Report to Congress on Medicaid and CHIP

JUNE 2025

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.

Report to Congress on Medicaid and CHIP

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and Access Commission

MACPAC

Advising Congress on
Medicaid and CHIP Policy

June 11, 2025

The Honorable JD Vance
President of the Senate
The Capitol
Washington, DC 20510

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

Dear Mr. Vice President and Mr. Speaker:

On behalf of the Medicaid and CHIP Payment and Access Commission (MACPAC), I am pleased to submit the June 2025 *Report to Congress on Medicaid and CHIP*. This report includes recommendations on transitions from pediatric to adult care for Medicaid-covered children and youth with special health care needs (CYSHCN) and chapters addressing appropriate access to residential behavioral health treatment services for children with Medicaid coverage, access to medications for opioid use disorder (MOUD) in Medicaid, the Program of All-Inclusive Care for the Elderly (PACE), and self-direction for Medicaid home- and community-based services (HCBS).

Chapter 1 includes four recommendations aimed at addressing challenges with transitioning from pediatric to adult care in Medicaid. Medicaid plays an important role in covering health care services for CYSHCN. Almost one in five children has special health care needs, and Medicaid covers almost half of these children. As these children reach adulthood, they need to transition from a pediatric to an adult model of care.

Findings from MACPAC's work demonstrate that Medicaid-covered CYSHCN can experience challenges during this time, which include transitioning to new adult providers, potential loss of covered benefits, medical complications, and poor health outcomes. State transition of care strategies lack both clear documentation and communications as well as individualized transition of care plans. There is also little guidance to states on coverage of services to support transitions of care and a lack of data collection on this population. Finally, there is limited state Medicaid and Title V agency coordination on CYSHCN transitions of care.

The recommendations would require states to develop a strategy for transitions of care for CYSHCN, which includes developing an individualized transition of care plan and making the strategy publicly available, issuing guidance to states on existing authorities to cover transition of care-related services for CYSHCN, requiring states to collect and report data on access to transition of care-related services as well as beneficiary and caregiver experiences with transitions, and requiring interagency agreements between state Medicaid and Title V agencies to specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care.

Chapter 2 focuses on appropriate access to residential behavioral health treatment services for children. Medicaid supports a wide range of behavioral health services for children, including residential treatment programs, when they are necessary. States are required to provide treatment for individuals with disabilities, including serious mental illness and serious emotional disturbance, in community-based settings if appropriate. However, for children who need more intense care or pose a safety risk to themselves or their families, it is important that they can access residential treatment when necessary. The chapter provides an overview of Medicaid coverage for residential treatment services, how children are referred to residential treatment, what is known about the use of residential treatment, the use of out-of-state placement, access considerations related to the continuum of care, and barriers to appropriate residential treatment.

Chapter 3 describes findings from the Commission's analytic work on access to MOUD in Medicaid. In 2020, the drug overdose death rate was two times higher for Medicaid beneficiaries compared to all U.S. residents. Medicaid and the State Children's Health Insurance Program (CHIP) cover a substantial portion of the U.S. population with opioid use disorder (OUD), and the programs have an important role in facilitating access to OUD treatment. In recent years, Congress and federal agencies have approved a variety of policies and funding to improve access to MOUD. The chapter includes a discussion of recent federal policies and funding that have affected access to MOUD, an overview of MOUD coverage and estimates of use, and barriers to MOUD. The Commission plans to further investigate the use of utilization management practices and how they affect Medicaid beneficiaries' receipt of timely and effective care.

Chapter 4 provides an overview on PACE, which provides fully integrated care to adults ages 55 and older with nursing-facility level of care needs while allowing them to remain in the community. Most PACE enrollees are dually eligible for Medicare and Medicaid, and PACE is considered a care approach that provides fully integrated coverage. The Commission has had a long-standing interest in integrated care for dually eligible individuals because of its potential to better align care and improve health outcomes for beneficiaries, including many with complex care needs. The chapter begins with background on PACE, which is currently available in 33 states and the District of Columbia, and highlights findings on the design and administration of PACE.

The final chapter of the June report looks at self-direction for Medicaid HCBS. The chapter begins with a discussion of the required elements in self-direction and the key stakeholders in program administration. The chapter continues by reviewing state design considerations, including Medicaid HCBS authorities, populations served, services provided, and flexibilities for beneficiaries. Next, it describes state administrative considerations, including information and assistance supports; approaches to financial management services; and quality reporting, monitoring, and oversight. The Commission plans to continue exploring the self-direction model as a coverage option that gives beneficiaries choice and may help to alleviate the HCBS workforce shortage.

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

Verlon Johnson, MPA

Chair

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Executive Summary: June 2025 *Report to Congress on Medicaid and CHIP*

MACPAC's June 2025 *Report to Congress on Medicaid and CHIP* contains five chapters of interest to Congress: (1) recommendations to address the challenges with transitioning from pediatric to adult care in Medicaid, (2) appropriate access to residential behavioral health treatment services for children, (3) access to medications for opioid use disorder (MOUD) in Medicaid, (4) an overview of the Program of All-Inclusive Care for the Elderly (PACE), and (5) self-direction for Medicaid home- and community-based services (HCBS).

CHAPTER 1: Children and Youth with Special Health Care Needs Transitions of Care

Chapter 1 includes four recommendations aimed at addressing challenges with transitioning from pediatric to adult care in Medicaid for children and youth with special health care needs (CYSHCN). Medicaid plays an important role in covering health care services for CYSHCN. Almost one in five children has special health care needs, and Medicaid covers almost half of these children.

When CYSHCN age out of pediatric care and into adult health care, they and their caregivers must navigate the transition to new adult providers and a potential loss of covered benefits. Findings from MACPAC's work demonstrate that during this time, Medicaid-covered CYSHCN can experience challenges, which include transitioning to new adult providers, potential loss of covered benefits, medical complications, and poor health outcomes. State transition of care strategies lack both clear documentation and communications as well as individualized transition of care plans. In addition, there is little guidance to states on coverage of services to support transitions of care and a lack of data collection on this population. Finally, there is limited state Medicaid and Title V agency coordination on CYSHCN transitions of care.

In this chapter, we make the following recommendations:

1.1 Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

1.3 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to

CMS beneficiary and caregiver experience with transitions of care.

1.4 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

CHAPTER 2: Appropriate Access to Residential Behavioral Health Treatment for Children in Medicaid

Chapter 2 focuses on appropriate access to and use of residential behavioral health treatment services for children. Medicaid supports a wide range of behavioral health services for children, including residential treatment programs, when they are necessary. States are required to provide treatment for individuals with disabilities, including serious mental illness and serious emotional disturbance, in community-based settings if appropriate. However, for children who need more intense care or pose a safety risk to themselves or their families, it is important that they can access residential treatment when necessary.

The chapter provides an overview of Medicaid coverage for residential treatment services, how children are referred to residential treatment, what is known about the use of residential treatment, the use of out-of-state placement, access considerations related to the continuum of care, and barriers to appropriate residential treatment.

MACPAC found that numerous factors affect access to residential treatment for Medicaid-covered children. Those factors include a lack of home- and community-based behavioral health services, existing federal policies that pose barriers to appropriate residential treatment, state challenges finding information on facility and bed availability, a lack of uniformity in assessing children's need for residential behavioral health care, no single national source of data on children who access residential treatment services, and workforce issues that make it challenging for states to operate facilities at their full licensed residential bed capacity.

MACPAC will continue to look at issues affecting access to home- and community-based behavioral health services for children as well as additional topics related to the safety and quality of appropriate residential treatment services.

CHAPTER 3: Access to Medications for Opioid Use Disorder in Medicaid

Chapter 3 describes findings from the Commission's analytic work on access to MOUD in Medicaid. In 2020, the drug overdose death rate was two times higher for Medicaid beneficiaries compared to all U.S. residents. Medicaid and the State Children's Health Insurance Program (CHIP) cover a substantial portion of the U.S. population with opioid use disorder (OUD), and the programs have an important role in facilitating access to OUD treatment.

In recent years, Congress and federal agencies have approved a variety of policies and funding to improve access to MOUD. Some of these efforts have been specific to Medicaid, while others affect access to MOUD more broadly. Although the share of Medicaid beneficiaries with OUD receiving these medications has increased in recent years and is relatively high nationally, there is considerable variation across states. Although there has been improvement in rates of MOUD treatment over time, a substantial gap remains, with nearly 30 percent of beneficiaries with OUD not receiving MOUD.

MACPAC identified a variety of factors that contribute to the MOUD treatment gap. Social stigma and limited provider availability are persistent challenges. Prior authorization for MOUD generally, and daily dosage caps for oral buprenorphine, are also commonly cited as barriers to timely and effective treatment.

The Commission plans to further investigate the use of utilization management practices and how they affect Medicaid beneficiaries' receipt of timely and effective care.

CHAPTER 4: Understanding the Program of All-Inclusive Care for the Elderly

Chapter 4 provides an overview of PACE, which provides fully integrated medical and non-medical care to adults age 55 and older with nursing-facility level of care needs while allowing them to remain in the community. PACE is optional for states, and enrollment is voluntary for participants. Most PACE enrollees are dually eligible for Medicaid and Medicare. The Commission has had a long-standing interest in integrated care for dually eligible individuals because of its potential to better align care and improve health outcomes for beneficiaries, including many with complex care needs.

The chapter begins with background on PACE, which is currently available in 33 states and the District of Columbia, and highlights key program design and administration requirements. Research suggests that PACE participants generally have better health outcomes compared to similar groups, and studies have found that PACE participants experience reduced mortality rates and nursing facility use when compared to non-PACE individuals.

The chapter includes findings on the experiences of PACE participants and the program's design to provide community-based care for individuals with complex care needs. MACPAC interviews with PACE organizations, state Medicaid agencies, federal officials, and consumer advocates revealed key findings across six aspects of the model: eligibility and enrollment, provider application and procurement, service delivery, grievances and disenrollment, federal and state oversight, and financing.

Stakeholders largely agreed that PACE represents the most fully integrated form of care available to dually eligible individuals and also identified two key challenges for the program. Oversight responsibilities, particularly for states, are complicated in federal statute and regulation. In addition, although limited data exist on PACE beneficiaries' service utilization, challenges exist in capturing that data due to the integrated nature of the program.

CHAPTER 5: Self-Direction for Home- and Community-Based Services

The final chapter of the June report examines self-direction for Medicaid HCBS, which is designed to allow people who need long-term services and supports to manage their own care and live in their homes or a homelike setting in the community. Medicaid is the primary payer of self-directed HCBS, supporting 66 percent of all self-directed services in 2019.

In self-direction, depending on the flexibility offered by their respective state, the beneficiary can hire HCBS workers directly, set their workers' hourly wages or purchase approved goods and services that help the beneficiary remain in a home- or community-based setting, or both. Compared with traditional agency-directed HCBS, self-direction offers beneficiaries increased autonomy in how their services are delivered. States have considerable flexibility when designing and administering self-direction programs.

The chapter begins with a discussion of the required elements in self-direction and the key stakeholders in program administration. The chapter continues by reviewing state design considerations, including Medicaid HCBS authorities, populations served, services provided, and flexibilities for beneficiaries. Next, it describes state administrative considerations, including information and assistance supports, approaches to financial management services, and quality reporting, monitoring, and oversight.

The Commission plans to continue exploring the self-direction model as a coverage option that can offer Medicaid beneficiaries choice and may help alleviate the HCBS workforce shortage.

Chapter 1:

Children and Youth with Special Health Care Needs Transitions of Care

Children and Youth with Special Health Care Needs Transitions of Care

Recommendations

1.1 Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

1.3 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to CMS beneficiary and caregiver experience with transitions of care.

1.4 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

Children and Youth with Special Health Care Needs Transitions of Care

Key Points

- Medicaid covers almost half of children and youth with special health care needs (CYSHCN).
- Transitioning from child to adult care is a multistep process that can involve support and facilitation from state Medicaid and Title V agencies, Medicaid managed care organizations, health care providers, and family members and caregivers.
- CYSHCN who have structured transitions to adult care that include a transition of care plan have been shown to have improved health outcomes, use of services, and experience with care.
- There are few federal Medicaid requirements and little guidance related to CYSHCN transitions to adult care, so state Medicaid agencies have the flexibility to define transition of care strategies.
- Beneficiaries and caregiver focus group participants shared feeling ill prepared for the transition to adult care due to the lack of a clearly documented process, support from their assigned coordinator, and a transition of care plan that included identifying adult providers.
- MACPAC's analysis identified five key challenges to be addressed in federal Medicaid policy and guidance. These include no federal requirement for states to clearly document their transition of care strategy and develop individualized transition of care plans, a lack of guidance to states on covering transition-related services, a lack of data collection on transitions and post-transition health outcomes, and a lack of coordination between state Medicaid and Title V agencies.
- CYSHCN navigate multiple simultaneous transitions as they reach adulthood. As a continuation of MACPAC's work on CYSHCN experiences with transitions, the Commission will examine coverage transitions between child and adult Medicaid eligibility.

CHAPTER 1: Children and Youth with Special Health Care Needs Transitions of Care

Medicaid plays an important role in covering health care services for children and youth with special health care needs (CYSHCN). Up to a quarter of children meet the criteria for having special health care needs, and almost half of these children are covered by Medicaid (Black et al. 2024, MACPAC 2024a). The Maternal and Child Health Bureau (MCHB), within the Health Resources & Services Administration (HRSA), broadly defines CYSHCN as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition; require health and related services of a type or amount beyond that required by children generally; and have one or more health or functional limitations (Black et al. 2024, McPherson et al. 1998).[1]

When CYSHCN age out of pediatric care and into adult health care, they and their caregivers must navigate many changes, including transitioning to new adult providers and the potential loss of health coverage. It is estimated that more than 90 percent of children with chronic medical conditions and special health care needs will live to adulthood (Mahan et al. 2017). The transition to adult care is a multistep process that often begins several years before the transfer to adult care and can involve support and facilitation from state Medicaid agencies as well as state Medicaid managed care organizations (MCOs), health care providers, additional care team members, and family members and caregivers (White et al. 2018). State Medicaid agencies have the flexibility to define their own transitions of care strategy, including specifying the population of focus, transition planning procedures (e.g., when the transition process begins, who is responsible for facilitating transition), and covered services to support transitions to adult care. State Medicaid agencies are also required to collaborate with state Title V agencies, which administer the federal Maternal and Child Health Services Block Grant, but the level of collaboration on transitions of care varies by state.[2]

Decades of research demonstrate that CYSHCN and their families face barriers when transitioning to adult care. When CYSHCN lack sufficient information, support, and planning to prepare for this transition (e.g., education, care coordination, community resources, and assistance in finding adult primary and specialty providers), they often experience delays in transition, discontinuity of care, loss of coverage, medical complications, and poor health outcomes (McManus et al. 2024, Validova et al. 2023, Flanagan et al. 2022, Okumura et al. 2022, White et al. 2018, Gabriel et al. 2017, Sawicki et al. 2017). Additionally, the lack of communication between pediatric and adult providers, adult providers knowledgeable in caring for pediatric onset conditions, and support from the adult care system can make the transfer to the adult care system difficult for CYSHCN and their families (McManus et al. 2020a, White et al. 2018, Gabriel et al. 2017).

CYSHCN is a broad population that may be defined differently depending on the state or program. To establish a comparable population across states, our analysis focuses on children eligible for Medicaid through Social Security Income (SSI)-related eligibility pathways and the Katie Beckett pathway for children with disabilities through either a state plan or waiver (enacted under the Tax Equity and Fiscal Responsibility Act, which amended § 1902(e) of the Social Security Act (the Act) to add (3); 42 CFR 435.225) authority (Appendix 1A)).[3]

The Commission sought to understand the roles of state Medicaid agencies, MCOs, and Title V programs in addressing the transition from pediatric to adult care for Medicaid-covered CYSHCN, their families, and their caregivers. Our analysis focused on understanding beneficiary and caregiver experiences with and associated barriers to the transition of care process for this population. We conducted a literature review, federal and state policy scan, stakeholder interviews, beneficiary and caregiver focus groups, and an analysis of the National Survey of Children's Health (NSCH) (Appendix 1A).

Findings from this work identified key challenges and barriers to CYSHCN receiving the services and supports needed to transition to adult care. State strategies for transition planning (e.g., developing a transition of care plan and assessing transition readiness) and transfer and integration into adult care (e.g., identifying in-network adult providers, warm handoffs, and consultation among multiple providers) are often not clearly documented and communicated. The lack of clearly documented and communicated expectations for this process can lead to a confusing and disorderly transition experience for beneficiaries and their families and be a barrier to CYSHCN transferring their care to adult providers. Additionally, state transition strategies often do not include developing individualized transition of care plans, which have been shown to improve health outcomes and use of services after the transition (McManus et al. 2020a, White et al. 2018, Gabriel et al. 2017). Furthermore, the Centers for Medicare & Medicaid Services (CMS) provide little guidance to states on coverage of services to support transitions of care for CYSHCN, so states may lack awareness on how to cover and reimburse providers for transition-related services, which may limit beneficiary access to these services. Additionally, there is a lack of data collection on transitions of care for CYSHCN, presenting a challenge to states in assessing beneficiary experience with the transition process and outcomes after the transfer to adult care. Finally, there is limited state Medicaid and Title V agency coordination on CYSHCN transitions of care and unaligned expectations and responsibilities for supporting CYSHCN in their transition planning and transfer to adult care.

