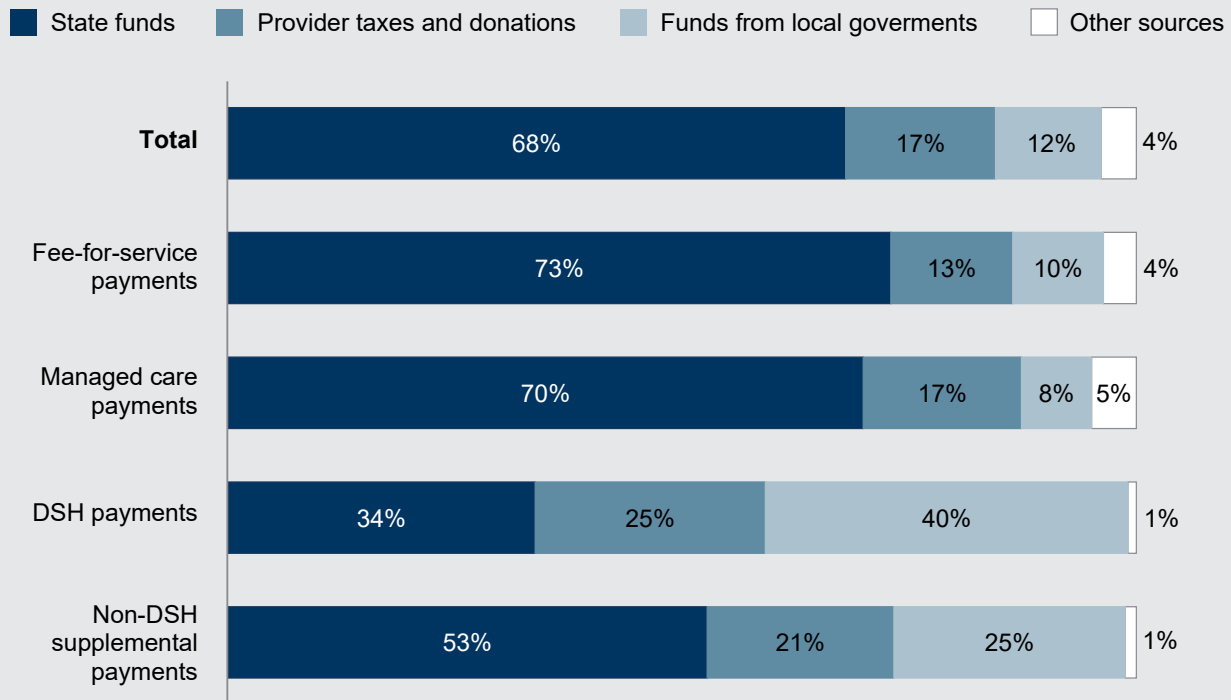
In addition, states cannot hold providers harmless for the cost of the tax, including through direct or indirect guarantees that providers will be repaid for all or a portion of the taxes that they pay. In practice, health care-related taxes are often used to offset low state general funding and increase payments to providers who pay the tax. These arrangements are not considered an indirect guarantee so long as the total tax amount is less than 6 percent of the provider's net patient revenue. This threshold is commonly referred to as the provider tax safe harbor.

Voluntary donations from providers are permissible if they are bona fide donations. CMS presumes

donations up to \$5,000 a year from health care providers and \$50,000 a year from health care organizations to be bona fide donations so long as there is no hold harmless provision.

Local governments, including providers owned by local governments, can contribute up to 60 percent of the non-federal share of total Medicaid spending through intergovernmental transfers (IGTs) or certified public expenditures (CPEs).³ IGTs involve a transfer of funding from another public agency or local government to the state. In contrast, under CPEs, public agencies or local governments can certify the costs or expenditures for services covered by Medicaid or CHIP, and the state claims federal funding based on those amounts.

Public providers, such as public hospitals, can derive the funds that they use for IGTs or CPEs from any public funds, including local tax revenue or patient revenue. If local governments impose health care-related taxes, the federal rules that apply to statewide taxes also apply.

FIGURE 1-1. Share of Non-Federal Funds for Medicaid Payments from Different Sources, SFY 2018


Notes: SFY is state fiscal year. DSH is disproportionate share hospital. State funds include state general funds and interagency transfers. Funds from local governments include intergovernmental transfers and certified public expenditures. Other sources include funds, such as tobacco settlement funds, that are used to fund the state’s non-federal share of Medicaid expenditures and are not considered to fit in the other categories listed. Numbers do not sum to 100 due to rounding. Data reflect all Medicaid payments, not just Medicaid payments to hospitals.

Source: GAO 2021.

IGTs can be used to finance payments for providers transferring the funding, to finance specific payments to other providers, or for overall Medicaid spending. Federal rules on provider donations also apply to local units of government. As a result, public agencies that provide IGTs for payments to a non-governmental provider cannot receive impermissible donations from these providers.

States are not required to pay the federal share associated with CPEs to providers. Any CPE from a public provider can be used only to finance payments to the provider certifying the allowable Medicaid service. Current statute and federal regulations provide little guidance about CPEs, but in 2023, CMS issued subregulatory guidance describing allowable

costs and the process for certifying expenditures for school-based services (CMS 2023).

Current uses of Medicaid financing

In state fiscal year (SFY) 2018, 68 percent of the non-federal share of Medicaid spending came from state general funds, 17 percent came from health care–related taxes, and 12 percent came from local governments, according to a GAO survey (Figure 1-1). Between SFY 2008 and SFY 2018, the use of state general funds declined from 75 to 68 percent of the non-federal share, and the use of health care–related taxes more than doubled, from 7 to 17 percent of the non-federal share (GAO 2021, 2014).

States often rely on providers to finance the non-federal share of supplemental payments, which are lump sum payments to providers that are made in addition to base payment rates for Medicaid services. In prior MACPAC interviews with stakeholders about the evolution of hospital and nursing facility payment policy, we heard about the funding dynamics that often lead to this outcome. Although providers generally prefer base payment rate increases financed by state general funds, states often look to providers to help finance additional payments because of state budget constraints. Providers prefer to finance supplemental payments instead of base payment rate increases because it is easier for states to target supplemental payments to providers that contribute the non-federal share (MACPAC 2020, Marks et al. 2018).

In MACPAC’s prior analyses of Medicaid disproportionate share hospital (DSH) payments, we observed that states’ financing methods relate to how DSH payments are targeted. States that finance DSH payments with broad-based provider taxes often distribute DSH payments broadly. States that finance DSH payments with funds from local governments

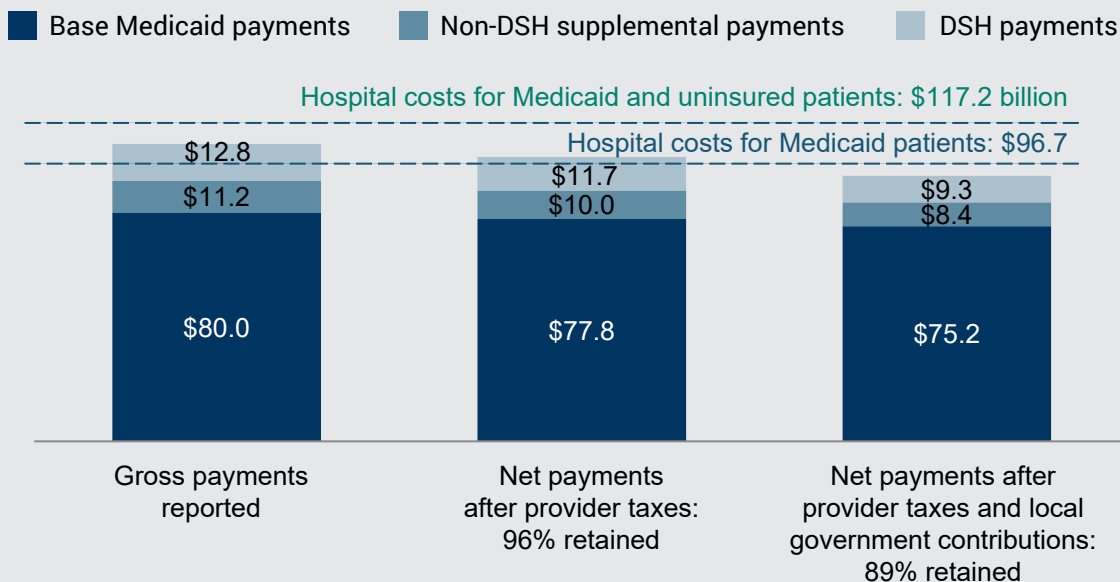
(typically through public hospitals) often target DSH funds to public hospitals (MACPAC 2017).

Effects of provider contributions on net payments to providers

The amount providers pay in health care–related taxes, IGTs, and CPEs can be seen as additional costs that effectively reduce the gross payments. As such, the net payment that providers can use to cover the cost of providing services is lower than the gross amount initially received. For example, assuming that DSH hospitals pay provider taxes and contribute local funds at the same rate as other providers, we estimated that these costs reduced total gross Medicaid payments to DSH hospitals by 11 percent in 2011 (Nelb et al. 2016).

Accounting for the costs of provider contributions to the non-federal share can affect calculations of Medicaid payment adequacy. For example, in 2011, gross payments to DSH hospitals exceeded hospitals’ Medicaid costs, but net payments were less than Medicaid costs in the aggregate (Figure 1-2).

FIGURE 1-2. Gross and Net Payments to DSH Hospitals, SPRY 2011



Notes: DSH is disproportionate share hospital. SPRY is state plan rate year. Analysis excludes institutions for mental diseases.

Source: Nelb et al. 2016.

Effects of state financing methods on state general funding

Under current law, states cannot reduce the amount, duration, or scope of Medicaid services because of a lack of available funding from providers or other local sources (§1902(a)(2) of the Act). However, in practice, states have limited state general funds and set payment policies based on state budget constraints. If some currently permissible financing methods were eliminated, it is likely that states would reduce payments to providers instead of offsetting the lost non-federal funding with state general funds.

In recent years, as Medicaid coverage has grown, Medicaid has accounted for a growing share of state budgets (MACPAC 2016b). However, funding from the federal government and providers has offset some of these costs. For example, the coverage expansions under the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) are matched at an increased FMAP of 90 percent, which has helped to reduce the state costs of these expansions. In addition, some states have further reduced their state general fund costs by relying on providers to finance the non-federal share. Calculations of Medicaid spending as a share of state budgets differ substantially depending on whether this financing from providers and the federal government is considered (Figure 1-3).

In the future, states may face increased pressure to rely on providers to finance Medicaid payments as enhanced federal funding provided during the COVID-19 pandemic phases out. Between 2020 and 2023, FFCRA provided a 6.2 percentage point increase in FMAP to states that maintained Medicaid coverage and eligibility standards. The Consolidated Appropriations Act, 2023 (P.L. 117-238) phased down the enhanced FMAP beginning April 1, 2023, fully eliminating the increase after December 31, 2023. Congress has also provided enhanced federal funding for HCBS under the American Rescue Plan Act of 2021 (ARPA, P.L. 117-2), which expires March 31, 2025.

Existing transparency requirements

CMS currently collects information on state financing methods when it reviews state plan amendments

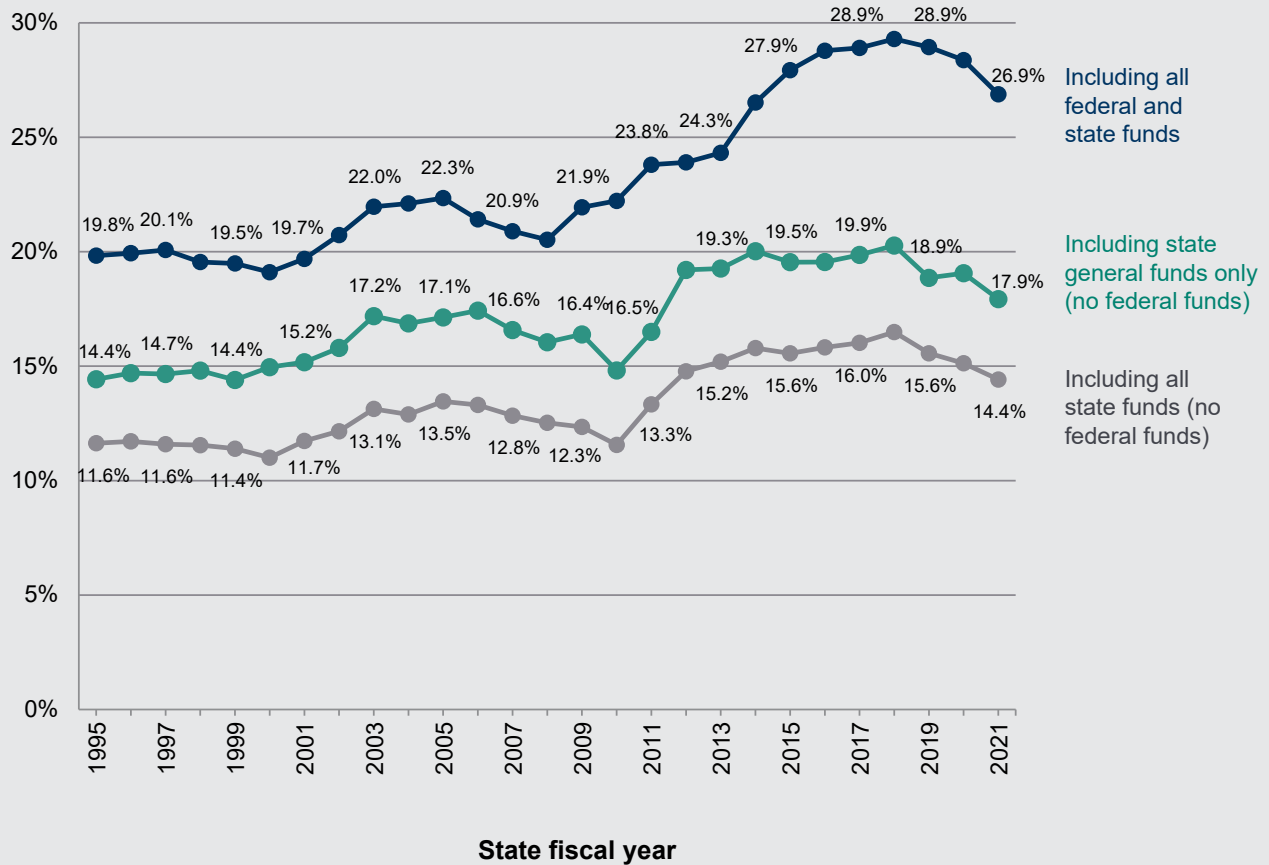
(SPAs) that make changes to Medicaid payment methods. Specifically, CMS requires states to answer a standard set of five funding questions. These questions are primarily intended to identify impermissible provider donations and require states to describe how the non-federal share of each type of payment is funded.

CMS also requires additional information on health care–related taxes that are not broad based or uniformly applied. To receive waivers of these federal requirements, states must demonstrate that the net effect of the tax is generally redistributive and that the tax amount is not directly correlated with Medicaid payment amounts. In practice, these rules mean that states must submit provider-level information on anticipated taxes and Medicaid payments when the tax waiver is approved. Most health care–related taxes receive federal tax waivers, but states are not required to resubmit information to demonstrate continued compliance with the tax waiver requirements after the tax is approved so long as the parameters of the tax have not changed.⁴ CMS has begun to ask states to provide more detail on what a tax funds when reviewing tax waivers and has asked states to provide the total amount of payments funded by the tax compared to the total tax imposed at the provider level when possible. However, not all states are able to provide this information, and these waiver data are not publicly available.

For managed care directed payments, states are required to describe the financing sources on CMS's standard application form, which is referred to as a preprint. The preprint requires states to include a table indicating government entities that are transferring IGTs to finance directed payments. The preprint also collects information to demonstrate that the health care–related taxes used are permissible but does not collect information on the specific entities paying the tax or the amount of taxes collected.

When states submit claims for federal Medicaid funding, they must certify that the non-federal share of Medicaid spending complies with federal requirements, but they do not describe the source of non-federal share for each payment. States submit expenditures for federal Medicaid funding on Form CMS-64 in the Medicaid Budget and Expenditure System (MBES). Form CMS-64 captures fee-for-service (FFS) expenditures for different types of

FIGURE 1-3. Medicaid as a Share of State Budgets Including and Excluding Federal Funds, SFYs 1995–2021



Notes: SFY is state fiscal year. Amounts shown here reflect the most recent information available in cases in which data for a given year were published and then updated in a subsequent report.

The all federal and state funds category reflects amounts from any source. The state general funds only category reflects amounts from revenues raised through income, sales, and other broad-based state taxes and excludes federal funds. The all state funds category reflects amounts from any non-federal source; these include state general funds, other state funds (amounts from revenue sources that are restricted by law for particular government functions or activities, which for Medicaid includes provider taxes and local funds), and bonds (expenditures from the sale of bonds, generally for capital projects) and excludes federal funds.

Source: MACPAC 2023d.

service categories (including supplemental payments), but it reports only the amount of capitation payments paid to managed care organizations (MCOs). It does not separately identify expenditures that MCOs made for specific services or to specific providers, such as directed payments.

States are statutorily required to report annually on the amount of health care–related taxes that they collect each year (§1903(d)(6) of the Act).⁵ States currently submit this information on Form CMS-64.11 in MBES. This form is used for informational purposes and is not tied to the amount of federal funding that states claim.

States are not currently required to collect and report provider-level financing data. However, states have the option to include the Medicaid-attributable costs of provider taxes when calculating the upper payment limit (UPL) for FFS supplemental payments. States that select this cost-based approach to demonstrate the UPL include provider-level tax data in their annual UPL demonstrations, a standard reporting template used to calculate the UPL.

CMS occasionally collects more detailed information about Medicaid financing as part of its financial management reviews in selected states with identified issues. These reviews include close examinations of state budget documents and financing records. However, CMS does not currently have the capacity to conduct these reviews for all states at all times. In addition, these reviews are primarily focused on ensuring compliance with federal rules and may not collect information that is needed to calculate net Medicaid payments to providers.

Prior MACPAC transparency recommendations

Understanding Medicaid payment amounts is a key component of MACPAC’s provider payment framework. Specifically, MACPAC needs payment amounts to assess whether payments are consistent with the statutory goal of economy. In addition, this information can inform analyses of how payment amounts relate to the other statutory goals of access, quality, and efficiency (MACPAC 2015).

In 2016, MACPAC recommended that CMS collect provider-level data on the sources of non-federal share necessary to calculate net Medicaid payments to hospitals, and in 2023, the Commission similarly recommended that CMS collect provider-level financing data necessary to calculate net payments to nursing facilities (MACPAC 2023a, 2016a). Because provider-financed supplemental payments account for such a large share of Medicaid payments to hospitals and nursing facilities, collecting provider-level financing data is necessary to enable more accurate analyses of Medicaid payment amounts for these providers.

The recommendations discussed in this chapter expand on MACPAC’s prior recommendations in the following ways:

- applying recommendations to all Medicaid providers, not just hospitals and nursing facilities;
- specifying a method for collecting provider-level data;
- including state-level financing information about all types of Medicaid financing methods, not just provider contributions to the non-federal share; and
- including state-level financing amounts that could help validate the provider-level data collected and put these data in context.

Taken together, MACPAC’s payment and financing recommendations would enable analyses of all types of Medicaid payments to providers and represent a substantial improvement over current law (Table 1-1). Although this chapter focuses on methods for improving transparency of Medicaid financing, the Commission continues to endorse all of its unimplemented payment recommendations (Box 1-2). Policymakers need both payment and financing data to assess whether Medicaid payment policy is consistent with statutory goals.

TABLE 1-1. Payment and Financing Transparency Elements in Current Law and MACPAC Recommendations

Transparency elements	Type of payment				
	FFS base	DSH	Non-DSH	Managed care base	Managed care directed payment
Payment					
Methods ¹	State plan	State plan	State plan	Rate certification	Directed payment preprint
State-level amounts ²	CMS-64	CMS-64	CMS-64	CMS-64	Directed payment preprint (projected) ⁴
Provider-level amounts ^{2,3}	T-MSIS	DSH audit	New non-DSH report	T-MSIS (not public)	Not available ⁴
Financing					
Methods ⁵	Standard funding questions	Standard funding questions	Standard funding questions	Not available ⁶	Directed payment preprint
State-level amounts ⁵	Not available	Not available	Not available	Not available ⁶	Not available
Provider-level amounts ⁵	Not available	Not available	Not available	Not available ⁶	Directed payment preprint (IGTs only)

Notes: FFS is fee for service. Base is base payments for services. DSH is disproportionate share hospital. Non-DSH is non-DSH supplemental payments, including FFS supplemental payments based on the upper payment limit and supplemental payments authorized under Section 1115 demonstration authority. CMS-64 is Form CMS-64 in the Medicaid Budget and Expenditure System (MBES) (Form CMS-64.11 collects information on state-level provider tax amounts). T-MSIS is the Transformed Medicaid Statistical Information System. IGT is intergovernmental transfer. Managed care rate certifications describe how capitation rates are developed, but they do not describe how managed care plans pay providers.

¹ MACPAC March 2023 recommendation would provide information on all nursing facility payment methods though rate studies.

² MACPAC June 2022 recommendations would provide state-level and provider-level information on the actual amounts of directed payments.

³ MACPAC March 2016 and March 2023 recommendations would provide state-level and provider-level information on total payments to hospitals and nursing facilities, including supplemental payments.

⁴ The 2024 final managed care rule requires that states report directed payments at the provider level into T-MSIS; however this requirement will not go into effect until CMS releases reporting instructions (CMS 2024a).

⁵ The recommendations made in this chapter would build off of the March 2016 and March 2023 MACPAC recommendations to provide information on financing methods, state-level financing amounts from different sources, and provider-level financing amounts for all services, not just hospitals and nursing facilities.

⁶ If a state uses a pass-through payment, it must submit a description of the non-federal share for the pass-through payment, including the source and amount of the non-federal share financing. For any payment funded by IGTs, the state would also report a complete list of entities transferring funds and the total amount transferred by each entity.

Sources: MACPAC, 2024, analysis of current law and CMS guidance; MACPAC 2023a, 2022, 2016a.

BOX 1-2. Status of Prior MACPAC Recommendations Related to Payment and Financing Transparency

March 2016

Improving data as the first step to a more targeted disproportionate share hospital policy

- The Secretary of the U.S. Department of Health and Human Services (the Secretary) should collect and report hospital-specific data on all types of Medicaid payments for all hospitals that receive them. In addition, the Secretary should collect and report data on the sources of non-federal share necessary to determine net Medicaid payment at the provider level.
 - **Note:** This recommendation was partially implemented under the Consolidated Appropriations Act, 2021 (P.L. 116-260), which requires the U.S. Department of Health and Human Services to establish a system for states to submit non-disproportionate share hospital supplemental payment data in a standard format, beginning October 1, 2021. However, the legislation did not include managed care payments or information on the sources of non-federal share necessary to determine net Medicaid payments at the provider level. Additionally, the Centers for Medicare & Medicaid Services has yet to make these data publicly available.

June 2022

Oversight of managed care directed payments

- To inform assessments of whether managed care payments are reasonable and appropriate, the Secretary of the U.S. Department of Health and Human Services should make provider-level data on directed payment amounts publicly available in a standard format that enables analysis.
 - **Note:** This report also included other recommendations to improve the oversight of directed payments to ensure that these payments advance statutory goals. In April 2024, the Centers for Medicare & Medicaid Services finalized requirements for states to report the total dollars expended by each plan for state directed payments, including amounts paid to individual providers (CMS 2024a).

March 2023

Principles for Assessing Medicaid Nursing Facility Payment Policies

- To improve transparency of Medicaid spending, the Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to collect and report the following data in a standard format that enables analysis:
 - facility-level data on all types of Medicaid payments to nursing facilities, including resident contributions to their cost of care;
 - data on the sources of non-federal share of spending necessary to determine net Medicaid payment at the facility level; and
 - comprehensive data on nursing facility finances and ownership necessary to compare Medicaid payments to the costs of care for Medicaid-covered residents and to examine the effects of real estate ownership models and related-party transactions.

BOX 1-2. (continued)

- To help inform assessments of whether Medicaid nursing facility payments are consistent with statutory goals of efficiency, economy, quality, and access, the Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to update the requirement that states conduct regular analyses of all Medicaid payments relative to the costs of care for Medicaid-covered nursing facility residents. This analysis should also include an assessment of how payments relate to quality outcomes and health disparities. CMS should provide analytic support and technical assistance to help states complete these analyses, including guidance on how states can accurately identify the costs of efficient and economically operated facilities with adequate staff to meet residents' care needs. States and CMS should make facility-level findings publicly available in a format that enables analysis.

Evolution of Permissible Medicaid Financing Methods

Since Medicaid's inception, states have had the flexibility to generate their share of Medicaid expenditures through multiple sources, including state general revenue and contributions from local governments. Medicaid was initially designed to build on existing state and local indigent care programs, so the extent to which states rely on funding sources other than state revenue may reflect how states have historically split financing with localities for indigent care and other social services programs. Medicaid financing has changed over time as policymakers debated permissible sources of non-federal funding, permissible uses of federal Medicaid funding, and permissible limits on Medicaid payments to providers.

History of permissible sources of non-federal funding

In the 1980s, Medicaid costs grew as Congress expanded the number of people that the program served and added new statutory requirements for states to ensure access to care and support safety-net providers. To help offset these costs, states and the federal government began exploring new ways to finance the non-federal share of Medicaid spending (Tudor 1995).

In 1985, CMS (then known as the Health Care Financing Administration) issued regulations permitting states to expand the use of public and private donations to finance the non-federal share of Medicaid spending. This regulation was intended to help states facing budget challenges and provide more flexibility in administering their programs. At the time, CMS acknowledged the possibility that this policy could be abused to create quid pro quo arrangements in which entities that donated funds directed how the state used them. To limit this possibility, CMS required that donated funds be under the administrative control of the state and prohibited states from using donated funds to increase payments to for-profit providers (HCFA 1985).

Many states took advantage of this new financing flexibility to expand Medicaid coverage and increase payments to providers. For example, in Tennessee, which began authorizing provider donations in 1987, Medicaid spending grew from about \$1 billion in FY 1988 to \$2.3 billion in FY 1992. This growth was largely driven by increased payments to high-volume Medicaid hospitals, statutorily required expansions in coverage for low-income mothers and children, and health care inflation. Provider donations helped support these expenses. For example, 20 percent of Tennessee's hospitals donated \$19 million to the Medicaid program in the first year of the donation program, which generated \$63 million in state and federal funds.⁶ Approximately \$24 million of the funding raised was distributed to hospitals (resulting in a net payment of \$5 million for these providers), \$31 million went to expanded Medicaid coverage, and the

remaining \$8 million was used to extend the state's annual inpatient hospital coverage limit from 14 to 20 days (Matherlee 2002).

CMS initially disallowed Tennessee's use of provider donations, which led the state to develop a provider tax instead. In 1987, CMS first issued subregulatory guidance about the use of health care–related taxes, but the specific parameters of permissible taxes were not well defined. The U.S. Department of Health and Human Services Departmental Appeals Board later reversed the disallowance of the provider donation mechanism, thus allowing Tennessee and other states to continue using multiple financing sources. In 1989 and 1990, Congress imposed moratoria to prevent CMS from changing these financing policies that states were relying on (Matherlee 2002).

In the early 1990s, states began using newly permissible financing mechanisms to rapidly increase DSH payments. In 1987, Congress required states to make payments to deemed DSH hospitals, which serve a high share of Medicaid and uninsured patients, and CMS also clarified that the UPL on Medicaid payments to hospitals did not apply to DSH payments. DSH spending increased from \$1.3 billion in 1990 to \$17.7 billion in 1992 (Matherlee 2002, Klemm 2000, Holahan et al. 1998).

In 1991, Congress passed the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments of 1991 (P.L. 102-234) to limit federal spending. The law substantially limited the use of provider donations, established parameters for health care–related taxes, required state reporting of provider tax amounts, and established state and federal limits on DSH payments. CMS issued regulations in 1992 and 1993 implementing these provisions. The law prohibited CMS from restricting the use of funds derived from state or local taxes transferred from or certified by units of government (e.g., IGT, CPE) unless the funds are derived from impermissible donations or taxes.⁷

Since the early 1990s, the federal rules on permissible sources of Medicaid financing have been largely unchanged. Under the Deficit Reduction Act of 2005 (P.L. 109-171), Congress expanded the managed care provider class to include all MCOs and not just Medicaid MCOs to align with the broad-based requirement for all provider taxes. In 2006, Congress

temporarily changed the provider tax safe harbor from 6 percent to 5.5 percent as part of the Tax Relief and Health Care Act of 2006 (P.L. 109-432), but the threshold reverted back to 6 percent in 2011. Some policymakers continue to propose reducing the provider tax safe harbor to reduce the federal budget deficit. However, this policy would also reduce payments to providers, which could affect access to care for beneficiaries. For example, the Congressional Budget Office (CBO) estimates that reducing the provider tax safe harbor from 6 percent to 5 percent would reduce federal spending on Medicaid services by \$42 billion over 10 years because states are unlikely to offset the full amount of lost provider tax revenue with state general funds or other sources of non-federal share (e.g., taxes on other provider classes) (CBO 2022).

CMS has proposed changes to permissible financing sources that were subject to moratoria or were rescinded. In 2007, CMS released regulations that limited payment to government providers to no more than cost and clarified what entities are considered units of government allowed to contribute to the non-federal share (CMS 2007). This rule was vacated in federal court and later rescinded (*Alameda County Medical Center, et al. v. Leavitt, et al.*, 559 F. Supp. 2d 1 (D.D.C. 2008), CMS 2010). In 2008, CMS published regulations clarifying the standard for determining the existence of a hold harmless tax arrangement (CMS 2008). These changes to the hold harmless provisions were subject to moratoria until 2010.⁸ In 2019, CMS published the Medicaid Fiscal Accountability Rule (MFAR), which included provider tax policy changes, limits on the permissible state or local funds that could be used for IGTs and CPEs, and other financing and payment policy changes (CMS 2019). MFAR was never finalized and was withdrawn in 2021 (CMS 2021).

History of permissible uses of funding

After Congress clarified permissible Medicaid financing sources in 1991 and CMS implemented the accompanying regulations, states continued to explore creative ways to use these financing mechanisms to support their budgets and providers. In particular, after Congress set new limits on provider taxes, states began exploring greater use of IGTs from government-owned providers.

In 1994, GAO investigated the use of IGTs in three states and identified a financing strategy that became known as recycling. Under these arrangements, states used IGTs from government-owned providers to make payments to these providers and then required the provider to return most of the payment to the state. On net, these arrangements reduce the share of state general funding contributed to Medicaid expenditures and increase the federal share of Medicaid spending (GAO 1994). These recycling practices also raised several policy questions about whether federal funds were being used for services to Medicaid beneficiaries, as required by Section 1903(a)(1) of the Act, or whether funds were being diverted for other purposes.⁹

To address these concerns, CMS introduced a standard set of funding questions in 2002 for states to answer when they submit SPAs to change their payment methodologies. Specifically, states are required to clarify whether any portion of payments is returned to the state or local government and to identify the funding source of the payment. States also are required to provide detailed information on funds transferred from other government entities (e.g., IGTs, CPEs), including the entities making the transfer, the operational nature of each entity, and the total amounts transferred or certified by each entity.

To enforce the new funding questions, CMS created a national institutional reimbursement team that systematically reviewed all state supplemental payment arrangements. Between 2003 and 2005, CMS identified and resolved problematic financing arrangements in 29 states. GAO commended CMS's efforts at the time but also raised concerns about the lack of transparency of CMS's process (GAO 2007).

History of permissible limits on payments

At the same time that CMS was reviewing permissible uses of provider-financed payments, Congress and CMS also established new limits on supplemental payments as a way to control federal spending. The Omnibus Budget Reconciliation Act of 1993 (P.L. 103-166) established hospital-specific DSH limits based on hospitals' unpaid costs of care for Medicaid patients and uninsured individuals. These hospital-specific limits are applied in addition to the state-specific

allotments that Congress created in 1991 based on states' DSH spending in 1992.

After DSH payments were limited, states began exploring greater use of non-DSH supplemental payments, such as UPL payments, to support providers. The UPL for Medicaid FFS payments to providers is not defined in statute, but CMS first established a UPL in 1981 when states were given the flexibility to pay institutional providers (e.g., hospitals and nursing facilities) different rates than Medicare. To enforce the statutory goals of economy and efficiency, CMS allowed individual institutional providers to be paid more than Medicare as long as aggregate payments for the class of providers were less than a reasonable estimate of what Medicare would have paid for the same service.¹⁰ The use of UPL payments grew rapidly in the early 2000s, from \$4.5 billion in FY 2000 to \$19.8 billion in FY 2021. As a result, CMS increased its review of UPL payments and revised the process for calculating the UPL (MACPAC 2019).¹¹

States are not permitted to make UPL supplemental payments for services provided in managed care. However, in 2016, CMS permitted states to require MCOs to pay providers according to specific rates or methods, which is referred to as a directed payment. Some of the largest directed payments are used to make large rate increases to providers that are similar to supplemental payments in FFS. More than half of directed payments are financed by IGTs or provider taxes, and these arrangements account for 81 percent of directed payment spending identified in our analysis. Spending on directed payments has increased rapidly in recent years, from \$25.7 billion a year as of December 2020 to \$69.3 billion a year as of February 2023, according to MACPAC's review of the limited data available (MACPAC 2023e).¹² To manage directed payment spending, CMS has limited directed payments for hospitals, nursing facilities, and academic medical centers to the average commercial rate, which is defined as the average rate paid for services by the highest claiming third-party payers for specific services based on claims volume (CMS 2024a).

When calculating DSH, UPL, and directed payment limits, CMS does not fully account for providers' costs of financing the non-federal share of Medicaid payments.¹³ CMS has begun to ask states to report health care–related tax amounts and Medicaid

payments funded by those taxes when submitting a tax waiver. However, not all states are able to provide this information, and not all tax arrangements require a waiver. As a result, CMS also does not collect all of the provider-level financing data needed to determine net payments to providers.

Themes from Stakeholder Interviews

To learn more about barriers to improving the transparency of Medicaid financing, we interviewed 17 national experts, state officials, federal officials, and provider associations between September 2023 and January 2024. The interviews identified several considerations for improving transparency, which are discussed further below:

- mistrust about how CMS would use additional financing data;
- lack of comprehensive tracking of current state financing methods;
- incomplete reporting of state-level financing amounts;
- challenges attributing financing sources to specific payments; and
- challenges tracking financing and payments within health systems.

Mistrust about how financing data would be used

The stakeholders we interviewed noted that states and providers may be reluctant to share additional financing data with CMS because of concerns that CMS would use these data to reconsider financing arrangements that it previously approved. Recent CMS oversight actions, such as MFAR, have added to a general feeling of mistrust and lack of clarity about the purpose of increasing transparency. Although CMS described many of the proposed MFAR policies as codifying existing policies, several of the stakeholders we interviewed viewed this rule as creating new limits

on state financing methods.¹⁴ CMS never finalized this rule and ultimately withdrew MFAR.

In contrast to MFAR, the experts we spoke with were generally supportive of new guidance that CMS recently issued on claiming and funding for school-based services with CPEs (CMS 2023). CMS developed this new guidance collaboratively with states and primarily focused on how to help states expand the use of this financing method, rather than limit it.

Overall, many of the stakeholders we interviewed were supportive of improving financing transparency to strengthen payment analyses. Some experts we spoke with questioned why CMS would need to improve the transparency of sources for the non-federal share if they are already permissible. However, the providers we spoke with acknowledged that many providers make internal decisions based on net payment amounts and view taxes and IGTs as considerable costs that affect their overall finances. The state officials we spoke with noted that they currently provide financing data to their state legislatures and were primarily concerned about increased administrative burden of any new federal reporting requirement.

Lack of comprehensive information on state financing methods

The experts we interviewed noted that CMS's current funding questions work well to ensure compliance with existing requirements; however, they had mixed views on whether making these funding questions public would meaningfully improve transparency for external stakeholders. Because states often submit multiple payment SPAs each year, stakeholders cannot easily use the responses to the questions to understand a state's overall approach to Medicaid financing.

The experts we interviewed noted that CMS's current funding questions likely capture information about most state financing policies and do not impose much administrative burden on states. However, adding to the general feeling of mistrust that experts cited, one interviewee raised concerns that some of the standard funding questions refer to financing policies that CMS previously proposed but never went into effect, such as

a 2007 proposal to establish a cost limit on payments to government-owned providers (CMS 2007).

The funding questions also do not include much information on the parameters of health care–related taxes. States that implement health care–related taxes that are not broad based or uniformly applied must submit provider-level data on taxes and payments to ensure that they meet the statutory criteria for waivers of these rules. However, not all states would submit these data because provider taxes that are broad based and uniform would not need a waiver. Furthermore, this waiver information does not need to be updated once it is initially approved unless the parameters of the tax have changed. For example, at least 27 arrangements that are included on KFF’s 2020 survey of health care–related taxes were not included on CMS’s internal list of states that applied for tax waivers, according to MACPAC’s review of CMS’s internal documentation (CMS 2020, Gifford et al. 2020).

Incomplete reporting of state-level financing amounts

Stakeholders we interviewed confirmed that the data on health care–related taxes that states currently report on Form CMS-64.11 are unreliable and incomplete. For example, in SFY 2018, MACPAC found that states reported only \$29 billion in health care–related taxes on Form CMS-64.11 in MBES, but they reported \$37 billion in health care–related taxes on GAO’s survey. In addition, MBES does not include any information about local government funds used to finance the non-federal share; in SFY 2018, states reported that \$26 billion in local government funds were used to finance Medicaid expenditures (GAO 2020).

The experts we interviewed noted that states have not prioritized submission of Form CMS-64.11 data, which may explain some of the discrepancies we observed. Currently, Form CMS-64.11 is used only for informational purposes. If states don’t submit complete and accurate data, CMS’s only enforcement mechanism is to withhold federal funding, which is a substantial penalty that is rarely used. In addition, experts noted that differences in definitions and reporting periods may also explain some discrepancies.

The stakeholders we interviewed noted that most state budget officers are already tracking Medicaid financing amounts, but states may do so in different ways that make it difficult to standardize reporting. Some states track financing and supplemental payments through stand-alone spreadsheets, while other states use more sophisticated accounting systems that integrate with their overall Medicaid management information systems. Because state funding for Medicaid can include interagency transfers outside the Medicaid agency, experts noted that state budget officers with responsibility for overseeing multiple state agencies would likely have the most comprehensive understanding of overall Medicaid financing.

Challenges attributing financing sources to specific payments

State officials noted that it could be challenging to attribute specific financing sources to specific types of Medicaid payments, since some states commingle provider contributions with other sources of funding that support the overall Medicaid budget. The GAO survey of state financing methods attempted to separately identify the sources of non-federal share used for FFS base payments, managed care payments, DSH payments, and non-DSH supplemental payments. However, GAO reported challenges collecting financing data at more granular levels of detail (GAO 2020, 2014).

Experts highlighted a number of circumstances in which health care–related taxes and IGTs paid by providers are not returned in the form of increased payments. For example, states may use these funds to pay for other Medicaid services, or they may retain some of the funds as an administrative fee. For CPEs, states are not required to disburse the federal funding that is claimed to the local government entity that incurred the costs of the service.

States’ use of taxes and IGTs for other purposes does not change providers’ costs of contributing to the non-federal share of Medicaid payments, so this practice would not affect calculations of net provider payments overall. However, some of the experts whom we spoke with suggested that it would be better to characterize taxes and IGTs as provider costs rather than

contributions, a term that may imply that providers are paid back the amount that they contribute.

Challenges using provider-level financing data to determine net payments

Similar to the challenges states have attributing financing to specific Medicaid categories of service, providers reported challenges attributing financing sources to specific payments at their facilities. Some of the experts we interviewed noted that Medicare cost reports already collect some information about the taxes that hospitals, nursing facilities, and other Medicare-certified institutional providers pay.¹⁵ However, CMS does not currently require these providers to separately identify health care–related taxes that are used to finance Medicaid payments or to track how those costs are allocated across specific services. Experts noted that smaller providers would likely face substantial administrative burden tracking how financing related to specific payments.

For hospitals that are part of larger health systems, experts noted that it may be difficult to determine how provider-financed supplemental payments affect net payments for specific services. For example, many states have begun making large directed payments to physicians affiliated with academic medical centers that are financed by state university hospitals. Although this payment is nominally intended to pay for physician services, the hospital finances the payment and often uses it to support overall hospital finances.

Because funding within health systems is fungible, some experts we spoke with noted that it may be more appropriate to examine how financing affects payment rates at the facility level instead of trying to calculate net payments for individual Medicaid services, such as inpatient or outpatient hospital services. Although some experts noted that many facilities are now part of larger health systems, facility-level reporting is likely more useful and feasible to analyze. Many health care–related taxes are imposed based on facility-level characteristics (e.g., number of beds), and CMS currently requests facility-level information for states submitting health care–related tax waivers.

Using Financing Data to Assess Net Payments

Some of the experts we spoke with highlighted new financing transparency requirements in Texas that could be a model for other states to follow. Since 2019, the Texas state legislature has required the state Medicaid agency to collect provider-level information on mandatory payments and all uses for such payments made to local governmental entities that create local provider participation funds (LPPFs), which are accounts into which health care–related taxes imposed by local units of government are deposited and are then transferred to the state by an IGT to finance Medicaid payments. In 2021, the legislature required the state Medicaid agency to expand its review and reporting efforts to all sources of non-federal share and to make this information publicly available (TX HHSC 2023a).

In 2023, Texas released its first public report of Medicaid financing for FY 2022 that includes information on LPPFs, other sources of IGTs, and CPEs used to support Medicaid expenditures. Financing amounts are assigned to specific supplemental payment programs or other specific services, such as school-based care. The tax amounts collected by local government entities and deposited in each LPPF are reported at the hospital level (even for hospitals that are part of a larger health system), and the report also identifies administrative fees collected by local governments for administering the LPPF program. Other IGTs and CPEs are identified by the transferring governmental entity, such as a public hospital district, school district, local mental health authority, and units of local government that do not directly provide services (TX HHSC 2023b).

Illustrative examples of net payments

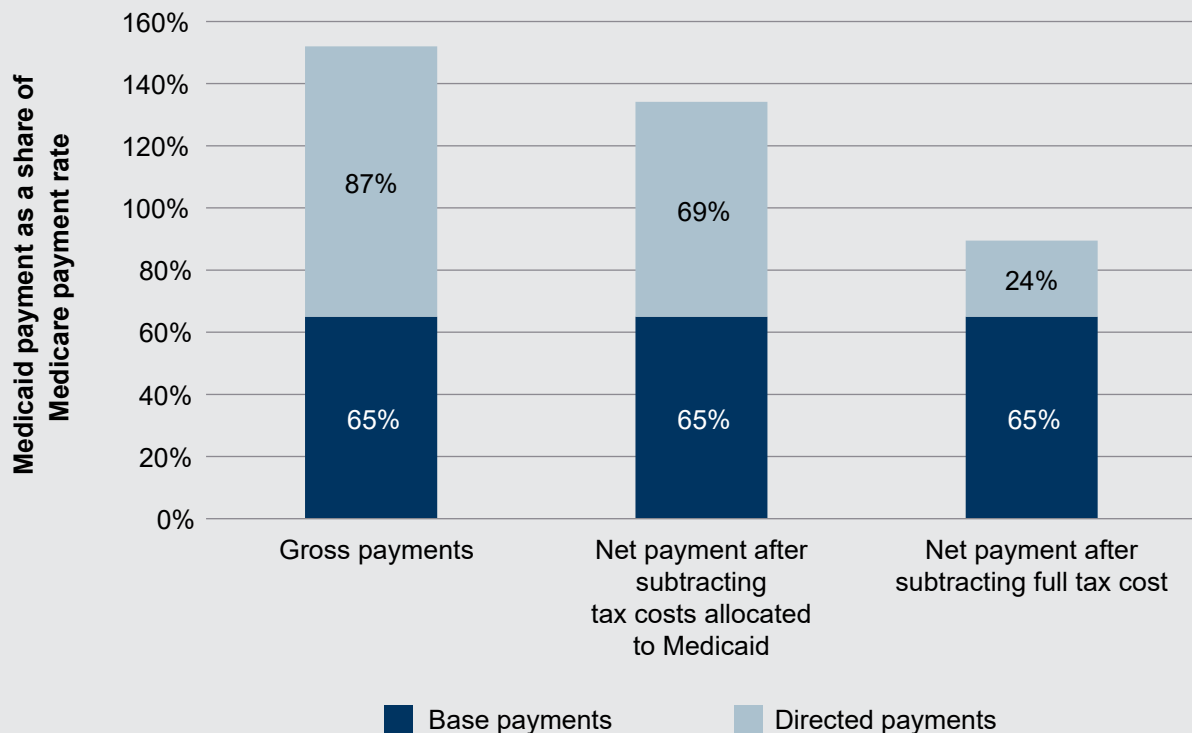
To illustrate how provider-level financing data could be used to enhance our understanding of Medicaid provider payments, we combined available payment and financing data for a public and private hospital in Texas.¹⁶ Texas makes multiple types of supplemental payments to hospitals, and for this example we focused on the state’s managed care directed payments because the state has already estimated how managed care directed payments compare to

Medicare payment rates on the directed payment preprints approved by CMS. One limitation of this data source is that it reports only projected spending, not actual spending.

The private hospital that we examined was projected to receive managed care base payments that were 65 percent of what Medicare would have paid and managed care directed payments that were 87 percent

of what Medicare would have paid, resulting in total gross payments of 152 percent of what Medicare would have paid (Figure 1-4). According to Texas’s provider-level financing report, this provider paid taxes that were equivalent to 63 percent of what Medicare would have paid, which were used to help finance the managed care directed payment.

FIGURE 1-4. Example of Gross and Net Medicaid Managed Care Payments for a Private Texas Hospital, 2022



Note: Analysis excludes fee-for-service payments and supplemental payments.

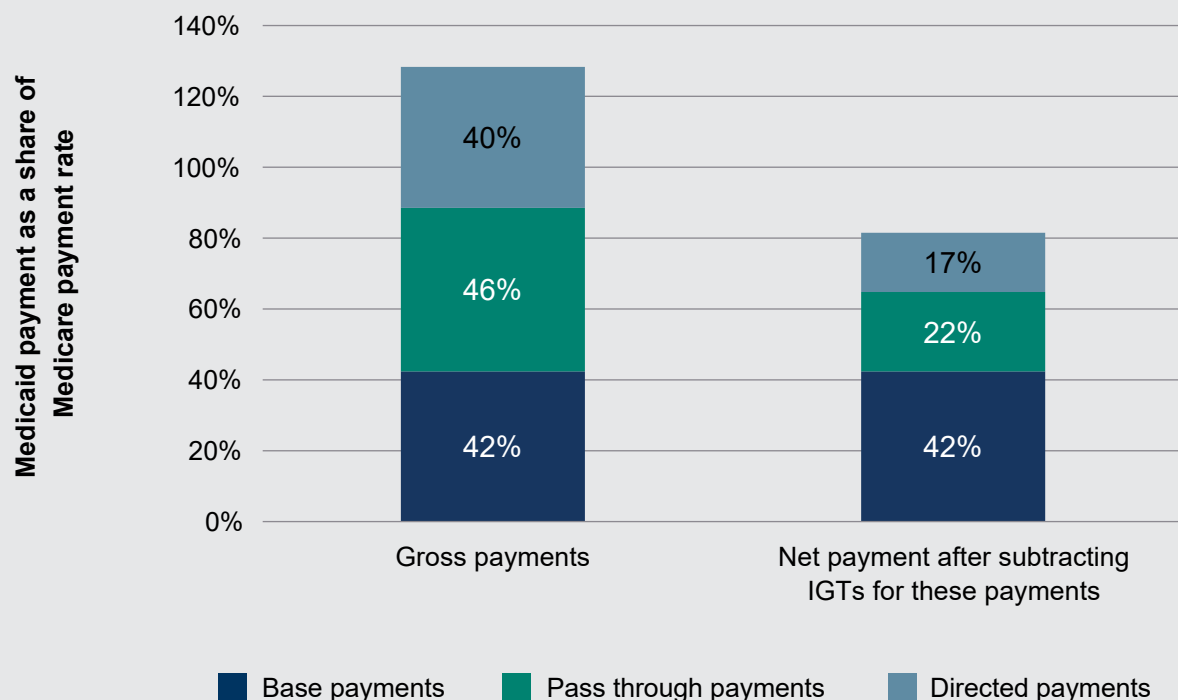
Sources: MACPAC, 2024, analysis of managed care directed payment preprint; TX HHSC 2023b.

There are two potential ways to calculate the effect of this provider tax on net Medicaid payments to this provider. One option is to subtract the Medicaid-attributed share of the tax cost based on Medicaid revenue as a share of total patient revenue that was taxed (29 percent in this example). This approach is similar to the approach of including the Medicaid-attributed share of tax costs in a cost-based methodology when calculating the UPL. Another approach is to subtract the full amount of the provider tax cost. Providers generally believe this approach is more reflective of their costs because the tax dollars attributable to Medicare and commercial revenue are still being used to support the Medicaid program. These different approaches result in different perspectives of Medicaid payment adequacy: total net payments are

134 percent of the Medicare rate if only the Medicaid-attributed share of the tax is subtracted and 89 percent of Medicare if the full amount of the tax is subtracted.

The public hospital we examined was projected to receive managed care base payments that were 42 percent of what Medicare would have paid and managed care pass through and directed payments equal to 86 percent of what Medicare would have paid, resulting in a total gross payment of 128 percent of what Medicare would have paid (Figure 1-5). However, after subtracting the costs of the IGTs to finance this directed payment, the net managed care payments to this hospital were 82 percent of what Medicare would have paid.

FIGURE 1-5. Example of Gross and Net Medicaid Managed Care Payments for a Public Texas Hospital, 2022



Notes: IGTs are intergovernmental transfers. Analysis excludes fee-for-service payments and supplemental payments. Pass through payments will be discontinued by fiscal year 2027 in accordance with federal regulations.

Sources: MACPAC, 2024, analysis of managed care directed payment preprint; TX HHSC 2023b.

Hospitals in Texas receive a variety of supplemental payments in addition to directed payments, and it is difficult to determine how these payments should be accounted for when assessing payment adequacy. Some payments are intended to pay for unpaid costs of care for uninsured individuals (as authorized under Texas's Healthcare Transformation and Quality Improvement Program Section 1115 demonstration waiver), and others are intended to pay for care for non-hospital services.

Payments to private providers that are financed through IGTs from public hospitals are particularly challenging to track from a financing perspective. For example, a subset of public hospitals in Texas provide IGTs for private providers in the state. Because private providers do not finance these payments, the IGT contributions do not reduce the net payments that private providers receive. In contrast, public providers do have an added cost for providing IGT contributions. It is not clear how best to account for the financing costs borne by a small subset of providers when assessing net payments across all providers.

In Texas, it is also important to note that a portion of the managed care directed payments to hospitals includes a portion that is for administration, risk margin, and premium tax associated with the administration of the directed payment program. Although this practice is different from administrative fees retained by government entities, it has a similar effect of reducing the ability of providers to retain the federal funding generated from their contributions to the non-federal share. In 2022, Texas estimated that about 6 percent of the \$4.7 billion in directed payments made to hospitals (\$274 million) were retained by MCOs as a fee.

State administrative costs

Texas's experience implementing transparency requirements on some elements of provider-level reporting of Medicaid financing can also help inform considerations of the administrative costs of this effort. The Texas state legislature initially required the state Medicaid agency to collect provider-level information from local units of government that created LPPFs in 2019 but did not provide additional administrative funding for this activity, and so the state was not able to complete this request as robustly as the state

deemed necessary and appropriate. In 2021, the legislature allowed the Medicaid agency to collect approximately \$4 million a year in administrative fees from non-public providers participating in supplemental and directed payment programs to support this reporting activity. The state used this funding to hire about 18 employees and to contract with an external vendor to assist in creating a new reporting database. This new approach was more successful, and in the FY 2022 reporting period that recently finished, 99 percent of the 1,242 local government entities required to report successfully submitted the required information during the month-long reporting period (TX HHSC 2024).

Medicaid administrative activities are typically matched at a 50 percent FMAP. States are eligible for a 90 percent FMAP for the design and development of Medicaid enterprise systems (MES) and 75 percent FMAP for their continued operation, which could reduce the cost to the state of any new reporting requirements. Although the new database used as part of Texas's new local funding reporting system could have potentially been classified as MES and eligible for higher federal match, the state reported that it used its regular 50 percent administrative match for this activity. To receive the enhanced FMAP for MES, states need prior approval from CMS of advanced planning documents describing their project and ongoing review of the system's operation. In addition, it is important to note that the state staff Texas hired to oversee the reporting would likely not be eligible for enhanced MES funding. Texas did not consider pursuing the enhanced FMAP for the system development costs because the primary cost of developing the system was staff resources.

Commission Recommendations

The Commission makes two complementary recommendations to Congress to improve the transparency of Medicaid and CHIP financing and enable analyses of net provider payments. These recommendations build on prior Commission recommendations to enable analyses of all types of Medicaid financing for all types of providers, not just

hospitals and nursing facilities. Stakeholders have stressed the importance of analyzing both gross and net payment amounts when developing payment policy and assessing how these payments are linked to goals of access and quality.

Recommendation 1.1

In order to improve transparency and enable analyses of net Medicaid payments, Congress should amend Section 1903(d)(6) of the Social Security Act to require states to submit an annual, comprehensive report on their Medicaid financing methods and the amounts of the non-federal share of Medicaid spending derived from specific providers. The report should include:

- a description of the methods used to finance the non-federal share of Medicaid payments, including the parameters of any health care-related taxes;
- a state-level summary of the amounts of Medicaid spending derived from each source of non-federal share, including state general funds, health care-related taxes, intergovernmental transfers, and certified public expenditures; and,
- a provider-level database of the costs of financing the non-federal share of Medicaid spending, including administrative fees and other costs that are not used to finance payments to the provider contributing the non-federal share.

This report should be made publicly available in a format that enables analysis.

Rationale

The Commission has long held that analyses of Medicaid payment policy require complete data on all Medicaid payments that providers receive as well as data on the costs of financing the non-federal share necessary to calculate net Medicaid payments at the provider level. In 2016, the Commission recommended that CMS improve the transparency of payment and financing data for hospitals, and in 2023, the Commission made a similar recommendation for nursing facility payments.

In 2020, Congress partially implemented MACPAC's recommendations by requiring reporting of provider-

level supplemental payment data, but Congress has not taken any action to date on other components of these recommendations related to the transparency of managed care payment data or transparency of the costs of provider contributions to the non-federal share.¹⁷ As a result, our ability to analyze the new data that states are reporting is severely limited.

The current data that CMS collects on the financing of the non-federal share of Medicaid payments are fragmented and incomplete. CMS collects information only on the methods that states use to finance Medicaid payments when a state makes changes to its state plan, and this information is not publicly available. In addition, because a state may make multiple changes to their state plan each year, it is difficult to use the financing data that CMS collects to get a comprehensive view of a state's overall Medicaid financing methods. For managed care directed payments, states are required to describe the financing sources on the preprint, but states do not report information on the specific entities paying the tax or the amount of taxes collected.

In 1991, Congress added Section 1903(d)(6) to the Act to improve the transparency of data on health care-related taxes and donations as part of the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments. However, states have not prioritized reporting of these data, and so these data are often incomplete. For example, in SFY 2018, states reported only \$29 billion in health care-related taxes on Form CMS-64.11 in MBES, but they reported \$37 billion in health care-related taxes on GAO's survey. In addition, MBES does not include any information about local government funds used to finance the non-federal share; in SFY 2018, states reported \$26 billion in local government funds used to finance Medicaid expenditures (GAO 2020).

Through interviews with state officials, provider associations, federal officials, and other experts, we learned that many stakeholders would be willing to share additional information on Medicaid financing methods publicly if the purpose and additional value of the reporting were clear. In particular, many stakeholders agreed that it would be helpful to assess how the costs of financing the non-federal share of Medicaid payments affect the net payments that providers receive. However, stakeholders cautioned

that improved transparency should not be used to limit financing methods that are currently permissible.

Stakeholders also noted the importance of limiting the administrative burden for states, which already face a number of other federal reporting requirements. To do so, stakeholders suggested that new reporting align with how states currently collect data on Medicaid financing. Specifically, stakeholders suggested that financing data be reported in the aggregate at the state and provider level rather than tying each source of Medicaid financing to a specific category of service.

In the process of our review, we also learned that the Texas state legislature recently required the state Medicaid agency to report provider-level financing data in a standard way that could be a model for other states. Since 2019, the Texas state legislature has required the state Medicaid agency to collect provider-level information on LPPFs, which are accounts into which health care–related taxes imposed by local units of government are deposited and then transferred to the state by an IGT to finance Medicaid payments. In 2021, the legislature required the state Medicaid agency to expand its review and reporting efforts to all sources of non-federal share and to make this information publicly available (TX HHSC 2023a). Because these data included standard identifiers, we were able to link the new financing data with other available data on Medicaid payments to create the illustrative examples of net payment to providers included in this chapter.

During our interviews, we also heard about the importance of tracking administrative fees and other costs that are not used to finance payments to the providers financing the non-federal share. Texas’s provider-level payment data include information on administrative fees collected by local governments (0.7 percent of taxes collected) but do not include information about administrative fees retained by the state. In the process of our review, we also learned that managed care capitation payments include 6 percent for administration, risk margin, and premium tax associated with the administration of the directed payment program, which is another type of administrative fee that could benefit from increased transparency.

It is important that CMS make any new financing data publicly available to enable analyses by all stakeholders, not just CMS and other federal entities. Congress also recognized the importance of transparency when it added the new supplemental payment reporting requirements in 2020. The Commission notes that CMS has not made these data publicly available despite the statutory requirement to do so on a timely basis (§1903(bb)(1)(C) of the Act).

Design considerations

When implementing the new comprehensive transparency requirements that the Commission recommends, CMS should collect information that is most relevant for analyses of net payments to providers and future policy development in this area. Doing so may require updates to the standard funding questions that CMS asks when it reviews state plan amendments and directed payment preprints.

In the Commission’s view, CMS should consider collecting the following information about financing methods:

- a summary of all types of health care–related taxes, IGTs, and CPEs used to finance Medicaid payments (currently included in question 2 of the standard funding questions);
- information about whether the financing source is used to finance a specific type of Medicaid payment, such as supplemental payments (currently included in question 3 of the standard funding questions);
- parameters of the health care–related tax, such as the entity that is being taxed, the tax rate, and whether the tax qualifies for a waiver of the statutory requirements for uniform and broad-based health care–related taxes;
- information on any administrative fees charged for IGT or CPE financing (not currently collected by CMS); and
- any other descriptive information that could help inform analyses of state- and provider-level financing information, such as details on the differences between the date of collection of the non-federal share and the time period for which

payments were made using that source of non-federal share (not currently collected by CMS).

CMS should also establish additional process controls to review the accuracy of the data submitted to ensure completeness. For example, CMS could incorporate this information into existing reporting structures, such as Form CMS-64.11, to reduce the administrative burden and consolidate reporting when possible. In doing so, CMS could implement procedures to ensure consistency across data sources. In addition, CMS could implement automated checks that ensure the sum of all sources of non-federal share at the state level match the state share reported on the other CMS-64 forms reported for the same time period. Another possibility would be to assign CMS staff to review state budget documents to validate the information that states are submitting.

Finally, to ensure that provider-level data are most useful for future analyses, CMS should adopt some of the most useful features of Texas's new provider level financing report, including the following:

- the ability to link provider-level financing data with Medicare cost reports and other claims data through provider-level identifiers;
- information to track the timing of the transfer relative to the date of payment; and
- an option to report financing for specific supplemental payment programs when available.

Implications

Federal spending. This recommendation would result in increased administrative effort for the federal government, but CBO does not estimate any change in federal direct spending. Federal administrative burden could be reduced if efforts to collect new financing data are coordinated with existing systems and reporting requirements.

States. Although many states already collect data on their Medicaid financing methods, reporting this information to CMS in a standard format will increase state administrative effort and could result in additional administrative spending. States may be able to claim enhanced FMAP for certain administrative expenses related to MES development and operations.

Additionally, states have the option to offset the costs of any increased administrative burden by retaining additional administrative fees from health care–related taxes, IGTs, or CPEs.

Enrollees. This policy would not have a direct effect on enrollees.

Plans. Health plans would not be directly affected by this policy unless a state imposes a health care–related tax on the health plan or the health plan retains administrative fees for provider-financed payments. If so, health plans may have some administrative burden to report financing information that states do not already collect. To calculate net payments under managed care, plans will have some administrative burden to report directed payments at the provider level; however, this information will be required under the 2024 managed care final rule.

Providers. This policy would not directly affect Medicaid payments to providers or change permissible sources of non-federal share for Medicaid expenditures. However, the data collected could be used to inform analyses of Medicaid provider payments, which could affect payment rates in the future. This recommendation may also increase administrative burden for some providers if they need to report information that states are not already collecting. Provider payments could be reduced if the state retains an administration fee.

Recommendation 1.2

In order to provide complete and consistent information on the financing of Medicaid and the State Children's Health Insurance Program (CHIP), Congress should amend Section 2107(e) of the Social Security Act (the Act) to apply the Medicaid financing transparency requirements of Section 1903(d)(6) of the Act to CHIP.

Rationale

States are permitted to finance the non-federal share of CHIP spending using the same methods that are permissible in Medicaid. However, there is little information available about how states finance CHIP and how sources of non-federal share affect net payments to providers.

States have the option to administer CHIP as expansions of Medicaid, as a separate CHIP, or as a combination of both programs. As of July 2023, 39 states operate a separate CHIP or combination program.

Medicaid expansion CHIP is subject to Medicaid financing rules, but separate CHIP is subject only to Medicaid rules described in Section 2107(e) of the Act and any additional requirements added by regulation. Federal regulations in 42 CFR 457.628 apply many of the federal financing policies to CHIP, but the statute does not explicitly require CHIP to comply with the financing transparency requirements of Section 1903(d)(6) of the Act (which were added before CHIP was created).

Applying consistent requirements for both Medicaid and CHIP will promote overall program transparency without adding substantial additional administrative burden.

Implications

Federal spending. This recommendation would result in increased administrative effort for the federal government, but CBO does not estimate any change in federal direct spending. Federal administrative burden could be reduced if efforts to collect new financing data are coordinated with existing systems and reporting requirements.

States. Although many states already collect data on their CHIP financing methods, reporting this information to CMS in a standard format will increase state administrative effort and could result in additional administrative spending. States have the option to offset the costs of any increased administrative burden by retaining additional administrative fees for health care–related taxes, IGTs, or CPEs.