The Commission makes four recommendations to address challenges and improve CYSHCN transitions from pediatric to adult care. The recommendations address CYSHCN as defined in our study as well as children who qualify to receive an institutional level of care who experience the same needs and similar challenges transitioning to adult care. The Commission's recommendations are:

1.1 Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

1.3 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to CMS beneficiary and caregiver experience with transitions of care.

1.4 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

This chapter begins with background on the Medicaid-covered CYSHCN population, the transition from pediatric to adult care process, and data availability on CYSHCN and transitions of care. It then summarizes federal requirements for transitions of care for state Medicaid and Title V agencies and presents findings on the role of states in transitions of care, including how states cover transitions of care and state Medicaid collaboration with Title V agencies. Then the chapter describes the five key challenges with transitions of care. Finally, the chapter presents the Commission's four recommendations and associated rationale as well as implications for federal spending, states, enrollees, plans, and providers.

Medicaid-Covered CYSHCN

Almost half of CYSHCN are covered by Medicaid or a combination of Medicaid and private insurance (37.2 percent and 7.6 percent, respectively) (MACPAC 2024a). CYSHCN can enroll in Medicaid through a variety of eligibility pathways. States can cover the CYSHCN on the basis of income or disability. The disability pathways include the SSI-related pathway or a state optional disability pathway, which includes the state medically needy pathway option, state plan options for the Family Opportunity Act, Section 1915(i) state plan home- and community-based services (HCBS) benefit pathway, and the optional Katie Beckett pathway for children with disabilities or Katie Beckett waiver (Musumeci and Chidambaram 2019).[4, 5] Under the Katie Beckett eligibility pathway and Katie Beckett waivers, states have the flexibility to cover children (up to age 19) with severe disabilities whose family income would ordinarily be too high to qualify for Medicaid. This option allows these children to receive services in their home and affords greater employment flexibility to beneficiary families (Colello and Morton 2019, CISWH 2016).

State Medicaid agencies provide coverage and services to CYSHCN under fee-for-service and managed care delivery systems. Historically, the majority of CYSHCN received care under fee for service, but it is becoming increasingly more common for these children to be enrolled in managed care, including specialty MCOs designed to meet the unique needs of CYSHCN or other specific populations of beneficiaries (e.g., SSI enrollees) (Randi and Honsberger 2020). Federal managed care regulations specify requirements for identifying, assessing, and producing a treatment plan for individuals with special health care needs, which includes children (42 CFR 438) (Silow-Carroll et al. 2016). State Medicaid programs can require child-only specialty MCOs to provide targeted benefits and to adhere to reporting requirements related to these populations (Randi and Gould 2022).[6]

All CYSHCN younger than age 21 who are enrolled in Medicaid through the categorically needy pathway are entitled to early and periodic screening, diagnostic, and treatment (EPSDT). EPSDT requires the provision of a comprehensive set of prevention, diagnostic, and treatment services. States are responsible for ensuring that families are informed about the EPSDT benefit, and they are required to provide access to any Medicaid-coverable service in any amount that is medically necessary, regardless of whether the service is covered in the state plan (42 CFR 441.56).

State Medicaid agencies can use a range of authorities to provide additional optional benefits to CYSHCN. Some states may use 1915(c) waivers to serve a specific population that could include CYSHCN or a subset of CYSHCN (MACPAC 2023).[7] Some children enrolled in Section 1915(c) waiver programs may receive services such as private duty nursing, attendant care, assistive technology, non-medical transportation to promote community integration, and respite (Williams and Musumeci 2021). States can also provide care coordination or other transition-related services under a number of other benefits (e.g., EPSDT, targeted case management (TCM), health home) under state plan and waiver authorities.

Transition of care process

The transition from pediatric to adult care is a multistep process that often begins several years before (as early as 12 years old) the child ages out of the pediatric model of care and transfers to the adult system, which typically occurs between 18 and 26 years old (McManus et al. 2023, 2020a, 2020b; White et al. 2018). CYSHCN and their families need support during this transition to ensure they are prepared for it and have the supports in place to facilitate continuity of care. Those who have structured transitions have been shown to have improved health outcomes, use of services, and experience with care (Schmidt et al. 2020, Gabriel et al. 2017).

Findings from the literature, stakeholder interviews, and MACPAC's analysis of the NSCH indicate that CYSHCN experience a number of challenges with the transition of care process, which can delay the transfer to adult providers. Some of the challenges with the transition to adult care include insufficient support with planning and identifying adult providers, lack of support from the adult health system in facilitating the transfer to adult providers, few adult providers with experience in pediatric onset conditions, complex conditions, and disabilities (Van Cleave et al. 2022, Iezzoni et al. 2021, McManus et al. 2020b, White et al. 2018). For example, MACPAC's analysis of the NSCH found many CYSHCN (age 12 to 17) may not receive the transition services needed to maintain continuity of care when transitioning to adult care (MACPAC 2024a).[8] Only 42 percent of children have worked with their provider to create a transition plan, and of those with a plan, only 36 percent have one that addresses the transition to health care providers who treat adults (MACPAC 2024a). Furthermore, CYSHCN often experience challenges with the transition due to loss of Medicaid benefits and services (e.g., optional state plan services, waiver-specific services) and those received from other federal, state, and local agencies (e.g., Title V, State Disability Determination Services, department of education, child welfare, juvenile justice, and developmental services) (McManus et al. 2024) (Box 1-1).

Findings from the literature also identify differences in experiences and outcomes among different demographic groups. For example, CYSHCN in rural areas may experience additional challenges due to long travel distances for care (including out of state) because of shortages in primary care and specialist providers, particularly for adult providers experienced in treating pediatric onset conditions and complex conditions (Van Cleave et al. 2022). Furthermore, there are differences among racial groups in their transition experiences and health outcomes. For example, CYSHCN are more likely to report that they received care in a well-functioning system if they are white, non-Hispanic and do not have a disability and are more financially resourced than their peers (Houtrow et al. 2022).

BOX 1-1. Children and Youth with Special Health Care Needs Types of Transitions

Children and youth with special health care needs (CYSHCN) may be involved with and receive supports from several agencies at the federal, state, and local levels. Therefore, they can experience multiple age-related transitions that occur simultaneously or near simultaneously with health care transitions. Advocates, beneficiaries, and their families shared it can be difficult to balance insurance coverage and educational, employment, and health care-related transitions that occur simultaneously. During this transition period, CYSHCN may experience a reduction or loss of services and supports from multiple agencies, which some researchers refer to as the "services cliff" (Steinway et al. 2017).

The following are examples:

Medicaid and State Children's Health Insurance Program (CHIP) coverage: The majority of CYSHCN are covered as children by Medicaid up to age 19, unless the state has extended coverage for individuals up to age 21 (42 CFR 435.118 and 42 CFR 435.223). Similarly, CHIP-covered CYSHCN are covered up to age 19 (42 CFR 457.320). When the individual is no longer eligible for Medicaid as a child or for CHIP, they transition their coverage to adult Medicaid or another form of insurance or become uninsured.

Early and periodic screening, diagnostic, and treatment: Early and periodic screening, diagnostic, and treatment-eligible beneficiaries up to age 21 are entitled to Medicaid coverage of services that are medically necessary to correct or ameliorate defects and physical and mental illnesses and conditions even if those services are not included in the state plan (§ 1905(a) of the Social Security Act). The termination of early and periodic screening, diagnostic, and treatment at age 21 for all children, including CYSHCN, may limit access to services that are less likely to be or are not covered for the adult population (McManus et al. 2024, MACPAC 2021, Williams and Tolbert 2007).

BOX 1-1. (continued)

Title V Maternal and Child Health program services: CYSHCN receive services and supports from state Title V programs such as coordination and case management services as well as educational resources. The age at which CYSHCN lose these benefits is typically by age 21 (McManus et al. 2024).[9]

Section 1915(c) home- and community-based services: CYSHCN can receive services and supports in a child-specific home- and community-based services waiver that may differ from adult waiver services (CMS 2015). Additionally, CYSHCN may be placed on a waiting list while transitioning to an adult waiver, and during the waiting period, they may not have access to needed services and supports if they age out of the child-specific waiver (MACPAC 2020). The age at which these transitions occur can vary across and within states depending on waiver age limits.

Special education school services: Under the Individuals with Disabilities Education Act, children with disabilities are required to receive an individualized education plan that details the child's level of academic achievement and functional performance; academic and functional goals; and types of services and supports the child will receive, including transitions services. Transition services include postsecondary education, vocational rehabilitation, and independent living (34 CFR 300.320). After graduation (or until they reach 22), CYSHCN are no longer eligible for these special education services (McKinney 2024).

Supplemental Security Income (SSI): CYSHCN receive cash assistance and can be enrolled in Medicaid on the basis of SSI eligibility. CYSHCN must go through redetermination at age 18 to receive SSI benefits as an adult. The redetermination can result in loss or reduction of benefits. Additionally, if an individual does not qualify for SSI as an adult, they may lose their Medicaid coverage (Colello and Morton 2019).

Child welfare: Children involved in the child welfare system receive supports through Title IV-E, including but not limited to payment for room and board for certain settings (e.g., group homes and institutions), case management services, and services to facilitate their transition to greater independence (MACPAC 2015). Although children age out of the child welfare system at 18 years old, all state Medicaid agencies are required to extend Medicaid coverage for former foster care children in their state until their 26th birthday (Patient Protection and Affordable Care Act, P.L. 111-148, as amended).

Structured health care transitions

Structured health care transitions are evidence-based approaches for transitioning from pediatric to adult models of care, some of which build on the principles established by the American Academy of Pediatrics overarching principles for transition (e.g., Got Transition's Six Core Elements) (McManus et al. 2020a; White et al. 2020, 2018; Gabriel et al. 2017; Cooley and Sagerman 2011). These approaches to structured health care transitions include many similar steps related to planning and facilitating the beneficiary's transition and integration into the new adult model of care. Some key planning services and supports include a provider or other non-clinical professionals meeting with the beneficiary and family to discuss the transition process, assessing transition readiness, coaching the beneficiary to gain self-care skills, and developing a transition of care plan based on the child's unique needs. Other key steps include receiving support from the pediatric provider and care coordinator in identifying and communicating with the adult providers during the transition period and following up with beneficiary and adult providers after the transition to ensure the beneficiary's care needs are being met (Got Transition 2020, White et al. 2018, AMCHP and NASHP 2017, Gabriel et al. 2017, Steinway et al. 2017).[10]

One of the key planning components of structured health care transitions is developing a transition of care plan. A 2014 Evidence-Based Practice Center technical brief from the Agency for Healthcare Research and Quality indicates that the literature supports a formal, documented individualized transition plan, noting that such plans generally describe the goals for the transition and specific actions for achieving the goals (McPheeters et al. 2014).[11] These plans are similar to those of individualized care plans developed for other Medicaid populations with complex health care needs. For example, federal rules require a written person-centered service plan for HCBS that reflects the individual's strengths and preferences, the identified clinical and support needs, the services and supports that will assist the individual in meeting their identified goals, and the providers of those services (§ 1915(c)(1) of the Act, 42 CFR 441.301(c), 42 CFR 441.725(b), 42 CFR 441.540). Some states' HCBS waivers include transition of care planning as a required element of person-centered service plans. Similarly, federal regulation requires that during admission to a psychiatric residential treatment facility, youth must receive active treatment specified in an individualized plan of care that must be reviewed at least every 30 days (42 CFR 141.154-156).[12]

Without a structured transition process, CYSHCN can experience loss of coverage, discontinuity of care, problems with treatment and medication adherence, higher care costs, higher emergency department use, and excess morbidity and mortality (Flanagan et al. 2022, Lemke et al. 2018, White et al. 2018). Two systematic reviews of studies on CYSHCN and transitions of care found that CYSHCN who engaged in a structured transition of care approach were more likely to experience statistically significant beneficial outcomes compared to those who did not. These outcomes include greater transition readiness, adherence to care, reduced anxiety related to their health, decreased hospital visits, increased adult care utilization, and improved patient-reported health and quality of life (Schmidt et al. 2020, Gabriel et al. 2017).

Data availability and limitations

Few data sources collect information about CYSHCN. Even fewer collect consistent and comparable measures that could be used to assess the size of the transition-age Medicaid-covered CYSHCN population, which individuals have a transition of care plan, how many transfer their care to adult providers, health outcomes and service use after transitioning to adult care, and differences in transition experience by demographic characteristics (McManus et al. 2023, NASHP 2019). The NSCH is an annual survey of households with children and youth up to age 17 that uses a validated screening tool to identify households with CYSHCN.[13] Adult caregiver respondents provide information about the children in their household, including the child's type of health insurance coverage and whether they are receiving transition of care planning services. The survey cannot be used to evaluate care or service use after age 17.[14] Medicaid eligibility and enrollment and claims data can be used to identify beneficiaries with disabilities, including children, and measure outcomes related to health service use for these populations. However, Medicaid claims data may underestimate the number of individuals with disabilities, including those receiving long-term services and supports (MACPAC 2024b).

More research is needed to identify and establish standardized CYSHCN health care transition process and health outcome measures that capture information about the experience during and after the transition to adult care. Some existing quality measures are related to CYSHCN, their care coordination, and access to and use of services that states and MCOs can collect, including a few related to transitions to adult care (Girmash and Honsberger 2022). However, none of these measures capture information about the experience after the transition to adult providers, including utilization of care and health outcomes (McManus et al. 2023, Girmash and Honsberger 2022, Okumura et al. 2022). The National Care Coordination Standards for CYSHCN include many quality measures related to CYSHCN and their care, including a few measures focused on the preparation for the transition to adulthood. These measures include, for example, whether the child has a transition plan and whether and how the provider is preparing them for the transition to adult providers. Furthermore, other Medicaid data reporting efforts, such as the Child Core Set and HCBS Quality Measure Set, include some measures that may be applicable to some CYSHCN (e.g., those with attention deficit hyperactivity disorder or asthma) but do not include measures that are specific to all CYSHCN or their transitions from pediatric to adult care (CMS 2023a, 2022a). Given the variation in state CYSHCN definitions and transition of care processes, it is challenging to establish Medicaid reporting measures that would be comparable and meaningful across states.

Federal Transition of Care Requirements

Few federal requirements and guidance are related to CYSHCN and supporting their transitions to adult care. Furthermore, both state Medicaid and Title V agencies provide services and supports to overlapping CYSHCN populations, and coordination requirements exist between these agencies to support CYSHCN and their receipt of care and services. However, these requirements are not specific to health care transitions.

Medicaid

Medicaid statute and its implementing regulations do not specify requirements for CYSHCN transitions from pediatric to adult care. However, there are expectations for states to provide transition planning for beneficiaries enrolled in Section 1915(c) waivers with age limits. The Section 1915(c) HCBS technical guide specifies that there “should be transition planning procedures” for waivers with a maximum age limit to support beneficiaries and that states should “provide continuity of services to the extent feasible” (CMS 2024a). The guidance indicates that transition planning may include certain activities, such as identifying and informing individuals about public programs and waivers that they may qualify for and providing them with priority consideration for other state waivers. However, the guidance does not specify or prescribe specific parameters for these planning procedures (e.g., who is responsible for identifying individuals in need of transition planning, who is responsible for developing and providing these transition supports), which ensure that individuals receive these planning services and are connected to appropriate services after aging out of the waiver (CMS 2024a).

Certain provisions of the federal managed care rules address issues that are important for ensuring access to care for beneficiaries with special health care needs across their lifespan, though these provisions are not directly related to child to adult transitions of care (42 CFR 438.206 and 42 CFR 438.208). For example, there are requirements related to continuity of care during transitions to managed care (e.g., ensuring out-of-network coverage and continuing care with existing providers), but these requirements are not specific to transitions from pediatric to adult care (42 CFR 438.208). Although these regulations neither specify requirements for children nor address CYSHCN transitions from pediatric to adult care, some states may require specific MCO activities related to CYSHCN and transition to adult care. For example, our analysis of Medicaid MCO contracts found some states require a transition plan of care, transition readiness assessment and discussion, self-care skill development, care coordination to assist with the transition, and follow-up after the transfer to adult care.

CMS guidance on transitions of care. In recent years, CMS has provided some guidance to states related to identifying CYSHCN and providing some transition-related services.