Enrollees. This policy would not have a direct effect on enrollees.

Plans. Health plans would not be directly affected by this policy unless a state imposes a health care–related tax on the health plan or the health plan retains administrative fees for provider-financed payments. If so, health plans may have some administrative burden to report financing information that states do not already collect.

Providers. This policy would not directly affect CHIP payments to providers or change permissible sources of non-federal share for CHIP expenditures. However, the data collected could be used to inform analyses of CHIP provider payments, which could affect payment rates in the future. This recommendation may also increase administrative burden for some providers if they need to report information that states are not already collecting. Provider payments could be reduced if the state retains an administration fee.

Next Steps

The Commission will continue to examine Medicaid payment policies guided by MACPAC’s provider payment framework, which is based on the statutory Medicaid payment goals of efficiency, economy, quality, and access (MACPAC 2015). For example, the Commission is currently engaging in a long-term work plan to further examine all types of payments to hospitals using newly available data on non-DSH supplemental payments and directed payments. However, lack of data on the costs of provider financing of the non-federal share of Medicaid payments will substantially limit our ability to understand the net payments that providers receive.

The Commission will also continue to monitor larger trends in federal Medicaid spending, including the share of Medicaid spending financed by states, providers, and the federal government. The Commission has previously examined alternative approaches to federal Medicaid financing that are intended to alter the trajectory of federal spending (MACPAC 2016c). However, we cannot examine the full effects of these policies until more state- and provider-level financing data are available.

Endnotes

¹ A complete list of statutory exceptions to the FMAP is available on MACPAC's website (MACPAC 2024).

² The year 2015 was selected for CHIP because of temporary increases in the CHIP enhanced FMAP (E-FMAP) from FYs 2016–2020. Under the Patient Protection and Affordable Care Act (P.L. 111-148, as amended), beginning on October 1, 2015, and ending on September 30, 2019, the E-FMAP was increased by 23 percentage points, not to exceed 100 percent, for all states. Under the HEALTHY KIDS Act (P.L. 115-120), beginning on October 1, 2019, and ending on September 30, 2020, the E-FMAP was increased by 11.5 percentage points, not to exceed 100 percent, for all states.

³ Federally owned providers, such as the Indian Health Service or Veterans Affairs hospitals, cannot contribute IGTs to state Medicaid or CHIP expenditures. Intragovernmental transfers (i.e., between states) are also not permissible.

⁴ For example, in 2020, CMS provided MACPAC with its internal tracking list of states that applied for health care–related tax waivers. Of the 43 states that reported hospital provider taxes in the KFF survey, 38 states were included in CMS's list of hospital tax waivers (CMS 2020, Gifford et al. 2020).

⁵ The statutory requirement to report health care–related tax amounts was added by the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments of 1991 (P.L. 102-234).

⁶ Thirty of Tennessee's 150 hospitals donated in the first year of Tennessee's provider donation program. Regional Medical Center in Memphis, the largest public hospital in the state, was the largest donor. Provider donations were matched by the federal government at the state's 70 percent FMAP.

⁷ Section 5 of the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments prohibited CMS (then the Health Care Financing Administration) from issuing any interim final rules that changed the treatment of public funds as the source of non-federal share and also required the agency to consult with states before issuing any rules under the law.

⁸ Congress issued moratoria on CMS implementing provisions in the final rule through the Supplemental Appropriations Act of 2008 (P.L. 110-252) and the American Recovery and Reinvestment Act of 2009 (P.L. 111-5) until July 1, 2009. CMS subsequently issued regulations further

delaying enforcement of the changes made in the 2008 rule until June 30, 2010 (CMS 2009).

⁹ Section 1903(a)(1) of the Act requires that federal Medicaid funding be based on spending for medical assistance approved in the Medicaid state plan. CMS cites this authority as justification for asking about the retention of payments in its standard funding questions (CMS 2024b). Section 1902(a)(32) of the Act also requires payments to be made to the providers of services and has been cited in CMS's proposed rule to require providers to retain the Medicaid payments that they receive (CMS 2019). Section 1903(i)(17) of the Act prohibits federal match for any amount expended for roads, bridges, stadiums, or any other item or service not covered under the Medicaid state plan.

¹⁰ Initially CMS defined two classes of providers: state owned and non-state owned. In 2001, CMS created a third class of providers for non-state government owned providers. At first, the UPL for non-state government owned providers was 150 percent of Medicare to reflect these providers' costs of financing payments through IGTs. However, in 2002, this limit was reduced to 100 percent of Medicare, the same limit as other provider classes.

¹¹ Specifically, CMS added questions about UPL to its standard funding questions in 2002, and in 2013, CMS issued a state Medicaid director letter requiring states to demonstrate compliance with UPL requirements annually (CMS 2013).

¹² The projected spending reported as of February 2023 is more complete than information on projected spending previously available due to CMS's new preprint template. However, we still found that projected spending amounts were not always reported in a consistent format. Another limitation of this analysis is that actual spending amounts may be higher or lower than the amount projected in approval documents.

¹³ States are permitted to include Medicaid's share of the costs of health care–related taxes according to Medicare payment principles when calculating DSH limits and the UPL. Certain California public hospitals have a statutory exemption to receive gross DSH payments up to 175 percent of their costs. Because these hospitals fully finance the non-federal share of these DSH payments, the net payments that these hospitals receive are less than costs, even after applying this statutory exemption.

¹⁴ MFAR proposed new reporting requirements related to DSH and UPL payments, which would have created new

definitions of public funds, new requirements for the use of IGTs and CPEs, and new limitations for provider tax waivers and hold harmless arrangements, including prohibiting private mitigation arrangements.

¹⁵ On the Medicare cost report worksheet S-10, hospitals are instructed to report the amount of Medicaid revenue for inpatient and outpatient services net of associated provider taxes or assessments (CMS 2022).

¹⁶ Data from Texas are being used as an illustrative example, and the state's use of different supplemental and directed payments and financing of non-federal share may not be applicable to other states. For example, Texas makes supplemental payments through an uncompensated care pool and delivery system reform incentive payments program authorized under Section 1115 waiver expenditure authority; these arrangements are used in only a small number of states. Additionally, the LPPF structure of financing the non-federal share may not be applicable to other states.

¹⁷ In 2022, MACPAC recommended additional transparency related to managed care directed payments that have also not yet been fully implemented (MACPAC 2022).

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Commission Vote on Recommendations

In its authorizing language in the Social Security Act (42 USC 1396), Congress requires MACPAC to review Medicaid and CHIP program policies and make recommendations related to those policies to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states in its reports to Congress, which are due by March 15 and June 15 of each year. Each Commissioner must vote on each recommendation, and the votes for each recommendation must be published in the reports. The recommendations included in this report, and the corresponding voting record below, fulfill this mandate.

Per the Commission’s policies regarding conflicts of interest, the Commission’s conflict of interest committee convened prior to the vote to review and discuss whether any conflicts existed relevant to the recommendations. It determined that, under the particularly, directly, predictably, and significantly standard that governs its deliberations, no Commissioner has an interest that presents a potential or actual conflict of interest.

The Commission voted on these recommendations on April 12, 2024.

Improving the Transparency of Medicaid and CHIP Financing

1.1 In order to improve transparency and enable analyses of net Medicaid payments, Congress should amend Section 1903(d)(6) of the Social Security Act to require states to submit an annual, comprehensive report on their Medicaid financing methods and the amounts of the non-federal share of Medicaid spending derived from specific providers. The report should include:

- a description of the methods used to finance the non-federal share of Medicaid payments, including the parameters of any health care-related taxes;
- a state-level summary of the amounts of Medicaid spending derived from each source of non-federal share, including state general funds, health care-related taxes, intergovernmental transfers, and certified public expenditures; and,
- a provider-level database of the costs of financing the non-federal share of Medicaid spending, including administrative fees and other costs that are not used to finance payments to the provider contributing the non-federal share.

This report should be made publicly available in a format that enables analysis.

1.2 In order to provide complete and consistent information on the financing of Medicaid and the State Children’s Health Insurance Program (CHIP), Congress should amend Section 2107(e) of the Social Security Act (the Act) to apply the Medicaid financing transparency requirements of Section 1903(d)(6) of the Act to CHIP.

1.1-1.2 voting results	#	Commissioner
Yes	16	Allen, Bella, Bjork, Brooks, Duncan, Gerstorff, Giardino, Heaphy, Hill, Ingram, Johnson, Killingsworth, McCarthy, McFadden, Snyder, Weno
Not present	1	Medows

Chapter 2:

Optimizing State Medicaid Agency Contracts

Optimizing State Medicaid Agency Contracts

Recommendations

- 2.1 State Medicaid agencies should use their contracting authority at 42 CFR 422.107 to require that Medicare Advantage dual eligible special needs plans (D-SNPs) operating in their state regularly submit data on care coordination and Medicare Advantage encounters to the state for purposes of monitoring, oversight, and assurance that plans are coordinating care according to state requirements. If states were required by Congress (as previously recommended by the Commission) to develop a strategy to integrate Medicaid and Medicare coverage for their dually eligible beneficiaries, states that include D-SNPs in their integration approach should describe how they will incorporate care coordination and utilization data and how these elements can advance state goals.
- 2.2 The Centers for Medicare & Medicaid Services should update guidance that supports states in their development of a strategy to integrate care that is tailored to each state's health coverage landscape. The guidance should also emphasize how states that contract with Medicare Advantage dual eligible special needs plans can use their state Medicaid agency contracts to advance state policy goals.

Key Points

- People who are dually eligible for Medicaid and Medicare may experience fragmented care and poor health outcomes when their benefits are not coordinated. Integrated care is an approach meant to align the delivery, payment, and administration of Medicaid and Medicare services for individuals eligible for both programs.
- Medicare Advantage (MA) dual eligible special needs plans (D-SNPs) are the primary source of integrated coverage for dually eligible beneficiaries. D-SNPs are available in 45 states and the District of Columbia, enrolling more than 40 percent of the 12.8 million people who are dually eligible. The level of integration offered in these plans can vary greatly.
- Federal law sets minimum requirements that define how D-SNPs coordinate and cover Medicaid benefits, yet states may impose additional requirements to further integration through the state Medicaid agency contract (SMAC). D-SNPs are required to sign a SMAC to operate within a state, which means that state Medicaid agencies can greatly affect the care a D-SNP delivers.
- Although more states are leveraging their contracting authority, state adoption of SMAC provisions is uneven.
- States may require D-SNPs to submit a variety of data reports, including Medicare data. These reports are typically reviewed for timeliness, completeness, and accuracy rather than used to measure health plan performance or shape policymaking. State officials shared that limited staff capacity and a lack of Medicare expertise hinder their ability to monitor and oversee D-SNP performance. These challenges constrain how the state imposes additional requirements through their SMACs.
- Care coordination is central to the D-SNP model. State and federal officials described data on care coordination as key for evaluating D-SNP performance as well as the value of MA encounter utilization data for informing care coordination efforts. Currently, states struggle with these data, particularly ingesting and analyzing MA encounter data. However, in the Commission's view, these data are necessary for states to improve integrated care. States should prioritize these data in directing resources to their monitoring and oversight efforts and consider them if states were required to develop an integration strategy.
- The Commission also recommends that the Centers for Medicare & Medicaid Services update guidance to inform states about available integrated care models and how states can use SMACs to advance state goals.

CHAPTER 2: Optimizing State Medicaid Agency Contracts

Dually eligible beneficiaries are people eligible for both Medicaid and Medicare. They may experience fragmented care and poor health outcomes when their benefits are not coordinated (CMS 2023a). The most widely available vehicles for integrating Medicaid and Medicare benefits are Medicare Advantage (MA) dual eligible special needs plans (D-SNPs), which operated in 45 states and the District of Columbia in 2023 (CMS 2023b). To operate, D-SNPs must sign a state Medicaid agency contract (SMAC) that details the federal minimum requirements describing how the D-SNP must coordinate Medicaid services for beneficiaries, as well as additional requirements the state chooses to include. This authority affords state Medicaid programs great influence on the care a D-SNP delivers in their state.

Although efforts to enroll dually eligible beneficiaries in integrated care models have spread, the share of individuals enrolled in integrated care remains about 21 percent of the country's full-benefit dually eligible population, or 1.75 million full-benefit dually eligible beneficiaries in 2022 (CMS 2023a).¹ For those who are enrolled in integrated care, most are enrolled in a D-SNP. In 2021, of full-benefit dually eligible beneficiaries receiving their Medicare benefits exclusively from managed care, 60 percent were enrolled in a D-SNP (MACPAC and MedPAC 2024). Notably, not all individuals enrolled in a D-SNP receive fully integrated care, as the majority of these plans meet only minimum federal requirements on coordinating a beneficiary's Medicaid benefits.

In the Commission's previous reports to Congress, we highlighted the benefits of integrated care, several barriers that states face in developing these models, and the strategies available to states to integrate care through their contracts with D-SNPs. Through interviews with states and federal officials, we found that many contracting strategies were not widely used across states (MACPAC 2021). Building on that work,

we set out to better understand the degree to which states use their contracting authority to promote care coordination and integrate care for their dually eligible beneficiaries, as well as to understand how states consider, oversee, and enforce their contracts.

Over the past year, we have reviewed SMACs and interviewed stakeholders about the tools and requirements that state Medicaid agencies have for overseeing their contracts with D-SNPs. Interviewees in selected states shared how they choose whether to contract with a D-SNP, the types of requirements they include in their contracts, and how they oversee and enforce those requirements. Although the states we studied, which all require moderate to high levels of integration for D-SNPs, include a broad array of requirements in their contracts, interviewees identified two key elements for overseeing plan performance and developing a fuller understanding of the health of D-SNP enrollees: data on care coordination and MA encounters.

Through these interviews, states also raised a lack of state capacity as the primary barrier for setting and overseeing additional requirements in their contracts with D-SNPs as well as the importance of securing buy-in from state leadership before implementing new requirements. These barriers mirror the overarching challenges that states face in integrating care for their dually eligible populations, which the Commission has raised repeatedly since 2020. In its June 2020 report to Congress, the Commission recommended that Congress provide additional funds to enhance state capacity to develop Medicare expertise and to implement integrated care models. In its June 2022 report to Congress, recognizing that states are at different stages of integrating care for their dually eligible populations, the Commission recommended that Congress require all states to develop a strategy to integrate Medicaid and Medicare coverage with additional federal funding to support that effort.

With these recommendations, we seek to provide states with a starting point for optimizing and overseeing their D-SNP contracts and to understand how integrated care may best fit their circumstances. We recommend that states use their contracting authority to require that D-SNPs submit data on care coordination and MA encounters given the

identified usefulness of these two types of data and their applicability to D-SNPs of all integration levels. Additionally, we recommend that the Centers for Medicare & Medicaid Services (CMS) provide guidance to support states in developing a strategy to integrate care that fits each state's health coverage landscape, including how states can leverage their SMACs to advance state policy goals.

In this chapter, the Commission recommends the following:

- 2.1 State Medicaid agencies should use their contracting authority at 42 CFR 422.107 to require that Medicare Advantage dual eligible special needs plans (D-SNPs) operating in their state regularly submit data on care coordination and Medicare Advantage encounters to the state for purposes of monitoring, oversight, and assurance that plans are coordinating care according to state requirements. If states were required by Congress (as previously recommended by the Commission) to develop a strategy to integrate Medicaid and Medicare coverage for their dually eligible beneficiaries, states that include D-SNPs in their integration approach should describe how they will incorporate care coordination and utilization data and how these elements can advance state goals.
- 2.2 The Centers for Medicare & Medicaid Services should update guidance that supports states in their development of a strategy to integrate care that is tailored to each state's health coverage landscape. The guidance should also emphasize how states that contract with Medicare Advantage dual eligible special needs plans can use their state Medicaid agency contracts to advance state policy goals.

Background

In 2021, 12.8 million individuals were dually eligible for Medicaid and Medicare (MACPAC and MedPAC 2024). Most were full-benefit dually eligible beneficiaries (73 percent), who qualify for full Medicaid benefits, in addition to Medicare benefits. Partial-benefit dually eligible beneficiaries—whose only

form of Medicaid coverage is assistance with paying Medicare premiums (and in many cases cost sharing through the Medicare Savings Programs)—made up the other 27 percent (MACPAC and MedPAC 2024). Medicaid and Medicare offer dually eligible beneficiaries different benefits. Medicare serves as the primary payer for services that overlap with those offered by Medicaid, providing coverage for services such as inpatient hospital care and physician services, while Medicaid covers long-term services and supports (LTSS) and other services that Medicare does not such as certain behavioral health services.

Even as the dually eligible population has grown, the number of beneficiaries enrolled in integrated care products remains relatively small. In 2022, about 21 percent of full-benefit dually eligible beneficiaries, or 1.75 million individuals, were enrolled in integrated products under managed care arrangements (CMS 2023a). Although partial-benefit dually eligible beneficiaries may also be enrolled in some integrated care products, efforts tend to focus on full-benefit dually eligible beneficiaries because they have full Medicaid coverage to coordinate with Medicare coverage (MACPAC 2022).

Although use of managed care by dually eligible beneficiaries is growing, most still receive coverage of their Medicaid services through fee for service (FFS). About half of states do not enroll their dually eligible population in Medicaid managed care, and a number of states that enroll dually eligible beneficiaries in Medicaid managed care do so at the beneficiary's election. In 2021, 40 percent of dually eligible beneficiaries were enrolled exclusively in Medicaid FFS, and 17 percent were enrolled in Medicaid FFS with a limited-benefit Medicaid managed care plan (MACPAC and MedPAC 2024). In 2021, only 30 percent of full-benefit dually eligible individuals had at least one month of simultaneous enrollment in Medicare managed care (i.e., MA) and comprehensive Medicaid managed care (Table 2-1).² Enrollment in a managed care product for a dually eligible individual's Medicaid or Medicare benefits does not necessarily equate to integrated care because the enrollee's benefits may still not be coordinated between health plans and across Medicaid and Medicare.

TABLE 2-1. Overlap between Medicare and Medicaid Managed Care Enrollment for Dually Eligible Beneficiaries, 2021

Enrollment status	Dually eligible beneficiaries				
	Total	Under age 65	Age 65 and older	Full benefit	Partial benefit
At least one month of simultaneous enrollment in Medicare managed care and comprehensive Medicaid managed care	25%	22%	26%	30%	10%
Some enrollment in Medicare managed care and/or comprehensive Medicaid managed care, but never in the same month	48	44	49	44	58
No months of enrollment in either Medicare managed care or comprehensive Medicaid managed care	28	33	25	27	31

Notes: Exhibit includes all dually eligible beneficiaries (fee for service, managed care, and end-stage renal disease). Medicare managed care includes Medicare-Medicaid Plans (MMPs) under the Financial Alignment Initiative, Programs of All-Inclusive Care for the Elderly (PACE), and Medicare Advantage plans. Percentages may not sum to 100 due to rounding.

Source: Medicare Payment Advisory Commission (MedPAC) and MACPAC, 2024, Exhibit 13: Overlap between Medicare and Medicaid managed care enrollment for dual-eligible beneficiaries, CY 2021, In *Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid*.

D-SNPs are the primary source of integrated coverage for dually eligible beneficiaries. Some states have other integrated products such as Medicare-Medicaid plans (MMPs) under the Financial Alignment Initiative (FAI) or Programs of All-Inclusive Care for the Elderly (PACE). The MMPs cover nearly all Medicaid and Medicare benefits under a single health plan. PACE also covers both sets of benefits and provides adult day services for people who are age 55 and older and qualify for a nursing facility level of care but can live safely in the community. Although these programs both offer fully integrated coverage, they enroll fewer people than D-SNPs. In 2023, about 300,000 dually eligible beneficiaries were enrolled in MMPs, and 71,000 were enrolled in PACE (ICRC 2023, NPA 2023).³

D-SNPs

D-SNPs are one of three types of MA special needs plans (SNPs) that are designed to provide coverage tailored to a specific population.⁴ People enrolled in D-SNPs are dually eligible for both Medicaid and Medicare. In 2023, D-SNPs were available in 45 states and the District of Columbia.⁵

In 2019, CMS finalized regulations for D-SNPs that updated classifications of plans depending on their level of integration (CMS 2019a). Today, three types of D-SNPs contract with states and offer varying levels of integration: coordination-only dual eligible special needs plans (CO D-SNPs), highly integrated dual eligible special needs plans (HIDE SNPs), and

fully integrated dual eligible special needs plans (FIDE SNPs). CO D-SNPs are the most common type of D-SNP. They coordinate Medicaid services but typically do not cover Medicaid benefits. Each of these D-SNP types may also be designated as an applicable integrated plan (AIP) if they operate with exclusively aligned enrollment (EAE). If a state requires EAE, D-SNPs may enroll only full-benefit dually eligible beneficiaries who are enrolled in a Medicaid managed care plan under the same parent organization as the D-SNP or who receive their Medicaid benefits directly from the D-SNP itself. AIPs must create a unified appeals and grievance process for their enrollees.

Beginning in 2021, D-SNPs are designated as HIDE SNPs if they have a contract with the state Medicaid agency to cover either LTSS or behavioral health services or both.⁶ HIDE SNPs provide moderate levels of integration for beneficiaries. As of December 2023, HIDE SNPs are available in 15 states and the District of Columbia, enrolling more than 1.8 million beneficiaries, or about 35 percent of all dually eligible beneficiaries enrolled in D-SNP products (CMS 2023b).

D-SNPs are designated as FIDE SNPs if they cover both LTSS and behavioral health services, in addition to other Medicaid benefits under their SMACs, unless the state carves behavioral health services out of the capitation rate.⁷ FIDE SNPs provide the highest level of integration in a D-SNP. Enrolling about 421,000 beneficiaries in 12 states or about 8 percent of dually eligible beneficiaries in D-SNP products, these plans must cover nearly all Medicaid and Medicare benefits (CMS 2023b, MACPAC 2020a).⁸

In 2021, 46 percent of individuals dually eligible for Medicaid and Medicare services were enrolled in managed care for their Medicare benefits for the entire year, and of that group, most received coverage through D-SNPs (MACPAC and MedPAC 2024). Among dually eligible individuals who were enrolled only in Medicare managed care, about half were enrolled in D-SNPs (54 percent) (Table 2-2). Full-benefit dually eligible beneficiaries were more likely to enroll in D-SNPs (60 percent), while those with partial-benefit dual eligibility were more likely to enroll in other types of plans (57 percent).

TABLE 2-2. Medicare Managed Care Enrollment Among Dually Eligible Beneficiaries, 2021

Type of Medicare enrollment among individuals enrolled in managed care only	Dually eligible beneficiaries					Non-dual Medicare beneficiaries
	Total	Under age 65	Age 65 and older	Full benefit	Partial benefit	
D-SNP	54%	59%	52%	60%	43%	<1%
Other Medicare managed care	46	41	48	40	57	100
Total	100	100	100	100	100	100

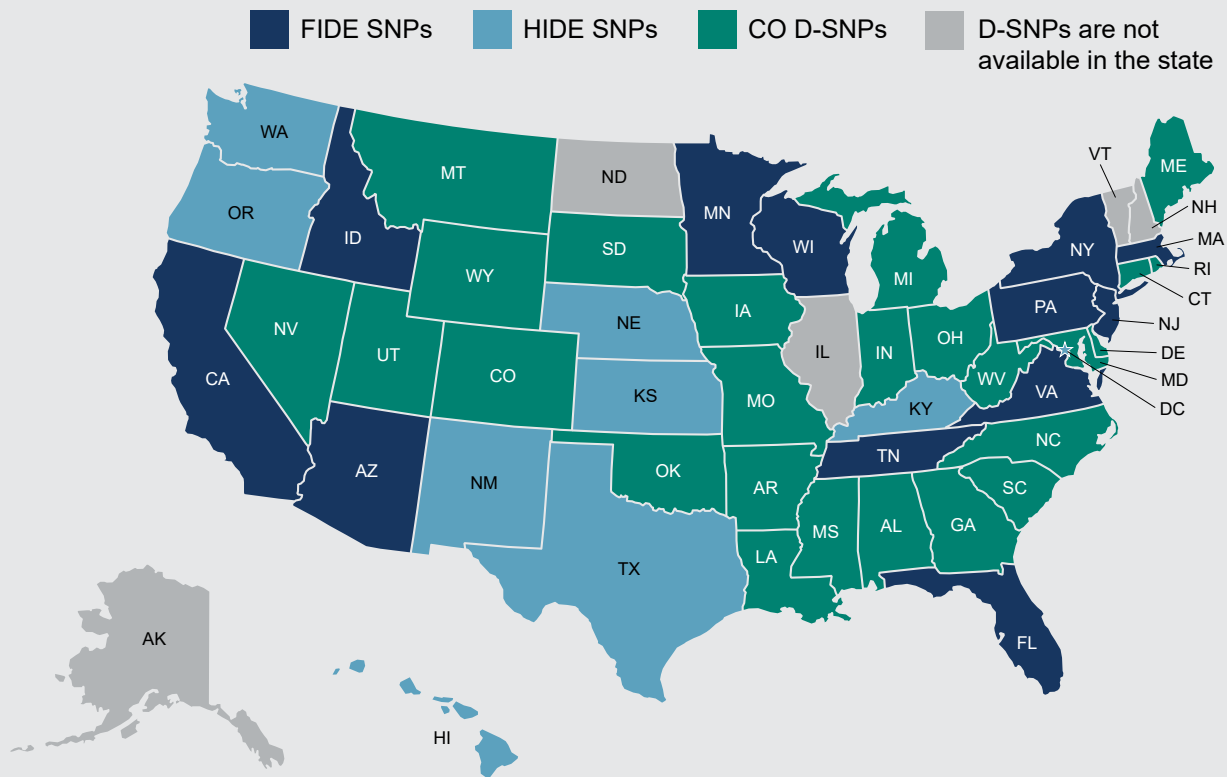
Notes: D-SNP is dual eligible special needs plan. All numbers are percentages. D-SNPs include coordination-only dual eligible special needs plans (CO D-SNPs), highly integrated dual eligible special needs plans (HIDE SNPs), and fully integrated dual eligible special needs plans (FIDE SNPs). Other Medicare managed care plan types include: Medicare-Medicaid Plans (MMPs) under the Financial Alignment Initiative; Programs of All-Inclusive Care for the Elderly (PACE); and other Medicare Advantage plans, including other types of special needs plans and non-D-SNP Medicare Advantage plans.

Source: Medicare Payment Advisory Commission (MedPAC) and MACPAC, 2024. *Data Book: Beneficiaries Dually Eligible for Medicare and Medicaid.*

Enrollment in D-SNPs has increased steadily since they first began operating in 2006 (Archibald et al. 2019).⁹ As of December 2023, more than 40 percent of the 12.8 million people who are dually eligible were enrolled in D-SNPs (CMS 2023b).¹⁰ The majority of D-SNP enrollees, 54 percent, were enrolled in

minimally integrated CO D-SNPs and the remainder were enrolled in HIDE SNPs or FIDE SNPs (CMS 2023b). See Figure 2-1 and Figure 2-2 for the availability of integrated plan types by state and state-level requirements for EAE.

FIGURE 2-1. Most Integrated Dual Eligible Special Needs Plan Available by State, 2023

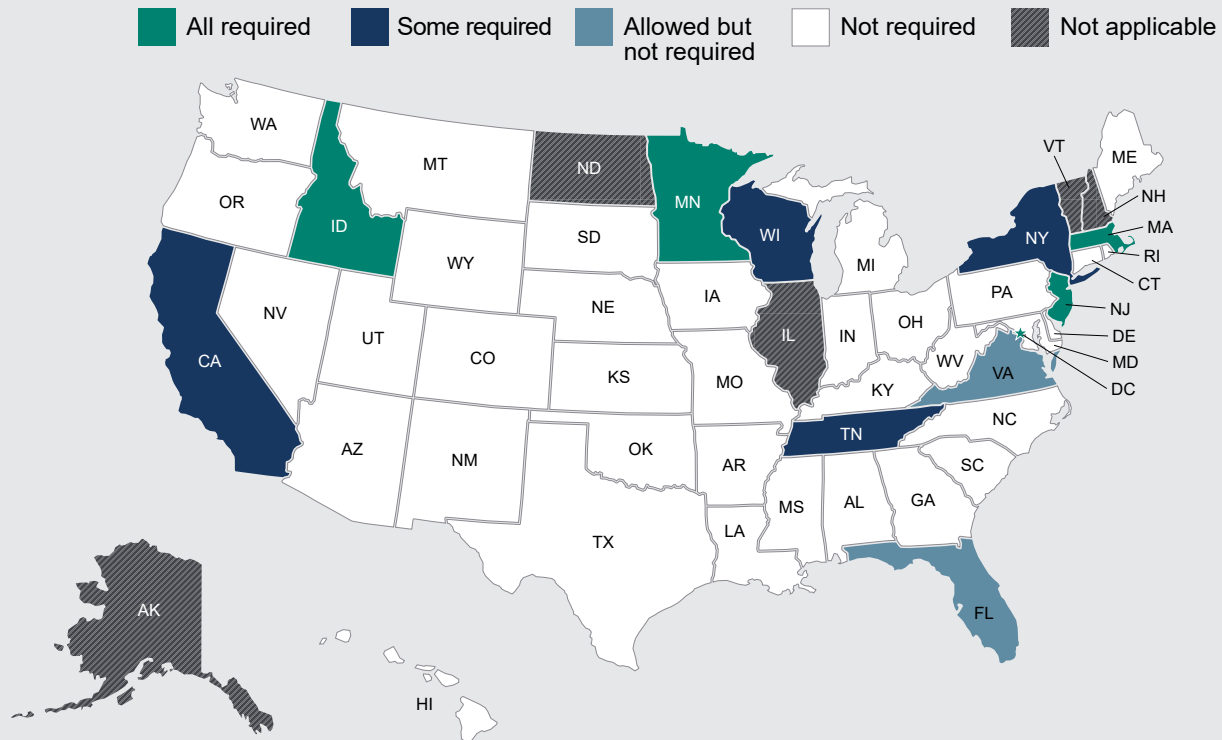


Notes: FIDE SNP is fully integrated dual eligible special needs plan. HIDE SNP is highly integrated dual eligible special needs plan. CO D-SNP is coordination-only dual eligible special needs plan. This figure shows the most integrated type of D-SNP available in the state or District of Columbia as of February 2023. Puerto Rico is excluded from this figure. States may contract with more than one type of D-SNP, but plans are not always available statewide. HIDE SNPs were first available starting in 2021.

Washington does not have comprehensive Medicaid managed care for dually eligible beneficiaries, but it does have HIDE SNPs formed by aligning D-SNPs with organizations that cover behavioral health services.

Source: CMS 2023b.

FIGURE 2-2. Exclusively Aligned Enrollment Requirements for Dual Eligible Special Needs Plans by State, 2023



Notes: States are categorized by whether they require exclusively aligned enrollment (EAE) for all dual eligible special needs plans (D-SNPs) operating in the state, for only some plans, or for those without requirements. Not applicable indicates states that do not have D-SNPs. Florida and Virginia do not require D-SNPs to use EAE, but both states allow plans to use this tool, and there are plans in each state that have EAE. In Virginia, plans may establish separate plan benefit packages for different populations that would allow for EAE. In Florida, highly integrated dual eligible special needs plans (HIDE SNPs) that limit enrollment to full-benefit individuals have EAE because the state Medicaid agency directly contracts with those plans to cover Medicaid benefits. However, HIDE SNPs in the state are not required to limit enrollment. Puerto Rico is excluded from this figure.