In 2024, CMS published a State Health Official (SHO) letter on EPSDT best practices, which included information for states on using care coordination and case management to facilitate the development of a plan to outline the transition process, including referrals, to appropriate providers and services. The guidance describes Medicaid authorities under which states can deliver care coordination and case management but does not provide specific details about how these services can be used to facilitate transitions to adult care. Additionally, the guidance indicates that when children transition to adult Medicaid eligibility and are no longer eligible for EPSDT, the services they relied on may no longer be available (or in some cases limited in how often they can be used) because states are not required to cover optional Section 1905(a) benefits for adults (CMS 2024b).

In 2023, CMS issued guidance to ensure that eligible children maintain Medicaid and State Children’s Health Insurance Program (CHIP) coverage during the unwinding of the COVID-19 public health emergency, which includes steps for identifying CYSHCN. CMS called on state Medicaid agencies, in partnership with MCOs, other agencies, and family organizations, to identify CYSHCN based on disability eligibility pathways, receipt of specialized or high-risk care for physical or behavioral health needs, and claims and encounter data and assess if they are in an active course of treatment for a complex illness (CMS 2023b).

In 2023, CMS published a SHO letter on coverage and payment of interprofessional consultation in Medicaid and CHIP. The SHO letter provides states with guidance on reimbursing for clinical consultation between a treating provider and a provider who does not provide face-to-face care to the patient but whose expertise is needed. The SHO letter discusses the importance of same-day access to care and warm handoffs for youth with behavioral health needs. However, it does not specify the permissibility of payment for interprofessional consultation, same-day billing, and ongoing care from multiple primary providers in the context of pediatric to adult care transitions (CMS 2023c).

In 2022, CMS issued guidance on care coordination services for children with medically complex conditions under the Section 1945A health home optional state plan benefit.[15] Such services include comprehensive care management, care coordination, and transitional coordination services (CMS 2022b).

Recent CMS guidance describes strategies for using Medicaid authorities to cover case management and care coordination, which could be used to facilitate transitions of care. However, CMS has not published guidance specifically on the development of state strategies for transitions of care and payment for services to support transitions for CYSHCN. For example, some states may provide transition of care services through TCM. Nothing in federal policy precludes state Medicaid programs from providing transition of care services as part of the TCM benefit or requiring MCOs to provide transition services for pediatric to adult care for a state-defined population of CYSHCN (42 CFR 440.169). However, CMS officials indicated that they were unaware of any states explicitly providing transition-related services through TCM. Additionally, there are no federal restrictions on states covering transition of care services and reimbursing for transition-related Current Procedural Terminology (CPT) codes, but states have not been given guidance on how to cover particular services, such as billing for a transition care plan, provider warm handoffs, and billing for same-day services from multiple primary care providers. Furthermore, additional guidance may be needed on integrating and implementing the transition of care planning into routine preventive care provided as part of EPSDT and supporting transition-age youth in getting access to services and supports that they might lose after aging out of EPSDT.

Health Resources & Services Administration

A key policy and programmatic focus of HRSA and MCHB is improving the well-being of CYSHCN, including their transitions from pediatric to adult care. MCHB developed the Blueprint for Change, which includes a focus on health care transitions for CYSHCN, as a guide for improving the health outcomes of CYSHCN. The blueprint identifies several resources that detail the lack of transition services for CYSHCN, the importance of supporting this population through each transition they experience, and opportunities to improve transitions for CYSHCN (e.g., integrating systems that serve CYSHCN, providing care coordination, and listening to the needs of CYSHCN and their families) (McLellan et al. 2022).

State Title V programs. MCHB funds state Title V programs through the Maternal and Child Health Services Block Grant Program. The purpose of this program is to address health service needs and improve the health and well-being of women, children including CYSHCN, and families through family-centered and community-based efforts (Honsberger et al. 2018, NASHP 2018). HRSA requires state Title V programs to use at least 30 percent of the Title V Block Grant funds to provide and improve services for CYSHCN (MCHB 2024, Platt et al. 2020). State Title V programs use these funds to provide direct care (e.g., primary care), enabling services (e.g., care coordination), and public health services and systems (e.g., activities and infrastructure support). In 2023, about 19 percent of total state funds for CYSHCN were spent on direct services and enabling services. States spent the remaining funds on public health services and systems, and many states used these funds to partner with or fund advocacy organizations. For example, family-centered and community-based networks support the programs' efforts related to providing and improving services for CYSHCN, including transition-related services and supports

(Mickler 2024, McLellan et al. 2022, Honsberger et al. 2018, NASHP 2018, NCMHI and NASHP 2018).

HRSA requires state Title V programs to conduct a statewide needs assessment every five years and report annual performance data on a minimum of 5 (out of 15) national performance measures. States use these measures to track annual progress and to evaluate the effectiveness of the state strategies. One of these national performance measures is transitions from pediatric to adult care, which 36 states currently are addressing. The transitions from pediatric to adult care national performance measures uses data from the NSCH to calculate the percentage of adolescents (both CYSHCN and non-CYSHCN) who are between age 12 and 17 and receiving services from their health care provider to prepare for transitioning from pediatric to adult care (Mickler 2024, MCHB n.d.).

State Medicaid and Title V agency coordination requirements. State Medicaid and Title V agencies both serve CYSHCN, and they are required to coordinate with each other. State Medicaid agencies are required to cooperate with health agencies, including Title V (§ 509(a)(2) and § 1902(a)(11) of the Act). The implementing regulations require that each state Medicaid agency describe cooperative arrangements with the state Title V agency, called inter-agency agreements (IAAs). The IAAs must specify certain information related to the roles and responsibilities (42 CFR 431.615). IAAs are important for ensuring close collaboration and clear communication and should outline coordination efforts for CYSHCN, such as coordinated care and case management (AMCHP 2019).

State Medicaid and Title V agencies coordinate on the delivery of services to CYSHCN, data sharing, and payment, with state Medicaid agencies reimbursing Title V agencies for direct services provided to Medicaid-covered CYSHCN (CISWH n.d.-a, n.d.-b). In states in which CYSHCN are enrolled in managed care, state Medicaid programs may delegate coordination with state Title V programs to managed care plans and include provisions in MCO contracts regarding the delivery of services and supports (Honsberger et al. 2018). Furthermore, given the expertise of Title V agencies in providing care coordination services to this population, some state Title V agencies provide training services to MCOs (NASHP 2018). Additionally, Title V agencies coordinate with state Medicaid agencies and MCOs to provide EPSDT services and to avoid duplicating services (CISWH n.d.-b, Honsberger et al. 2018). For example, in some states, Title V agencies may conduct outreach to providers to ensure that they understand EPSDT services, contact families to encourage them to stay up to date on EPSDT screenings, and assist in the development of EPSDT provisions in managed care contracts (CMS 2014).

State Role in Transitions

State Medicaid agencies have the flexibility to define their transition of care strategy. The approaches can include defining the child populations the strategy applies to, establishing the steps and expectations of a process for transition of care (e.g., use of evidence-based approaches to health care transitions, development of a transition of care plan), and identifying who is responsible (e.g., case manager) for ensuring that these steps occur and that CYSHCN are assisted in the transition to adult providers. Furthermore, states determine which services are covered to support transitions of care and whether to collect data to track these populations, their transitions, and experiences and health outcomes related to their transition to adult care.

Transition of care approach

Based on our review of state Section 1915(c) waivers and state Medicaid MCO contracts, state approaches to transitions vary based on their decisions on how to address a number of key components of the transition process. Some of the components include (1) identifying the population requiring a transition to adult care; (2) establishing the timeline and process for identifying and notifying the beneficiary and their family of the upcoming transition; (3) developing a transition of care plan; (4) identifying who is responsible for developing the transition of care plan, supporting the beneficiary during the transition, and ensuring that the steps identified in the transition of care plan occur; and (5) ensuring the exchange of current medical information between the pediatric and adult provider (Schmidt et al. 2020, White et al. 2020, Gabriel et al. 2017, Cooley and Sagerman 2011).

Population definition. States can define the CYSHCN populations to achieve their policy goals and may tailor certain programs for specific subpopulations of CYSHCN. Thus, definitions of CYSHCN served in and across states may vary depending on specific eligibility pathways, waiver authorities, and state plan options. For example, some Section 1915(c) waivers serve beneficiaries eligible for Medicaid through the Katie Beckett or SSI-related eligibility pathways. Alternatively, under Section 1915(c) waivers, states may choose to serve individuals with life-limiting illnesses, medically fragile or medically complex conditions, autism spectrum disorder, or intellectual or developmental disabilities and children who need an institutional level of care. Additionally, in states with managed care, states are required to define and identify individuals with special health care needs as part of the state managed care quality strategy (42 CFR 438.208(c)(1)). In our review of state Section 1915(c) waivers and MCO contracts, these definitions varied and were not always inclusive of all children with special health care needs.

Identification and notification. State Medicaid agencies and MCOs both have a role in identifying and notifying those approaching transition age and specifying who is responsible for providing transition services. State age-limited Section 1915(c) waivers often specify how far in advance the waiver program (or a designated state case worker) notifies an individual and their family about aging out of the waiver program. Depending on the state, the amount of advance notice specified in age-limited Section 1915(c) waivers can range from 8 years to 60 days before the child becomes ineligible for the child waiver program. In contrast, our review of MCO contracts found that identification and notification timelines are seldom specified.

In the five interviewed states, the state Medicaid agency (or MCO), another state agency (e.g., partner agencies serving adults with special health care needs), or a state-assigned case manager initiates the identification and notification processes. In fee-for-service states and states with age-limited Section 1915(c) waivers, the states shared that they assign state care coordinators or case managers to identify and notify beneficiaries approaching transition age to assist with transitioning to a new waiver program, if they are eligible. If beneficiaries are ineligible, the care coordinators assist them with finding non-waiver supports. Additionally, in one state, beneficiaries are referred to county resource centers to receive resources and enrollment assistance for transitions to adult health insurance coverage and care. In the interviewed states with managed care and in our review of MCO contracts, only a few states included provisions in the MCO contract related to assisting individuals with transitioning care or identifying and notifying individuals who will transition from pediatric to adult care. One state official shared that the MCOs are contractually required to address transitions of care for CYSHCN, and the Medicaid agency sends their MCOs a daily file, which includes beneficiary information that care coordinators use to identify and notify youth approaching transition age. The state official shared that the MCO, although not specified in the contract, convenes a care team of nurses, case managers, and other clinical providers to meet with the beneficiary and family and discuss the youth's goals for the transition to adult health care.

Transition of care planning. States are required to include information about transition planning procedures in their age-limited Section 1915(c) waiver applications.[16] In our review of age-limited 1915(c) waivers that are specific to children and youth, almost all include some information about transition planning in their waiver applications, but the transition planning procedures and level of specificity vary. Some waivers specify services to support the transition of care and the individual or group responsible for helping the beneficiary through the transition, but not all specify the development of a transition plan. Of those that do, the transition plans include a number of different components, including establishing a timeline for the transition; identifying a service coordinator to support the transition; and detailing individualized supports and services needed to transition to adult care, such as identifying adult health care providers. For example, in one state waiver program, a service coordinator is assigned to each CYSHCN and is responsible for implementing and documenting the transition steps taken based on the individual's service plan. Additionally, two state age-limited 1915(c) waiver applications specify that the assigned case managers are required to document and inform families of community supports and other coverage options the child may be eligible for, including adult eligibility pathways and waiver programs.

In our review of 43 MCO contracts, 13 included provisions specific to the transition from pediatric to adult care for CYSHCN, but few included provisions to specify who is responsible for the transition of care and the development of transition of care plans. In states using specialty MCOs to serve CYSHCN, the contracts include more specificity about the transition of care, including, in some cases, requiring MCOs to identify transition specialists or benefits coordinators to support the development of transition plans years in advance of the transition and to ensure continuity of coverage and care. For example, one state's specialized MCO contract requires, as part of the adult transition planning for all youth 15 years and older, the MCO to create and regularly update a comprehensive person-centered individual service plan that includes steps and goals related to transitioning the care. In contrast, in states without specialty MCOs, only a few contracts require the development of a transition plan of care for CYSHCN. State officials in one state without specialty MCOs shared that although contract language does not specify the development of a transition of care plan, the MCO has all transition-age beneficiaries complete a transition assessment at age 14 to identify their needs and assigns them a multidisciplinary team that develops a comprehensive transition of care plan.

Coverage of services to support transitions of care

There are no federal restrictions on states covering services to support transitions of care (e.g., care coordination, TCM). These services may be provided through state plan and waiver authorities; however, states may not always be aware of how to cover services to support transitions through these existing authorities or which CPT codes apply. Transition of care services can include a variety of services, such as meetings to discuss the transition process, provider warm handoffs (e.g., provider-to-provider meetings, multiple primary care providers, same-day visits), developing a transition of care plan, assessing transition readiness, and following up with the beneficiary after the transition. Additionally, a variety of providers and other clinical professionals can provide these services, and depending on the needs of the beneficiary and their family, these services may require longer visits (Got Transition 2020, Lebrun-Harris et al. 2018, White et al. 2018).

A number of existing CPT codes are available for transition of care-related services, including medical team conferences, care management, interprofessional consultations, and patient education (Schmidt et al. 2023). However, states may not always include them in their Medicaid fee schedules. For example, state officials and advocates in two states shared a list of transition-related CPT codes that are not included in the state Medicaid fee schedule or covered by the state managed care plans. In both states, the state Medicaid agencies were aware that these codes exist, and one state shared that the codes were not covered due to financial constraints. Officials in other states we interviewed were not aware of these transition-related CPT codes or whether other existing covered codes could be used to cover transition-related services. States may also build these CPT codes into the MCO capitation rates to ensure they are covered as part of the transition planning process and care coordination services (STAR Kids Managed Care Advisory Committee 2023, McManus et al. 2020a, White et al. 2018). State officials and plans shared that transition of care services may be provided as care coordination services and built into the capitation rate, but these billing codes may not always account for the time and added work related to longer provider visits needed for transition planning.

Some states use TCM in their Medicaid program to provide case management services to specific populations, and state Medicaid programs may choose to do so for CYSHCN to support their transitions of care (42 CFR 440.169). Interviews with federal and state officials indicate that although states could use TCM to provide transition of care-related services for CYSHCN, currently states do not. However, a couple of state officials shared that they provide case management services through TCM to populations that may include some CYSHCN (e.g., beneficiaries with intellectual or developmental disabilities) and that these services could include those related to transitions of care.

Data collection on transitions of care

CMS does not require state Medicaid programs to collect or report data related to transitions of care for CYSHCN or their outcomes. Thus, in general, state Medicaid programs do not. Some state agencies and MCOs may collect quality data that capture some information related to CYSHCN. For example, one state we spoke to conducts a utilization case review to assess if MCOs are correctly assessing beneficiaries' needs and if beneficiaries are receiving the needed services. This review may collect information about whether beneficiaries receive transition services that are detailed in their care plan. Additionally, another state's external quality review organization reviews the state's child-only Section 1915(c) waiver to monitor whether service and support coordinators assessed and documented beneficiaries' goals for their health care, including if they will need support during the transition to adult health care, in the beneficiaries' individual support plan. Interviewed state Medicaid officials shared that they have not previously used these data to monitor CYSHCN transitions to adult care and that they do not collect information about beneficiary health outcomes after transitioning to adult care. However, the state has identified transition planning as a priority, and staff are investigating how these data could be used to evaluate the state transition planning process.

Collaboration with state Title V agencies

State Medicaid agencies are required to establish IAAs with Title V agencies (42 CFR 431.615). Our review of all states and the District of Columbia's IAAs identified four states that outline roles and responsibilities related to CYSHCN transitions of care. For example, in one state, the Medicaid and Title V agencies jointly administer a phone line that connects families of CYSHCN to resources, some of which support transitions of care. Two other state IAAs specify collaborative efforts related to a number of different types of health care transitions, including steps to facilitate continuity of care for CYSHCN transitioning from pediatric to adult care. Furthermore, one state IAA specifies that the Title V agency is responsible for providing technical assistance to Medicaid providers on CYSHCN and their transition needs. IAAs in other states address program coordination and collaboration more generally or with respect to promoting access to care without mentioning transitions specifically. One state Medicaid official indicated that the Medicaid agency coordinates with the Title V and MCOs around transition services even without an explicit IAA provision.

Challenges with Medicaid-Covered CYSHCN Transitions to Adult Care

Findings from our work indicate that there are a number of challenges with the transition of care process and barriers to CYSHCN transferring to adult care and to states understanding the experiences of CYSHCN with this transition. These challenges include the absence of a federal requirement for states to clearly document or communicate their transition of care strategy, including developing transition of care plans to facilitate the transition to adult care, lack of guidance to states on how to cover services that support transitions of care, lack of data collection on transitions and post transition health outcomes, and lack of coordination between state Medicaid agencies and Title V programs on transitions of care.

Lack of clearly documented and communicated state transitions of care strategy

No federal requirement exists for states to document or publicly communicate their transition of care strategy for CYSHCN. States may specify minimum expectations or requirements related to transitions of care and planning procedures for children in waiver applications and in MCO contracts, but these vary in their specificity of transition steps and often lack information about who is responsible for facilitating the transition and ensuring beneficiaries transition their care to adult providers. Furthermore, states rarely publish online resources about the transition of care process, and the available resources typically are not published in a centralized location on state websites and are not always specific to transitions from pediatric to adult care (e.g., apply to other care transitions, such as transition from inpatient to home).

Many interviewed beneficiaries, families and caregivers, and advocates described the transition process as frustrating and confusing due to the lack of a publicly documented state transition of care process with clearly assigned responsibilities for helping beneficiaries and families prepare for and navigate the transition to adult care. Many beneficiaries reported feeling uninformed and ill-prepared to transition to adult care. They also felt that the burden is on them to identify resources, learn from peers about how the transition of care process works, and identify adult providers that meet the needs of their child.

Focus group participants indicated that they needed an assigned knowledgeable transition coordinator whose full-time job is to support beneficiaries through transitions from pediatric to adult care. Furthermore, they suggested that states should provide clear and easily accessible information about the transition process, including publishing an up-to-date list of Medicaid-enrolled providers that includes information about the age range, conditions, and disabilities the providers care for and whether the providers are accepting new patients.[17]

Not all CYSHCN receive a transition of care plan

There is no federal requirement for states to develop a transition of care plan for each CYSHCN, although research shows such plans to be important for improving outcomes related to quality of care, access to and use of adult care services, and continuity of care and coverage (McManus et al. 2020a, White et al. 2018, Gabriel et al. 2017). Thus, not all states develop or require MCOs to develop pediatric to adult transition plans for CYSHCN. Even in states that require transition of care plans or delegate these requirements to MCOs, the requirements may not specify whom to include in the development of the plan (e.g., transition specialist, case manager, and pediatric and adult providers) or include planning steps that have been shown to improve outcomes, which leads to variation in what is included in a transition of care plan (White et al. 2020, Cooley and Sagerman 2011). For example, plans may not specify which transition steps should be included in the plan, such as conducting transition readiness and identifying goals and the timing for when to identify and transition care to adult providers, sharing medical summaries with adult providers, and including adult providers in the planning of the transfer to adult care. Additionally, the plans may not identify how often the plan should be updated and who is responsible for ensuring these updates occur.

Interviewed beneficiaries and their families emphasized the important role that a transition of care plan can provide in preparing the beneficiary for the transition, facilitating the transition to adult care, and identifying adult providers far in advance of aging out of pediatric care. Beneficiary and caregiver focus group participants shared that transition of care plans were helpful if they laid out specific transition steps, prepared young adults for how to advocate for themselves and their needs with new providers, and addressed connecting with and learning to trust adult providers and if they were updated as the child aged and their needs changed. However, not all plans addressed all of these components of the transition process, few assigned a care coordinator to support the young adult through the care transition, and many families with less robust transition of care plans relied heavily on their pediatrician and other specialty providers and peers for navigating the transition. Several families shared that they did not have a designated service coordinator, social worker, or provider to help them through the transition process, and those who had coordination support reported that it was not as helpful as it could have been. Some focus group participants shared that state-assigned service coordinators or MCO care coordinators lacked awareness and knowledge of the state transition of care process and were not prepared to support the families. Furthermore, others shared that they had poor experiences due to the high turnover in these care coordinator positions. The majority of focus group participants described seeking transition of care support and services from other organizations and programs such as Title V and family-to-family health information centers and relying on their own research and other parents as resources.[18] Additionally, interviewed beneficiaries and families shared that they had challenges with receiving sufficient support to identify adult providers in advance of transitioning from the pediatric provider. This prevented them from establishing an early relationship to build rapport and trust with the adult providers or determining whether the adult providers could meet their health care needs, and in some cases, this delayed the transfer of their care from their pediatrician.

Lack of guidance to states on coverage of services to support transitions of care

Existing authorities for providing transition-related care could be applied to CYSHCN. CMS has provided states with guidance on how to use Medicaid authorities for case management and care coordination but has not provided specific guidance on covering services to support transitions from pediatric to adult care for these children. States may be unaware of how to use them to cover services to support transitions of care, including provider warm handoffs (e.g., provider-to-provider meetings, multiple primary care providers, same-day visits) and longer visits needed for transition planning.

States' lack of awareness on how to cover transition of care services to providers can be a barrier to ensuring providers are reimbursed for providing transition-related services to beneficiaries and their families. Challenges with reimbursement can result in providers choosing not to bill for provided transition-related services, such as warm handoffs between pediatric and adult providers and same-day visits by two providers when one is providing consultative services (McManus et al. 2020a, 2020b; White et al. 2018). For example, in states in which provider warm handoffs occur, state officials and plans were unsure of how or whether both providers are currently reimbursed for providing the same service. In some cases, interviewees shared that pediatric and adult providers deliver transition-related consultation services without billing for their time.

Lack of data collection on transitions of care and outcomes

There is no federal Medicaid requirement to collect or report data on CYSHCN and transitions of care from pediatric to adult care, and state Medicaid agencies often do not measure the experiences of CYSHCN with their transitions or outcomes. State Medicaid agencies and MCOs may capture some information related to CYSHCN in their current child quality measurement and reporting activities. However, these efforts are not focused on CYSHCN and do not capture specific information about the transition of care process (e.g., notification of beneficiary and family of aging out of pediatric care, receipt of transition of care planning, identification of adult providers) or about health outcomes after the transition to adult care. Thus, currently collected data cannot be used to assess whether CYSHCN are transitioning from pediatric to adult care and to understand health outcomes related to transitions.

There is a need for collecting meaningful and comparable data about CYSHCN and their transitions from pediatric to adult care to understand how current state transitions of care strategies serve CYSHCN, where gaps are in access to services, and what the effect is on health outcomes. Currently, few federal or state Medicaid data collection efforts are focused on CYSHCN and their transitions from pediatric to adult care. Furthermore, given the widely varying health conditions and needs of this population, there are challenges with identifying standardized outcome measures for understanding post transition health outcomes (McManus et al. 2023, Girmash and Honsberger 2022, Okumura et al. 2022).

Limited state Medicaid and Title V agencies coordination on transitions of care

Federal requirements related to Title V and Medicaid IAAs are silent about what the agreements should address regarding transitions of care. Few state IAAs outline roles and responsibilities related to transitions of care for CYSHCN, and interviewed state Medicaid and Title V officials shared that there is often little cross-agency collaboration on CYSHCN, including on their transitions of care.

Cross-agency coordination and collaboration on CYSHCN transitions of care can improve clarity related to agency expectations and responsibilities for supporting individuals in their transition to adult care. Without cross-agency communication and coordination, beneficiaries may not receive needed support, and the state agencies may be unaware of the challenges beneficiaries experience with their transitions. Some state Title V officials shared that there was an interest to improve coordination and to have the state agencies work more closely on transition of care policies to address gaps in the transition process. However, a couple of state officials shared that the state Medicaid and Title V agencies as well as others that are involved in providing services and supports to CYSHCN (e.g., social services or child welfare, juvenile justice, developmental services, and behavioral health) are not always under the same state departments, which can be an additional barrier to collaboration.

Commission Recommendations

The Commission makes four recommendations to Congress to improve transitions from the pediatric to the adult model of care for CYSHCN.

Recommendation 1.1

Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

Rationale

The recommendation is intended to ensure that states have a clear and well-documented strategy to facilitate health care transitions for CYSHCN as well as beneficiary and stakeholder awareness of what the beneficiary's transition will entail. CYSHCN who have a structured transition strategy that begins several years in advance of the transfer to adult care and includes a documented individualized transition of care plan with transition goals and specific actions for achieving the goals experience better outcomes compared to those without a structured transition. These outcomes include but are not limited to improved transition readiness and adherence to care, decreased hospital visits, better experience with care, and increased primary care and specialist utilization (Schmidt et al. 2020, Gabriel et al. 2017, McPheeters et al. 2014).

Although the benefits of having a structured transition strategy are well researched, there is no federal statutory or regulatory requirement for states to document or publicly communicate their transition of care strategy for CYSHCN. Based on our analysis of Section 1915(c) waivers and MCO contracts, not all states have a documented transition of care strategy, and among states that do, only a few include the development of an individualized transition of care plan. Ensuring that states publicly document their transition of care strategy will address the difficulties that beneficiaries, their families, and their providers experience with finding information about states' transition strategies.

The Commission notes federal Medicaid statute and rules acknowledge the importance of and require states to publicly document state strategies for other aspects of the program and require individualized care plans for certain beneficiaries. For example, states contracting with MCOs are required to develop and implement a quality assessment and performance improvement strategy (§ 1932(c)(1) of the Act).[19] In addition, federal rules require a written, person-centered service plan for individuals enrolled in HCBS programs with elements similar to those that would be important to address in a CYSHCN transition plan (e.g., clinical and support needs, the services and supports that will assist the individual to meet their identified goals, and the providers of those services) (§ 1915(c)(1) of the Act, 42 CFR 441.301(c), 42 CFR 441.725(b), 42 CFR 441.540).

This recommendation maintains state flexibility to determine their transition strategy, including the definition of the CYSHCN transition population and covered transition-related services based on the needs of their CYSHCN population, delivery system, and program design. The Commission identified several considerations for states as they assess and develop their transitions of care strategies for CYSHCN. For example, states should consider including other vulnerable groups of children (e.g., children involved in the child welfare system) in addition to the minimum population described in the recommendation. Furthermore, although Medicaid does not prescribe the use of a specific structured transition of care approach, states should consider adopting an existing evidence-based approach to inform their strategy. States should engage and solicit feedback from relevant stakeholders that may have a role in youth transitions, including other state agencies that serve CYSHCN (e.g., state Title V agencies, child welfare, developmental disabilities agencies), pediatric and adult provider groups, and consumer advocates as well as beneficiaries, their families, and their caregivers. Engaging beneficiaries and stakeholders would help states develop a strategy that is patient centered and culturally competent and could help with coordination with other entities involved in these transitions. Last, states should consider reviewing and updating individualized transition of care plans on a routine basis to ensure that transition plans do not become out of date, including as the child approaches the transfer to adult care.

The Commission emphasizes the importance of engaging adult providers in the transition process to ensure close collaboration and communication between the pediatric and adult systems before and after the transition. Identifying and engaging adult providers in accepting new young adults with special health care needs is a key step in the transition process, especially given the challenges with finding adult providers with the expertise to care for this population. It is the Commission's view that transition plans should be shared with and signed off on by an adult provider before the transfer to adult care, once they are identified, to ensure continuity of care.

Implications

Federal spending. The Congressional Budget Office (CBO) estimates this recommendation would not have a direct effect on federal Medicaid spending.

States. States would need to allocate resources to develop or expand on existing processes and publicly document their strategy for transitions of care and establish parameters for individualized transition of care plans for CYSHCN. States may need to engage in activities to monitor the development of individualized transition of care plans, if those responsibilities are delegated (e.g., MCOs).

Enrollees. Beneficiaries, their families, and their caregivers will have greater clarity around their state's transition of care strategy and where to find resources related to transitions of care. Beneficiaries, their families, and their caregivers will also have a better understanding of expectations for their own transition of care.

Plans. Plans will have greater clarity around the state's transition of care strategy and expectations for how they should support CYSHCN during their transitions. There may be administrative effort for plans to customize or develop the individualized transition of care plans if they are delegated this responsibility.

Providers. Providers may engage in the development of individualized transition of care plans, resulting in greater transparency about the transition process and how to support CYSHCN during their transition planning and transfer to the adult system of care.

Recommendation 1.2

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

Rationale

To date, CMS has issued little guidance to states on the existing authorities for coverage services that support transitions of care. CMS has published some guidance related to transitions of care and CYSHCN, including recently issued guidance on EPSDT, which provides authorities for covering case management and care coordination, identifying CYSHCN to ensure children maintain Medicaid and CHIP coverage during the unwinding of the public health emergency, and providing transitional services under the health home option (CMS 2024b, 2023b, 2022b). Additionally, CMS has published guidance on interprofessional consultation, which includes guidance on reimbursing for warm handoffs between multiple providers and same-day services (CMS 2023c). Currently, some state Medicaid agencies and MCOs already cover and pay for transition of care services, but MACPAC analysis found that other states were not aware of the authorities or the CPT codes for doing so. Therefore, states need additional guidance that is specific to the coverage of transition of care-related services, including the existing CPT codes that may apply.

In the Commission's view, in developing the guidance, CMS should consider addressing transition of care payment concerns raised by states and stakeholders as well as offer technical assistance to states. Stakeholders indicated a need for guidance on claiming for transition-related services (including longer visits related to transition preparation and the transfer to adult care), capitation rate setting that accounts for these services, and opportunities to cover interprofessional consultation and pediatric to adult provider consultations (e.g., warm handoff, patient co-management). Additionally, the guidance could provide information about opportunities for providing transition services under the TCM benefit, the health home option, and the application of EPSDT to transitions of care. Although CMS has recently issued guidance on EPSDT and payment of interprofessional consultation, more guidance is needed on how EPSDT can be used to facilitate transition planning and how transition care plans, interprofessional consultation, same-day visits, and warm handoffs could be covered in the context of transitions from pediatric to adult care (CMS 2024b, 2023c).

Implications

Federal spending. CBO estimates this recommendation would not have a direct effect on federal Medicaid spending.

States. As a result of this guidance, states will have greater clarity on how to use existing authorities to pay for services that support transitions of care for CYSHCN. If a state chooses to use existing authorities to pay for transition-related services, there would be administrative effort for the state to implement these payment policy changes and develop guidance for plans and providers.

Enrollees. Beneficiaries, their families, and their caregivers may experience increased access to transition-related services and supports.

Plans. If states choose to use existing authorities to pay for transition-related services, plans will need to implement provider payment changes. Additionally, there would be administrative effort for plans to develop payment policy and guidance for providers.

Providers. As a result of this guidance, providers may receive payment for transition-related services and gain more knowledge on interprofessional consultation and other collaborative efforts, such as warm handoffs. In addition, providers may engage CYSHCN in transitions earlier.

Recommendation 1.3

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to CMS beneficiary and caregiver experience with transitions of care.

Rationale

No federal requirements exist for state Medicaid agencies to collect or report data related to transitions of care for CYSHCN, and in most cases, states are not collecting these data. The lack of data collection limits CMS, state Medicaid and Title V agencies, and other stakeholders from understanding the extent to which CYSHCN receive transition of care services and the transition experience of these beneficiaries, their families, and their caregivers.

Although state Medicaid agencies and MCOs may capture some information related to CYSHCN in their current child quality measurement and reporting activities, these efforts do not capture specific information about the transition of care process (e.g., notification of beneficiary and family of aging out of pediatric care, receipt of transition of care planning, and identification of adult providers).

This recommendation is focused on improving data collection and reporting on the use of transition of care-related services, the number of CYSHCN receiving these services, and receipt of an individualized transition of care plan. The goal of reporting these data is to first establish a baseline to understand this population, their use of services, and their receipt of an individualized transition of care plan. Then, through continued reporting, the goal is to evaluate whether the state strategy is leading to an improvement in these measures.

The Commission urges CMS to consider what data states and MCOs already collect related to their CYSHCN populations, transition preparedness, and planning. CMS should consider opportunities to leverage existing data collection (e.g., the Transformed Medicaid Statistical Information System (T-MSIS), Medicaid Data Collection Toolkit, and Child Core Set and HCBS Quality Measure Set) to prevent duplicative efforts and minimize the burden on states and MCOs. Furthermore, CMS should consider the input of beneficiaries, their families, their caregivers, and other stakeholders on what information would be most meaningful for assessing whether beneficiaries are receiving necessary services to support their transition to adult care.

In considering this recommendation, the Commission discussed the importance of collecting data about both transition-related processes and outcomes, including health outcomes, service use, and receipt of care from adult providers. There are several existing process measures that states could collect to evaluate service use and supports received, including receipt of a transition of care plan (NASHP 2019). Outcome measures are important for evaluating whether states' transition of care strategies lead to improved quality of care, such as reduced hospitalizations during and after the transition. However, given the diverse population health needs of CYSHCN, it is challenging to collect comparable and meaningful outcomes data. More research is needed to develop these outcome measures.

Implications

Federal spending. CBO estimates this recommendation would not have a direct effect on federal Medicaid spending.

States. Depending on the reporting requirements, some states may not have to collect additional data, but states that are not currently collecting transition-related data would need to make some system and policy changes. These data will provide states with insight into their beneficiary populations who receive transition-related services, whether these beneficiaries receive an individualized transition of care plan, and whether the plans and services adequately meet their needs. These data will also aid states' assessments of the effectiveness of their CYSHCN transition strategy.

Enrollees. The data collected should be used to understand how beneficiaries, their families, and their caregivers experience transitions of care and, in turn, how to improve transitions for this population.

Plans. Plans may already be collecting data related to transitions of care for CYSHCN as a part of their current data collection. Depending on the requirement, some plans may have to collect additional data or update how they report them. These data will provide plans with insight into their beneficiary populations who receive transition-related services, whether these beneficiaries receive an individualized transition of care plan, and whether the plans and services adequately meet their needs.