Source: MACPAC analysis of contract year 2023 state Medicaid agency contracts, CMS 2023c.

Model of care. To operate, D-SNPs must have an approved model of care (MOC), which federal law requires all SNPs to have and which describes the basic framework for how the plan will meet the needs of its enrollees (§1859(f)(7) of the Social Security Act).¹¹ The requirement for an approved MOC differentiates SNPs from other MA plans, which do not develop models of care (42 CFR 422.101(f)). The MOC is a tool that ensures that the plan has identified the needs of its enrollees and is addressing them through its care management practices (CMS 2023d). The MOC must be approved by the National Committee for

Quality Assurance (NCQA). The Secretary of the U.S. Department of Health and Human Services (HHS) sets the standards for how the MOC is scored by NCQA, including clinical and non-clinical elements. The MOC is scored in four areas: description of the population served, care coordination, provider network, and MOC quality measurement and performance improvement. Each of the four areas contain detailed scoring guidelines on how the requirements will be assessed by NCQA. SNPs are required to develop MOCs based on the specific populations they serve and their own organizational structure and operations. For example,

for the description of the population standard, SNPs are required to include specific characteristics of their populations, such as age, gender and ethnicity profiles, incidence and prevalence of major diseases, and other barriers that their target population faces (NCQA 2024). The care coordination standard requires plans to describe in detail their processes for conducting health risk assessments (HRAs), developing individualized care plans, and operating interdisciplinary care teams (NCQA 2024). States can build on these federal requirements by including additional care coordination requirements in their SMACs. This could include requirements for how a D-SNP conducts HRAs for beneficiaries or the composition of the beneficiary's individualized care plan and interdisciplinary care team.

Comparison with other MA plans. D-SNPs also differ from other MA plans due to certain flexibilities and requirements imposed on D-SNPs that are intended to ensure that the plans can address the needs of dually eligible individuals. Unlike traditional MA plans, organizations that offer D-SNPs are required to establish and maintain enrollee advisory committees that include at least a reasonably representative sample of the enrolled population and solicit input on ways to improve access, care coordination, and health equity (42 CFR 422.107(f)). Additionally, as of the start of 2024, D-SNPs, like all SNPs, are required to screen for health-related social needs during an enrollee's initial HRA by using one or more questions from screening instruments specified by CMS on housing stability, food security, and access to transportation (42 CFR 422.101(f)(1)(i)). D-SNPs may also have greater flexibility to provide supplemental benefits—which are benefits that MA organizations can provide to enrollees that go beyond the services offered in traditional Medicare, such as dental or vision—in cases in which CMS finds that such benefits could further integrate care (42 CFR 422.102(e)).¹²

D-SNPs face competition from other traditional MA plans in the market and dually eligible individuals often have a large number of plan options from which to pick. Some traditional MA plans may seek to enroll a substantial number of dually eligible individuals with benefits targeted to that population because the plans find that enrolling these beneficiaries may be profitable (MedPAC 2019a). These plans are known as “D-SNP look-alikes” because they are designed to attract dually eligible individuals despite not being subject to D-SNP requirements. The Commission has previously voiced

concern that such plans draw beneficiaries away from integrated models (MACPAC 2020b). Through rulemaking in 2019, 2022, and 2024, CMS implemented contracting requirements for MA organizations intended to prevent MA plans other than D-SNPs from operating if dually eligible individuals make up more than 80 percent of their enrollees (CMS 2024a, 2022, 2019a). This threshold will gradually be reduced to 60 percent for plan year 2026 (CMS 2024a).

State Medicaid Agency Contracts

All SMACs must include certain minimum elements set by the federal government, and they also serve as important tools for states to establish additional requirements for D-SNPs. The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) established minimum requirements for SMACs, including requirements on coordination of Medicaid benefits, and gave states the authority to add requirements (42 CFR 422.107(c) and (d)) (see Box 2-1). For example, the contracts must document the Medicaid benefits that are covered under a capitated contract and the service area covered by the D-SNP. Although MIPPA's implementing regulations include coordination between the D-SNP and the state, they do not result in fully integrated coverage (MedPAC 2019a). Subsequent legislation permanently authorized D-SNPs and added new minimum SMAC requirements. The Bipartisan Budget Act of 2018 (BBA 2018, P.L. 115-123) required D-SNPs to take additional steps to promote integration, beyond what was originally required in MIPPA. Specifically, it required D-SNPs to meet one of three criteria to improve integration or coordination of care: (1) meet the requirements to be designated as a FIDE SNP, (2) meet the requirements to be designated as a HIDE SNP, or (3) notify the state of hospital or skilled nursing facility admissions for at least one group of high-risk enrollees (CMS 2019a). For D-SNPs to comply with the third requirement, the state must specify, within its SMAC, the group of high-risk, full-benefit dually eligible individuals for whom a notification must be sent and the time frame and process for sending notifications to either the state or a designee of the state's choosing. The BBA 2018 also required the HHS Secretary to unify plan-level appeals and grievance processes across Medicaid and Medicare for some D-SNPs (42 CFR 422.107(c)(9)).¹³

BOX 2-1. State Medicaid Agency Contract Statutory Language at 42 CFR 422.107

(c) **Minimum contract requirements.** At a minimum, the contract must document—

- (1) The MA [Medicare Advantage] organization's responsibility to—
 - (i) Coordinate the delivery of Medicaid benefits for individuals who are eligible for such services; and
 - (ii) If applicable, provide coverage of Medicaid services, including long-term services and supports and behavioral health services, for individuals eligible for such services.
- (2) The category(ies) and criteria for eligibility for dual eligible individuals to be enrolled under the SNP [special needs plan], including as described in sections 1902(a), 1902(f), 1902(p), and 1905 of the Act [Social Security Act].
- (3) The Medicaid benefits covered under a capitated contract between the State Medicaid agency and the MA organization offering the SNP, the SNP's parent organization, or another entity that is owned and controlled by the SNP's parent organization.
- (4) The cost-sharing protections covered under the SNP.
- (5) The identification and sharing of information on Medicaid provider participation.
- (6) The verification of enrollee's eligibility for both Medicare and Medicaid.
- (7) The service area covered by the SNP.
- (8) The contract period for the SNP.
- (9) For each dual eligible special needs plan that is an applicable integrated plan as defined in § 422.561, a requirement for the use of the unified appeals and grievance procedures under §§ 422.629 through 422.634, 438.210, 438.400, and 438.402.

(d) **Additional minimum contract requirement.**

- (1) For any dual eligible special needs plan that is not a fully integrated or highly integrated dual eligible special needs plan, except as specified in paragraph (d)(2) of this section, the contract must also stipulate that, for the purpose of coordinating Medicare and Medicaid-covered services between settings of care, the SNP notifies, or arranges for another entity or entities to notify, the State Medicaid agency, individuals or entities designated by the State Medicaid agency, or both, of hospital and skilled nursing facility admissions for at least one group of high-risk full-benefit dual eligible individuals, identified by the State Medicaid agency. The State Medicaid agency must establish the timeframe(s) and method(s) by which notice is provided. In the event that a SNP authorizes another entity or entities to perform this notification, the SNP must retain responsibility for complying with the requirement in this paragraph (d)(1).
- (2) For a dual eligible special needs plan that, under the terms of its contract with the State Medicaid agency, only enrolls beneficiaries who are not entitled to full medical assistance under a State plan under title XIX of the Act, paragraph (d)(1) of this section does not apply if the SNP operates under the same parent organization and in the same service area as a dual eligible special needs plan limited to beneficiaries with full medical assistance under a State plan under title XIX of the Act that meets the requirements at paragraph (d)(1) of this section.

Leveraging SMACs

D-SNPs are widely available across the country and enroll a large swath of dually eligible people. Therefore, they have become an area of focus for policymakers interested in integrating Medicaid and Medicare coverage. Under federal law, states have authority that they can use to increase integration in the D-SNPs in their states and better tailor D-SNP coverage to serve the needs of their dually eligible populations and meet state goals. Over the last several years, MACPAC has developed a body of work in this area. In our June 2021 report to Congress, we described the contracting strategies available to states to promote greater integration through D-SNPs. We identified strategies that could be used in all states and strategies that are easiest to use in states that enroll full-benefit dually eligible beneficiaries in Medicaid managed care. Through interviews with states and federal officials, we found that many strategies were not widely used across states (MACPAC 2021). Building on that work, MACPAC contracted with Mathematica to review all SMACs for contract year 2023 to establish a baseline

of how states are leveraging their contracting authority to achieve greater integration, as well as to determine which provisions were most and least commonly used.

Review of contract year 2023 SMACs

To better understand how states currently leverage their SMACs, MACPAC conducted a review of SMAC language for plans operating in contract year 2023 as well as a scan of federal regulatory and subregulatory guidance pertaining to D-SNPs. We reviewed SMACs across all states with D-SNPs and observed state use of particular strategies. As part of this review, we examined contracts with provisions that went beyond minimum federal requirements (Boxes 2-1 and 2-2) and reflected the ways in which states use their SMAC authority to increase integration for dually eligible beneficiaries across benefit design, administration, and beneficiary experience. We also noted where states included provisions intended to enable state Medicaid agencies to oversee the performance and quality of D-SNPs operating in their state, particularly through data sharing.

BOX 2-2. Key Federal Requirements for D-SNPs

- **Eligibility:** The state Medicaid agency contract must identify the categories of dually eligible individuals who may enroll in the dual eligible special needs plan (D-SNP) (e.g., only full-benefit dually eligible individuals) and the processes used by D-SNPs to verify these individuals' eligibility for the plan before enrolling them (42 CFR 422.52(f)).
- **Care coordination:** D-SNPs must create an evidence-based model of care that guides their care management and care coordination; conduct an initial health risk assessment (HRA) within 90 days of enrollment and an annual reassessment of each enrollee's physical, psychosocial, and functional needs; develop an individualized care plan for each enrollee based on the HRA findings that address each member's needs and goals; and use interdisciplinary care teams to manage care.
- **Member materials:** D-SNPs must develop materials and content that meet the requirements at 42 CFR 422.2267 and abide by the Centers for Medicare & Medicaid Services communication and marketing guidelines, which require D-SNPs to send certain Medicare-related materials to enrollees, including the evidence of coverage, explanation of benefits, annual notice of change, summary of benefits, provider directory, and member identification card (42 CFR 422.2267(e)).
- **Enrollee advisory committee:** As of 2023, all D-SNPs must establish and maintain an enrollee advisory committee that includes a "reasonably representative sample" of the population enrolled in the D-SNP (42 CFR 422.107(f)).

Based on our review of the contracts, additional state requirements for D-SNPs largely fell under five domains: coverage of Medicaid benefits, care coordination, integrating member materials and experience, data sharing, and improving quality and reducing health disparities (Appendix 3A).

Coverage alignment. Many states address coverage of Medicaid benefits in their SMACs, as well as the alignment of those benefits with Medicare benefits. To meet the federal designation of a HIDE SNP or FIDE SNP, the D-SNP must cover Medicaid services for full-benefit dually eligible beneficiaries with the minimum standards for coverage determined by the specific designation, ranging from some to nearly all of a beneficiary's Medicaid benefits. States can also include additional requirements intended to better align coverage of Medicaid and Medicare benefits.

One way that states may seek to improve alignment of Medicaid and Medicare benefits is by limiting D-SNP enrollment to only full-benefit dually eligible beneficiaries. Since full-benefit dually eligible beneficiaries receive both Medicaid and Medicare benefits, they can benefit from care coordination in a way that partial-benefit dually eligible beneficiaries cannot because they are eligible only for Medicaid assistance with Medicare premiums and cost sharing. This strategy allows uniformity for plan enrollees, including a single set of benefits and rules for care coordination. Another way states may require greater coverage alignment is through EAE. EAE occurs when the state's contract with the D-SNP limits enrollment to full-benefit dually eligible beneficiaries who receive Medicaid benefits from the D-SNP or an aligned Medicaid managed care plan owned by the D-SNP's parent organization. By receiving coverage of both Medicaid and Medicare benefits from the same parent organization, dually eligible beneficiaries may experience more integrated and streamlined member materials and care coordination (MACPAC 2021).¹⁴

Care coordination. For many policymakers, care coordination is a primary focus of integrating care for dually eligible beneficiaries and an area in which several states have included additional requirements in their SMACs. States may include care coordination requirements, such as stipulating that certain Medicaid services be considered in developing an individualized care plan, in their SMACs for CO D-SNPs, HIDE SNPs, and FIDE SNPs (Appendix

3A). At a minimum, federal law requires that D-SNPs coordinate the delivery of Medicaid benefits for dually eligible beneficiaries, which might entail assisting beneficiaries in obtaining Medicaid-covered services or helping beneficiaries file a Medicaid appeal. These minimum requirements can also be applicable to a CO D-SNP that neither covers a beneficiary's Medicaid services nor aligns with the beneficiary's Medicaid plan. However, states may be more likely to add care coordination requirements into SMACs for D-SNPs that cover Medicaid benefits or have affiliated Medicaid managed care plans because they pay capitation payments to those plans for Medicaid services. For CO D-SNPs, which typically do not cover Medicaid benefits, the D-SNP would be expected to meet state requirements above what federal law requires without payment from the state.

Integrated member materials and member experience. Beneficiaries who receive Medicaid and Medicare notices can experience confusion. Navigating two separate summaries of plan benefits to understand one's combined Medicaid and Medicare benefits can be challenging. Unless a D-SNP is required to use EAE, beneficiaries may also have to navigate different appeals and grievance processes for Medicaid and Medicare, which may be difficult for beneficiaries who need to understand which of their services are covered by which program or plan before filing an appeal or grievance.

States may use their SMACs to set requirements for member materials and communications. Some communications requirements are relevant to all states with D-SNPs, while others are applicable only to D-SNPs with affiliated Medicaid managed care plans or to integrated plans with EAE. For example, all states can require their review of the Medicaid information included in a D-SNP's marketing materials or communications to beneficiaries (19 states). Meanwhile, for D-SNPs with EAE, states could require the D-SNP to issue fully integrated plan materials, such as issuing plan enrollees a single ID card to use for their Medicaid and Medicare coverage (nine states). In Minnesota, FIDE SNPs are required to provide beneficiaries with a single ID card, a single member handbook, and an integrated customer service phone line to address Medicaid and Medicare concerns (Minnesota DHS 2023).

Data sharing. Data sharing requirements are some of the most common ways that states currently leverage their SMACs with D-SNPs (Appendix 3A). These requirements are designed to help states monitor and assess D-SNP performance. MA plans are required to report certain data, such as encounter data or Medicare quality measures to CMS, but for the most part states lack access to Medicare data unless the states include reporting requirements in their SMACs. A number of states use their SMACs to require D-SNPs to submit data to the state, such as information about CMS warnings, sanctions or other actions related to a D-SNP; plan enrollment (18 states) and provider network information (13 states); data on plan determinations and appeals and grievances (13 states); quality measure reports (19 states); and HRA scores (11 states).

SMAC requirements can also facilitate data sharing from the state to the D-SNP. In states in which dually eligible beneficiaries receive their Medicaid services under FFS or Medicaid services are provided through a Medicaid managed care plan that is not aligned with the D-SNP, the D-SNP would lack access to Medicaid data that could assist in care management unless the state provides it. Additionally, states that choose to use default enrollment, which automatically assigns Medicaid beneficiaries who become eligible for Medicare to the D-SNP affiliated with their Medicaid managed care plan, must share enrollment and eligibility information with the D-SNP to facilitate the process (MACPAC 2022).

Improving quality and reducing health disparities. States have a vested interest in improving quality outcomes for their dually eligible beneficiaries, and in recent years, many states have developed a specific focus on addressing health disparities. Several states seek to improve quality of care and the experience of receiving care by including requirements in their SMACs that the D-SNP participate in state Medicaid quality improvement initiatives (7 states) or provide certain supplemental benefits (13 states) (Appendix 3A).

Supplemental benefits are additional Medicare benefits that a D-SNP may provide that go beyond what traditional Medicare offers, such as vision or dental benefits. D-SNPs may also provide “extra benefits,” which refer to supplemental benefits that

enhance traditional Medicare benefits. These benefits are funded through rebates MA plans receive, which represent the difference between the plan’s annual bid and the benchmark rate CMS sets for the county (GAO 2023). In their SMACs, states can require that D-SNPs offer specific supplemental benefits that are primarily health related and overlap with Medicaid benefits, such as adult day care, or they may require plans to offer special supplemental benefits for those with chronic conditions which can be non-medical, such as transportation for nonmedical needs (GAO 2023, CMS 2019b).

In a small number of states, SMACs include requirements that D-SNPs collect data on and work to reduce health disparities among their enrollees (Appendix 2A). One such state, California, requires in its SMAC that D-SNPs identify potential health disparities in its enrollee population as part of its MOC (California DHCS 2023).

Variation in SMAC provisions

State adoption of SMAC provisions is uneven without identifiable, consistent patterns. States are incorporating contract language in their SMACs intended to improve alignment and integration for dually eligible beneficiaries to varying degrees. For example, about a third of states with D-SNPs use their SMACs to limit D-SNP enrollment to full-benefit dually eligible individuals, which allows the D-SNP MOC to be tailored more precisely to their Medicaid services and needs. Some of these states allow partial-benefit dually eligible individuals to enroll in a D-SNP under a separate plan benefit package, which acknowledges that partial-benefit dually eligible individuals are still likely to benefit from a MOC even if they do not receive Medicaid services and would allow them to receive the supplemental benefits a D-SNP may offer. Data sharing provisions were also commonly included in SMACs, for both states with more integrated D-SNP types and those with only CO D-SNPs (Appendix 2A). However, it is unclear how states use the data they require D-SNPs to report.

Other contract provisions have had relatively limited use in SMACs so far. Certain areas, such as identifying health disparities, may reflect new

priorities for states. Others, such as specific training requirements for D-SNP care coordinators, reflect basic tools to improve integration or beneficiary experience yet were included by only a small number of states.

Optimizing and Overseeing SMACs

Few states have taken steps to optimize use of their SMACs, and we needed further information to understand the barriers states face in doing so. Through a series of interviews, MACPAC sought to learn how states consider which provisions to include in their contracts, what types of relationships states have with D-SNPs, how states operationalize their requirements and to what purpose, and, importantly, how states oversee and enforce the requirements they set in their SMACs.

Methodology

We contracted with Mathematica to conduct interviews with state officials in five case study states, federal officials at the CMS Medicare-Medicaid Coordination Office, and health plan representatives for two plans operating across our case study states. We selected case study states that require greater levels of integration in their SMACs, such as a HIDE SNP or FIDE SNP designation, go beyond federal minimum requirements, and conduct monitoring and oversight activities of those requirements. Selected states included California, the District of Columbia, Idaho, Minnesota, and New Jersey.

States that contract with HIDE SNPs or FIDE SNPs represent a minority of those contracting with D-SNPs. However, MACPAC determined that interviews with states that have experience contracting with and overseeing integrated D-SNPs could underscore the level of optimization that leveraging a SMAC can achieve while spotlighting implementation challenges and considerations for states at any stage of experience with D-SNPs or integrated care. More information about our case study states and their dually eligible populations can be found in Appendix 2B.

Key themes

Our interviews with SMAC stakeholders highlighted key themes within four domains: contracting considerations, data and reporting requirements, monitoring and oversight processes, and performance improvement and enforcement. When considering whether to contract with a D-SNP, state officials said that they set priorities for state goals, such as increasing alignment between Medicare and Medicaid plans under the same parent organization, as well as limiting disruptions for beneficiaries. They also emphasized the importance of regularly engaging with the D-SNPs operating in the state to solicit feedback on proposed policy changes ahead of releasing the annual SMAC. Although all states we spoke with require D-SNPs to submit a range of data in the form of reports, officials said that many of those reports are assessed only for timeliness, completeness, and accuracy and are not used for oversight. Instead, officials said that appeals and grievance data and complaints to the ombudsman office typically help to spotlight issues. To ensure compliance with their SMAC requirements, states rely on a number of enforcement tools and penalties, but few states currently include performance incentives in their SMACs. Some of these states have chosen to incorporate enforcement tools within the Medicaid managed care contract rather than the SMAC, which CMS said could influence how and when states choose to use them.

Contracting considerations. States told us that they consider several factors when deciding which D-SNPs to contract with, including opportunities for Medicaid and Medicare alignment and limiting disruptions for existing enrollees. MIPPA requires D-SNPs to have contracts with the state in which they operate, but states are not required to contract with D-SNPs, allowing states to choose whether to contract with D-SNPs at all, and if so, contract with organizations that meet state goals.^{15,16} Officials told us that they see value in their authority to be selective about which plans to contract with. Officials in one state shared that a competitive procurement process allows them to negotiate with plans and hold them accountable more than they would be able to if plans felt “entitled” to contract with the state. A state’s level of experience

with managed care contracting and marketplace factors may also influence how states decide to contract with D-SNPs. Health plans also have the choice not to operate in a state with requirements they find too burdensome. Some state officials described the need to strike a balance between additional requirements and ensuring beneficiaries have access to a D-SNP.

Additionally, all case study states require the use of EAE. Officials said they see EAE as a benefit to care coordination. For states to use EAE, there must be alignment of D-SNPs and Medicaid managed care plans, so state officials said their Medicaid agencies consider whether a D-SNP has an affiliated Medicaid managed care plan when awarding SMACs. By contracting only with D-SNPs with affiliated Medicaid plans, states can ensure plan alignment that may improve care coordination and limit the number of D-SNPs operating.¹⁷ States may also consider the existing health care landscape for dually eligible individuals to avoid disrupting care for beneficiaries. When the District of Columbia began the process of developing its HIDE SNPs in 2018, officials told MACPAC that one plan already enrolled the majority of beneficiaries in the local CO D-SNP marketplace. Although that organization was ultimately the only plan to submit a bid to operate a D-SNP in the District of Columbia, officials noted they saw value in selecting that plan as choosing a different operator could have disrupted provider networks and care.¹⁸

During the SMAC development process, stakeholders said that input from health plans plays a substantial role even if plan suggestions do not ultimately alter the contract provisions the state chooses to include. Both states and health plans told us that states meet regularly and often with D-SNPs, as they do with Medicaid managed care plans, to solicit input on SMAC requirements and incorporate suggestions when appropriate. Interviewees described good working relationships between state Medicaid officials and health plan representatives that keep the health plans informed about relevant program changes. Health plans said their feedback is heard, even if states do not always accept plan requests. State officials told MACPAC that a cornerstone of these relationships is regular meetings that they said engender familiarity and allow the state and health plans to engage with

one another about proposed SMAC requirements and program operations.¹⁹

Health plans told MACPAC that they find value in these feedback sessions and that they recognize that state officials make efforts to use plans' operational knowledge to improve SMAC design, even as health plan representatives refrained from describing the conversations as a contract negotiation. During its annual SMAC negotiations, health plan representatives said Minnesota sometimes incorporates plans' ideas into the SMAC. In New Jersey, officials give health plans a few weeks to provide comments on draft SMAC language, especially when a requirement may pose a technical lift for plans. However, health plans also identified several challenges in the SMAC contracting process.

Data and reporting requirements. CMS requires D-SNPs to submit a wide variety of data and reports. For example, as with all MA plans, MA contracts that include D-SNPs must submit Healthcare Effectiveness Data and Information Set (HEDIS) and Consumer Assessment of Healthcare Providers and Systems (CAHPS) measures related to quality and experience of care. D-SNPs are also required to submit an additional set of plan-level quality measures specific to SNPs, including data related to the SNP quality improvement program (42 CFR 422.152(g)). Although states can leverage data and reports that D-SNPs share with CMS, states must require D-SNPs to share this information with the state if they want guaranteed data access. States, which receive Medicaid reports from the D-SNP or the D-SNP's affiliated Medicaid managed care plan under its Medicaid managed care contract, do not automatically receive any D-SNP data directly from CMS. However, recent rulemaking allowed for states to request MA encounter data from CMS (CMS 2024a). Additionally, with the codification of D-SNP-only contracts in 2022, states that choose to require D-SNP-only contracts can receive reporting of quality measures and calculations of Medicare Star Ratings specific to dually eligible individuals in the state (CMS 2022).

All five case study states require D-SNPs to submit data and reports related to appeals and grievances, provider networks, care coordination, and enrollment and disenrollment. States indicated that encounter

data and care coordination data were the most important for monitoring D-SNP compliance and quality; however, the states we interviewed are limited in their current use of MA encounter data. California officials said the state is working on internal systems changes to receive and use MA encounter data for oversight of D-SNP compliance, quality improvement, care coordination, and utilization in key areas, such as understanding the impact of social determinants of health and to inform policy development for care coordination and transitions of care. Although the state can currently review Medicaid data and FFS Medicare claims, officials said that MA encounter data are crucial for understanding the MA component of its integrated D-SNPs. The District of Columbia, which uses MA encounter data in developing capitation rates to pay D-SNPs to cover Medicare cost sharing, said that any data that inform program operations are critical to effective oversight. For example, officials noted that enrollment data have been especially important during the unwinding of the COVID-19 public health emergency, and that they use other finance reports for Medicaid rate setting.

Each case study state also requires plans to submit care coordination data, such as information related to HRA and individualized care plan completion rates, care transitions, and discharge planning. For example, Minnesota officials said that care coordination data, quality assurance assessments, and appeals and grievance data help to demonstrate compliance and identify gaps in a service area. The state requires its D-SNPs to submit an annual care coordination report in which the D-SNP audits a sample of their care plans and the delegates they contract with for case management. Although Minnesota does not require plans to resubmit their MOCs during this process, the plans' annual care coordination audits can surface changes that need to be made and officials described them as useful in assessing the health of the program. CMS officials agreed that measures focused on HRA completion are a good indicator to states of plan performance. Other types of required data reports include financial reports and information on marketing activities. One national health plan shared that the D-SNP reporting requirements in its SMACs are largely consistent with the Medicaid managed care reporting requirements in those states. Increasingly, CMS said states are using their SMACs to ask plans

to submit MA data that the plans report to CMS. For example, among our case study states, California, Minnesota, and New Jersey ask D-SNPs to report Medicare Part C and Part D data, CMS Star Ratings, and CMS audit findings.

Health plan representatives said that state data reporting requirements can sometimes pose technical challenges, particularly when the requirements are inconsistent with other requirements in the SMAC or there are delays on the part of the state in communicating the requirements. A health plan that operates a D-SNP in California shared that the reporting requirements in its SMAC are based on the requirements used in the state's FAI demonstration; however, these requirements do not always align with the language in each D-SNP's MOC. For example, California requires D-SNPs to submit information about how many HRAs the plan completed within 90 days of enrollment, but the plan's MOC indicates that the plan may conduct the HRA within 90 days before enrollment. The health plan said it believes that this misalignment between reporting requirements and the MOC creates an inaccurate understanding of the plan's performance on care coordination measures. For the state to be able to compare plans directly as California does, the health plan said that California should determine whether each plan meets the reporting requirements according to the definitions used in the MOC approved by CMS.²⁰ A national health plan shared that state-specific quirks can also pose challenges to data reporting. For example, in Minnesota the health plan experienced additional burden reporting on benefit denials, service terminations, and service reductions because the state has its own coding system that does not align with universal billing codes.

In addition to reporting data to the state, plans may be required to share data with other plans to coordinate care for those with unaligned enrollment. Although all of our case study states require EAE, California currently allows unaligned CO D-SNPs to continue operating in several counties.²¹ A D-SNP operating in California said it can be difficult to implement requirements to use Medicaid and Medicare data for members who are enrolled in a Medicaid plan offered by a different organization. The D-SNP identified that unaligned enrollees are a particular challenge for care coordination because without active data sharing

between the Medicaid plan and the D-SNP, the plan cannot monitor the enrollee's Medicaid utilization to facilitate care coordination. In an attempt to address this challenge, state officials in California said they instituted an IT solution to help plans meet information sharing requirements and streamline coordination between unaligned Medicaid plans and D-SNPs, including communication with one another about admission and discharge information to hospitals and skilled nursing facilities.

Monitoring and oversight. States use data and reports to monitor and oversee D-SNPs to ensure they meet the contract requirements and performance targets included within their SMACs, with oversight often a collaboration across several Medicaid agency departments and other state agencies. In particular, state officials cited appeals and grievance data and care coordination data as primary sources for identifying issues. However, states also noted that limited staff capacity means that frequently data reports are checked only for timeliness, completion, and accuracy rather than undergoing deeper analysis.

CMS explained that it is responsible for overseeing D-SNPs' compliance with Medicare requirements and quality in covering Medicare benefits, but the state is primarily responsible for oversight and delivery of Medicaid services, especially LTSS. CMS said that states are beginning to enforce SMAC provisions and improving their oversight by collecting their own data or using CMS data. For example, states are starting to collect MA encounter data, but a lack of staff capacity makes it difficult for states to use the data to assess D-SNP compliance or performance. CMS noted that state D-SNP compliance efforts are often driven by a certain state goal. For example, CMS officials said that if a state is using information sharing to coordinate the delivery of services for LTSS recipients, the state may be more interested in ensuring that the D-SNP is compliant on that measure.

All of the case study states require at least some D-SNPs to be AIPs, which are required to use unified appeals and grievance procedures (42 CFR 422.107(c)(9)). States said they use appeals and grievance data to identify trends and track areas that need improvement.²² Officials in New Jersey said the state uses appeals and grievance data to identify the

most frequent problems and inform adjustments to SMAC language. For example, the state said it noticed a disproportionate number of denials for durable medical equipment. After investigating the problem, New Jersey identified a misunderstanding with the language around powered wheelchairs, which caused incorrect denials. Through this monitoring and oversight, New Jersey said it was able to ultimately implement clarified SMAC language to resolve the issue.

Meanwhile, officials in Minnesota noted the importance of care coordination data, such as HRA completion rates.²³ Officials at CMS agreed that measures focused on HRA completion act as a good indicator to states of plan performance. However, officials in Idaho said they do not have enough data to hold D-SNPs accountable for care coordination and case management, but they are exploring additional data reporting requirements that they could then tie to quality withholds. A quality withhold is an arrangement in which a portion of the state's capitation payment to the plan is withheld and repaid to plans according to their performance on certain quality measures.

Case study states also rely on a range of other health plan data and reports to monitor performance, such as reporting of quality measures like HEDIS, CAHPS, and Health Outcomes Survey measures. In California, officials said the state requires D-SNPs to submit HEDIS measures and plans to report them on a publicly available dashboard, which they are developing using data from a variety of sources to provide timely information about key performance metrics.²⁴ Although Idaho collects HEDIS and CAHPS measures, officials said they do not use them to monitor plan performance due to a lack of staff capacity.

Several state agencies and departments are involved in different aspects of D-SNP oversight, according to officials in case study states. The District of Columbia and Minnesota said they both have core groups that are responsible for D-SNP oversight and collaborate with other teams within the Medicaid agency. For example, in the District of Columbia, these divisions include: the Office of the General Counsel for review of the SMAC and legal advice; a policy team that ensures they have the authority to operate the program; a program integrity unit that assures compliance; and an office of rates, reimbursement, and financial analysis

that does the financial planning, projects enrollment for budgeting purposes, and reviews the financial reporting. In addition, officials said that other staff manage appeals and grievances. Often, policy staff overseeing D-SNPs in case study states and the staff conducting analyses of data reports are separate. Several states, including the District of Columbia, Idaho, and Minnesota, said they rely on a data team within their department to assess encounter data accuracy and completeness, analyze utilization trends, and then share the results with policy staff.²⁵

Although some states focused on Medicaid compliance, other states indicated that it was important to also use Medicare data to have a more complete understanding of dually eligible individuals' care. As California collects more data from D-SNPs, including MA encounter data, officials said they are identifying what data are most relevant for informing Medicaid operations. However, officials in New Jersey said they focus on oversight of Medicaid benefits because staff do not have sufficient Medicare knowledge to oversee D-SNP compliance or performance with Medicare data. Nevertheless, New Jersey indicated that it would like to improve its ability to conduct such oversight.