Providers. Depending on the state's approach for collecting data, providers may have new reporting requirements. Additionally, these data may assist providers in understanding this population and their experiences with transitions.

Recommendation 1.4

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

Rationale

State Medicaid agencies are required to describe in IAAs how they coordinate with Title V agencies on their overlapping populations, including CYSHCN (42 CFR 431.615). Additionally, Title V agencies are required to submit the most recent IAAs to HRSA as a part of their annual reporting requirements (HRSA 2023). However, there are no federal requirements related to collaborating specifically on transitions to adulthood and adult care, and few state IAAs specify cross-agency collaboration on CYSHCN transitions.

To improve cross-agency coordination on transitions of care for their overlapping CYSHCN populations, CMS should require IAAs between state Medicaid and Title V agencies to specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. This requirement could include clarifying which agency is responsible for providing which services to support transitions of care; pertinent training and educational resources to plans, providers, and CYSHCN, their families, and their caregivers; and providing other supports to facilitate the transition from pediatric to adult care for this population.

Additionally, the Commission encourages states to consider opportunities to engage with other state agencies that serve CYSHCN (e.g., departments of developmental disabilities, education agencies) to coordinate on transition-related activities. CYSHCN may also experience age-related transitions out of other state agency programs, which may occur nearly simultaneously with the transition to adult care. Thus, intra-agency coordination would increase agency awareness of the multiple transitions CYSHCN experience and may surface opportunities for reducing beneficiary burden and harmonizing processes.

Implications

Federal spending. CBO estimates this recommendation would not have a direct effect on federal Medicaid spending.

States. State Medicaid and Title V agencies would need to update their IAAs to meet new requirements related to describing roles and responsibilities for both agencies in supporting CYSHCN during their transitions of care.

Enrollees. As a result of this recommendation, beneficiaries, their families, and their caregivers may experience more coordination and support from both agencies.

Plans. To the extent state Medicaid agencies delegate IAA roles and responsibilities to the plans, plans may need to collaborate and coordinate with the state Title V agency to deliver transition-related services and supports.

Providers. Depending on the roles and responsibilities described in IAAs, providers may experience changes to their roles in supporting CYSHCN during their transitions of care.

Looking Ahead

Findings from our literature review and stakeholder interviews indicated that there are many simultaneous (or near simultaneous) transitions that CYSHCN must navigate as they reach adulthood. In addition to transitions from pediatric to adult care, Medicaid-covered CYSHCN must also transition from child eligibility to adult Medicaid eligibility (if they are still eligible), and they may experience challenges with maintaining continuity of coverage. As a continuation of MACPAC's work on CYSHCN, staff is beginning work on the transitions of Medicaid-covered CYSHCN between child and adult Medicaid eligibility and transitions between age-limited child Section 1915(c) waivers to adult Section 1915(c) waivers.

Endnotes

[1] In 2025, MCHB broadened its definition of CYSHCN to include children age 0 to 17 who meet the criteria for the children with special health care needs screener as part of the National Survey of Children's Health. The screener is used to determine health consequences and functional limitations a child experiences as a result of having an ongoing health condition (Black et al. 2024).

[2] State Title V agencies administer the federal Maternal and Child Health Block Grant. States use the funds from the block grant to provide services for up to 59 million people, including CYSHCN. The Title V Block Grant is important for ensuring pregnant women, children, and infants have access to health care services and to improve their health outcomes. States are required to use at least 30 percent of the Title V Block Grant funds to provide and improve services for CYSHCN (MCHB 2024, Platt et al. 2020).

[3] States can use a number of authorities to cover children with disabilities whose family income may be too high to qualify for Medicaid through other eligibility pathways. States may refer to these beneficiaries and programs by a variety of names. Beginning in 1981, before the Tax Equity and Fiscal Responsibility Act (TEFRA), states could establish a Katie Beckett waiver to allow children with disabilities to receive treatment in the home. In 1982, TEFRA established the optional Katie Beckett state plan pathway for children with disabilities. This pathway allows states to cover children with severe disabilities whose family income may otherwise be too high to qualify for Medicaid through their state plan. Only the child's own income and assets are counted (42 CFR 435.225). After TEFRA established this state plan option, many states converted their existing Katie Beckett waiver program into a program under the state plan. Some states refer to this as a "Katie Beckett program" or a "TEFRA waiver program." In addition, some states provide similar services to the same population under Section 1915(c) waivers rather than under the state plan. Some states refer to this as an "HCBS waiver," "Katie Beckett waiver," or "Katie Beckett-like waiver," and it differs from the pre-TEFRA Katie Beckett waiver. However, unlike the TEFRA state plan option, states that serve this population under a Section 1915(c) waiver can limit the number of waiver slots (MACPAC 2023, Colello and Morton 2019, CISWH 2016). As of 2022, forty-three states and the District of Columbia use the Katie Beckett eligibility pathway or have a comparable 1915(c) waiver (Musumeci et al. 2022).

[4] The Family Opportunity Act allows children with disabilities whose family income is below 300 percent of the federal poverty level to buy into Medicaid. As of 2022, eight states have adopted the option authorized in the Family Opportunity Act (Musumeci et al. 2022).

[5] The Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA, P.L. 97-248) changed Medicaid income counting rules to allow severely disabled children to receive their care at home while retaining their Medicaid coverage (Smith et al. 2000). This expanded the Katie Beckett waiver. Under this pathway (called the "Katie Beckett eligibility pathway"), states count only the income and financial resources of a child with a disability who needs long-term services and supports. Many states converted their Katie Beckett waivers to the state plan option, and some provided institutional long-term services and supports or Section 1915(c) waiver benefits to individuals eligible under this pathway who meet institutional criteria (MACPAC 2022, CISWH 2016).

[6] In a 2023 scan of all 50 states and the District of Columbia, the National Academy for State Health Policy identified that 11 states and the District of Columbia enroll specific populations of children, including CYSHCN, into specialized managed care plans. Additionally, at least 30 states and the District of Columbia include specific provisions related to CYSHCN in their managed care contracts (Gould et al. 2023).

[7] States most commonly use a waiver under Section 1915(c), but they can also choose to operate HCBS under their state plan through Sections 1915(i), 1915(j), or 1915(k). HCBS provided under Section 1915(c), 1915(i), and 1915(j) may be targeted to specific populations; Section 1915(k) services may not (MACPAC 2025).

[8] MACPAC's analysis used data from the 2021 and 2022 NSCH to compare demographic and health characteristics between CYSHCN and non-CYSHCN. Additionally, the analysis compared differences with accessing care and quality of care, insurance adequacy, and transition planning between Medicaid-covered CYSHCN, CYSHCN covered by private insurance, CYSHCN covered by a combination of the two, and those who are uninsured (MACPAC 2024a).

[9] Between 2022 and 2024, the National Alliance to Advance Adolescent Health's Got Transition program conducted a survey of state Title V CYSHCN programs. The survey included questions about the programs, including the age cutoffs. The Title V statute does not specify when CYSHCN age out of Title V program services, so the age cutoff can

vary. Among the states that completed the survey, 61 percent reported their age cutoff was 21 (McManus et al. 2024).

[10] The Six Core Elements framework was developed in response to the need identified in the 2018 Clinical Report on Health Care Transition from the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians. The Six Core Elements define the basic components of a structured transition process and include customizable sample tools for each core element (Got Transition 2020). The Six Core Elements of Transition include these steps: (1) transition and care policy or guide, (2) tracking and monitoring, (3) transition readiness, (4) transition planning, (5) transfer of care, and (6) transfer completion (White et al. 2018). The overarching principles for transition include (1) importance of youth- and/or young adult-centered, strength-based focus; (2) emphasis on self-determination, self-management, and family and/or caregiver engagement; (3) acknowledgment of individual differences and complexities; (4) recognition of vulnerabilities and need for a distinct population health approach for youth and young adults; (5) need for early and ongoing preparation, including the integration into an adult model of care; (6) importance of shared accountability, effective communication, and care coordination between pediatric and adult clinicians and systems of care; (7) recognition of the influences of cultural beliefs and attitudes as well as socioeconomic status; (8) emphasis on achieving health equity and elimination of disparities; and (9) need for parents and caregivers to support youth and young adults in building knowledge regarding their own health and skills in making health decisions and using health care (White et al. 2018).

[11] To develop the technical report, researchers reviewed published and gray literature and engaged key informants, including clinical, policy, and research experts as well as advocates. The technical report refers to documenting the individualized plan in the medical record (McPheeters 2014).

[12] The individualized plan of care must be based on a diagnostic evaluation, be developed by an interdisciplinary team of licensed mental health providers, include state treatment objectives, prescribe specific therapies and activities, and include post discharge plans to ensure continuity of care with the youth's family, school, and community (42 CFR 141.154–156).

[13] The CYSHCN population includes those who meet the criteria from the screening tool as well as children with both one or more health conditions and one or more functional difficulties asked about in the NSCH (Black et al. 2024).

[14] In 2023 and 2024, the NSCH conducted a longitudinal cohort study to follow up with households interviewed as part of the 2018 and 2019 survey. The follow-up includes individuals up to age 24, so some of these data may be used to assess access to and use of care after age 18, when many children transition out of pediatric care. The survey questionnaire includes six questions related to the transition to an adult primary care provider. These data will not be available until spring 2025 at the earliest (USCB 2025a, 2025b).

[15] The health home option established by Section 1945A of the Act allows states to cover "care coordination, care management, patient and family support, and similar services that are expected to support a family-centered system of care for children with medically complex conditions, and that could help to improve health outcomes for these children." Additionally, many of these children require specialty care that may not be available from providers in their state, so the coordination of care and services can also be provided by out-of-state providers (CMS 2022b).

[16] The Section 1915(c) HCBS technical guide specifies that there "should be transition planning procedures" for waivers with a maximum age limit to support beneficiaries and that states should "provide continuity of services to the extent feasible" (CMS 2024a).

[17] CMS issued guidance on provider directory requirements to states that directories should be updated quarterly, detail which accommodations providers can offer (e.g., for physical disabilities), and detail if the providers are accepting new Medicaid or CHIP patients (CMS 2024c).

[18] HRSA administers family-to-family health information centers, and some of these centers provide one-on-one transition guidance or support. These centers are staffed by individuals with lived experience, so they can be particularly helpful to families navigating complex health-related challenges, including transitions to adult care (HRSA 2024).

[19] The statute requires that state quality assurance and program improvement strategies address access standards, examining measures related to improved quality of care, monitoring procedures, and periodic reviews of the strategies.

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APPENDIX 1A: Methods

To inform our work, we completed a literature review and an analysis of transition of care-related measures from the National Survey of Children's Health (NSCH) and contracted with Abt Global to complete a federal and state policy scan; 26 structured interviews; and 4 focus groups with beneficiaries, their families, and their caregivers. The literature review and federal and state policy scans focused on both transitions of coverage and care and used a broad definition of children and youth with special health care needs (CYSHCN) to be inclusive of all federal and state population definitions. Our findings from the literature review, policy scan, and preliminary interviews indicated that narrowing the project to transitions of care and the population scope to children with more complex health conditions and service needs would be helpful for the in-depth interviews with states and stakeholders and for assessing comparability of transition policies across states. For these two analytical tasks, we defined this population as those enrolled in Social Security Income-related eligibility pathways; those enrolled in the Katie Beckett pathway for children with disabilities, which was enacted under the Tax Equity and Fiscal Responsibility Act (TEFRA) authority; and those enrolled in a Katie Beckett waiver (some states refer to these as a "TEFRA waiver").

The literature review examined both peer-reviewed research and gray literature on the transition of care process to identify research gaps on this population and their experiences with transition to adult care. We also reviewed frameworks for supporting CYSHCN transitioning to adult health care (e.g., Association of Maternal & Child Health Programs National Standards and 2011 American Academy of Pediatrics transition process); the effects of efforts to implement transition processes on access, costs, and health outcomes; family and beneficiary barriers to transitioning from pediatric to adult Medicaid; and other considerations for providing transition services (e.g., availability and use of any standards of care).

We used data from the 2021 and 2022 NSCH to assess the experiences of Medicaid-covered CYSHCN with the transition of care process (MACPAC 2024a). Children and youth were identified as having special health care needs by using the NSCH children with special health care needs screener. The screener includes five questions that were developed based on the federal Maternal and Child Health Bureau's definition of children with special health care needs. The screener is used to identify children with one or more chronic health conditions that are expected to last 12 months or longer. Respondents are the parents or guardians of randomly selected children from all 50 states and the District of Columbia. The survey provides national and state-level estimates on measures related to the health of children age 0 to 17 (CAHMI n.d.).

The objective of the federal policy scan was to identify provisions pertaining to pediatric to adult transitional care and coverage. The scan included a review of federal statutory, regulatory, and subregulatory language for Title V, Medicaid, and the State Children's Health Insurance Program as well as guidance from the Maternal and Child Health Bureau of the Health Resources & Services Administration and the Centers for Medicare & Medicaid Services (CMS). CMS guidance included CMS state health official letters and CMS informational bulletins related to Medicaid and State Children's Health Insurance Program eligibility, enrollment, benefits, managed care, and quality from 2019 to the time of the review in October 2023.

The objective of the state policy scan was to identify state Medicaid program, managed care organization (MCO) contract, and Title V agency policies related to coverage and care transitions for CYSHCN and to understand how these programs and MCO contracts define, identify, and support CYSHCN through their pediatric to adult transitions of coverage and care. The review included a subset of state Medicaid program and research demonstration waivers, including home- and community-based services Section 1915(c) waivers in nine states, Katie Beckett waiver and TEFRA documentation for eight states, and Section 1115 demonstrations. We also reviewed MCO contracts, including MCO contracts specialized on CYSHCN.[1] The state Medicaid waiver review represented 14 unique states that do not enroll any CYSHCN populations in full, risk-based managed care but do enroll some or all CYSHCN in other managed care models (i.e., primary care case management and prepaid health plans).

The purpose of the stakeholder interviews was to better understand how state Medicaid agencies operationalize their waiver and MCO policies for transitions of care and challenges with these transitions. Interviewees included federal officials from CMS, Health Resources & Services

Administration, and Maternal and Child Health Bureau; state Medicaid and Title V officials from Alaska, Nebraska, Oklahoma, Texas, and Wisconsin; state CYSHCN advocacy groups in the five selected states; managed care plans in Nebraska and Texas; and national experts and researchers.

The purpose of the beneficiary and family and caregiver focus groups was to understand the beneficiary experience with navigating the transition of care process from pediatric to adult care. Abt Global conducted four virtual focus groups, two of which included beneficiaries and their families and other caregivers who are in the process of transitioning from pediatric to adult care or have recently transitioned to adult care.[2, 3] The Abt Global Institutional Review Board reviewed the scope of the focus groups and determined that it did not require formal board review because it does not meet the definition of research per the human subjects' regulations. In collaboration with MACPAC, Abt Global developed eligibility criteria and a consent process for all participants:

- The eligibility criteria for the beneficiaries included being between 14 and 26 years of age, being enrolled in Medicaid at the time of transition and eligible for Social Security Income-related pathways or the Katie Beckett pathway, not living in foster care, residing in one of the five states selected for state interviews, having special health care needs, having transitioned to adult services of care or preparing to transition to adult care, and being proficient with the English or Spanish language.
- The eligibility criteria for the caregivers included being 18 years of age or older, serving as the primary caregiver of a beneficiary who is 14 to 26 years of age who has special health care needs and has transitioned to adult services of care or is preparing to transition to adult care, caring for a beneficiary (or former beneficiary if they transitioned their care) in one of the five states selected for state interviews, and being proficient with the English or Spanish language.

The consent process was developed by Abt Global for all participants, including those who had not reached the legal age of assent in their state of residence (19 years in Nebraska, 18 years in all other selected states). Participants who were adults provided consent on their own behalf. For those who were not adults, Abt Global obtained consent from a parent, legal guardian, or other individual with legal custody on behalf of participants who were minors under their applicable state laws. It was not required for minors to provide consent to these activities for which an adult was consenting on their behalf. However, Abt Global provided minors with the same consent information as adults (e.g., benefits and risks of participating, whom to contact with questions, ability to stop participating without penalty), and any refusal of a minor to participate in or contribute to a focus group session was honored.

Endnotes

[1] The contract analysis did not include a review of specialty contracts that cover only children and youth in foster care, youth receiving adoption assistance, or youth with behavioral health conditions, since they are not inclusive of the broader population of CYSHCN.

[2] Recruitment efforts identified six to eight beneficiaries for each focus group. However, an examination by Abt Global found that several responses were likely submitted by a single person trying to impersonate multiple respondents, so we excluded these responses from focus group findings. Furthermore, on outreach calls during which Abt Global confirmed eligibility and obtained consent, there were a few cases for which it could not confidently confirm a guardian provided consent (versus a youth or young adult posing as the guardian). In other cases, information that potential participants reported in the online eligibility survey conflicted with what they told Abt Global over the phone (e.g., age, state of residence). Abt Global excluded individuals if there was any doubt about eligibility or guardian consent.

[3] Recruitment efforts included translating all materials into Spanish and sending out materials to groups with Spanish-speaking members. However, due to low response rates, we did not conduct any of the focus groups in Spanish.

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 11, 2025.

Children and Youth with Special Health Care Needs (CYSHCN) Transitions of Care

1.1 Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

1.2 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

1.3 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to CMS beneficiary and caregiver experience with transitions of care.

1.4 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

1.1–1.4 voting result	#	Commissioner
Yes	16	Allen, Bjork, Brooks, Brown, Duncan, Gerstorff, Giardino, Heaphy, Hill, Ingram, Johnson, Killingsworth, McCarthy, McFadden, Nardone, Snyder
Vacancy	1	

Chapter 2:

Appropriate Access to Residential Behavioral Health Treatment for Children in Medicaid

Appropriate Access to Residential Behavioral Health Treatment for Children in Medicaid

Key Points

- The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement mandates that states provide Medicaid beneficiaries age 21 and younger access to any treatment, including residential treatment, for physical or mental conditions. Residential treatment services for youth may be provided in a psychiatric residential treatment facility (PRTF), qualified residential treatment program (QRTP), or in other residential settings that do not meet the requirements of a PRTF or QRTP.
- Federal law prohibits Medicaid payments for services provided to beneficiaries residing in an institution for mental disease, however there are several exceptions, including the psych under 21 benefit. The benefit allows states to cover medically necessary services delivered in PRTFs, a psychiatric hospital, or a psychiatric unit of a general hospital to beneficiaries under age 21.
- Lack of a single federal data source and other data limitations make it difficult to conduct comprehensive analysis of how Medicaid-enrolled children utilize residential treatment services.
- Identifying available residential treatment when needed is challenging due to the lack of easily attainable and specific information about the facilities serving Medicaid beneficiaries, such as their bed availability and specialty area.
- States may seek out-of-state placement for children if in-state placement cannot be found. In-state PRTFs may deny admission due to the child’s diagnosis or functional or behavioral health characteristics, or to reserve beds for out-of-state patients to secure higher payment rates.
- Access to services along the continuum of behavioral health care, in particular home- and community-based behavioral health services, also affects access to residential behavioral health treatment. MACPAC previously found that intensive home- and community-based behavioral health services can help children with significant mental health conditions remain in their communities and avoid residential placement, but are often unavailable or difficult to access.
- MACPAC will continue to explore work that focuses on addressing the behavioral health needs of children with Medicaid coverage across the continuum of care.

CHAPTER 2: Appropriate Access to Residential Behavioral Health Treatment for Children in Medicaid

Medicaid supports a wide range of behavioral health services for children, including residential treatment programs when determined medically appropriate (MACPAC 2021). Federal laws are in place to ensure that children with Medicaid receive appropriate access to behavioral health services. The Americans with Disabilities Act of 1990 (ADA, P.L. 101-336) prohibits discrimination against individuals with disabilities, including Medicaid beneficiaries with serious mental illness (SMI), and requires that services such as necessary mental health treatment be provided in the most integrated setting appropriate. Under the U.S. Supreme Court's ruling in *Olmstead v. L.C.* (119 S. Ct. 2176 (1999)), states must provide treatment for individuals with disabilities, including SMI and serious emotional disturbance (SED), in community-based settings if the individuals do not oppose such services and if such placement is appropriate and can be reasonably accommodated by the state.[1] Intensive home- and community-based behavioral health services can help children and adolescents with significant mental health conditions remain in their communities and avoid unnecessary residential treatment. However, for children who need more intense care or pose a safety risk to themselves or their families, it is important that they can access residential treatment when appropriate (SAMHSA 2025b).

Residential treatment services for children are behavioral health interventions intended to provide intensive clinical treatment to children with SED or co-occurring conditions such as substance use disorder (SUD) (SAMHSA 2019). Residential treatment settings for children include psychiatric residential treatment facilities (PRTFs); qualified residential treatment programs (QRTPs) for children in foster care; residential programs such as SUD programs; and therapeutic boarding schools, wilderness camps, therapeutic ranches, boot camps, group homes, and other congregate care settings (Herbell and Ault 2021, Teich and Ireys 2007). Although the literature is limited, some research finds that individuals with disabilities experience barriers to treatment, such as inaccessible treatment facilities and communication difficulties (Clemans-Cope and Lynch 2025).

The 2021 U.S. Surgeon General's Advisory on Protecting Youth Mental Health described the ongoing youth mental crisis as an urgent public health issue and highlighted the consequences of mental health challenges, including poor health outcomes and the potential for future disability (HHS 2021). A Centers for Disease Control and Prevention analysis of Youth Risk Behavior Survey data indicated that from 2013 to 2023, certain indicators, such as experiencing persistent feelings of sadness or hopelessness and seriously considering attempting suicide, worsened (CDC 2024).[2] In addition, visits to emergency departments (EDs) by children for mental health-related issues increased (Hoge et al. 2022, ISPN 2022). For example, mental health-related ED visits in the United States increased 24 percent for children age 5 to 11 and 31 percent for those age 12- to 17-years-old between March 2020 and October 2020, compared to the same period in 2019 (Leeb et al. 2020). ED boarding also increased (MHPC 2025, Snow et al. 2025). ED boarding of children who need behavioral health treatment occurs when these patients remain in the ED, sometimes for prolonged periods, while awaiting needed behavioral health treatment. In 2017, about 12 percent of mental health encounters in the ED resulted in boarding in children's hospitals compared to 16 percent in 2023 (Snow et al. 2025). During the same time period, the median length of stay for boarding increased from 3 to 4 days, with a range of 2 to 589 days (Snow et al. 2025). ED boarding may cause patients to experience increased stress and delay mental health treatment that could mitigate the need for an inpatient stay (The Joint Commission 2021).[3]

In 2022, approximately one in four noninstitutionalized Medicaid-enrolled youth age 12- to 17-years-old reported experiencing a major depressive episode in their lifetime, and one in seven experienced a major depressive episode with severe role impairment (SHADAC 2024).[4] One study found that major depressive episodes and other mood, disruptive, and psychotic disorders were predictive of admission to residential treatment for Medicaid-enrolled children (Rose and Lanier 2017). Other factors associated with admission for children were a trauma-associated behavioral health diagnosis, one or more antipsychotic drug prescriptions, a history of prior placement in a residential facility, a history of physical or sexual abuse, high levels of aggressive behaviors, family dysfunction including parental substance use, being older (with highest admission rates among adolescents), being male, and being Black (Wulczyn et al. 2015, Connor et al. 2004).

In response to the ongoing behavioral health crisis for children, the challenges in finding timely treatment when needed, and the health consequences of not being able to find timely treatment, MACPAC examined access to and use of appropriate residential treatment. This chapter describes the findings from this work. Although few children with Medicaid coverage require residential treatment services, the families of children that do require this level of treatment often experience barriers in finding an appropriate placement. This chapter begins with an overview of Medicaid coverage of residential behavioral health treatment, how children are referred to residential treatment, the use of residential services, the use of out-of-state placements, and barriers to appropriate access to residential treatment.

Medicaid Coverage of Residential Treatment Services

Children with behavioral health needs eligible for treatment under Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirements have a statutory right to any treatment or procedure that fits within any of the categories of Medicaid-covered services listed in Section 1905(a) of the Social Security Act (the Act), if that treatment or service is medically necessary. Residential treatment services for children are behavioral health interventions intended to provide intensive clinical treatment for children with SED or co-occurring conditions such as SUD. Medicaid-enrolled children access this intensive level of care in PRTFs, QRTPs for children in foster care, and other settings that are not defined in federal law (e.g., therapeutic boarding schools, boot camps) (Appendix 2A).

Early and Periodic Screening, Diagnostic, and Treatment

EPSDT requirements entitle Medicaid beneficiaries age 21 and younger to any treatment, including residential treatment, that is necessary to correct or ameliorate physical or mental conditions. EPSDT is designed to identify health issues early in the life course to promote early intervention and treatment, including for behavioral health. Identification of health needs often occurs through regular screenings and assessments at each well-child visit from birth through adolescence based on a state's periodicity schedule (CMS 2022). For example, screenings may address conditions including developmental delays, autism, depression, and suicide risk in adolescence. States must ensure availability of Medicaid coverable (under Section 1905(a) of the Act), medically necessary services to treat conditions identified during screening and diagnostic visits. Many residential facilities do not accept Medicaid, which limits the available treatment options for beneficiaries (BPC 2025).

The EPSDT requirement applies to children enrolled in the State Children's Health Insurance Program (CHIP) through Medicaid-expansion CHIP but not those in separate CHIP. However, several states with separate CHIP coverage have elected to provide EPSDT to beneficiaries in that program. In addition, in 2018, the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act (SUPPORT Act, P.L. 115-271) required coverage of behavioral health services in CHIP. The Centers for Medicare & Medicaid Services (CMS) urges states to "leverage a comprehensive array of Medicaid providers...in meeting EPSDT coverage obligations" (CMS 2022).

Institution for mental disease exclusion

Federal law defines an institution for mental disease (IMD) as a "hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services" (§ 1905(i) of the Act).

The term "institution for mental disease" is broad and has meaning only within the context of the Medicaid program; IMDs are not identified as a specific type of provider by other payers, state licensure agencies, or accrediting bodies. The definition encompasses several different types of facilities, including inpatient SUD and mental health treatment facilities as well as residential SUD and mental health programs (MACPAC 2019). The term "mental diseases" includes diseases listed as mental disorders in the *International Classification of Diseases*, with the exception of mental retardation, senility, and organic brain syndrome.

Since its inception in 1965, Medicaid has largely prohibited payments for services provided to beneficiaries residing in IMDs. The exclusion was designed to ensure that states and local governments retained their historical responsibility for funding inpatient psychiatric care (MACPAC 2019). The IMD exclusion applies to facilities with more than 16 beds and is one of the few instances in which no Medicaid federal financial participation (FFP) is available for any medically necessary and otherwise covered services for certain Medicaid beneficiaries receiving treatment in a specific setting (MACPAC 2019, CMS 2012).

Exceptions to the IMD exclusion for children younger than age 21

The Social Security Amendments of 1972 (P.L. 92-603) allowed an exemption to the IMD exclusion for children younger than age 21, commonly referred to as the "psych under 21" benefit (§§ 1905(a)(16), 1905(h), and paragraph (B) following the last numbered paragraph of § 1905(a) of the Act).[5] This optional benefit allows states to provide coverage for services delivered in PRTFs, a psychiatric hospital, or a psychiatric unit of a general hospital. Although this is an optional benefit, states must cover it if an assessment under EPSDT determines that the level of service is medically necessary. If the state lacks a facility to meet the assessed need, the state Medicaid program must pay for placement in an out-of-state facility (CMS 2012).

Section 1115 demonstrations also permit states to receive FFP for services provided to children with SED and adults with SMI during short-term stays in psychiatric hospitals or residential treatment settings that qualify as IMDs. FFP for services provided to children younger than 21 is limited to settings that qualify under the "Psych Under 21" benefit and to QRTPs that comply with restraint and seclusion requirements (CMS 2021). States must commit to improving connections to community-based care following stays in acute care settings, ensure a continuum of care is available to address the needs of beneficiaries with SED or SMI, provide a full array of crisis stabilization services, and promptly engage beneficiaries in treatment (CMS 2018). States may also use Section 1115 SMI/SED demonstrations to receive FFP for services delivered to Title IV-E beneficiaries (i.e., children in foster care) in a QRTP that is an IMD (CMS 2019).[6]

States may also use demonstration authority to waive the IMD exclusion and receive FFP for SUD treatment services delivered to beneficiaries during short-term IMD stays. Demonstration approval and funding are contingent on states pursuing efforts to meet specified milestones, such as providing access to all levels of care, ensuring the use of evidence-based patient placement criteria, and improving transitions between levels of care. States that receive waivers are expected to maintain a statewide average IMD length of stay of 30 days or less for individuals with SUD, and they cannot use FFP to pay for room and board (MACPAC 2024).

PRTFs

PRTFs are non-hospital-based facilities that have an agreement with a state Medicaid agency to provide the psych under 21 benefit (Appendix 2A). PRTFs must be accredited by one of the following: The Joint Commission, the Commission on Accreditation of Rehabilitation Facilities, the Council on Accreditation of Services for Families and Children, or any other accrediting organization with comparable standards that is recognized by the state (42 CFR 441.151).

Before admission to a PRTF, a child's health care team is required to certify that community resources do not meet the treatment needs of the child, treatment of the child's psychiatric condition requires an inpatient level of care under the direction of a physician, and services can be reasonably expected to improve the child's condition or prevent regression. Emergency admissions must be certified within 14 days of admission (42 CFR 441.152). The team must include a physician with competence in the diagnosis and treatment of mental illness (42 CFR 441.153). During their admission, a child must receive active treatment specified in an individualized plan of care that must be reviewed at least every 30 days. The individualized plan of care must be based on a diagnostic evaluation, be developed by an interdisciplinary team of licensed mental health providers, outline treatment objectives, prescribe specific therapies and activities, and include post-discharge plans to ensure continuity of care with the child's family, school, and community (42 CFR 141.154-156).

PRTFs, like all health care facilities receiving any federal support, are required to protect and promote the rights of all residents, including the right to be free from any restraint or involuntary seclusion imposed for discipline, convenience, or retaliation (42 CFR 441 and 42 CFR 483). PRTFs are permitted to use restraint or seclusion only to ensure the safety of the resident or others during an emergency safety situation (42 CFR 483.356). Restraint or seclusion must be ordered by a physician or licensed practitioner and must not exceed four hours for residents age 18 to 21, two hours for residents age 9 to 17, or one hour for residents younger than age 9 (42 CFR 483.358). Staff must document the use of restraint or seclusion in the resident's record, notify the parent or guardian, monitor the safety and condition of the resident, and conduct a post-incident debriefing within 24 hours (42 CFR 483.358-370).

QRTPs

Enacted as part of the Bipartisan Budget Act of 2018 (P.L. 115-123), the Family First Prevention Services Act (FFPSA) made substantial reforms to the child welfare system, including placing restrictions on the use of federal funding for congregate care. The FFPSA generally restricts the availability of Title IV-E foster care maintenance payments to 14 days unless the child is placed in a QRTP, a newly defined category of group homes (Appendix 2A).[7]

QRTPs provide time-limited trauma-informed treatment for children in foster care with behavioral health disorders. For a QRTP to receive Title IV-E payment on behalf of a child, the child must be assessed by a qualified individual not associated with the public agency or the residential program within 30 days of placement. Within 60 days of placement, the court must consider the assessment to determine if the placement in the residential facility is necessary and approve the placement (ACF 2018).

Title IV-E funds may be used to pay QRTPs for maintenance costs, which include room and board, supervision, case management, and allocated indirect costs for children who are eligible. Title IV-E does not reimburse the cost of any treatment services received by any child regardless of the child's IV-E eligibility. Medicaid may reimburse for clinical, therapeutic, and rehabilitation services, depending on the state's Medicaid plan, as long as the QRTP is not an IMD or has been exempted from the IMD exclusion (e.g., under a Section 1115 SMI/SED demonstration). If the QRTP claims FFP for state plan services authorized under Section 1915(i), it must meet the home- and community-based setting requirements in accordance with 42 CFR 441.710(a)(1) and (2). QRTPs may also claim FFP for Section 1915(i) services if the facility meets the state's requirements for Section 1915(i) participants in addition to federal home- and community-based settings requirements.

QRTPs with more than 16 beds are likely to be subject to the IMD exclusion as they are facilities that are "primarily engaged in providing diagnoses, treatment or care of persons with mental diseases including medical attention, nursing care, and related services" (42 USC § 1396d(i)). If the QRTP is an IMD, FFP is available only if the facility meets one of the exceptions described above; that is, it must comply with PRTF standards or the state must use a Section 1115 SMI/SED demonstration to receive FFP for services delivered to children in foster care who reside in a QRTP that is an IMD (CMS 2019). State Medicaid agencies must review each QRTP to determine whether it is an IMD (CMS 2019).

Other types of residential facilities

Other residential settings include public or private congregate or group care settings that do not meet the requirements of a PRTF or QRTP. These placement settings may be state licensed and can take the form of group homes, therapeutic boarding schools, therapeutic wilderness programs, boot camps, ranch programs, and other treatment settings. No federal laws define residential programs, and there are no uniform or commonly recognized definitions for program types (Huefner 2018, Kutz 2008).[8] Although states typically regulate publicly funded programs, some do not license or regulate private or faith-based programs that operate behavioral health facilities (GAO 2008, GAO 2007). Although state regulations for licensing and regulating programs may vary, some states have used the American Society of Addiction Medicine criteria for patient placement to help ensure appropriate placement for SUD (O'Brien et al. 2021).