Performance improvement and enforcement.

Although states have the flexibility to include a spectrum of additional SMAC requirements, requirements are not meaningful without enforcement. In our interviews, state officials described a number of enforcement mechanisms to ensure plan compliance with contract requirements, including penalties and, to a lesser degree, incentives for good performance. Federal officials also emphasized that although states may rely on enforcement tools included in their Medicaid managed care contract or other policy documents, the SMAC should include language defining enforcement tools that a state wishes to use with D-SNPs for compliance purposes.

States said that they tend to implement penalties in an escalating fashion, using intermediate penalties, such as corrective action plans (CAPs), withholds for non-compliance, and sanctions that are intended to remedy poor performance before contract termination. CAPs and letters of noncompliance are the most common penalties, though states can also levy financial penalties. The District of Columbia's SMAC contains

language outlining the CAP process, which begins with a verbal notification of non-compliance, followed by the Office of Contract Procurement requesting a CAP. Several states apply financial penalties or enrollment freezes for non-compliance with SMAC requirements. If Minnesota and Idaho state staff identify an area of non-compliance, officials said that they issue a CAP, notify the D-SNP that it is in breach of contract, and fine it for each day that it is out of compliance. The District of Columbia and New Jersey also said they use financial penalties for non-compliance, while the District of Columbia may also implement enrollment freezes.²⁶

Though states said they saw financial penalties as effective in ensuring plan compliance with the SMAC, officials said it is not a tool they use lightly. Idaho officials described a previous experience when the threat of a financial penalty, when large enough, encouraged a plan to agree to a CAP and quickly resolve the identified issue. Officials in New Jersey view liquidated damages, a contractually determined financial penalty for breach of contract, as an effective enforcement mechanism because there is a well-established financial penalty for lack of performance or compliance. However, New Jersey said it often relies on CAPs rather than a notice of deficiency with a direct financial impact. Several states said they also hope that publicly sharing plan performance in a data dashboard may facilitate compliance when financial penalties are ineffective.

Few states included incentives for D-SNPs in their SMACs, noting a lack of resources or clear quality benchmarks. Minnesota said it allows plans to earn back payment withholds if they meet certain quality performance thresholds, such as HRA completion. Officials said the state started out by requiring 50 percent of the HRAs to be completed within 30 days for its Minnesota Senior Health Options program—increasing the percentage of HRA's submitted by 5 percent each year over the course of a few years (Minnesota DHS 2021). Currently, officials said plans are required to submit 95 percent of the HRAs within 30 days, and that all the plans are compliant.²⁷

Several states, including California and the District of Columbia, use Medicaid managed care contracts and policy guidance documents to detail requirements

outside of the SMAC. Officials said they appreciate these documents as they allow for regular updates and refinements outside the contract amendment process. Given their responsibility for overseeing Medicaid benefits, officials in California, the District of Columbia, and New Jersey described a greater degree of ownership and enforcement mechanisms in their Medicaid managed care contracts than their SMACs, which some described as one of several legally binding documents. The District of Columbia noted that its Medicaid managed care contract with the D-SNP provides an enforcement lever for the state because the state pays the plan for services through that contract. As there are no payments associated with the SMAC, states said the Medicaid managed care contract was a more effective oversight tool. However, CMS told us that states should include D-SNP requirements directly in the SMAC, including penalties and incentives, as it may be more difficult to implement enforcement tools that do not sit within the contract. Officials in New Jersey confirmed this point of view, saying that they would be hesitant to apply penalties not described within their SMAC.

Considerations for States

States looking to integrate care for their dually eligible beneficiaries face a range of complex considerations. Even states with a wealth of experience in integrating care like our case study states encounter challenges in leveraging and overseeing their SMACs. Although the Commission is cognizant of these challenges and has made several prior recommendations to Congress that seek to address them, we believe that states can still leverage certain data to effectively monitor and oversee their SMACs and to develop an integration strategy in the absence of a congressional requirement.

States at any stage along the path to integrating care for dually eligible beneficiaries should understand their contracting authority and ensure they are collecting data necessary to effectively oversee D-SNPs. Through our interviews, we have identified data on care coordination and MA encounters as meaningful data elements that could represent a starting point for states that are beginning to leverage their SMACs and lay the groundwork for future data analysis. As

states continue to struggle with state capacity issues, they should consider how they will support oversight of these data—and how these data can support state goals—if Congress acts to take up MACPAC’s June 2022 recommendation on state integration strategies.

Even without congressional action, federal guidance from CMS could support states in developing an integration strategy by outlining various options for integrating care. These options could include a range of currently available integrated care models, which states could leverage as best suits their health coverage landscape. Our review of SMACs for contract year 2023 found wide variation in which provisions states included in addition to federal minimum requirements, and only a small share of states in which D-SNPs operate currently use these contracting strategies. Federal guidance from CMS can provide clarity to states with minimal experience in integrating care for their dually eligible populations on how they can optimize their SMACs under existing federal authority, as well as explain the value that states may gain from leveraging these contracts.

Barriers to optimizing SMACs

Through interviews with state and federal officials, we heard that the barriers states face in leveraging and overseeing their SMACs with D-SNPs are reflective of the challenges that states have previously described in pursuing integrated care models for dually eligible beneficiaries. State officials said that a lack of staff capacity and Medicare knowledge place operational limits on what they believe they can require in their SMACs, and several officials highlighted the importance of connecting SMAC requirements to state goals to garner buy-in from state leadership.

Officials in several states said that they were reluctant to add a requirement to their SMAC without the staff available to oversee health plan compliance with it, emphasizing that additional requirements equate to additional oversight work for state staff. MACPAC’s prior work echoes this sentiment as other state officials have described their lack of dedicated staff for the resource-intensive work of launching and overseeing integrated care models, noting that staff working on policies affecting dually eligible beneficiaries juggle a range of other responsibilities (MACPAC 2022,

2020b). With few full-time equivalent staff tasked with overseeing SMACs, several states said in our recent interviews that they seek to only include requirements or collect data for which the state has a clear use. Although states we interviewed acknowledged the broad flexibilities allowed by 42 CFR 422.107, citing capacity issues as the main factor limiting how they leverage their SMACs, CMS said that other states are still learning that they can include additional contract requirements in their SMACs and how to do so.

State officials admitted that staff capacity also poses challenges to overseeing existing requirements. For example, Idaho officials said that due to the limited number of staff, the state has not yet been able to use data they collect from D-SNPs to inform decision making on revising requirements in future SMACs. Instead, Idaho officials said the state currently monitors submitted data to make sure it is on time, complete, and accurate, which was an approach used at least occasionally by several case study states. Additionally, states said they encounter difficulties in building and retaining staff expertise needed to oversee the D-SNP program, highlighting Medicare expertise in particular. For example, Medicaid officials in the District of Columbia said that staff lack detailed Medicare knowledge that could help to avoid duplicative requirements, such as determining whether the D-SNP, in meeting its Medicare obligations, has already met the Medicaid requirements. There are some ongoing efforts to build state expertise in Medicare. For example, in California the state Medicaid agency has joined a Medicare Academy training program operated by the Center for Health Care Strategies to introduce staff to Medicare basics (CHCS 2024). In an interview, California officials said they saw the training program as an opportunity to help staff understand where state requirements may best complement Medicare requirements and to be able to spot issues, particularly as California prepares to receive MA encounter data.

Efforts to integrate care for dually eligible beneficiaries are also competing with other state priorities for limited resources. In a 2021 MACPAC roundtable, state officials talked about how other agency priorities, which change frequently, can affect integration efforts. Those officials said that securing state leadership support for integrated care may be difficult given that the models do not necessarily lead to timely or direct

reductions in spending. With competing priorities, roundtable participants said leadership commitment to integrated care is crucial to progress (MACPAC 2022). In our recent interviews, California officials described leadership, including the governor's office, as fully invested in the recent launch of its integrated D-SNPs in 2023. Officials said this progress is in part due to the inclusion of integration efforts in the state's larger Medi-Cal reform project, known as CalAIM (California DHCS 2019).

At its December 2023 public meeting, MACPAC convened a panel of experts, including representatives from CMS, a health plan, and a non-profit providing technical assistance to states, to discuss the transition away from MMPs to integrated D-SNPs (CMS 2022). During a moderated conversation, experts agreed that state capacity issues, including a lack of familiarity with Medicare and how MA plan bids are developed, are preventing many states from integrating care for their dually eligible populations. However, panelists pointed to states that participated in the FAI, and have agreed to transition to integrated D-SNPs by the demonstration's conclusion at the end of 2025 as possible examples for other states. Additionally, citing MACPAC's prior recommendations as discussed below, one panelist argued that without additional federal funding to support the development of an integration strategy, many states will be forced to continue treating integrated care as a side-of-the-desk activity subject to other state priorities (MACPAC 2023).

Prior recommendations

The Commission made recommendations in its June 2020 and June 2022 reports that directed Congress to provide states with additional federal funding to build staff capacity to implement integrated care models and to require that states develop a state integration strategy, respectively (Box 2-3). As of early 2024, Congress has not enacted these recommendations, but several bills have been introduced that would do so.

BOX 2-3. Prior MACPAC Recommendations

June 2022

- Congress should authorize the Secretary of the U.S. Department of Health and Human Services to require that all states develop a strategy to integrate Medicaid and Medicare coverage for full-benefit dually eligible beneficiaries within two years with a plan to review and update the strategy as needed, to be determined by the Secretary. The strategy should include the following components—integration approach, eligibility and benefits covered, enrollment strategy, beneficiary protections, data analytics, and quality measurement—and be structured to promote health equity. To support states in developing the strategy, Congress should provide additional federal funding to states to assist with these efforts toward integrating Medicaid and Medicare coverage for full-benefit dually eligible beneficiaries.

June 2020

- Congress should provide additional federal funds to enhance state capacity to develop expertise in Medicare and to implement integrated care models.

It is the Commission's position that these recommendations remain the best approach to resolving the barriers that states face in developing integrated care options for dually eligible individuals, including those related to contracting with and overseeing D-SNPs.

Examining strategies for effective SMAC oversight

The case study states we examined include an array of requirements in their SMACs that address differing populations, state goals, and priorities. However, interviewees indicated data on care coordination and MA encounters are necessary to monitor D-SNP compliance and assess quality. Although we spoke with officials in states that require greater levels of integration, requirements for plans to submit data on care coordination and MA encounters are applicable to any D-SNP, even those with minimal levels of integration.

Care coordination. States may use their SMAC to require that D-SNPs incorporate certain care coordination practices into their MOC, so long as state

requirements do not contradict federal requirements and the MOC is approved by NCQA and CMS. States can add care coordination requirements, including: additional specifications for federally required HRAs, such as requiring D-SNP HRAs to be completed in fewer than 90 days; requirements that Medicaid services or providers be incorporated into beneficiaries' individualized care plans; or specific training requirements for care coordinators. Each case study state requires health plans to submit care coordination data, such as information related to HRA and individualized care plan completion rates, care transitions, and discharge planning to support state goals. For example, a state might request that D-SNPs submit HRA responses stratified by a variable of interest, such as race and ethnicity, if the state has a focus on health equity across its Medicaid program.

Both state and federal officials noted the importance of care coordination data, such as HRA completion rates, in assessing plan performance and the overall health of the integrated care program. Officials said that using data ensures they are setting attainable targets for their plans and establishes a precedent of monitoring and goal setting.

MA encounter data. Currently, D-SNPs submit MA encounter data to CMS but states did not receive these data in 2023 unless they included a requirement in their SMAC. Without MA encounter data, state officials lack a full picture of service utilization among dually eligible beneficiaries because Medicare acts as the primary payer for a wide range of services. Unless Medicaid receives a claim to cover Medicare cost-sharing, Medicaid officials will not receive data on the use of Medicare-covered services.

In April 2024, CMS finalized a rule for contract year 2025 that opened an avenue for states to request to receive MA encounter data from CMS for purposes of improving the Medicaid program (CMS 2024a). Previously, CMS was allowed to release MA encounter data to states to support evaluations and administration of a Medicare-Medicaid demonstration after risk adjustment reconciliation for the applicable payment year had been completed, which created a time lag for states to use such data for care coordination purposes. To allow states to receive and use MA encounter data in support of the state's Medicaid program, CMS revised 42 CFR 422.310(f) to permit the release of MA encounter data to states for Medicaid program activities and evaluations before final reconciliation of the data (CMS 2024a). Though these data would be subject to change after reconciliation, CMS indicated in the final rule that states have experience addressing potential data concerns from using Medicare FFS claims for care coordination, quality improvement, and program integrity. Concerns remain regarding the accuracy and completeness of MA encounter data. The Medicare Payment Advisory Commission made recommendations to improve the collection of MA encounter data in 2019, and CMS recently issued a request for information soliciting feedback on improving MA data collection, including for dually eligible populations (CMS 2024b, MedPAC 2019b).

Analysis of MA encounter data quality is an ongoing effort. States can leverage MA encounter data for a number of analyses, such as: comparing service use among D-SNP enrollees to those not enrolled in a D-SNP, identifying disparities among the dually eligible population, or developing quality improvement goals for future SMACs. In our interviews, several state officials said that it is important to use Medicare

data to have a more complete understanding of dually eligible individuals' care. Additionally, states may be able to leverage enhanced federal administrative matching funds for state expenditures for operation of a Medicaid Enterprise System module or component approved by CMS (CMS 2023e). An enhanced match could support states in making information technology (IT) system improvements necessary to ingest and use MA encounters in their state Medicaid Management Information System.

Commission Recommendations

The Commission recommends that states require D-SNPs to submit data to the state on care coordination and MA encounters to bolster monitoring and oversight efforts. The Commission also recommends that CMS update guidance to support states in pursuing integrated care models and leveraging their SMACs.

Recommendation 2.1

State Medicaid agencies should use their contracting authority at 42 CFR 422.107 to require that Medicare Advantage dual eligible special needs plans (D-SNPs) operating in their state regularly submit data on care coordination and Medicare Advantage encounters to the state for purposes of monitoring, oversight, and assurance that plans are coordinating care according to state requirements. If states were required by Congress (as previously recommended by the Commission) to develop a strategy to integrate Medicaid and Medicare coverage for their dually eligible beneficiaries, states that include D-SNPs in their integration approach should describe how they will incorporate care coordination and utilization data and how these elements can advance state goals.

Rationale

Care coordination is central to integrating Medicaid and Medicare services and serves as a key feature of the D-SNP model. Both CMS and state officials identified care coordination data as a useful measure of D-SNP performance and the overall health of the

integrated program. As more states take steps toward requiring greater integration from D-SNPs, states should use their SMACs to require that D-SNPs submit care coordination data so that states may ensure that dually eligible beneficiaries in these products are receiving the levels of care coordination the state expects. Although few states currently collect and use MA encounter data to oversee D-SNPs, state officials said these data are necessary to understand the health of the dually eligible population and inform quality improvement efforts. Importantly, these data elements are applicable to more integrated plans as well as minimally integrated CO D-SNPs, which means that states at any level of integration can begin requiring these data as a first step.

State staff identify a lack of Medicare expertise as an impediment to more fully optimizing and overseeing D-SNPs operating in their state. In some states, limited resources and experience handling managed care data also complicate states' ability to push for higher levels of integration through SMACs. It is unclear how many states may require IT systems upgrades to receive and process health plan data, and some states currently have negligible or no state requirements regarding care coordination beyond the minimum requirements set by federal law. However, should states set priorities tied to their monitoring and oversight efforts, the potential value of these data in improving integrated care would presumably increase. States should consider how data on care coordination and utilization could support quality improvement for dually eligible beneficiaries enrolled in D-SNPs and how analyses of such data might inform policy developments aimed at achieving greater integration for the dually eligible population.

Although the changes in the final rule create new opportunities for states to access MA encounter data, the Commission recommends going a step further by encouraging states to require that the plans submit the data directly to the states. This approach puts the onus on the health plan to provide the data without states having to request it from CMS. It has the potential to allow states to engage with the D-SNP to specify how they want the data presented or reported and may support a stronger working relationship between the state and the D-SNP.

Implications

Federal spending. The Congressional Budget Office (CBO) does not estimate any changes in federal direct spending as a result of this change.

States. Given limits on state capacity, this recommendation may pose a substantial upfront administrative burden for states to implement, particularly with regard to IT systems that may require upgrades to automatically ingest MA encounter data. However, states have an obligation to monitor and oversee SMAC requirements, and this recommendation offers states with any level of experience with D-SNPs a place to begin effective oversight, as well as data elements that could support program improvements. Additionally, states may be eligible for enhanced federal matching funds to support such upgrades.

Enrollees. Although there is no direct effect of this recommendation on enrollees, dually eligible beneficiaries enrolled in D-SNPs may experience more integrated care if states begin receiving and using care coordination and MA encounter data to ensure that plans are meeting state expectations for coordinating or covering Medicaid benefits. Enrollees may potentially see even greater benefit should states use these data for quality improvement and to inform the development of future SMAC requirements in addition to monitoring for compliance with existing requirements.

Plans. D-SNPs may experience some added administrative burden if states require the submission of data on care coordination and MA encounters as plans will likely need to format and package data according to state requirements, which can differ across the states in which the D-SNP or its parent organization operate. However, plans effectively agree to accept these terms if they opt to sign a SMAC with a state.

Providers. There is no direct effect on providers.

Recommendation 2.2

The Centers for Medicare & Medicaid Services should update guidance that supports states in their development of a strategy to integrate care that is tailored to each state's health coverage landscape.

The guidance should also emphasize how states that contract with Medicare Advantage dual eligible special needs plans can use their state Medicaid agency contracts to advance state policy goals.

Rationale

CMS guidance could prompt states to begin developing a strategy by outlining the tools available, even in the absence of congressional action requiring such strategies. States are increasingly adding requirements to their SMACs to tailor those contracts to serve their dually eligible populations and align with state priorities. However, federal officials said that a lack of awareness of state contracting authority and its limitations, as well as the value of leveraging the SMAC, continues to hinder states in optimizing these contracts to further integration. Although the Integrated Care Resource Center (ICRC), which provides technical assistance to states integrating Medicaid and Medicare, has published a number of resources, federal guidance could provide states with clarity on the boundaries of their contracting authority and emphasize for states how leveraging their SMACs can add value to their Medicaid program.

Implications

Federal spending. CBO does not estimate any changes in federal direct spending as a result of this change, although it does anticipate this recommendation would increase federal discretionary spending to cover the development of guidance. Issuing guidance does pose some administrative burden on CMS, but the agency can draw on prior guidance and existing educational materials produced by the federally funded ICRC. Technical assistance channels, such as ICRC, already handle questions and requests from state Medicaid agencies, and so we anticipate little additional burden even if many states engage CMS for assistance in developing state integration strategies after publication of this guidance.

States. State Medicaid agencies may benefit from greater clarity on the types of integrated care models available and how each model might function according to the state's own health care landscape for dually eligible beneficiaries. For states that have yet to invest in integrated care for their dually eligible populations, federal guidance that explains the value that states may gain from integration could catalyze these agencies and

their leadership to discuss how their programs could benefit from integrated care models.

Enrollees. If federal guidance encourages states to develop an integrated care strategy for dually eligible individuals, enrollees may gain greater access to integrated care options and, with a less fragmented health care landscape, enjoy a more streamlined beneficiary experience.

Plans. There is no direct effect for plans.

Providers. There is no direct effect for providers. However, some providers may benefit from greater clarity on available integrated care models in which they could participate within their state, and such guidance may enable certain providers to better engage with their state Medicaid agency in any stakeholder processes.

Looking Ahead

We plan to continue investigating how integrated care models can achieve greater administrative and financial alignment as well as how dually eligible beneficiaries might receive a more streamlined integrated experience and improved outcomes. In addition, we will monitor ongoing legislative efforts and agency rulemaking related to integrating care for dually eligible beneficiaries.

Endnotes

¹ Integrated care is an approach that is intended to align the delivery, payment, and administration of Medicaid and Medicare services with the goals of improving care, eliminating incentives for cost shifting, and reducing spending that may arise from duplication of services or poor care coordination. In its report, CMS calculates integrated care enrollment to include only full-benefit dually eligible individuals with aligned Medicaid and Medicare enrollment (CMS 2023a).

² Without exclusively aligned enrollment, which requires that beneficiaries be enrolled only in the D-SNP affiliated with their Medicaid managed care plan, simultaneous enrollment in managed care for both Medicaid and Medicare benefits does not mean that all individuals in this category are enrolled in aligned plans under the same parent organization.

³ CMS finalized rulemaking that sunsets the MMPs as of calendar year 2025 (CMS 2022). States are in the process of transitioning their MMPs to integrated D-SNPs.

⁴ Other types of special needs plans (SNPs) include chronic condition SNPs (C-SNPs) and institutional SNPs (I-SNPs).

⁵ D-SNPs are also available in Puerto Rico but enrollment in the territories is excluded from this analysis.

⁶ D-SNPs are designated as HIDE SNPs if their parent organizations have a contract with the state to cover either LTSS or behavioral services or both. In the case in which Medicaid benefits are covered by an aligned Medicaid managed care plan, this would be a managed care contract. In the case in which D-SNPs directly contract to cover Medicaid benefits, this requirement could be conveyed within the SMAC between the D-SNP and the state or a separate Medicaid managed care contract with the D-SNP.

⁷ D-SNPs are designated as FIDE SNPs when LTSS and behavioral health services are covered by the same legal entity as the D-SNP. FIDE SNPs are not required to cover behavioral health services if the state carves them out of the capitation rate. FIDE SNPs must also use aligned care management and specialty care network methods to meet the needs of high-risk enrollees and “coordinate or integrate beneficiary communication materials, enrollment, communications, grievance[s] and appeals, and quality improvement” (42 CFR 422.2). More details on these models can be found in Chapter 1 of MACPAC’s June 2020 report to Congress (MACPAC 2020a).

⁸ Beginning in 2025, plans must cover LTSS, behavioral health, Medicare cost sharing, home health, and medical equipment, supplies, and appliances to qualify as a FIDE SNP (CMS 2022).

⁹ The Bipartisan Budget Act of 2018 (BBA 2018, P.L. 115-123) permanently authorized D-SNPs to operate as part of the MA program.

¹⁰ These figures include D-SNP enrollees in Puerto Rico, where, unlike in the states, almost all dually eligible beneficiaries, about 301,000 individuals, are enrolled in a D-SNP (Freed et al. 2024, CMS 2023b).

¹¹ In April 2024, CMS codified previous guidance regarding MOC scoring and submission procedures in a final rule (CMS 2024a).

¹² Flexibility to offer certain supplemental benefits is available only to HIDE SNPs and FIDE SNPs that meet minimum performance and quality-based standards. All MA plans may offer supplemental benefits that are primarily health-related or that reduce cost sharing for enrollees. Additionally, MA plans may offer special supplemental benefits for the chronically ill to enrollees with complex chronic conditions and high needs, including benefits that are not primarily health related but are reasonably expected to maintain or improve the health or overall function of an enrollee (42 CFR 422.102(f)).

¹³ D-SNPs that use EAE and cover at least some Medicaid benefits qualify as AIPs, which must unify certain appeals and grievance processes.

¹⁴ In April 2024, CMS issued a final rule that would increase the number of beneficiaries with EAE, requiring D-SNPs whose parent organizations also contract as a Medicaid managed care plan enrolling full-benefit dually eligible individuals in the same service area to operate with EAE by 2030 (CMS 2024a).

¹⁵ Of the five case study states, four use a competitive procurement process to select the D-SNP or Medicaid managed care plans with which they will contract. Idaho currently contracts with all qualified vendors that wish to operate (Idaho DHW 2022). However, state officials said they are drafting procurement requirements and selection criteria to transition to a competitive procurement process.

¹⁶ CMS is responsible for approving a MA organization’s application to contract to cover Medicare services. A MA organization may not operate without this contract.

Application requirements and evaluation procedures are described at 42 CFR 422.501-3.

¹⁷ The District of Columbia, Idaho, and New Jersey directly capitate coverage of Medicaid services to the D-SNP, which means that the D-SNP also holds the Medicaid managed care contract for provision of services to D-SNP enrollees.

¹⁸ Enrollment in managed care through a D-SNP for dually eligible beneficiaries in the District of Columbia is voluntary (DC DHCF 2021).

¹⁹ In California, interviewees said the state also informs plans about proposed policies in its D-SNP policy guide, a separate document referenced in the SMAC that provides plans with operational and technical details for requirements such as data reporting.

²⁰ Since reporting requirements are listed in the D-SNP policy guide in California, rather than the SMAC, health plan representatives said delays between the SMAC execution date and the policy guide release can complicate efforts to submit reports as contractually required. A health plan said that it frequently does not receive reporting requirements from the state early enough to undergo necessary IT systems changes, and on occasion has had to resubmit data reports because guidelines on data reporting were released after reports were due. Health plan representatives also described an experience where it said that materials it printed to meet CMS deadlines needed to be reprinted due to the state's timing in providing guidance for required language, creating administrative burden and expenses for the plan.

²¹ When California replaced the Financial Alignment Initiative demonstration with D-SNPs in seven counties in 2023, it limited D-SNP contracts to plans that operate affiliated Medicaid plans in those counties and will require all Medicaid plans to have a D-SNP by 2026 (California DHCS 2022). California restricts new enrollment in non-AIP D-SNPs in counties in which AIP CO D-SNPs operate.

²² Minnesota said it tracks complaints from providers, which it uses as a flag to investigate further and determine how plans are performing. For example, state officials said one plan received complaints related to transportation and Minnesota spoke directly to the plan to address the issue. When the District of Columbia identifies spikes in appeals and grievances for certain types of services, officials said they escalate these issues with the plan as necessary.

²³ Minnesota uses data, including HRA completion and quality measures to set quality performance targets for its withholds and ensure plans are meeting those targets. Officials said that using data ensures they are setting attainable targets for their plans and establishes a precedent of monitoring and goal setting.

²⁴ Similarly, the District of Columbia said it receives HEDIS data and compiles it with measures reported by other health plans in the District. However, officials said these measures are not yet being used to inform operations, such as in the District's initiative focused on health equity.

²⁵ Departments may also divide oversight duties by plan contract. Minnesota said it has a team of contract managers who are responsible for compliance and oversight, with a team responsible for contract compliance assigned to each health plan. In Idaho, officials said a core D-SNP team oversees the state's four contracts and works with other groups on an ad hoc basis.

²⁶ Officials in several states said that other monetary tools, such as invoice reductions, are most effective in ensuring plan compliance. Idaho's SMAC has a detailed list of invoice reductions for plans that fail to report data or that do not meet specific metrics.

²⁷ In New Jersey, officials said FIDE SNP quality incentives are focused on Medicaid program goals that may apply to dually eligible beneficiaries, such as blood pressure, home and community-based service delivery, and nursing facility transition measures. For example, the state said it uses claims data to evaluate if services delivered match what the plan is authorized to provide. If the percentage match is high enough, plans can receive performance incentives.

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APPENDIX 2A: State Use of Selected Contracting Strategies in State Medicaid Agency Contracts

To better understand how states use their state Medicaid agency contracts (SMACs) to further integrated care for dually eligible beneficiaries enrolled in Medicare Advantage dual eligible special needs plans (D-SNPs), MACPAC enlisted Mathematica to conduct a review of all SMACs for contract year 2023. Our review found most contract provisions that go beyond federal minimum requirements fell under five categories: coverage alignment, care coordination, integrated materials and member experience, data sharing, and reducing health disparities and improving quality.

In Table 2A-1, column A includes all 45 states and the District of Columbia that contracted with D-SNPs in contract year 2023 and displays how many of these states use selected contracting strategies in their SMACs. Column B features the subset of these states that contract with highly integrated dual eligible special needs plans or fully integrated special needs plans, although these states may also contract with coordination-only dual eligible special needs plans.

TABLE 2A-1. State Use of Selected Contracting Strategies in State Medicaid Agency Contracts, May 2023

Contract provision category	Count of states with any D-SNP type that use selected contracting strategies (A)	Count of states with HIDE SNPs or FIDE SNPs that use selected contracting strategies (B)
Total number of states with plan type	46	21¹
Coverage alignment		
Limits enrollment to FBDE or requires separate PBPs ²	15	14
Requires EAE	9	9
Requires default enrollment	10	9
Care coordination		
Requirements regarding health risk assessments	11	10
Requirements regarding individualized care plans	9	8
Requirements regarding interdisciplinary care teams	7	6
Requirements for care coordinators	11	9
Requirements for aligned Medicare and Medicaid provider networks	6	6
Integrated materials and member experience		
State review of Medicaid information in D-SNP marketing or communication materials	19	14
State provides template language on Medicaid benefits for marketing or communication materials	6	4

TABLE 2A-1. (continued)

Contract provision category	Count of states with any D-SNP type that use selected contracting strategies (A)	Count of states with HIDE SNPs or FIDE SNPs that use selected contracting strategies (B)
Requires provider directory to indicate providers that accept both Medicaid and Medicare	17	10
Requires single ID card	9	9
Provides integrated customer service line	3	3
Requires integrated communication materials	9	9
Provides translation of enrollee materials	6	6
Data sharing		
Send MA encounter data	15	12
Send quality measure data	19	11
Data on plan determinations, appeals, grievances	13	11
HRA scores	11	9
Enrollment and disenrollment data	18	11
Medicare provider network data	13	10
Reducing health disparities and improving quality		
Requirements related to enrollee advisory committees	5	4
Requirements related to supplemental benefits	13	9
D-SNPs must identify and reduce health disparities among their members or share data on disparities	6	6
D-SNPs must participate in state Medicaid quality improvement initiatives	7	6

Notes: D-SNP is dual eligible special needs plan. HIDE SNP is highly integrated dual eligible special needs plan. FIDE SNP is fully integrated dual eligible special needs plan. FBDE is full-benefit dual eligible. PBP is plan benefit package. EAE is exclusively aligned enrollment. MA is Medicare Advantage. HRA is health risk assessment.

¹ The total number of states with HIDE SNPs or FIDE SNPs includes all states and the District of Columbia in which at least one plan with either designation operates.

² This category includes states that limit D-SNP enrollment to full-benefit dually eligible individuals for all or some of their D-SNPs, as well as states that require a separate PBP for partial-benefit dually eligible beneficiaries.

Source: MACPAC analysis of contract year 2023 state Medicaid agency contracts.

APPENDIX 2B: Case Study State Profiles

With Mathematica, MACPAC interviewed five case study states: California, the District of Columbia, Idaho, Minnesota, and New Jersey. Below, we provide brief summaries of the Medicare Advantage (MA) dual eligible special needs plan (D-SNP) coverage landscape for dually eligible individuals in each state.

Summaries describe the state’s dually eligible population, how Medicaid benefits—including medical services, behavioral health services, home- and community-based services, nursing facility services, and Medicare cost sharing—are covered, and the D-SNP parent organizations that operate within the state. Although both the full-benefit dually eligible population, comprising those that receive full Medicaid benefits, and partial-benefit dually eligible population, which includes those eligible only for Medicare cost sharing and premium assistance, are described, summaries describe only how Medicaid services are covered for the full-benefit dually eligible population.

Each summary details the number of D-SNP parent organizations operating in the state as of contract year 2023 as well as the range of experiences that D-SNPs have operating in that state.

D-SNPs operate at varying levels of integration and have additional requirements depending on the types of Medicaid services that the D-SNP covers. Integration types include coordination-only dual eligible special needs plans (CO D-SNPs), highly integrated dual eligible special needs plans (HIDE SNPs), and fully integrated dual eligible special needs plans (FIDE SNPs), which are described in this chapter. Each of these plan types may qualify as an applicable integrated plan (AIP) if states require that they use exclusively aligned enrollment, which allows D-SNPs to enroll only beneficiaries who are enrolled in an affiliated Medicaid managed care plan under the same parent organization.

TABLE 2B-1. Characteristics of Case Study States and their Dually Eligible Populations

State	Description
California	<p><u>Population</u></p> <p>Dually eligible individuals, 2022:</p> <ul style="list-style-type: none"> • Full benefit: 1,644,120 (98 percent) • Partial benefit: 28,773 (2 percent) <p>As of September 2023, full-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee-for-service or traditional MA: 1,213,455 (74 percent) • CO D-SNP: 164,300 (10 percent) • AIP CO D-SNP: 245,331 (15 percent) • AIP FIDE SNP: 21,034 (1 percent) <p><u>Services</u></p> <ul style="list-style-type: none"> • Medi-Cal managed care plans provide most services, excluding some behavioral health benefits that are delivered through county behavioral health agencies. Home- and community-based services are mostly fee for service, except through an affiliated Medi-Cal managed care plan for AIP FIDE SNPs <p><u>D-SNP parent companies</u></p> <ul style="list-style-type: none"> • Nineteen parent organizations (1 year–16 years)

TABLE 2B-1. (continued)

State	Description
<p>District of Columbia</p>	<p><u>Population</u></p> <p>Dually eligible individuals, 2022:</p> <ul style="list-style-type: none"> • Full benefit: 26,330 (70 percent) • Partial benefit: 11,059 (30 percent) <p>As of September 2023, full-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 17,219 (65 percent) • AIP HIDE SNP: 9,111 (35 percent) <p>As of September 2023, partial-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee-for-service or traditional MA: 5,239 (47 percent) • CO D-SNP: 5,820 (53 percent) <p><u>Services</u></p> <ul style="list-style-type: none"> • Most services are included in the D-SNP capitated rate, excluding some behavioral health services <p><u>D-SNP parent companies</u></p> <ul style="list-style-type: none"> • One parent organization (5 years–7 years)
<p>Idaho</p>	<p><u>Population</u></p> <p>Dually eligible individuals, 2022:</p> <ul style="list-style-type: none"> • Full benefit: 34,524 (63 percent) • Partial benefit: 20,324 (37 percent) <p>As of September 2023, full-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 20,192 (58 percent) • AIP FIDE SNP: 14,332 (42 percent) <p>As of September 2023, partial-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 19,149 (94 percent) • CO D-SNP: 1,175 (6 percent) <p><u>Services</u></p> <ul style="list-style-type: none"> • AIP FIDE SNPs, known in Idaho as Medicare-Medicaid Coordinated Plans, cover all services except Medicare cost sharing, which the state Medicaid agency pays to providers directly <p><u>D-SNP parent companies</u></p> <ul style="list-style-type: none"> • Two parent organizations (5 years–15 years)

TABLE 2B-1. (continued)

State	Description
Minnesota	<p><u>Population</u></p> <p>Dually eligible individuals, 2022:</p> <ul style="list-style-type: none"> • Full benefit: 137,246 (90 percent) • Partial benefit: 16,066 (10 percent) <p>As of September 2023, full-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 78,777 (57 percent) • AIP HIDE SNP: 11,618 (9 percent) • AIP FIDE SNP: 46,851 (34 percent) <p>As of September 2023, partial-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee-for-service or traditional MA: 19,149 (94 percent) <p><u>Services</u></p> <ul style="list-style-type: none"> • All services are provided by Minnesota Senior Health Options plans for AIP FIDE SNPs or through affiliated Special Needs Basic Care plans for AIP HIDE SNPs. The state Medicaid agency pays Medicare cost sharing directly to D-SNPs <p><u>D-SNP parent companies</u></p> <ul style="list-style-type: none"> • Eight parent organizations (1 year–16 years)
New Jersey	<p><u>Population</u></p> <p>Dually eligible individuals, 2022:</p> <ul style="list-style-type: none"> • Full benefit: 222,243 (88 percent) • Partial benefit: 29,489 (12 percent) <p>As of September 2023, full-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 129,118 (58 percent) • AIP FIDE SNP: 93,125 (42 percent) <p>As of September 2023, partial-benefit dually eligible individuals received their Medicare coverage through:</p> <ul style="list-style-type: none"> • Traditional Medicare fee for service or traditional MA: 29,489 (100 percent) <p><u>Services</u></p> <ul style="list-style-type: none"> • All services are included in the D-SNP capitated rate <p><u>D-SNP parent companies</u></p> <ul style="list-style-type: none"> • Five parent organizations (2 years–15 years)

Notes: MA is Medicare Advantage. Co D-SNP is coordination-only dual eligible special needs plan. AIP is applicable integrated plan. FIDE SNP is fully integrated dual eligible special needs plan. HIDE SNP is highly integrated dual eligible special needs plan. D-SNP is dual eligible special needs plan.

Sources: California DHCS 2024a, 2024b, 2023, 2022; CMS 2023a, 2023b, 2023c, 2022; DC DHCF 2022; Idaho DHW 2023; Minnesota DHS 2023, 2021, 2019; interviews with New Jersey Department of Human Services Division of Medical Assistance and Health Services staff.

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Commission Vote on Recommendations

In its authorizing language in the Social Security Act (42 USC 1396), Congress requires MACPAC to review Medicaid and CHIP program policies and make recommendations related to those policies to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states in its reports to Congress, which are due by March 15 and June 15 of each year. Each Commissioner must vote on each recommendation, and the votes for each recommendation must be published in the reports. The recommendations included in this report, and the corresponding voting record below, fulfill this mandate.

Per the Commission’s policies regarding conflicts of interest, the Commission’s conflict of interest committee convened prior to the vote to review and discuss whether any conflicts existed relevant to the recommendations. It determined that, under the particularly, directly, predictably, and significantly standard that governs its deliberations, no Commissioner has an interest that presents a potential or actual conflict of interest.

The Commission voted on these recommendations on April 12, 2024.

Optimizing State Medicaid Agency Contracts

- 2.1** State Medicaid agencies should use their contracting authority at 42 CFR 422.107 to require that Medicare Advantage dual eligible special needs plans (D-SNPs) operating in their state regularly submit data on care coordination and Medicare Advantage encounters to the state for purposes of monitoring, oversight, and assurance that plans are coordinating care according to state requirements. If states were required by Congress (as previously recommended by the Commission) to develop a strategy to integrate Medicaid and Medicare coverage for their dually eligible beneficiaries, states that include D-SNPs in their integration approach should describe how they will incorporate care coordination and utilization data and how these elements can advance state goals.
- 2.2** The Centers for Medicare & Medicaid Services should issue guidance that supports states in their development of a strategy to integrate care that is tailored to each state’s health coverage landscape. The guidance should also emphasize how states that contract with Medicare Advantage dual eligible special needs plans can use their state Medicaid agency contracts to advance state policy goals.

2.1-2.2 voting results	#	Commissioner
Yes	16	Allen, Bella, Bjork, Brooks, Duncan, Gerstorff, Giardino, Heaphy, Hill, Ingram, Johnson, Killingsworth, McCarthy, McFadden, Snyder, Weno
Not present	1	Medows

Chapter 3:

Medicare Savings Programs: Enrollment Trends

Medicare Savings Programs: Enrollment Trends

Key Points

- The Medicare Savings Programs (MSPs), which provide Medicaid coverage of Medicare premiums and cost sharing, have the potential to improve access to care for low-income Medicare beneficiaries. State Medicaid programs administer the MSPs. Most MSP enrollees are also eligible for full Medicaid benefits, known as “full-benefit dually eligible beneficiaries.” MSP enrollees are considered dually eligible even if their only Medicaid benefit is coverage under the MSPs. These individuals are considered “partial-benefit dually eligible beneficiaries.”
- In 2020, the Commission made recommendations aimed at improving participation in the MSPs. Those recommendations were based on an analysis of MSP participation in 2009 and 2010 that found relatively low rates of participation in the Qualified Medicare Beneficiary (QMB) eligibility group, the largest of the four MSPs.
- The Centers for Medicare & Medicaid Services subsequently addressed aspects of our recommendations in rulemaking aimed at streamlining eligibility and enrollment policies in Medicaid, including better aligning state MSP eligibility policies with those of the Medicare Part D Low-Income Subsidy program.
- The policy landscape has changed since our study of MSP participation. Major health care policy changes have occurred that have likely increased MSP enrollment. For example, the Patient Protection and Affordable Care Act (ACA; P.L. 111-148, as amended) was enacted in 2010 and gave states the option, in 2014, to expand to a new adult population. Since then, most states have adopted that expansion, leading to millions of new Medicaid enrollees. Although these new adult enrollees are not eligible for Medicare and would lose Medicaid eligibility upon becoming eligible for Medicare, some of them would likely become eligible for an MSP.
- Our new analysis found that about 10 million dually eligible beneficiaries were enrolled in an MSP in 2021, representing a majority of the 12.8 million dually eligible beneficiaries. Of those, 8 million were enrolled in the QMB group. Our analysis did not estimate participation in the MSPs. We also found higher MSP enrollment growth among partial-benefit dually eligible beneficiaries than the full-benefit population.
- Looking ahead, the disparate enrollment patterns we identified between full- and partial-benefit populations may represent areas for further research.

CHAPTER 3: Medicare Savings Programs: Enrollment Trends

Dually eligible beneficiaries, people who are eligible for both Medicare and Medicaid, may be eligible to receive Medicaid assistance with their Medicare premiums and cost sharing through the Medicare Savings Programs (MSPs). State Medicaid programs administer the MSPs, including determining eligibility and enrolling beneficiaries. Most MSP enrollees are also eligible for full Medicaid benefits and are considered full-benefit dually eligible beneficiaries (CMS 2024a). MSP enrollees are also considered dually eligible beneficiaries even if their only Medicaid benefit is coverage under the MSPs. These individuals are considered partial-benefit dually eligible beneficiaries.

The Commission has had a long-standing interest in the MSPs because of their potential to improve access to care for low-income Medicare beneficiaries. In 2020, the Commission made recommendations tied to increasing participation in the MSPs (MACPAC 2020). The Centers for Medicare & Medicaid Services (CMS) subsequently addressed aspects of the Commission's recommendations through proposed rulemaking aimed at streamlining eligibility and enrollment policies in Medicaid, including better aligning MSP eligibility policies with those of the Medicare Part D Low-Income Subsidy (LIS) program, which is administered by the Social Security Administration (SSA) (CMS 2022). After publishing the proposed rule in 2022, CMS indicated plans to publish the final rule in two parts with the first part focused on the MSPs. In that final rule, published in September 2023, CMS addressed many of the misalignments between state and SSA eligibility policies for MSPs and the LIS program (CMS 2023a). Additional changes streamlining eligibility and enrollment in Medicaid by aligning requirements for non-modified adjusted gross income (non-MAGI) populations with those of MAGI groups were included in the second part of the rule, which was recently finalized (CMS 2024b).

Our 2020 recommendations were based on an analysis of MSP participation that we did under contract with the Urban Institute and published in 2017 (Caswell and Waidmann 2017). In that study, we found relatively low rates of participation: 53 percent of people eligible for the Qualified Medicare Beneficiary (QMB) group and 32 percent of people eligible for the Specified Low-income Medicare Beneficiary (SLMB) group. We also previously found that assistance with cost sharing, which is available under the QMB eligibility group, could have a positive effect on access to care (Haber et al. 2014). Although payment policies are just one of several factors that could affect access, we found that as the Medicaid contribution toward Medicare cost sharing increases, beneficiaries are more likely to use selected outpatient services (Haber et al. 2014).

The policy landscape has changed since our study of MSP participation, particularly when considering the data we used represented the latter parts of calendar years 2009 and 2010. Participation rates in those years would not have accounted for several major health care policy changes that have occurred since then and that have likely contributed to increased MSP enrollment. The Patient Protection and Affordable Care Act (ACA; P.L. 111-148, as amended) was enacted in 2010 and gave states the option to expand Medicaid coverage to a new adult population beginning in 2014. The new adult population was not eligible in 2009 and 2010, the data years represented in our study of MSP participation. Since then, most states have adopted the Medicaid expansion under the ACA. Adults in the expansion population are not eligible for Medicare, and when they become eligible for Medicare, they lose their Medicaid coverage. However, states are required through federal regulation to determine if someone losing coverage in their original eligibility group is eligible under any other eligibility group included in the state plan. This procedure can result in MSP enrollment for individuals who became eligible for Medicare while enrolled in the new adult group—people who before 2014 would not have applied for Medicaid. Given the number of adults who gained Medicaid coverage in those states and the propensity those states showed to extend coverage to eligible groups by adopting the expansion, expansion adults who turned age 65 and became eligible for Medicare may have contributed to an increase in MSP enrollment.

Enrollment in the Medicare Advantage program has increased substantially in the last decade. From 2011 to 2022, the number of eligible Medicare beneficiaries enrolled in Medicare Advantage plans increased from 26 percent to 49 percent (Serna and Johnson 2023). Medicare Advantage plans have an incentive to make sure their enrollees are getting available Medicaid assistance with their Medicare premiums and cost sharing because that assistance conveys dually eligible status on the Medicare Advantage enrollee, and CMS's risk adjustment system pays higher capitation rates for dually eligible individuals than for individuals who are not dually eligible because of the higher risk scores associated with the dually eligible population.

To better understand MSP policy in today's changed landscape, we contracted with the Urban Institute to revisit the MSPs, this time by analyzing enrollment for calendar years 2010–2021 using Medicare administrative data from the Medicare Master Beneficiary Summary File. We set out to describe enrollment trends across the MSPs over a 12-year period with a focus on the QMB plus group, for individuals who meet the QMB eligibility criteria and also qualify for full Medicaid benefits, which accounts for more than 60 percent of all MSP enrollees (Table 3-3). Our findings indicate that a majority of dually eligible beneficiaries are enrolled in an MSP. In 2021, around 80 percent of dually eligible beneficiaries, or about 10 million people, were enrolled in an MSP. Of these, 6.3 million were enrolled in the QMB plus group and were eligible for full Medicaid benefits. Our analysis did not estimate MSP participation rates and instead focused on actual enrollment using administrative data.

This chapter begins with an overview of each of the four MSPs, including eligibility criteria and benefits covered. It reviews our prior work estimating participation rates and describes recent federal and state efforts to streamline enrollment into the MSPs. Finally, it describes findings from our analysis of MSP enrollment trends over a 12-year period, including comparisons of enrollment in the QMB plus group by demographic characteristic such as age, sex, and urban or rural residence.¹

Overview of the MSPs

The MSPs provide Medicaid coverage of Medicare premiums and cost sharing to eligible low-income Medicare beneficiaries. Once Medicare beneficiaries enroll in an MSP, they are considered dually eligible. States receive their regular federal medical assistance percentage (FMAP) for MSP expenditures.² Four mandatory MSP eligibility pathways provide varying levels of assistance and have different eligibility criteria (Table 3-1). They include the QMB group, the SLMB group, the Qualifying Individual (QI) group, and the Qualified Disabled and Working Individual (QDWI) group. When individuals are enrolled only in MSP benefits, without being simultaneously enrolled in full Medicaid benefits, they are considered partial-benefit dually eligible beneficiaries. For example, people who are enrolled only in the QMB eligibility group, without full Medicaid benefits, are known as “QMB only enrollees.” This is a partial-benefit category of dual eligibility. People who are enrolled in both the QMB eligibility group and full Medicaid are known as “QMB plus enrollees” and are considered full-benefit dually eligible beneficiaries. The QI and QDWI groups cover only Medicare premiums. Few people are enrolled in the QDWI group because it serves a limited population: individuals with disabilities who have returned to work and are no longer eligible for premium-free Medicare Part A coverage. Because enrollment in QDWI is so low, we excluded it from our MSP enrollment analysis.

Benefits, eligibility, and structure

The QMB eligibility group was enacted in 1986 and is the most expansive of the MSPs in terms of the number of enrollees it covers and the benefits it provides. Originally a state option, Congress subsequently made the QMB group mandatory in the Medicare Catastrophic Coverage Act of 1988 (P.L. 100-360) (Rosenbach and Lamphere 1999). For QMB-eligible individuals, Medicaid pays for Medicare Part A (hospital insurance) premiums as well as Medicare Part B (supplementary medical insurance) premiums and Medicare coinsurance, deductibles, and copayments. To qualify for QMB, individuals must typically have income at or below 100 percent of the federal poverty level (FPL) and limited assets.³

TABLE 3-1. Medicare Savings Program Eligibility and Benefits, CY 2024

Medicare Savings Program (MSP) beneficiaries		Enrolled in full Medicaid benefits	Dual eligibility type	MSP income threshold as % of FPL	Qualify for Medicaid payment of:	Federal asset limits, 2024	
						Individual	Couple
QMB	Only	No	Partial	At or below 100%	Medicare Part A premiums (if needed); Medicare Part B premiums; Medicare coinsurance, deductibles, and copayments	\$9,430	\$14,130
	Plus	Yes	Full		Medicare Part A premiums (if needed); Medicare Part B premiums; Medicare coinsurance, deductibles, and copayments; all Medicaid-covered services under the state plan	2,000	3,000 ¹
SLMB	Only	No	Partial	101–120	Medicare Part B premiums	9,430	14,130
	Plus	Yes	Full		Medicare Part B premiums ² ; all Medicaid-covered services under the state plan	2,000 ¹	3,000 ¹
QI		No	Partial	121–135	Medicare Part B premiums	9,430	14,130
QDWI		No	Partial	At or below 200	Medicare Part A premiums	4,000	6,000

Notes: CY is calendar year. MSP is Medicare Savings Program. FPL is federal poverty level. QMB is Qualified Medicare Beneficiary. SLMB is Specified Low-income Medicare Beneficiary. QI is Qualifying Individual. QDWI is Qualified Disabled and Working Individual.

¹ Many states have spenddown programs in place that enable older adults and people with disabilities to qualify for full Medicaid benefits even if they have assets above these limits through a medically needy pathway (KFF 2022).

² States may choose to pay for Medicare Parts A and B coinsurance, deductibles, and copayments in their state plans.

Sources: MACPAC and MedPAC 2024 and CMS 2023b.

There are two types of QMB enrollees: those who receive only QMB benefits (QMB only) and those who are enrolled in both QMB and full Medicaid benefits (QMB plus). QMB only enrollees are considered partial-benefit dually eligible beneficiaries because they are eligible only for Medicaid payment of Medicare premiums and cost sharing through the QMB eligibility group. QMB plus enrollees receive assistance with their Medicare premiums and cost sharing plus full Medicaid benefits through eligibility pathways that include receipt of Supplemental Security

Income benefits and the aged, blind, and disabled pathway for individuals who are low income and age 65 or older or who have a qualifying disability.

The SLMB eligibility group was enacted as part of the Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508); it originally covered beneficiaries with incomes between 101 percent and 110 percent of the FPL and was later expanded to cover individuals with incomes up to 120 percent of the FPL (MACPAC 2017, GAO 2012, Rosenbach and Lamphere 1999). Medicaid pays Medicare Part B premiums only for eligible

enrollees. As with the QMB group, individuals with SLMB benefits are categorized as SLMB only or SLMB plus based on whether they are enrolled only in SLMB or are also enrolled in full Medicaid benefits.

The QI eligibility group was enacted in the Balanced Budget Act of 1997 (P.L. 105-33). It initially was authorized to provide Medicaid assistance with Medicare Part B premiums for beneficiaries with incomes between 120 and 175 percent of the FPL, but the upper income eligibility limit was effectively lowered to 135 percent of the FPL in 2002 (GAO 2004).⁴ Unlike the QMB and SLMB groups, QI funding is provided to states through a federal allotment that is set at a specific amount each year. States receive 100 percent federal match up to the amount of the allotment. To qualify for QI benefits, an individual may not be enrolled in any other Medicaid eligibility group (CMS 2024c).

The QDWI group was enacted as part of the Omnibus Budget Reconciliation Act of 1989 (P.L. 101-239). It is the smallest of the MSPs. QDWI is designed to help pay the Part A premium for people who are disabled and younger than age 65 who have lost premium-free Part A coverage because they returned to work—a relatively small population (CMS 2024c, Merlis 2005).

Eligibility linkage with Medicare Part D LIS program

An automatic eligibility link exists between the MSPs and the Medicare Part D LIS program, which is administered by the SSA. The MSPs and LIS program are designed to serve similar populations. The LIS program provides subsidized coverage of Medicare Part D premiums and cost sharing for low-income Medicare beneficiaries up to 150 percent of the FPL.⁵ Starting in 2024, some people who are eligible for the LIS program will not be eligible for the MSPs because the LIS income threshold is higher than the MSP standard of 135 percent of the FPL. Anyone eligible for or enrolled in the MSPs is automatically eligible for the LIS program. However, people eligible for the LIS program are not automatically eligible for the MSPs. MSP participation rates are also generally lower than participation in the LIS program, perhaps because most LIS program enrollees are deemed eligible for the LIS program because they are enrolled in Medicaid (Fung et al. 2024, CMS 2023a). CMS has worked

to ease enrollment into the MSPs by establishing requirements for states to better align their MSP eligibility policies with those of the LIS program. Most recently, CMS finalized rulemaking in September 2023 to streamline eligibility and enrollment by codifying policies designed to ease enrollment into the MSPs (CMS 2023a). For more details on the final rule, see the section on CMS rulemaking.

State flexibility

States must use income and asset thresholds for the MSPs that are no more restrictive than the federal standards, but states have the flexibility under Section 1902(r)(2) to adopt more generous levels (Table 3-1). In 2023, 18 states and the District of Columbia opted to use more generous income and asset levels (MACPAC and MedPAC 2024). States choosing to make changes to their eligibility criteria may need to submit a state plan amendment to CMS for approval.

Prior MACPAC Work on MSP Participation Rates

The Commission previously reviewed barriers to participation in the MSPs and made recommendations to Congress on ways to increase MSP enrollment. In June 2020, the Commission recommended that Congress amend the Medicaid statute to require that states align their MSP eligibility determination policies with those that the SSA uses to determine eligibility for the LIS program. The Commission also recommended that the SSA transfer continuing LIS program eligibility data to states annually to help enrollees whose circumstances have not changed maintain their enrollment in the MSPs (Box 3-1) (MACPAC 2020).

States have discretion over how they administer their MSPs, and in some cases, state eligibility policies for MSPs do not align with those the SSA uses for the LIS program. This complicates states' ability to use just the SSA data to determine MSP eligibility. Because the LIS program and the MSPs are both designed to provide financial assistance to low-income Medicare beneficiaries to cover out-of-pocket Medicare costs, policymakers have looked for opportunities to further align the two programs where possible. CMS estimated that over 1 million individuals who were receiving the full

BOX 3-1. MACPAC Recommendation from June 2020 Report to Congress

Congress should amend Section 1902(r)(2)(A) of the Social Security Act to require that when determining eligibility for the Medicare Savings Programs (MSPs), states use the same definitions of income, household size, and assets as the Social Security Administration (SSA) uses when determining eligibility for the Part D Low-Income Subsidy (LIS) program. To reduce administrative burden for states and beneficiaries related to MSP redeterminations, Congress should amend Section 1144 of the Social Security Act to require SSA to transfer continuing LIS program eligibility data to states on an annual basis.

LIS subsidy were not enrolled in an MSP, even though the eligibility criteria for the two programs is so closely aligned that they would have probably been eligible for an MSP (CMS 2023a). In rulemaking that CMS finalized in September 2023, the agency largely addressed the misalignments between state and SSA eligibility policies, with a few exceptions, including the treatment of burial funds (CMS 2023a). Some states require that individuals set aside at least \$1,500 intended to offset the cost of burial in a separate account, without which the state will not disregard them as assets. In contrast, the SSA disregards burial funds up to \$1,500 for an individual when calculating assets for purposes of eligibility for the LIS program.

Policymakers have also raised concerns that people eligible for the MSPs might lose their MSP coverage during regular Medicaid benefit renewals because of the need to resubmit paperwork. Although dually eligible beneficiaries typically do not have big fluctuations in income that are likely to make them ineligible for Medicaid, individuals have been dropped from the MSPs for failure to produce paperwork that verifies that their situations have not changed. Studies have found that almost 30 percent of new full-benefit dually eligible beneficiaries lost Medicaid coverage for at least 1 month during the 12 months after they became dually eligible (Chidambaram and Burns 2022, Feng et al. 2019). Of the people who lost coverage, nearly 30 percent had short breaks in coverage of one to three months, likely for administrative reasons such as lack of familiarity with Medicaid policies and eligibility verification procedures (Feng et al. 2019, Riley et al. 2014).

In 2017, we set out to estimate rates of participation in each of the MSPs and to better understand the population eligible for an MSP but not enrolled.⁶ Prior studies on MSP eligibility and enrollment were difficult to conduct because household surveys do

not collect information on MSP participation, and administrative data sources do not identify the universe of individuals eligible but not enrolled in MSPs. Our study linked Medicaid administrative data from the Medicaid Statistical Information System (MSIS), which we used to capture MSP enrollment, with data from the Survey of Income and Program Participation. The linked survey data enabled us to study the entire MSP-eligible population—those eligible and enrolled as well as those eligible but not enrolled—and rates of MSP participation. Previous studies also linked administrative data with survey data but did not estimate participation rates for each of the MSPs, instead presenting one combined participation rate across all MSPs (Sears 2002, Rupp and Sears 2000). One study found that about 63 percent of non-institutionalized eligible individuals had enrolled in the QMB and SLMB groups in 1999 (Rupp and Sears 2000). Another study estimated a combined participation rate of 64 percent in 2001 (Haber et al. 2003).

We estimated that 53 percent of MSP-eligible individuals participated in the QMB group and that 32 percent participated in the SLMB group. These participation rates are best interpreted as representing the latter parts of calendar years 2009 and 2010. We also found that adults eligible for but not enrolled in the QMB group, compared to QMB enrollees, had the following characteristics:

- more likely to be 65 and older;
- more likely to be white, non-Hispanic;
- more likely to report excellent or very good health; and
- less likely to report limitations in activities of daily living.

Moreover, about 45 percent of adults who enrolled in the QMB group were also enrolled in other public programs such as the Supplemental Nutrition Assistance Program or the Supplemental Security Income program.

Federal and State Efforts to Increase Enrollment

The federal government and states have been engaged over the years in efforts to align MSP enrollment policies with those the SSA uses for the LIS program because of similarities between the two programs. They provide similar benefits, namely assistance with Medicare premiums and cost sharing, to individuals with similar levels of income and assets.

CMS has provided ongoing guidance to states about ways to align state MSP eligibility policies with those used by the SSA for the LIS program with the goal of streamlining enrollment across the MSPs and LIS program. For example, in 2010, CMS published a state Medicaid director's letter explaining how states could use the data from the SSA as an application for the MSPs (CMS 2010). CMS reiterated this guidance in 2020 in chapter 1 of the *Manual for State Payment of Medicare Premiums* and again in 2021 in a CMS informational bulletin (CMS 2024d, 2021).

CMS rulemaking. In September 2023, CMS finalized the portions of a 2022 proposed rule on Medicaid eligibility and enrollment that pertain to better aligning MSP policies with those of the SSA (CMS 2023a, 2022). In that final rule, CMS codified existing policies related to facilitating enrollment in the MSPs, including the requirement enacted in the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) that mandates states use data from LIS applications, referred to as “leads data,” from the SSA to initiate an MSP application (CMS 2023a). States receive leads data from the SSA every business day (CMS 2023a). Although this requirement was enacted in MIPPA in 2008, CMS indicated concern that not all states were using the leads data and were instead requiring beneficiaries to complete a new MSP application (CMS 2023a). This process often includes providing information that the beneficiary has already shared with the SSA in their LIS application.

The final rule also encourages states to align their eligibility policies with those that the SSA uses so that states can more easily use the LIS leads data to determine MSP eligibility (CMS 2023a). For example, Medicaid policies differ from SSA policies in how certain assets are treated, such as burial funds and life insurance policies. States have the option under current law to align MSP eligibility criteria with those that the SSA uses, but not all states have done so. Under the 2023 final rule, states that have not aligned their policies with the SSA will be required to accept self-attestation from beneficiaries for income and assets that the MSPs count but the LIS program does not unless the state already has other recent information with which the self-attestation is not reasonably compatible. States that observe discrepancies between self-reported information and state data that are not reasonably compatible can require additional information from beneficiaries (Burns 2023). Under the final rule, states also retain the option to conduct a post-enrollment verification of income, such as interest or dividends, and request additional information from beneficiaries.

CMS notes in the final rule that feedback from states on the proposed rule indicated a lack of familiarity with the LIS leads data (CMS 2023a). CMS also acknowledged the burden on states of additional requirements while states are responding to the unwinding of the public health emergency. As a result, CMS extended the deadline for state compliance with most of the provisions of the rule to April 1, 2026.

The second part of the 2022 proposed rule was recently finalized and included changes to streamline eligibility, including enrollment and renewal procedures, by better aligning non-MAGI groups with MAGI groups (CMS 2024b). In the final rule, CMS acknowledged the relative stability of income for the non-MAGI populations relative to the MAGI groups and noted that changes to align the two groups promote equity across Medicaid beneficiaries (CMS 2024b).

MSP enrollees can benefit from these changes to the extent those policies prevent instability in their Medicaid eligibility and help them avoid potential Medicare coverage gaps as a result of a loss of Medicaid assistance with Medicare premiums and cost sharing. Currently, states are required to redetermine Medicaid eligibility at least every 12 months for Medicaid

enrollees, such as dually eligible beneficiaries, whose eligibility is determined on a basis other than MAGI (42 CFR 435.916(b)).⁷ States must attempt an ex parte renewal for all Medicaid beneficiaries, which means using information available to the state Medicaid agency, including information from electronic data sources, to renew eligibility without requiring additional beneficiary action (MACPAC 2023).⁸ Although many dually eligible beneficiaries may not have fluctuations in income that are likely to make them ineligible for Medicaid, as of January 2023, about half of states successfully completed ex parte renewals for about 50 percent or more of their Medicaid eligibility renewals, and only six states reported conducting more than 50 percent of Medicaid eligibility renewals for non-MAGI eligibility groups in July 2022 (Brooks et al. 2023, Musumeci et al. 2022). In the same survey, 28 states reported adopting at least 1 new strategy to increase the share of non-MAGI renewals completed using ex parte (Musumeci et al. 2022).

Some states have exercised their statutory flexibility to expand MSP income and asset thresholds beyond the federal standards, making more individuals eligible. As of November 2023, 18 states plus the District of Columbia have expanded income and asset thresholds above the federal standards (MACPAC and MedPAC 2024). Some states have also restructured their MSP eligibility policies to reduce confusion for beneficiaries and for the people administering the programs.

Interviews with states. To get a sense of state activity around the MSPs in light of CMS rulemaking, we talked to three states that made recent changes to the MSPs or are otherwise engaged in enrolling eligible beneficiaries. One state told us that the SSA LIS leads data transfer is not streamlined and requires a fair amount of work to use. We were told data arrive in a format that the state has had difficulty integrating into its existing eligibility systems. Another state told us that asset tests are a barrier to MSP enrollment and that other efforts, such as outreach, have brought in few new enrollees. We also heard that the structure of the MSPs could be more streamlined. Finally, we heard that while states are supportive of the recent CMS rulemaking, expectations around implementation time frames are challenging as states are still making their way through the unwinding of the public health emergency.