Some states permit Medicaid-enrolled providers to bill for clinical, therapeutic, or rehabilitative service components within these other types of children's residential facilities. For example, CMS approved a Maine state plan amendment in 2011 to establish a reimbursement methodology for private non-medical institutions, which include children's residential care facilities (CMS 2024a). These institutions receive FFP on a per diem basis for each child, which covers all staffing required by state law but excludes room and board (Maine DHHS 2025, 2021). Typically, room and board and non-treatment supports and services may be paid with Title IV-E dollars for eligible children subject to the time limits imposed by the FFPSA or with state or local general funds for children who are not Title IV-E eligible (CHCS 2020).

Referrals to Residential Treatment

Children with behavioral health needs may be referred to residential treatment providers from several sources, including providers, parents, and various child welfare agencies. Children may also be referred for residential care from EDs, mobile crisis response providers, urgent care, and home- and community-based service providers following a crisis or exacerbation in symptoms. In addition, in certain circumstances, courts may refer children who are involved in the child welfare system for placement in PRTFs or QRTPs if they have behavioral health needs that cannot be met in the community.[9]

In some cases, the lack of home- and community-based behavioral health services leads parents to relinquish custody of children to the child welfare or juvenile justice systems to obtain and pay for needed care (Gross et al. 2025, MACPAC 2021, GAO 2003). Parents may take such action when intensive home- and community-based behavioral health services are unavailable or inaccessible and when a family experiences a financial crisis due to the loss of income resulting from a parent or caregiver having to provide intensive supervision to ensure the safety of children and other family members (Herbell and Graaf 2023, GAO 2003). Between February 2017 and February 2019, an estimated 25,000 children were placed in foster care likely through custody relinquishment (Gross et al. 2025).[10]

Some states permit parents to enter a binding agreement with the state or local child welfare agency rather than relinquish custody. The agency assumes custody of the child for a specified period of time to provide the child access to residential treatment, typically after a family has exhausted private insurance benefits. Children who are voluntarily placed and are eligible for Title IV-E automatically become eligible for Medicaid (42 CFR 435.135). Federal foster care payment (under Title IV-E) for the children under voluntary placement agreements may not exceed 180 days unless there has been a judicial determination that such placement is in the best interest of the child (42 USC §§ 672(d)-(g)).

Use of Residential Treatment Services

No single federal data source systematically collects and analyzes the use of residential treatment by Medicaid-enrolled children age 0 to 21, which makes understanding their use of these services challenging (Lanier et al. 2024). In addition, federal regulations do not require that states collect and report information on the use of residential treatment in settings other than PRTFs for Medicaid and CHIP-covered children.

National estimates

Researchers use disparate data sources and methodologies to assess use of residential treatment services by children enrolled in Medicaid, including those involved in the child welfare system, in the absence of a single national data source. For example, a 2018 analysis examining children's behavioral health services and expenditures from 2005 to 2011 found that roughly 4 percent of children age 0 to 18 had a claim for residential services (Pires et al. 2018).

Another study of claims data found that in 2019, less than 0.1 percent of children age 3 to 17 enrolled in Medicaid with behavioral health conditions used residential treatment services (Radel et al. 2023).[11] A third study, using data from the National Survey on Drug Use and Health, found that in 2023 about 5 percent of noninstitutionalized youth age 12 to 17 with Medicaid and CHIP coverage received residential services, had been hospitalized, or received other inpatient treatment for a mental health condition (SAMHSA 2024b).

Prior analyses of Medicaid claims data have demonstrated that a small percentage of Medicaid-enrolled children use residential treatment (Pires et al. 2018). Studies in selected states have found that male, older age, and Black children have a disproportionately high use of residential treatment (Rose and Lanier 2017, Wulczyn et al. 2015, Connor et al. 2004). In addition, child welfare-involved youth represent a small share of the Medicaid population but a disproportionate share of admissions to residential behavioral health treatment settings, including through custody relinquishment and the use of voluntary placement agreements (Hill 2017).

According to national data from the Adoption and Foster Care Analysis and Reporting System, 4 percent of children in foster care reside in group homes, and 5 percent reside in an institution such as a residential treatment facility, child care institution, maternity home, nursing home, or hospital (ACF 2024, 2023).[12] Data from the Adoption and Foster Care Analysis and Reporting System do not, however, provide information by facility type or distinguish whether Medicaid-covered services are provided to children in those settings.

State estimates

Data from states indicate varied trends in the extent to which Medicaid- and CHIP-enrolled children are accessing residential treatment services. These data provide insight into trends within states but are not comparable across states due to differences in data collection methods and definitions of residential care settings. The use of residential care in North Carolina has declined since the COVID-19 public health emergency. The use of PRTFs among children age 5 to 18 who are enrolled in North Carolina's Medicaid program declined from a high of 1,213 in 2018 to 1,020 in 2022. Since 2018, less than 0.2 percent of Medicaid-enrolled children age 5 to 18 were admitted to a PRTF in North Carolina (North Carolina DHHS 2025). In Utah, the percentage of children with Medicaid using residential care has fluctuated in recent years, rising from 1.3 percent in 2022 to 2.9 percent in 2023 before declining to 2.0 percent in 2024 (Utah DHHS 2025). In one state, the number of children receiving care in group homes increased from 600 to 900 between 2020 and 2024, as there has been a shift away from other types of congregate settings.

Some state reports show disproportionate use of residential services by children in foster care. For example, children in foster care in North Carolina made up 26 to 42 percent of PRTF placements, depending on the year, despite making up less than 1 percent of children in the state (Lanier et al. 2024). In addition, 27 percent of children in residential treatment in Virginia in 2019 were in foster care at the time of admission (Virginia DBHDS 2021a).

Utilization data limitations

Data limitations make conducting a comprehensive claims analysis of residential treatment services by children difficult. PRTFs are assigned a specific place of service code, making it easier to identify claims associated with this provider type compared to others. Identifying QRTPs and other residential provider types is challenging, as they may not have a specific place of service code assigned by their respective state Medicaid agency. Without specific place of service codes, it is difficult to differentiate claims submitted for services delivered in a facility that is not a PRTF from those delivered in office-based settings. An analysis of PRTF-only claims would likely be of limited generalizability, as one study found that the majority of children receive residential treatment in non-PRTF settings (Brown et al. 2010).

Demographic data

Limitations in available national and state data prevent reporting detailed information about the characteristics of Medicaid-enrolled children using residential treatment. For example, stakeholders indicate that a lack of data on Medicaid beneficiaries who are referred for, admitted to, denied admission to, and discharged from residential treatment facilities has made it difficult to understand the scope and trends in these measures. Stakeholders also noted similar difficulties reporting on children who are in overstay—that is, children who were admitted to residential treatment and received treatment and are ready to be discharged to the community but for whom appropriate placement has not been identified and secured.

In addition, published national studies and literature do not report on the demographic characteristics or provide data on health conditions or needs of children enrolled in Medicaid who use residential treatment services. Although several states collect some data on use of residential treatment services for their own analytic and programmatic purposes, the data collected vary. For example, among the sample of five states in our analysis, only one reported collecting data on Medicaid-enrolled children who received residential treatment by county.[13]

Facility information

Some information to identify the number and locations of certain residential treatment facilities is publicly available, but a lack of easily attainable and specific information about the facilities serving Medicaid beneficiaries, such as their bed availability and specialty area, make it difficult for families, providers, and states to find placements.

Number of facilities. In fiscal year (FY) 2025, there are 341 PRTFs in 34 states (CMS 2025). CMS reports that nationwide, the number of PRTFs declined from 372 in 34 states in FY 2021 to 344 in 34 states in FY 2023 before increasing slightly in 2024 (346) (CMS 2025).[14] The number of PRTFs increased from FY 2021 to FY 2025 in six states: Colorado, Louisiana, Missouri, Oklahoma, Oregon, and Utah (as of May 2025). The number of PRTFs decreased by five or more from FY 2021 to FY 2025 in two states, New York (16 PRTFs to 11) and Pennsylvania (89 to 66) (CMS 2025). Other states had smaller or no decreases. Some stakeholders attribute declines in the number of residential facilities nationwide to closures during the COVID-19 public health emergency. After the public health emergency, some states could not reopen closed facilities, and some facilities reduced bed capacity.

Each state maintains a list of licensed QRTPs, but no publicly available database or repository includes, for example, the number of beds in each facility, the demographic and clinical profile of the children served by each facility, the total number of beds by state, or the number of children placed in out-of-state QRTPs under the Interstate Compact on the Placement of Children.[15]

Other types of information. No national or regional bed registries list complete information on all residential facilities (i.e., PRTFs, QRTPs, and other facilities) and their respective areas of expertise (e.g., the populations or conditions they treat). Although CMS and the Substance Abuse and Mental Health Services Administration (SAMHSA) maintain lists of facilities, they may be insufficient to meet state needs. CMS's Quality, Certification, and Oversight Reports website primarily provides information about state survey agency findings from health and safety surveys of PRTFs (Howard 2024).[16] It also provides information such as address, phone number, accreditation type, and ownership type but does not provide information about areas of expertise or treatment modalities. CMS does not independently verify the accuracy of the information from states (Howard 2024).

Assessment and Admissions

Federal PRTF and QRTP requirements direct that the need and appropriateness for admission be assessed to ensure that children are served in the least restrictive setting. Although the goal for the assessments is shared, federal requirements specify different approaches for PRTFs and QRTPs. No federal regulations govern the admissions process or certification of need for other types of residential treatment providers.

Assessment

Federal PRTF rules require a certification of need of services. The rules stipulate that a team that includes a physician with competence in diagnosis and treatment of mental illness, preferably child psychiatry, specify that resources available in the community do not meet the treatment needs of the child, that the child's condition requires inpatient care under the direction of a physician, and that the inpatient services can be reasonably expected to improve the child's condition or prevent further regression (42 CFR 441.152-153). PRTF rules do not require the use of a validated assessment tool before certifying the need for care in a PRTF.

Federal QRTP requirements call for an assessment of the appropriateness of a QRTP placement within 30 days of the placement. A qualified individual (e.g., trained professional or licensed clinician) who is not an employee of the state and who is not connected to or affiliated with any placement setting in which children are placed by the state must use an age-appropriate, evidence-based, validated, functional assessment tool to document the need for residential treatment (ACF 2018).

Evaluation of admission decisions

There is no federal requirement for CMS or states to audit the clinical appropriateness of admissions or denials of admission to PRTFs, QRTPs, or any other residential facility type for children with behavioral health needs. Most of the states in our study collect some data on denials of admission to residential treatment facilities. The most common reasons for denied admission included being older age; having current or previous child welfare or juvenile justice involvement; having a history of aggressive or sexualized behaviors or elopement; and having co-occurring conditions, including SUD, intellectual and developmental disabilities (I/DD), or autism. Some PRTFs may also deny admission due to co-occurring medical conditions. One state reported that it does not have any policies that forbid or limit facilities from denying admission to children; a facility could have an open bed and still deny placement from child welfare, youth court, or a community provider. In contrast, one state that has been involved in reforming its children's behavioral health delivery system reported that facilities must accept referred children and that denials of admission must be approved by the state.

Out-of-State Placement

Out-of-state placements may be necessary if in-state facilities lack the capacity to admit children or the expertise to address their behavioral health needs or deny admission. For example, in-state PRTFs may deny admission due to the child's diagnosis or functional or behavioral health characteristics or to reserve beds for out-of-state patients to secure higher payment rates. States typically make multiple attempts to find an appropriate in-state residential setting before making an out-of-state placement to provide the psych under 21 benefit. For example, a Medicaid official in one state reported having to make between 40 and 60 referrals to facilities before being able to find a placement, and that some facilities do not provide timely responses about denials or acceptances. A Medicaid official in another state reported that the state requires in-state denials before authorizing treatment in out-of-state PRTFs. If a state sends a beneficiary out of state, the state must ensure that the receiving PRTF is certified (CMS 2013).

Frequency

There is no single national data source for understanding the frequency of out-of-state placements or the circumstances surrounding that placement, length of stay, the outcomes of the placement, or transitions upon discharge (CMS 2017). The Medicaid State Operations Manual specifies that PRTFs must submit annual attestation statements to each state Medicaid agency with which they have an established provider agreement. The statement must include information on the number of Medicaid beneficiaries receiving the psych under 21 benefit in the facility, the number of such individuals from out of state, and a list of states from which it has ever received Medicaid payment for the psych under 21 benefit (CMS 2024b). State survey agencies, which are responsible for certifying PRTF compliance with

Medicaid participation requirements, must input this information into the Automated Survey Process Environment reporting system.

Data from some states indicate that out-of-state placements have increased in recent years. For example, the number of Montana children placed in out-of-state PRTFs increased from 174 in state fiscal year (SFY) 2023 to 198 in SFY 2024 (Montana DPHHS 2024). Similarly, Montana's out-of-state placement report for SFY 2024 showed the overall number of children who received residential treatment (not just in PRTFs) outside the state increased from 239 in SFY 2023 to 254 in SFY 2024.[17] In North Carolina, of the children placed in PRTFs, the percentage placed out of state increased from 27 percent in 2016 to 44 percent in 2022 (Lanier et al. 2024, North Carolina DHHS 2023). Still another state included in our study indicated that it makes few out-of-state placements but that there has been an increase in out-of-state children coming to the state for residential treatment services.

Some states are working to minimize out-of-state placements. For example, Montana tries to place the child in the lowest level of care in state and requires denials from the two in-state PRTFs before it places children out of state (Montana DPHHS 2024). Utah officials similarly reported focusing resources on placing children in state and avoiding out-of-state placements. North Carolina officials reported working with facilities to create specialized placements to keep children in in-state facilities, but the parents and guardians can decide to send children out of state. The state is also working to address the availability of community-based wraparound services so children can stay in a family-based setting.

PRTF capacity and expertise

PRTF capacity and expertise are key factors in determining whether a beneficiary is placed out of state for treatment. Nationally, the number of residential treatment centers for children declined by 61 percent from a little less than 800 in 2010 to about 300 in 2022 (Dziengelski 2024). Similarly, the number of PRTFs declined by 21 percent, from more than 400 in 2010 to less than 350 in 2023 (Dziengelski 2024). Some states experienced high rates of decline: PRTFs declined by more than 30 percent in 12 states from 2010 to 2023, faster than the national rate of decline for all residential treatment facilities (Dziengelski 2024). In 2024, 14 states did not have any PRTFs (CMS 2024c). Data from states reflect these national trends. For example, in North Carolina, the number of PRTFs decreased from 33 in 2018 to 27 in 2023, and the total number of licensed beds declined from 450 to 339 (North Carolina DHHS 2023). Officials from Utah reported closures of PRTFs, short-term crisis centers, and longer-term residential centers.

Some children are placed in out-of-state PRTFs when in-state facilities lack staff with expertise to address their behavioral health needs. Finding appropriate residential treatment options can be challenging for children with more complex needs, such as those with I/DD, SUD, sexualized behaviors, eating disorders, aggression, and more than one behavioral health diagnosis. Other demographic characteristics of populations struggling to access appropriate residential care include age, location, language, sexual orientation, and race. Specifically, Ohio officials reported difficulty finding placements for adolescent boys; Montana officials reported a lack of facilities accepting children younger than age 12; and Utah officials reported that children in rural counties may have additional barriers to finding facilities near their homes, limiting their families' involvement in their care.

Although out-of-state placements are made to secure residential treatment for children who need it, the placements do not guarantee the quality or receipt of needed care. For example, a Medicaid official in one state shared that sometimes the PRTFs receiving children from out of state find that they cannot adequately treat the complexity of the children. Some of those children subsequently present in crisis in an ED or become involved in the juvenile justice system. In addition, sending states sometimes find it difficult to monitor and oversee the care being provided to their beneficiaries in out-of-state facilities because they often must rely on information and reports from the receiving state (Larin 2024). Some state Medicaid officials reported that out-of-state placements can make it difficult for children to maintain connections with family and transition back to their respective states of residence.

Payment for out-of-state beneficiaries

States set payment rates for residential facilities, including the rates for out-of-state facilities, which can be higher than those for in-state facilities. One state in which PRTFs primarily serve out-of-state children reported that payments for such Medicaid beneficiaries are an estimated three to four times greater than payments for in-state children.

The need for residential care for certain children who cannot be served in their home states, combined with higher out-of-state payment incentives, creates a dynamic that may exacerbate the need for out-of-state placement. Under EPSDT, states must find a residential placement for a child requiring that level of care even if there is insufficient in-state PRTF capacity. In such situations, states must cover out-of-state care, paying the higher rate for care to out-of-state facilities. Facilities may be more willing to accept out-of-state children due to their higher Medicaid payments, which could lead to a lack of available in-state residential beds or denials by in-state facilities. No federal rules govern provider decisions to accept children from outside the state to access higher reimbursement rates. Similarly, some states do not have rules that prevent facilities from denying care or holding beds for out-of-state Medicaid beneficiaries.