MSP Enrollment Trends from 2010 to 2021

To better understand current MSP policy and to contribute to the renewed national conversation about the MSPs prompted by CMS rulemaking, we set out to describe MSP enrollment trends using the most recent available data. We contracted once again with the Urban Institute. Our prior work estimating participation rates was cited in the recent CMS rulemaking, but because of the challenges associated with obtaining the data needed to estimate those rates, we could not easily update our prior work (CMS 2023a). Instead, we pivoted to readily available monthly MSP enrollment data for calendar years 2010–2021 and analyzed MSP enrollment trends over that period. The final two years of the study period, 2020 and 2021, were affected by the COVID-19 public health emergency and the Medicaid continuous coverage requirement that was enacted, which paused Medicaid redeterminations in both years.

We used administrative data from the Medicare Master Beneficiary Summary File to analyze enrollment in each MSP and compare enrollment patterns across MSPs. We also compared enrollees in different MSPs by demographic characteristics, including age, sex, and urban or rural residence.⁹ In these comparisons, we focused on the QMB plus group because it has the most enrollees and offers the most comprehensive benefits. We describe the enrollment patterns below, but we are not able to draw conclusions or explain the take-up rates among eligible beneficiaries. We did not engage in comparisons of MSP enrollment patterns relative to the broader dually eligible population or attempt to place the MSP trends we identified into a larger programmatic context. Those elements were outside the scope of our project.

Enrollment. MSP enrollment steadily increased over the study period. In 2021, of the 12.8 million dually eligible beneficiaries in the country, 10 million were enrolled in an MSP (Table 3-2) (MACPAC and MedPAC 2024). Enrollment increased in all of the MSPs since 2010 at an average annual growth rate of 3.0 percent. This growth is slightly higher than the 2.4 percent average annual growth in the Medicare program from 2013 to 2022 (CMS 2023c).

TABLE 3-2. Medicare Savings Program Enrollment, CY 2010–2021 (millions)

Type of MSP	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	Average annual growth, 2010–2021
All MSPs	7.2	7.5	7.9	8.1	8.3	8.5	8.7	8.9	9.1	9.3	9.7	10.0	3.0%
QMB plus	4.8	4.8	5.0	5.1	5.3	5.3	5.4	5.6	5.6	5.8	6.1	6.3	2.6
QMB only	1.0	1.2	1.2	1.3	1.4	1.4	1.5	1.5	1.6	1.5	1.7	1.7	4.7
SLMB plus	0.2	0.2	0.2	0.2	0.3	0.3	0.3	0.3	0.3	0.3	0.3	0.3	4.0
SLMB only	0.8	0.9	0.9	0.9	0.9	1.0	1.0	1.0	1.0	1.0	1.0	1.0	2.6
QI	0.4	0.5	0.5	0.5	0.5	0.5	0.5	0.5	0.6	0.6	0.6	0.6	3.0

Notes: CY is calendar year. MSP is Medicare Savings Program. QMB is Qualified Medicare Beneficiary. SLMB is Specified Low-income Medicare Beneficiary. QI is Qualifying Individual. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

Most MSP enrollees, 6.3 million people in 2021, were enrolled in both QMB benefits and full Medicaid benefits, therefore qualifying as QMB plus enrollees (Table 3-2, Figure 3-1). QMB plus is the dual eligibility category with the highest levels of enrollment in any year. This group is also the most comprehensive in terms of the benefits offered, which include payment of both Medicare Part A and Part B premiums as well as coverage of Medicare cost sharing and full Medicaid benefits to pay for Medicaid-covered services that Medicare does not cover.

The SLMB plus group, in contrast, had the lowest enrollment of any of the categories (Table 3-2, Figure 3-2). To be eligible for SLMB benefits, beneficiaries must have incomes that fall between 101 percent and 120 percent of the FPL, a range within which most people will not qualify for full Medicaid benefits except through a medically needy pathway. Further, SLMB plus enrollees receive coverage for Medicare Part B premiums and full Medicaid benefits, and states can opt to cover Medicare cost sharing for these individuals as a state plan benefit. They are not eligible for Medicaid assistance with Medicare Part A premiums.

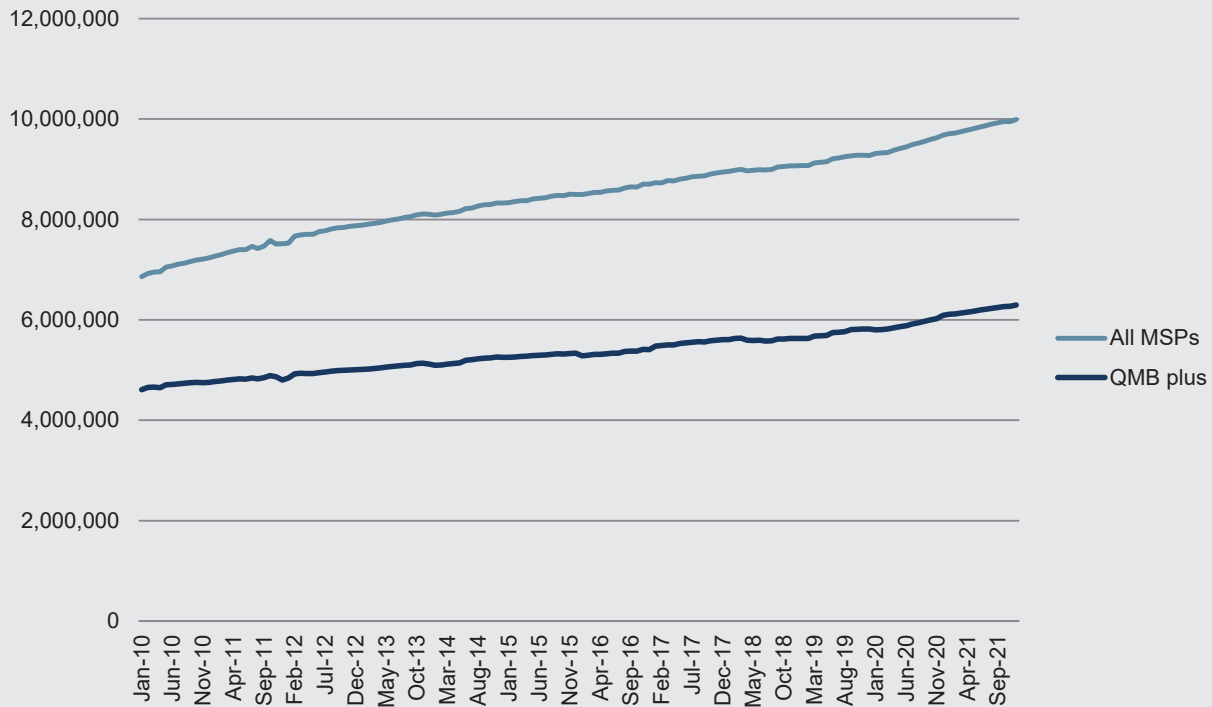
More analysis is needed to understand the differences in enrollment patterns between the full-benefit and partial-benefit groups. Enrollment in the QMB plus group is higher in every year than the QMB only group, but the opposite is true in the SLMB group (Table 3-2). SLMB only enrollment exceeds SLMB plus enrollment

in every year. There could be a smaller share of SLMB enrollees in the SLMB plus group because effective state income limits for the aged, blind, and disabled pathways, through which many SLMB plus individuals receive full Medicaid benefits, are generally less than the SLMB income limits. QMB plus enrollment grew at a slower average annual rate, 2.6 percent, than QMB only enrollment, for which the rate was 4.7 percent. In contrast, SLMB plus enrollment had higher average annual growth (4.0 percent) than SLMB only enrollment (2.6 percent).

The QI eligibility group had lower enrollment levels than the other MSPs and dual eligibility categories, with the exception of enrollment in SLMB plus (Table 3-2). The income eligibility range for the QI group, between 121 percent and 135 percent of the FPL, is narrower and higher than the range used for the SLMB group.

Share of enrollment. Enrollment was not distributed evenly across the MSPs. Although enrollment increased across the study period, the composition of enrollment by MSP did not change much. QMB plus, the dual eligibility category that offers the most comprehensive benefits to people with the lowest income, accounted for the largest share of MSP enrollment across the 12-year period, making up almost 63 percent of dually eligible beneficiaries with MSP benefits in 2021 (Table 3-3). The SLMB plus category had the lowest share of total enrollment across all years.

FIGURE 3-1. Comparison of Monthly Enrollment in All Medicare Savings Programs with Enrollment in the Qualified Medicare Beneficiary Plus Group, CYs 2010–2021



Notes: CY is calendar year. MSP is Medicare Savings Program. QMB is Qualified Medicare Beneficiary. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

The share of enrollment that each dual eligibility category comprised was fairly consistent over the 12-year period, with the exception of a steadier increase in QMB only enrollees as a share of total enrollment (Table 3-3). The QMB only group saw its share of enrollment increase in every year of the study period, with the exception of 2019. These steady increases could be related to the enactment of the ACA in 2010 and the subsequent implementation in 2014, which may have increased awareness of available coverage options, leading more people to enroll in those years (Table 3-3). In addition, MIPPA included increased federal funding for outreach to individuals eligible for the MSPs, which may have led to increased enrollment. Further analysis is needed to better understand the different enrollment patterns for partial-benefit dually eligible beneficiaries relative to full-benefit individuals.

Enrollment growth. QMB only enrollment experienced the highest rates of growth year over year with several years experiencing growth of 5 percent or higher, exceeding the growth in other dual eligibility categories in most years (Table 3-4, Figure 3-2). In addition, over the 12-year window, the QMB only group had the highest average annual enrollment growth at 4.7 percent relative to 2.6 percent in the QMB plus group and 4.0 percent in the SLMB plus group. We also noted the differing growth rates among partial-benefit dually eligible categories in comparison to growth rates among full-benefit dually eligible categories. Further research in these areas will help us better understand the reasons for higher enrollment growth rates among partial-benefit dually eligible beneficiaries, primarily QMB only, and the underlying causes of variation among growth rates.

SLMB enrollment experienced flatter growth than the other MSPs for most of the 12-year period, with enrollment in the SLMB only and SLMB plus categories growing at less than 1 percent in some years (Table 3-4). SLMB enrollment levels also were relatively low compared to the other MSPs. The District of Columbia and New York have changed the structure of their MSPs by effectively combining the SLMB group with the QMB group to simplify and reduce confusion for beneficiaries.¹⁰ Beneficiaries and states may find the current MSP structure confusing because it has multiple programs, each offering coverage of different benefits at different income and asset thresholds.

QMB plus group enrollment by demographic characteristics

In this section, we examine enrollment in the QMB plus group by demographic characteristics including sex, age, and urban or rural residence. We focus on the QMB plus group because it accounts for more than 60 percent of all MSP enrollees (Table 3-4). QMB plus enrollees are more likely to be women, to be age 65 or older, and to live in an urban area.

Sex. In 2021, 3.8 million QMB plus enrollees, or about 60 percent, were women (Figure 3-2). The average annual growth rate for female QMB plus enrollees was 3.2 percent compared to 2.2 percent among male enrollees.

TABLE 3-3. Share of Enrollment by Type of Medicare Savings Program, CYs 2010–2021

MSP	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
QMB plus	65.7	63.9	63.6	63.2	63.1	62.8	62.1	62.7	62.1	62.8	62.9	63.0
QMB only	14.4	15.4	15.4	15.9	16.4	16.5	17.1	17.2	17.2	16.7	17.4	17.2
SLMB plus	3.1	3.2	3.1	3.1	3.0	3.1	3.0	3.1	3.2	3.1	3.3	3.4
SLMB only	10.9	11.3	11.4	11.4	11.1	11.2	11.2	11.0	11.2	11.1	10.6	10.4
QI	5.9	6.2	6.5	6.4	6.4	6.4	6.2	6.0	6.3	6.3	5.9	5.9

Notes: CY is calendar year. MSP is Medicare Savings Program. QMB is Qualified Medicare Beneficiary. SLMB is Specified Low-income Medicare Beneficiary. QI is Qualifying Individual. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

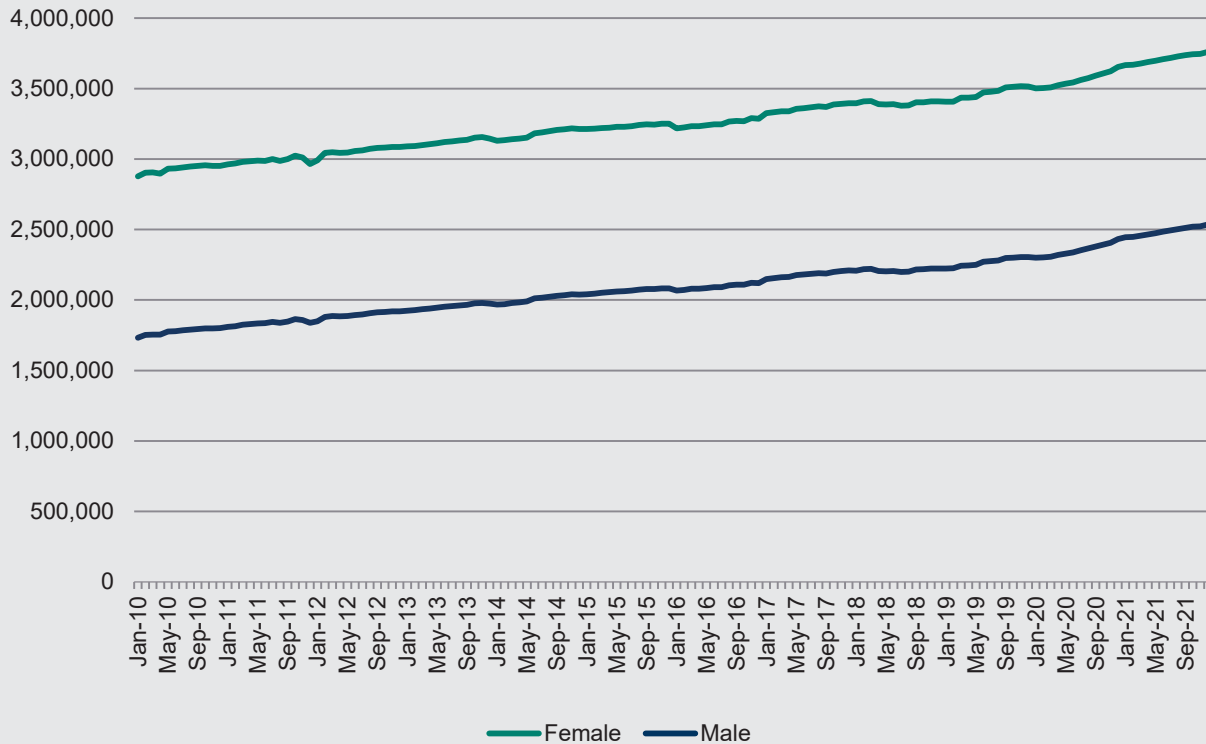
TABLE 3-4. Annual Medicare Savings Program Enrollment Growth Rates, CYs 2011–2021

MSP	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
All MSPs	4.0%	4.7%	2.9%	2.8%	2.0%	2.2%	3.0%	1.4%	2.3%	4.4%	3.2%
QMB plus	1.1	4.2	2.3	2.6	1.6	1.3	3.7	0.4	3.4	4.6	3.4
QMB only	11.4	4.3	6.9	5.4	2.7	6.6	3.3	1.2	-0.8	8.6	2.2
SLMB plus	5.6	3.1	2.2	1.6	3.7	1.0	4.9	3.4	0.7	9.0	8.7
SLMB only	8.2	5.6	2.2	0.4	3.1	2.7	0.4	3.5	1.3	-0.4	1.7
QI	9.4	10.3	1.3	2.7	1.8	-1.3	-0.4	6.9	2.1	-2.6	3.8

Notes: CY is calendar year. MSP is Medicare Savings Program. QMB is Qualified Medicare Beneficiary. SLMB is Specified Low-income Medicare Beneficiary. QI is Qualifying Individual. This table excludes the Qualified Disabled and Working Individual group because enrollment is too small to report. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

FIGURE 3-2. Qualified Medicare Beneficiary Plus Monthly Enrollment by Sex, CYs 2010–2021

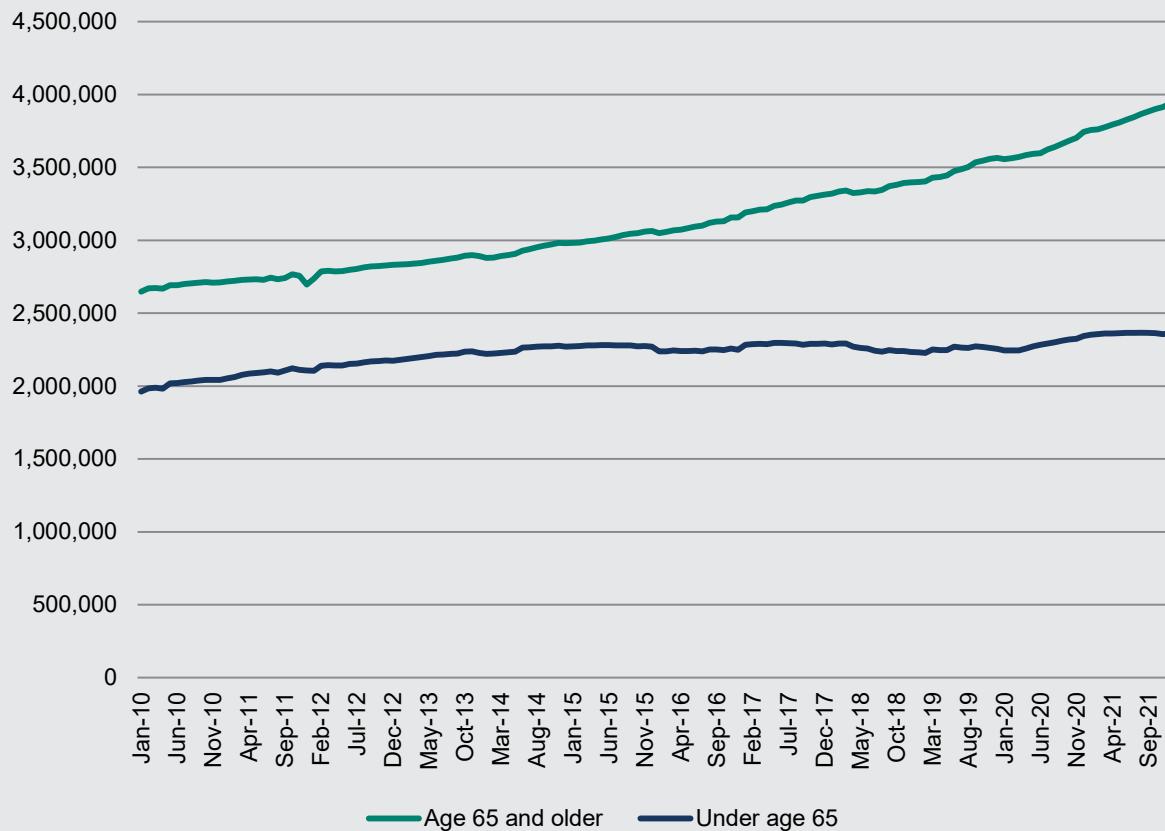


Note: CY is calendar year. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

Age. Among QMB plus enrollees, 62.5 percent were age 65 or older and 37.5 percent were younger than age 65 (Figure 3-3). Among all Medicare beneficiaries, the age split was different, with a larger share of the population (87 percent) older than 65 in 2021 (CMS 2023d). This indicates that a greater share of the younger dually eligible population (37.5 percent) is enrolled in the QMB plus group than we would have assumed (13.0 percent) if the proportions were aligned with Medicare (CMS 2023d). We found different growth patterns among people younger than age 65 and people who are 65 years old or older. Enrollment grew steadily among QMB plus enrollees age 65 or older (3.4 percent), which is consistent with overall Medicare enrollment growth rates

among the same age group (3.2 percent) (CMS 2023c). Among younger QMB plus enrollees, enrollment growth has been relatively flat (1.3 percent) but higher than average for Medicare beneficiaries who are disabled (-0.9 percent) (CMS 2023c). The differences between age groups may reflect the aging of the population, particularly among people born between 1946 and 1964 who are turning age 65 between the years 2011 and 2029, often referred to as the “baby boom generation.” This demographic shift may explain the upward trend among people age 65 and older and the flatter growth among the younger population (Figure 3-3).

FIGURE 3-3. Qualified Medicare Beneficiary Plus Monthly Enrollment by Age, CYs 2010–2021


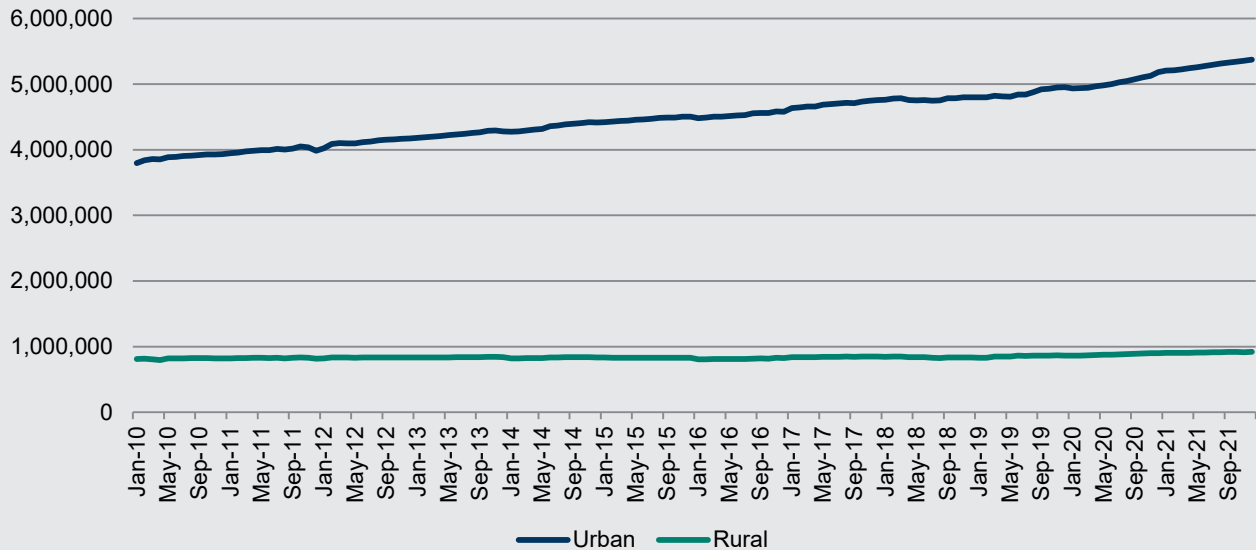
Note: CY is calendar year. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

Urban or rural residence. QMB plus enrollees lived primarily in urban areas (85 percent) rather than in rural areas (15 percent) in 2021 (Figure 3-4). This trend is consistent with the overall Medicare population, 83 percent of which lived in an urban area in 2021 (CMS 2024a). QMB plus enrollment grew steadily among people living in urban areas at an average annual growth rate of about 3 percent, but enrollment growth among people living in rural areas was relatively flat across the study period at 1 percent. This flat growth may indicate an area for more focused outreach efforts. Future work could explore whether a gap exists between the eligible but not enrolled populations in rural areas as compared to urban areas, perhaps indicating that more eligible people are enrolling in rural areas than in urban ones.

Race and ethnicity. The Medicare Master Beneficiary Summary File data on race and ethnicity were not of sufficient quality to use in this analysis, but in a prior analysis of calendar year 2020 data from the Transformed Medicaid Statistical Information System (T-MSIS), around 20 percent of QMB enrollees were Black or Hispanic, compared to 9 percent or less among non-dually eligible Medicare beneficiaries (Table 3-5). Efforts to increase enrollment in the MSPs may therefore have a disproportionate effect on these subpopulations, creating an opportunity to address potential health disparities. More research is needed to identify potential differences among subpopulations.

FIGURE 3-4. Qualified Medicare Beneficiary Plus Monthly Enrollment by Urban or Rural Residence, CYs 2010–2021



Note: CY is calendar year. CYs 2020 and 2021 were affected by the COVID-19 public health emergency and the enactment of the Medicaid continuous coverage requirement, which paused Medicaid redeterminations in both years.

Source: MACPAC, 2023, analysis of monthly administrative data from the Medicare Master Beneficiary Summary File, under contract with the Urban Institute.

Conclusions and Next Steps

The landscape of coverage for MSP-eligible individuals has changed since our prior work in ways that have likely increased enrollment in the MSPs, such as states opting to expand MSP eligibility beyond the federal standards. Our analysis of Medicare administrative data found that MSP enrollment increased from 2010 to 2021 across all categories of dual eligibility, with the majority of dually eligible beneficiaries enrolled in an MSP. These findings indicate that state and federal efforts over the last decade to increase awareness of the MSPs among eligible low-income Medicare beneficiaries have made substantial progress. The Commission applauds these efforts.

The enrollment analysis described in this chapter may indicate opportunities for further research to continue the progress toward enrolling MSP-eligible people in an MSP and to explain some of the

enrollment patterns we found. For example, higher enrollment growth rates among partial-benefit dually eligible beneficiaries, primarily among the QMB only group, differed from those of the full-benefit groups, but the reasons for those differences are unclear. Another study found similar differences between the full- and partial-benefit groups, identifying lower rates of disenrollment among partial-benefit dually eligible beneficiaries (Chidambaram and Burns 2022). Perhaps state and federal efforts to conduct MSP outreach had a greater effect on enrollment of QMB only beneficiaries because, unlike full-benefit individuals, they would not have contact with Medicaid agencies otherwise. More research is needed to understand these differing enrollment patterns, but given the relative stability of income among the non-MAGI groups, a more automatic enrollment mechanism could be worth exploring to address the disparity in enrollment between the full- and partial-benefit populations.

TABLE 3-5. Transformed Medicaid Statistical Information System (T-MSIS) Data on Race and Ethnicity among Qualified Medicare Beneficiary and Specified Low-Income Medicare Beneficiary Groups, CY 2020

Race and ethnicity	All dually eligible	QMB		SLMB		Non-dually eligible Medicare beneficiaries ¹
		QMB only	QMB plus	SLMB only	SLMB plus	
White, non-Hispanic	52%	53%	45%	61%	70%	82%
African American, non-Hispanic	21	24	20	23	18	9
Hispanic	17	18	20	12	8	6
Other	10	6	14	4	4	3

Notes: CY is calendar year. QMB is Qualified Medicare Beneficiary. SLMB is Specified Low-income Medicare Beneficiary.

¹ Data on non-dually eligible Medicare beneficiaries is from the MACPAC and Medicare Payment Advisory Commission (MedPAC) analysis of spending and utilization among dually eligible beneficiaries for CY 2020 (MACPAC and MedPAC 2024).

Sources: MACPAC, 2023, analysis of T-MSIS data for CY 2020, and MACPAC and MedPAC 2024.

MACPAC plans to monitor state efforts to come into compliance with the CMS final rule ahead of the April 1, 2026, deadline.¹¹ We are interested to see how states approach the new requirements. Some states may choose to use the final rule as an opportunity to consider more comprehensive changes to reduce confusion and make enrollment easier, which could include adopting more automatic enrollment procedures. For example, CMS approved the use of passive enrollment with an opt-out in states participating in the Financial Alignment Initiative demonstrations. Some stakeholders raised concerns at the time about limiting beneficiary choice, but we found passive enrollment to be a key factor in enrolling and retaining eligible individuals (MACPAC 2019). The Medicare Payment Advisory Commission described passive enrollment as a policy that would encourage the development of integrated plans and found that it was a key factor in plan decisions to participate in the Financial Alignment Initiative demonstration (MedPAC 2018).

It may also be useful for researchers to consider ways to communicate with beneficiaries about the MSPs and to collect their feedback on barriers to enrollment, including potential confusion around eligibility and benefits. MACPAC has found that although beneficiary communication preferences and ability to access technology vary, providing multiple avenues to connect with Medicaid ensures that

individuals complete processes in a way that best meets their needs (MACPAC 2022). Beneficiaries could highlight opportunities for policymakers interested in streamlining and simplifying MSP enrollment and marketing.

In the coming years, MACPAC will remain attentive to state and federal efforts to increase enrollment in the MSPs, particularly in the lead up to the 2026 deadline for the CMS final rule (CMS 2023a). MACPAC looks forward to opportunities to collaborate with researchers on the topic and share information we have gathered through our work on the MSPs.

Endnotes

¹ The Medicare Master Beneficiary Summary File data on race and ethnicity were not of sufficient quality to include in our study.

² The exception is the qualifying individual group, which is fully federally funded through annual allotments to states (CMS 2023b).

³ States have the option under Section 1902(r)(2) of the Social Security Act to use more generous income and asset criteria for MSPs than the federal standards. In 2023, 19 states did so (MACPAC and MedPAC 2024).

⁴ Originally, the QI program had two parts: QI-1 for individuals with incomes of at least 120 percent but less than 135 percent of the FPL and QI-2 for individuals with incomes of at least 135 percent but less than 175 percent FPL (GAO 2004). In December 2002, the QI-2 program was allowed to expire, but the QI-1 program was reauthorized. It was subsequently reauthorized a number of times before being made permanent with the passage of the Medicare Access and CHIP Reauthorization Act of 2015 (P.L. 114-10). That legislation funded the QI program through 2016 and established a formula for calculating funding allocations for all future years (CRS 2015).

⁵ With enactment of the Inflation Reduction Act of 2022 (P.L. 117-169), beginning in calendar year 2024, individuals with incomes up to 150 percent of the FPL are now eligible for the full subsidy under the LIS program (Feyman et al. 2024). Before enactment of the Inflation Reduction Act, the full subsidy was available to people with incomes up to 135 percent of the FPL.

⁶ The QDWI program was excluded from our study because enrollment in the program at less than 1,000 individuals was too small with respect to the data and methods we were using.

⁷ MAGI-based methods are used to determine income eligibility for most Medicaid beneficiaries, including children, pregnant people, parents, and adults younger than age 65 without dependent children. Eligibility groups for whom income eligibility is determined using other (non-MAGI) methods include those who are eligible based on age or disability; those whose eligibility for Medicaid does not require a Medicaid determination of income, such as individuals receiving Supplemental Security Income or Title IV-E child welfare assistance; those in need of long-term services and supports; and those applying for assistance

with Medicare cost sharing or through medically needy pathways (42 CFR 435.603).

⁸ When the state lacks sufficient information to renew eligibility or has information that would result in a loss of eligibility, it may send beneficiaries a prepopulated form containing the information available to the agency with instructions to provide any requested information and report relevant changes (42 CFR 435.916(b)).

⁹ The Medicare Master Beneficiary Summary File data on race and ethnicity were not of sufficient quality to include in our study.

¹⁰ The District of Columbia offers just one MSP group, the QMB group, at an expanded income level of 300 percent of the FPL. New York subsumed its SLMB group in its QMB group by increasing the QMB income threshold from 100 to 138 percent of the FPL and expanding QI income eligibility from 135 percent to 186 percent of the FPL (NCOA 2024). States can make this type of change through a state plan amendment using authority under Section 1902(r)(2).

¹¹ The CMS final rule includes one earlier deadline of October 1, 2024, for automatically enrolling Supplemental Security Income recipients into the QMB group (CMS 2023a). States must deem enrolled in the QMB group anyone in the mandatory Supplemental Security Income recipients group or the 209(b) group. CMS notes that people receiving Supplemental Security Income are already eligible for the QMB group. Also, states have processes in place for Medicare Part A buy-in programs that they can build on to comply with this requirement (CMS 2023a).

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Chapter 4:

Medicaid Demographic Data Collection

Medicaid Demographic Data Collection

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 LGBTQI+ 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).

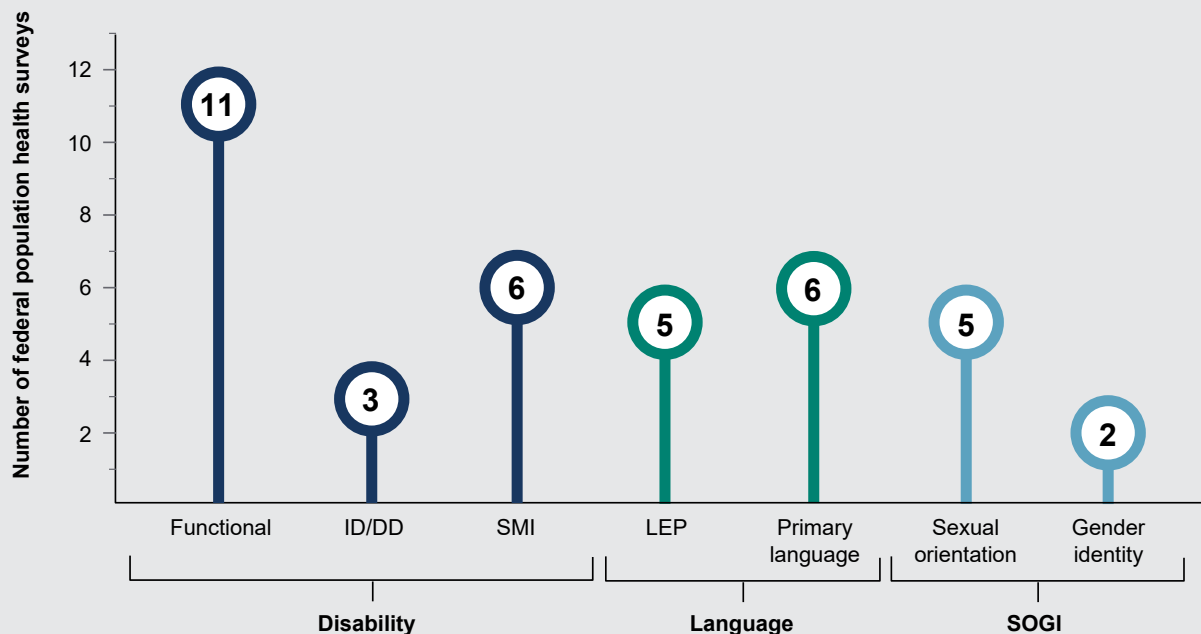
- Functional disability:** Two of the most commonly used measures of functional disability are the American Community Survey (ACS) and the Washington Group Short Set (WG-SS) on Functioning (Yee and Breslin 2023, Mont et al. 2022).²⁰ In 2011, HHS recommended using the ACS question set for collecting disability 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, Haverkamp 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

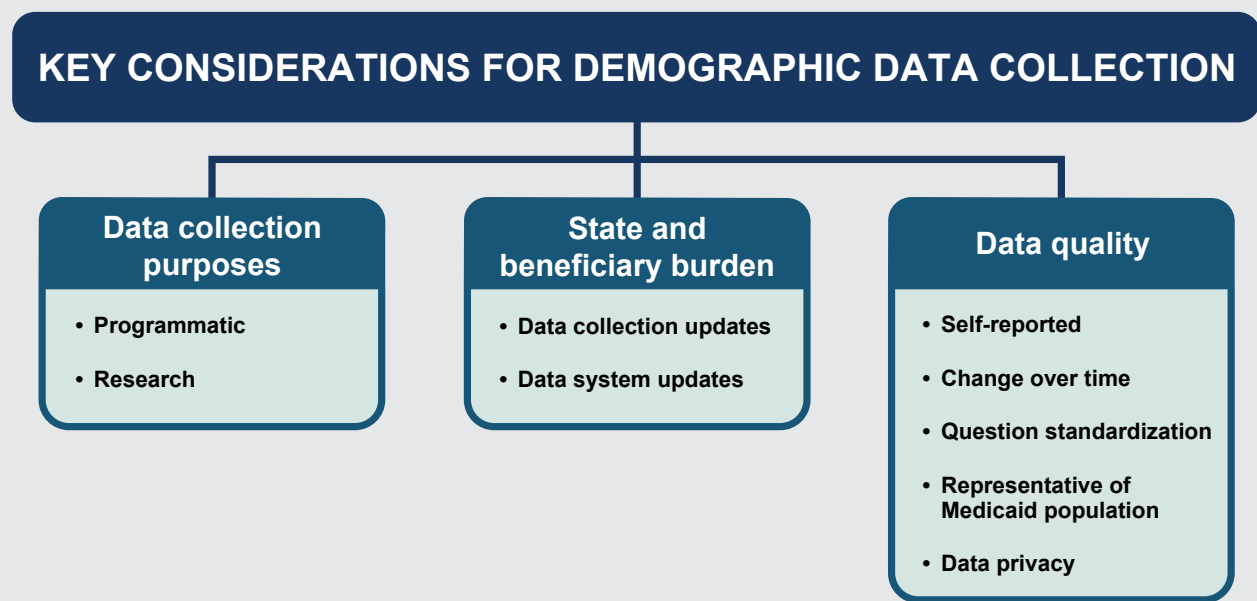
report usable LEP and self-reported disability data, and currently, states are unable to report SOGI data (CMS 2023a, 2023b, 2021a, 2021b). Most federal surveys ask questions about functional limitations; some ask about SMI using standardized screening tools; and only a few ask questions to identify 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. Assistors 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).

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.

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

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

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.

Appendix

Authorizing Language (§ 1900 of the Social Security Act)

Medicaid and CHIP Payment and Access Commission

- (a) ESTABLISHMENT.—There is hereby established the Medicaid and CHIP Payment and Access Commission (in this section referred to as “MACPAC”).
- (b) DUTIES.—
- (1) REVIEW OF ACCESS POLICIES FOR ALL STATES AND ANNUAL REPORTS.—MACPAC shall—
- (A) review policies of the Medicaid program established under this title (in this section referred to as “Medicaid”) and the State Children’s Health Insurance Program established under title XXI (in this section referred to as “CHIP”) affecting access to covered items and services, including topics described in paragraph (2);
- (B) make recommendations to Congress, the Secretary, and States concerning such access policies;
- (C) by not later than March 15 of each year (beginning with 2010), submit a report to Congress containing the results of such reviews and MACPAC’s recommendations concerning such policies; and
- (D) by not later than June 15 of each year (beginning with 2010), submit a report to Congress containing an examination of issues affecting Medicaid and CHIP, including the implications of changes in health care delivery in the United States and in the market for health care services on such programs.
- (2) SPECIFIC TOPICS TO BE REVIEWED.—Specifically, MACPAC shall review and assess the following:
- (A) MEDICAID AND CHIP PAYMENT POLICIES.—Payment policies under Medicaid and CHIP, including—
- (i) the factors affecting expenditures for the efficient provision of items and services in different sectors, including the process for updating payments to medical, dental, and health professionals, hospitals, residential and long-term care providers, providers of home and community based services, Federally-qualified health centers and rural health clinics, managed care entities, and providers of other covered items and services;
- (ii) payment methodologies; and
- (iii) the relationship of such factors and methodologies to access and quality of care for Medicaid and CHIP beneficiaries (including how such factors and methodologies enable such beneficiaries to obtain the services for which they are eligible, affect provider supply, and affect providers that serve a disproportionate share of low-income and other vulnerable populations).
- (B) ELIGIBILITY POLICIES.—Medicaid and CHIP eligibility policies, including a determination of the degree to which Federal and State policies provide health care coverage to needy populations.
- (C) ENROLLMENT AND RETENTION PROCESSES.—Medicaid and CHIP enrollment and retention processes, including a determination of the degree to which Federal and State policies encourage the enrollment of individuals who are eligible for such programs and screen out individuals who are ineligible, while minimizing the share of program expenses devoted to such processes.
- (D) COVERAGE POLICIES.—Medicaid and CHIP benefit and coverage policies, including a determination of the degree to which Federal and State policies provide access to the services enrollees require to improve and maintain their health and functional status.

- (E) QUALITY OF CARE.—Medicaid and CHIP policies as they relate to the quality of care provided under those programs, including a determination of the degree to which Federal and State policies achieve their stated goals and interact with similar goals established by other purchasers of health care services.
 - (F) INTERACTION OF MEDICAID AND CHIP PAYMENT POLICIES WITH HEALTH CARE DELIVERY GENERALLY.—The effect of Medicaid and CHIP payment policies on access to items and services for children and other Medicaid and CHIP populations other than under this title or title XXI and the implications of changes in health care delivery in the United States and in the general market for health care items and services on Medicaid and CHIP.
 - (G) INTERACTIONS WITH MEDICARE AND MEDICAID.—Consistent with paragraph (11), the interaction of policies under Medicaid and the Medicare program under title XVIII, including with respect to how such interactions affect access to services, payments, and dually eligible individuals.
 - (H) OTHER ACCESS POLICIES.—The effect of other Medicaid and CHIP policies on access to covered items and services, including policies relating to transportation and language barriers and preventive, acute, and long-term services and supports.
- (3) RECOMMENDATIONS AND REPORTS OF STATE-SPECIFIC DATA.—MACPAC shall—
- (A) review national and State-specific Medicaid and CHIP data; and
 - (B) submit reports and recommendations to Congress, the Secretary, and States based on such reviews.
- (4) CREATION OF EARLY-WARNING SYSTEM.—MACPAC shall create an early-warning system to identify provider shortage areas, as well as other factors that adversely affect, or have the potential to adversely affect, access to care by, or the health care status of, Medicaid and CHIP beneficiaries. MACPAC shall include in the annual report required under paragraph (1)(D) a description of all such areas or problems identified with respect to the period addressed in the report.
- (5) COMMENTS ON CERTAIN SECRETARIAL REPORTS AND REGULATIONS.—
- (A) CERTAIN SECRETARIAL REPORTS.—If the Secretary submits to Congress (or a committee of Congress) a report that is required by law and that relates to access policies, including with respect to payment policies, under Medicaid or CHIP, the Secretary shall transmit a copy of the report to MACPAC. MACPAC shall review the report and, not later than 6 months after the date of submittal of the Secretary's report to Congress, shall submit to the appropriate committees of Congress and the Secretary written comments on such report. Such comments may include such recommendations as MACPAC deems appropriate.
 - (B) REGULATIONS.—MACPAC shall review Medicaid and CHIP regulations and may comment through submission of a report to the appropriate committees of Congress and the Secretary, on any such regulations that affect access, quality, or efficiency of health care.
- (6) AGENDA AND ADDITIONAL REVIEWS.—
- (A) IN GENERAL.—MACPAC shall consult periodically with the chairmen and ranking minority members of the appropriate committees of Congress regarding MACPAC's agenda and progress towards achieving the agenda. MACPAC may conduct additional reviews, and submit additional reports to the appropriate committees of Congress, from time to time on such topics relating to the program under this title or title XXI as may be requested by such chairmen and members and as MACPAC deems appropriate.

- (B) REVIEW AND REPORTS REGARDING MEDICAID DSH.—
- (i) IN GENERAL.—MACPAC shall review and submit an annual report to Congress on disproportionate share hospital payments under section 1923. Each report shall include the information specified in clause (ii).
 - (ii) REQUIRED REPORT INFORMATION.—Each report required under this subparagraph shall include the following:
 - (I) Data relating to changes in the number of uninsured individuals.
 - (II) Data relating to the amount and sources of hospitals' uncompensated care costs, including the amount of such costs that are the result of providing unreimbursed or under-reimbursed services, charity care, or bad debt.
 - (III) Data identifying hospitals with high levels of uncompensated care that also provide access to essential community services for low-income, uninsured, and vulnerable populations, such as graduate medical education, and the continuum of primary through quaternary care, including the provision of trauma care and public health services.
 - (IV) State-specific analyses regarding the relationship between the most recent State DSH allotment and the projected State DSH allotment for the succeeding year and the data reported under subclauses (I), (II), and (III) for the State.
 - (iii) DATA.—Notwithstanding any other provision of law, the Secretary regularly shall provide MACPAC with the most recent State reports and most recent independent certified audits submitted under section 1923(j), cost reports submitted under title XVIII, and such other data as MACPAC may request for purposes of conducting the reviews and preparing and submitting the annual reports required under this subparagraph.
 - (iv) SUBMISSION DEADLINES.—The first report required under this subparagraph shall be submitted to Congress not later than February 1, 2016. Subsequent reports shall be submitted as part of, or with, each annual report required under paragraph (1)(C) during the period of fiscal years 2017 through 2024.
- (7) AVAILABILITY OF REPORTS.—MACPAC shall transmit to the Secretary a copy of each report submitted under this subsection and shall make such reports available to the public.
- (8) APPROPRIATE COMMITTEE OF CONGRESS.—For purposes of this section, the term “appropriate committees of Congress” means the Committee on Energy and Commerce of the House of Representatives and the Committee on Finance of the Senate.
- (9) VOTING AND REPORTING REQUIREMENTS.—With respect to each recommendation contained in a report submitted under paragraph (1), each member of MACPAC shall vote on the recommendation, and MACPAC shall include, by member, the results of that vote in the report containing the recommendation.
- (10) EXAMINATION OF BUDGET CONSEQUENCES.—Before making any recommendations, MACPAC shall examine the budget consequences of such recommendations, directly or through consultation with appropriate expert entities, and shall submit with any recommendations, a report on the Federal and State-specific budget consequences of the recommendations.

(11) CONSULTATION AND COORDINATION WITH MEDPAC.—

(A) IN GENERAL.—MACPAC shall consult with the Medicare Payment Advisory Commission (in this paragraph referred to as “MedPAC”) established under section 1805 in carrying out its duties under this section, as appropriate and particularly with respect to the issues specified in paragraph (2) as they relate to those Medicaid beneficiaries who are dually eligible for Medicaid and the Medicare program under title XVIII, adult Medicaid beneficiaries (who are not dually eligible for Medicare), and beneficiaries under Medicare. Responsibility for analysis of and recommendations to change Medicare policy regarding Medicare beneficiaries, including Medicare beneficiaries who are dually eligible for Medicare and Medicaid, shall rest with MedPAC.

(B) INFORMATION SHARING.—MACPAC and MedPAC shall have access to deliberations and records of the other such entity, respectively, upon the request of the other such entity.

(12) CONSULTATION WITH STATES.—MACPAC shall regularly consult with States in carrying out its duties under this section, including with respect to developing processes for carrying out such duties, and shall ensure that input from States is taken into account and represented in MACPAC’s recommendations and reports.

(13) COORDINATE AND CONSULT WITH THE FEDERAL COORDINATED HEALTH CARE OFFICE.—MACPAC shall coordinate and consult with the Federal Coordinated Health Care Office established under section 2081 of the Patient Protection and Affordable Care Act before making any recommendations regarding dually eligible individuals.

(14) PROGRAMMATIC OVERSIGHT VESTED IN THE SECRETARY.—MACPAC’s authority to make recommendations in accordance with this section shall not affect, or be considered to duplicate, the Secretary’s authority to carry out Federal responsibilities with respect to Medicaid and CHIP.

(c) MEMBERSHIP.—

(1) NUMBER AND APPOINTMENT.—MACPAC shall be composed of 17 members appointed by the Comptroller General of the United States.

(2) QUALIFICATIONS.—

(A) IN GENERAL.—The membership of MACPAC shall include individuals who have had direct experience as enrollees or parents or caregivers of enrollees in Medicaid or CHIP and individuals with national recognition for their expertise in Federal safety net health programs, health finance and economics, actuarial science, health plans and integrated delivery systems, reimbursement for health care, health information technology, and other providers of health services, public health, and other related fields, who provide a mix of different professions, broad geographic representation, and a balance between urban and rural representation.

(B) INCLUSION.—The membership of MACPAC shall include (but not be limited to) physicians, dentists, and other health professionals, employers, third-party payers, and individuals with expertise in the delivery of health services. Such membership shall also include representatives of children, pregnant women, the elderly, individuals with disabilities, caregivers, and dually eligible individuals, current or former representatives of State agencies responsible for administering Medicaid, and current or former representatives of State agencies responsible for administering CHIP.

- (C) MAJORITY NONPROVIDERS.—Individuals who are directly involved in the provision, or management of the delivery, of items and services covered under Medicaid or CHIP shall not constitute a majority of the membership of MACPAC.
 - (D) ETHICAL DISCLOSURE.—The Comptroller General of the United States shall establish a system for public disclosure by members of MACPAC of financial and other potential conflicts of interest relating to such members. Members of MACPAC shall be treated as employees of Congress for purposes of applying title I of the Ethics in Government Act of 1978 (Public Law 95–521).
- (3) TERMS.—
- (A) IN GENERAL.—The terms of members of MACPAC shall be for 3 years except that the Comptroller General of the United States shall designate staggered terms for the members first appointed.
 - (B) VACANCIES.—Any member appointed to fill a vacancy occurring before the expiration of the term for which the member’s predecessor was appointed shall be appointed only for the remainder of that term. A member may serve after the expiration of that member’s term until a successor has taken office. A vacancy in MACPAC shall be filled in the manner in which the original appointment was made.
- (4) COMPENSATION.—While serving on the business of MACPAC (including travel time), a member of MACPAC shall be entitled to compensation at the per diem equivalent of the rate provided for level IV of the Executive Schedule under section 5315 of title 5, United States Code; and while so serving away from home and the member’s regular place of business, a member may be allowed travel expenses, as authorized by the Chairman of MACPAC. Physicians serving as personnel of MACPAC may be provided a physician comparability allowance by MACPAC in the same manner as Government physicians may be provided such an allowance by an agency under section 5948 of title 5, United States Code, and for such purpose subsection (i) of such section shall apply to MACPAC in the same manner as it applies to the Tennessee Valley Authority. For purposes of pay (other than pay of members of MACPAC) and employment benefits, rights, and privileges, all personnel of MACPAC shall be treated as if they were employees of the United States Senate.
- (5) CHAIRMAN; VICE CHAIRMAN.—The Comptroller General of the United States shall designate a member of MACPAC, at the time of appointment of the member as Chairman and a member as Vice Chairman for that term of appointment, except that in the case of vacancy of the Chairmanship or Vice Chairmanship, the Comptroller General of the United States may designate another member for the remainder of that member’s term.
- (6) MEETINGS.—MACPAC shall meet at the call of the Chairman.
- (d) DIRECTOR AND STAFF; EXPERTS AND CONSULTANTS.—Subject to such review as the Comptroller General of the United States deems necessary to assure the efficient administration of MACPAC, MACPAC may—
- (1) employ and fix the compensation of an Executive Director (subject to the approval of the Comptroller General of the United States) and such other personnel as may be necessary to carry out its duties (without regard to the provisions of title 5, United States Code, governing appointments in the competitive service);
 - (2) seek such assistance and support as may be required in the performance of its duties from appropriate Federal and State departments and agencies;
 - (3) enter into contracts or make other arrangements, as may be necessary for the conduct of the work of MACPAC (without regard to section 3709 of the Revised Statutes (41 USC 5));

- (4) make advance, progress, and other payments which relate to the work of MACPAC;
- (5) provide transportation and subsistence for persons serving without compensation; and
- (6) prescribe such rules and regulations as it deems necessary with respect to the internal organization and operation of MACPAC.

(e) POWERS.—

- (1) OBTAINING OFFICIAL DATA.—MACPAC may secure directly from any department or agency of the United States and, as a condition for receiving payments under sections 1903(a) and 2105(a), from any State agency responsible for administering Medicaid or CHIP, information necessary to enable it to carry out this section. Upon request of the Chairman, the head of that department or agency shall furnish that information to MACPAC on an agreed upon schedule.
- (2) DATA COLLECTION.—In order to carry out its functions, MACPAC shall—
 - (A) utilize existing information, both published and unpublished, where possible, collected and assessed either by its own staff or under other arrangements made in accordance with this section;
 - (B) carry out, or award grants or contracts for, original research and experimentation, where existing information is inadequate; and
 - (C) adopt procedures allowing any interested party to submit information for MACPAC's use in making reports and recommendations.
- (3) ACCESS OF GAO TO INFORMATION.—The Comptroller General of the United States shall have unrestricted access to all deliberations, records, and nonproprietary data of MACPAC, immediately upon request.
- (4) PERIODIC AUDIT.—MACPAC shall be subject to periodic audit by the Comptroller General of the United States.

(f) FUNDING.—

- (1) REQUEST FOR APPROPRIATIONS.—MACPAC shall submit requests for appropriations (other than for fiscal year 2010) in the same manner as the Comptroller General of the United States submits requests for appropriations, but amounts appropriated for MACPAC shall be separate from amounts appropriated for the Comptroller General of the United States.
- (2) AUTHORIZATION.—There are authorized to be appropriated such sums as may be necessary to carry out the provisions of this section.
- (3) FUNDING FOR FISCAL YEAR 2010.—
 - (A) IN GENERAL.—Out of any funds in the Treasury not otherwise appropriated, there is appropriated to MACPAC to carry out the provisions of this section for fiscal year 2010, \$9,000,000.
 - (B) TRANSFER OF FUNDS.—Notwithstanding section 2104(a)(13), from the amounts appropriated in such section for fiscal year 2010, \$2,000,000 is hereby transferred and made available in such fiscal year to MACPAC to carry out the provisions of this section.
- (4) AVAILABILITY.—Amounts made available under paragraphs (2) and (3) to MACPAC to carry out the provisions of this section shall remain available until expended.

Biographies of Commissioners

Verlon Johnson, MPA, (Chair), is executive vice president and chief strategy officer at Acentra Health, a Virginia-based health information technology firm that works with state and federal agencies to design technology-driven products and solutions that improve health outcomes and reduce health care costs. Ms. Johnson previously served as an associate partner and vice president at IBM Watson Health. Before entering private industry, she was a public servant for more than 20 years, holding numerous leadership positions, including associate consortium administrator for Medicaid and CHIP at the Centers for Medicare & Medicaid Services (CMS), acting regional director for the U.S. Department of Health and Human Services, acting CMS deputy director for the Center for Medicaid and CHIP Services (CMCS), interim CMCS Intergovernmental and External Affairs group director, and associate regional administrator for both Medicaid and Medicare. Ms. Johnson earned a master of public administration with an emphasis on health care policy and administration from Texas Tech University.

Robert Duncan, MBA, (Vice Chair), is chief operating officer of Connecticut Children's – Hartford. Before this, he served as executive vice president of Children's Wisconsin, where he oversaw the strategic contracting for systems of care, population health, and the development of value-based contracts. He was also the president of Children's Community Health Plan, which insures individuals with BadgerCare Plus coverage and those on the individual marketplace, and Children's Service Society of Wisconsin. He has served as both the director of the Tennessee Governor's Office of Children's Care Coordination and the director of the Tennessee Children's Health Insurance Program, overseeing the state's efforts to improve the health and welfare of children across Tennessee. Earlier, he held various positions with Methodist Le Bonheur Healthcare. Mr. Duncan received his master of business administration from the University of Tennessee at Martin.

Heidi L. Allen, PhD, MSW, is an associate professor at Columbia University School of Social Work, where she studies the impact of social policies on health and financial well-being. She is a former emergency department social worker and spent several years in

state health policy, examining health system redesign and public health insurance expansions. In 2014 and 2015, she was an American Political Science Association Congressional Fellow in Health and Aging Policy. Dr. Allen is also a standing member of the National Institutes of Health's Health and Healthcare Disparities study section. Dr. Allen received her doctor of philosophy in social work and social research and a master of social work in community-based practice from Portland State University.

Sonja L. Bjork, JD, is the chief executive officer of Partnership HealthPlan of California (PHC), a non-profit community-based Medicaid managed care plan. Before joining PHC, Ms. Bjork worked as a dependency attorney representing youth in the child welfare system. During her tenure at PHC, she has overseen multiple benefit implementations and expansion of the plan's service area. Ms. Bjork served on the executive team directing the plan's \$280 million strategic investment of health plan reserves to address social determinants of health. These included medical respite, affordable housing, and substance use disorder treatment options. Ms. Bjork received her juris doctor from the UC Berkeley School of Law.

Tricia Brooks, MBA, is a research professor at the McCourt School of Public Policy at Georgetown University and a senior fellow at the Georgetown University Center for Children and Families (CCF), an independent, non-partisan policy and research center whose mission is to expand and improve health coverage for children and families. At CCF, Ms. Brooks focuses on issues relating to policy, program administration, and quality of Medicaid and CHIP coverage for children and families. Before joining CCF, she served as the founding CEO of New Hampshire Healthy Kids, a legislatively created non-profit corporation that administered CHIP in the state, and served as the Medicaid and CHIP consumer assistance coordinator. Ms. Brooks holds a master of business administration from Suffolk University.

Doug Brown, RPh, MBA, is senior vice president of value and access at COEUS Consulting, with more than 30 years of pharmacy management experience. Mr. Brown provides executive level health care consulting and market access support services to life science companies and health care organizations, including the development of value- and outcomes-based contracting strategies with state

Medicaid programs, pharmacy benefit administrators, manufacturers, and CMS. Before joining COEUS in 2020, he served in several roles for Magellan Rx Government, including as the chief strategy officer. While at Magellan, he led preferred drug list management for more than half the state Medicaid programs in the country, provided subject matter expertise on federal and state government legislation that impacted state Medicaid programs and offered policymakers a national view of evolving events in Medicaid. Mr. Brown is a registered pharmacist and holds a bachelor of science in pharmacy from the University of Rhode Island and a master's of business administration from Virginia Commonwealth University.

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Angelo P. Giardino, MD, PhD, MPH, is the Wilma T. Gibson Presidential Professor and chair of the Department of Pediatrics at the University of Utah's Spencer Fox Eccles School of Medicine and chief medical officer at Intermountain Primary Children's Hospital in Salt Lake City, Utah. Before this, Dr. Giardino worked at Texas Children's Health Plan and Texas Children's Hospital from 2005 to 2018. He received his medical degree and doctorate in education from the University of Pennsylvania, completed his residency and fellowship training at the Children's Hospital of Philadelphia, and earned a master of public health from the University of Massachusetts. He also holds a master in theology from Catholic Distance University and a master in public administration from the University of Texas Rio Grande Valley.

Dennis Heaphy, MPH, MEd, MDiv, is a health justice advocate and researcher at the Massachusetts Disability Policy Consortium, a Massachusetts-based disability rights advocacy organization. He

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Timothy Hill, MPA, is senior vice president at the American Institutes for Research (AIR), where he leads AIR's health division. Before joining AIR, Mr. Hill held several executive positions within CMS, including as a deputy director of the Center for Medicaid and CHIP Services, the Center for Consumer Information and Insurance Oversight, and Center for Medicare. Mr. Hill earned his bachelor's degree from Northeastern University and his master's degree from the University of Connecticut.

Carolyn Ingram, MBA, is plan president and senior vice president of Molina Healthcare, Inc., which provides managed health care services under the Medicaid and Medicare programs, as well as through state insurance marketplaces. Previously, Ms. Ingram served as the director of the New Mexico Medicaid program, where she launched the state's first managed long-term services and supports program. She also held prior leadership roles, including vice chair of the National Association of Medicaid Directors

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Patti Killingsworth is the senior vice president of long-term services and supports (LTSS) strategy at CareBridge, a value-based healthcare company dedicated to supporting Medicaid and dually eligible beneficiaries receiving home- and community-based services. Ms. Killingsworth is a former Medicaid beneficiary and lifelong family caregiver with 25 years of Medicaid public service experience, most recently as the longstanding assistant commissioner and chief of LTSS for TennCare, the Medicaid agency in Tennessee. Ms. Killingsworth received her bachelor's degree from Missouri State University.

John B. McCarthy, MPA, is a founding partner at Speire Healthcare Strategies, which helps public and private sector entities navigate the health care landscape through the development of state and federal health policy. Previously, he served as the Medicaid director for both the District of Columbia and Ohio, where he implemented a series of innovative policy initiatives that modernized both programs. He has also played a significant role nationally, serving as vice president of the National Association of Medicaid Directors. Mr. McCarthy holds a master's degree in public affairs from Indiana University's Paul H. O'Neill School of Public and Environmental Affairs.

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Michael Nardone, MPA, currently leads an independent consulting practice providing strategic advice on Medicaid health policy and long-term services and supports. He has extensive experience in leading health and human services programs at the state, local, and national levels, most recently as director of the Disabled and Elderly Health Programs Group at the Center for Medicaid and CHIP Services. Mr. Nardone previously led the Pennsylvania Department of Human Services as acting secretary and was the state's Medicaid director, serving on the executive committee of the National Association of Medicaid Directors. After leaving Pennsylvania state government, he joined Health Management Associates (HMA) as a managing principal and led establishment of the HMA Harrisburg office. He also served as the city of Philadelphia's deputy managing director for special needs housing and has held government relations positions for the Commonwealth of Massachusetts and the University of Pennsylvania Health System. Mr. Nardone received a master's degree in public affairs from the Princeton School of Public and International Affairs.

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Biographies of Staff

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Kirstin Blom, MIPA, is a policy director. Before joining MACPAC, Ms. Blom was an analyst in health care financing at the Congressional Research Service. Before that, she worked as a principal analyst at the Congressional Budget Office, where she estimated the federal budgetary effects of proposed legislation affecting the Medicaid program. Ms. Blom has also been an analyst for the Medicaid program in Wisconsin and for the U.S. Government Accountability Office. She holds a master of international public affairs from the University of Wisconsin, Madison, and a bachelor of arts in international studies and Spanish from the University of Wisconsin, Oshkosh.

Caroline Broder is the director of communications. Before joining MACPAC, she led strategic communications for a variety of health policy organizations and foundations, where she developed and implemented communications strategies to reach both the public and policymakers. She has extensive experience working with researchers across multiple disciplines to translate and communicate information for the public. She began her career as a reporter covering health and technology issues. Ms. Broder holds a bachelor of science in journalism from Ohio University.

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Martha Heberlein, MA, is the research advisor and a principal analyst. Before joining MACPAC, she was the research manager at the Georgetown University Center for Children and Families, where she oversaw a national survey on Medicaid and State Children's Health Insurance Program (CHIP) eligibility, enrollment, and renewal procedures. Ms. Heberlein holds a master of arts in public policy with a concentration in philosophy and social policy from The George Washington University and a bachelor of science in psychology from James Madison University.

Tamara Huson, MSPH, is the contracting officer and a senior analyst. Before joining MACPAC, she worked as a research assistant in the Department of Health Policy and Management at The University of North Carolina. She also worked for the American Cancer Society and completed internships with the North Carolina General Assembly and the Foundation for Health Leadership and Innovation. Ms. Huson holds a master of science in public health from The University of North Carolina at Chapel Hill and a bachelor of arts in biology and global studies from Lehigh University.

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Carolyn Kaneko is the graphic designer. Before joining MACPAC, she was design lead at the Artist Group, handling a wide variety of marketing projects. Her experience includes managing publication projects at all stages of design production and collaborating in the development of marketing strategies. Ms. Kaneko began her career as an in-house designer for an offset print shop. She holds a bachelor of arts in art from Salisbury University with a concentration in graphic design.

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