Continuum of Care

Access to residential treatment for behavioral health care is affected by access to services along the continuum of behavioral health care, in particular home- and community-based behavioral health services. State and federal officials, beneficiary advocates, researchers, and other stakeholders identified the availability of and access to home- and community-based behavioral health as critical to addressing the behavioral health needs, including the need for residential treatment, of children with Medicaid. The lack of intensive community-based services can also prevent residential treatment facilities from being able to discharge residents when appropriate, which can limit bed availability for other individuals in need of residential care. Researchers have previously noted the benefits of a system of care approach, or care continuum, in preventing the need for residential treatment for youth with SMI or SED and maintaining connections with their communities and families while receiving treatment for their mental health needs (Stroul et al. 2021).

Previous MACPAC work found that intensive home- and community-based behavioral health services, which can help children with significant mental health conditions remain in their communities and avoid residential placement, are often unavailable or difficult to access (MACPAC 2021). In addition, researchers have documented that many children and adolescents may receive treatment in a residential setting, be discharged, but then be readmitted within approximately three months (D'Aiello et al. 2021). Factors affecting access to home- and community-based behavioral health services include the systemic complexity brought on by the multiagency nature of serving children with substantial behavioral health needs and barriers to using certain Medicaid authorities designed to serve these children (MACPAC 2021). The Commission recommended that the Secretary of the Department of Health and Human Services direct CMS, SAMHSA, and the Administration for Children and Families to issue joint subregulatory guidance and provide education and technical assistance to states on improving access to home- and community-based behavioral health services. MACPAC also recommended that the Secretary examine options to use existing federal funding to support state activities to improve access (MACPAC 2021).

States are engaged in a variety of efforts to increase the capacity of or enhance the intensity of available home- and community-based behavioral health services. For example, some states are using the targeted case management benefit to increase the provision of coordinated services, such as respite care for children with behavioral health conditions to prevent caregiver burnout, which can lead to out-of-home placement.[18] States also use targeted case management to provide warm hand-offs between providers.[19]

One state in our study permits community providers to offer and receive Medicaid payment for services delivered concurrently with residential treatment to ensure a successful transition back to the child's home and community. Concurrent service delivery may include, for example, permitting Medicaid payment for home- and community-based behavioral health services and residential treatment while a child is on therapeutic leave from an institutional setting.[20] This state also increased reimbursement rates for many home- and community-based behavioral health services. A few states introduced new Medicaid-covered home- and community-based behavioral health services such as family-centered treatment to help children transition back to the community. One state reported that it developed and was implementing a prepaid inpatient health plan to increase availability of home- and community-based behavioral health services to reduce reliance on in- and out-of-state residential treatment facilities. Two states described efforts to expand mobile crisis and stabilization services for children and families.[21]

Barriers to Appropriate Residential Treatment

Our work surfaced numerous factors affecting appropriate access to residential treatment for Medicaid-covered children in need of that level of care.

Availability of home- and community-based behavioral health services

Addressing the lack of home- and- community-based behavioral health services for children is one of the most pressing issues facing the Medicaid program. Insufficient access to home- and community-based behavioral health providers to serve Medicaid beneficiaries can have both upstream and downstream effects on access to residential treatment. The lack of community-based treatment alternatives for youth with SMI, SED, and other mental or behavioral health concerns may result in placement of children who may not need a residential level of care into such treatment. Such placements may in turn reduce bed availability for those children who do. Home-and community-based behavioral health services can help to reduce the need for and use of residential treatment. Greater access to intensive home- and community-based behavioral health services may also allow for earlier intervention and shorten residential lengths of stay. In addition, with more home- and community-based behavioral health services available, facilities may be able to more quickly transition children out of the facility—for example, to partial hospitalization, intensive outpatient programs, or back into their communities—as soon as they can be safely treated in a less restrictive setting. Freeing up these beds may help with other beneficiaries' access to residential care when needed. Additionally, some states use in lieu of services to increase access to behavioral health services such as crisis stabilization and partial hospitalization, which may help reduce the need for residential care (NCSL 2023).

Federal policy limitations

States and stakeholders identified the IMD exclusion and prohibition on FFP for room and board as federal policies that pose barriers to appropriate residential treatment. The IMD exclusion is a long-standing policy established to advance deinstitutionalization efforts, provide care in the community, and prevent shifting the cost of psychiatric institutional care from the states to the federal government (MACPAC 2019). Although the IMD exclusion means that certain facilities are not accessible to Medicaid beneficiaries, unless states use non-Medicaid funds to support their stay, nearly all states are making payments for services provided in IMD settings via various exemptions and authorities. These exemptions and authorities include statutory exemptions related to older adults and children, Section 1115 demonstrations, a state plan option, and managed care arrangements under certain conditions (MACPAC 2019).

States that include QRTPs with more than 16 beds (i.e., QRTPs that are IMDs) in Section 1115 SMI/SED demonstrations may receive FFP for services provided to children residing in those QRTPs. States with Section 1115 SMI/SED demonstrations generally must achieve a statewide average length of stay of 30 days or less in participating IMDs (CMS 2019). However, states and stakeholders described 30 days as sometimes insufficient to treat behavioral health needs, and CMS will consider state requests for an exemption of up to two years from this requirement (CMS 2021). Some stakeholders indicated that the intersection of federal IMD, PRTF, and QRTP coverage policy is complex and confusing and is an area in which additional guidance would be useful.

Information on facility and bed availability

States have indicated that it can be difficult to find needed information to identify, in real time, facilities that may be able to serve children (North Carolina DHHS 2023, Morrisette 2021, Virginia DBHDS 2021b). As noted earlier, there is no single source of information on facility availability or areas of expertise. There is limited reporting on the facility waitlists that help parents and providers understand bed availability. A 2024 article focused on SUD and residential addiction treatment for youth, particularly for OUD, noted that approximately 40 percent of facilities surveyed did not have bed availability, nor did they have a waitlist. Of those facilities that did have a waitlist, the average time until a bed became available was 28 days. Approximately 57 percent of facilities with waitlists accepted Medicaid (King et al. 2024). The process of finding a residential placement for a child who requires it can take several hours to several days, which, in the case of children in crisis in an ED, can lead to longer stays in the ED than are needed.

Some state and federal agencies have taken steps to facilitate finding facilities and, in some cases, available beds. However, gaps remain. For example, to address challenges in identifying available and appropriate beds in residential facilities, North Carolina launched the Behavioral Health Statewide Central Availability Navigator, which monitors daily bed availability in inpatient, residential, and other settings.[22] However, the state notes that even with the bed registry, specialized care for sexualized behavior, autism spectrum disorder, co-occurring I/DD, and SUD is often unavailable (North Carolina DHHS 2023). Virginia's Office of Children's Services hosts a web-based directory of providers, but it does not provide a comprehensive source of information about bed availability, types of residential settings, or residential facilities with particular specialties (Virginia DBHDS 2021b). SAMHSA maintains a website, FindTreatment.gov, which allows users to search for behavioral health treatment facilities based on criteria such as location and acceptance of Medicaid, but it does not provide bed availability (SAMHSA 2025a).[23] Moreover, in a March 2025 report, the U.S. Department of Health and Human Services Office of the Inspector General described finding inaccurate or incomplete information (e.g., addresses, facility treatment approaches) for several facilities (OIG 2025).

In some cases, the lack of accessible residential treatment beds can lead to an out-of-state placement. Such placements can occur if in-state facilities lack the staff or expertise to address certain behavioral health conditions or if facilities decline an in-state placement in favor of an out-of-state placement due to financial incentives. Although these placements may help with access to treatment, it can be difficult for states to monitor the care of beneficiaries they have placed out of state and for beneficiaries to maintain connections to their communities in their home states.

Assessment requirements

States and stakeholders expressed concern that the processes by which children are assessed and admitted to residential treatment are fragmented and vary by agency involvement, facility type, and provider. This lack of uniformity in assessing children's need for residential behavioral health care could lead to the inappropriate use of this restrictive setting or its inconsistent use among different populations (e.g., children in foster care versus children who are not in foster care) (National Council 2023).

Some state officials expressed concern that many EDs lack psychiatric staff to evaluate children's behavioral health needs.[24] Thus, EDs may precipitously refer children to residential treatment because they are not aware of the full array of home- and community-based behavioral health services available in the community or the processes for referring children and families to local behavioral health agencies or providers. Some stakeholders viewed the lack of a follow-up assessment after the initial referral to residential care, the PRTF certification of need standard, and inconsistent requirements related to the use of validated assessment tools to document the need for residential care as areas in need of improvement to better prevent inappropriate residential placements.

Data

The lack of a single national source of data on the number, type, and characteristics of children accessing residential treatment services limits what can be known about beneficiaries using the services and their access. Without this information, it is difficult to determine what areas are most in need of improvement, if particular subgroups experience greater or particular types of barriers, and how interventions to address access concerns should be designed or targeted. Although some states are already collecting data, data collection varies by state.

Workforce issues

Difficulty hiring, training, and retaining clinical and direct care staff makes it challenging for states to operate facilities at their full licensed residential bed capacity. Two stakeholders interviewed reported that residential treatment facilities do not have the fiscal resources necessary to recruit, train, and retain clinical and direct care staff with proficiency to treat and manage children with co-occurring conditions, particularly autism and I/DD. One state official reported that it has thousands of licensed residential care beds across several facility types, such as PRTFs and QRTPs, but those facilities lack sufficient staff (e.g., awake overnight staff). Another state official reported that residential facilities closed because of a lack of sufficient staff and that the costs of operating a partially occupied facility were higher than the reimbursement received. Officials in three states named reasons for workforce shortages, including competition for staff as facilities reopened after COVID-19 closures, risk of injury to staff, and low wages for direct care staff compared to other industries. A provider noted that maintaining a workforce trained in evidence-based practices is costly and requires initial and ongoing investments to maintain fidelity to the selected evidence-based model. As staff depart, the facility must continually invest in training new providers.[25]

Looking Ahead

Addressing the behavioral health needs of children with Medicaid coverage will require an approach that addresses barriers along the continuum of care. Improving access to appropriate residential treatment requires addressing residential care-specific concerns (e.g., lack of information on available bed and facility expertise information) as well as improving access to home- and community-based behavioral health services. MACPAC's examination of these issues will continue and will include analysis of the considerations affecting access to home- and community-based behavioral health services for children as well as additional topics related to safety and quality of appropriate residential treatment services.

Endnotes

[1] SMI describes a diagnosable mental, behavioral, or emotional disorder (e.g., bipolar disorder and schizophrenia) experienced by someone older than age 18 that substantially interferes with their life and ability to function. SED has the same definition except that it used only for children (SAMHSA 2024a).

[2] The Centers for Disease Control and Prevention conducts the annual Youth Risk Behavior Survey of high school students regarding their health behaviors and experiences, including those related to behavioral health, sexual behavior, and experience with violence (CDC 2024).

[3] These stays consume ED resources, exacerbate ED crowding, delay treatment for other ED patients, and affect ED payment (Morrisette 2021).

[4] Severe role impairment is defined by the level of problems reported in four major life activities or role domains: (1) ability to do chores at home, (2) ability to do well at school or work, (3) ability to get along with family, and (4) ability to have a social life (SHADAC 2024).

[5] In addition to the psych under 21 benefit, states may pay for services in IMDs under Section 1115 demonstration authority, a state plan option and a limited exception for pregnant women under the Substance Use-Disorder Prevention that Promotes Recovery and Treatment for Patients and Communities Act (SUPPORT Act, P.L. 115-271), and through managed care arrangements under certain circumstances (MACPAC 2019).

[6] Title IV-E provides partial federal reimbursement to states, territories, and tribes for the cost of providing foster care, adoption assistance, and guardianship assistance for eligible low-income children who have been removed from their homes. As part of the Bipartisan Budget Act of 2018 (P.L. 115-123), the Family First Prevention Services Act expanded the allowable uses of Title IV-E funds to include certain foster care prevention services and kinship navigator programs (CRS 2014).

[7] The term "foster care maintenance payments" means payments to cover the cost of (and the cost of providing) food, clothing, shelter, daily supervision, school supplies, a child's personal incidentals, liability insurance with respect to a child, reasonable travel to the child's home for visitation, and reasonable travel for the child to remain in the school in which the child is enrolled at the time of placement. In the case of institutional care, such term shall include the reasonable costs of administration and operation of such institution as are necessarily required to provide the items described in the preceding sentence (42 USC § 675(4)).

[8] The International Work Group for Therapeutic Residential Care's 2016 consensus statement noted that a 2014 definition of therapeutic residential care "offered a useful starting point." "'Therapeutic residential care' involves the planful use of a purposefully constructed, multi-dimensional living environment designed to enhance or provide treatment, education, socialization, support, and protection of children and youth with identified mental or behavioral health needs in partnership with their families and in collaboration with a full spectrum of community-based formal and informal helping resources" (Whittaker et al. 2016). Researchers often define the facilities in developing the scope of their work. For example, noting the lack of a single definition, the U.S. Government Accountability Office defined a wilderness therapy program as a program that places youth in different natural environments, including forests, mountains, and deserts. Some wilderness therapy programs may include a boot camp element, but boot camps are also independent of wilderness programs. The U.S. Government Accountability Office defined a boot camp as a residential treatment program in which strict discipline and regime are dominant principles (GAO 2007). Therapeutic boarding schools combine educational components with therapy in a residential setting (Golightley 2020). Some of these facilities may also provide step-down care upon discharge from inpatient treatment or a PRTP or QRTP. If the facilities are community based, they may also provide treatment to prevent higher levels of care.

[9] Such placements may occur if the child welfare agency files a petition with the court for an out-of-home placement order after substantiating abuse or neglect and a finding of imminent harm or after prevention services and supports have been deemed unsuccessful. The court may place the child with kin; in foster care or therapeutic foster care; or in a QRTP, PRTF, or other congregate care setting, depending on the child's needs. Section 473(b)(1) of the Act requires that Title IV-E-eligible youth be considered to be receiving cash assistance. Section 1902(a)(10)(A)(i)(I) of the Act makes those cash assistance recipients eligible for Medicaid (42 CFR 435.135).

[10] This figure includes data on children from the Adoption and Foster Care Analysis and Reporting System for the 50 states, the District of Columbia, and Puerto Rico (Gross et al. 2025).

[11] The data include children with Medicaid or CHIP coverage for full or comprehensive benefits who were enrolled for at least six consecutive months.

[12] The U.S. Department of Health and Human Services Administration for Children and Families Children's Bureau maintains the Adoption and Foster Care Analysis and Reporting System. State and tribal Title IV-E agencies must report Adoption and Foster Care Analysis and Reporting System case-level information on all children in foster care and children who have been adopted with Title IV-E agency involvement (ACF 2025).

[13] This state maintains a data dashboard with this information.

[14] The count of PRTFs refers to the number of such providers for which CMS has survey records in the agency's online survey and certification reporting system.

[15] The Interstate Compact on the Placement of Children is a statutory agreement between all 50 states, the District of Columbia, and the U.S. Virgin Islands. The agreement governs children being placed in the custody of a state, being placed for private or independent adoption, or under certain circumstances being placed by a parent or guardian in a residential treatment facility from one state into another state (APHSA 2024).

[16] The website pulls data from the Automated Survey Process Environment and Certification reporting system used by state survey agencies to document their required health and safety surveys of PRTFs.

[17] The state placed these children in PRTFs or therapeutic group homes. Medicaid covers the cost of care for the majority of the children placed out of state, but care for some children is covered by another state agency, such as the state's Department of Corrections or the Child and Family Services Division (Montana DPHHS 2024).

[18] Respite care, in which another caregiver comes to the child's residence (in-home respite care) or the child is supervised and cared for in the community (out-of-home respite), is associated with reductions in out-of-

home placement in residential and child welfare settings, reductions in some areas of caregiver stress, and lower incidences of negative behaviors by the children (Bruns and Burchard 2010).

[19] For example, some states engage targeted case management coordinators to help beneficiaries establish care with community-based behavioral health providers after a call to a mobile crisis responder.

[20] Therapeutic leave is a short-term absence from a facility prescribed as part of the youth's individualized treatment program and acclimates the youth to community treatment and the family environment before discharge.

[21] Such services typically send trained providers to a caller's home or foster home within 60 to 90 minutes to address behavioral health challenges and to begin developing a plan of care that focuses on maintaining the youth in their home or current foster care placement.

[22] The state launched the Behavioral Health Statewide Central Availability Navigator in 2023.

[23] The 21st Century Cures Act (P.L. 114-255) required that SAMHSA develop and maintain an online, searchable behavioral health treatment services locator that includes providers' names, locations, contact information, and services provided (OIG 2025). SAMHSA also makes available a written directory of the facilities that are included at https://findtreatment.gov. The providers listed on the website and in the directory are public and private providers of behavioral health services that responded to the National Substance Use and Mental Health Services Survey (SAMHSA 2025a).

[24] A 2018 survey of Medicare-enrolled hospitals found that 30 percent of rural and 57 percent of urban hospitals had a psychiatrist on staff or available for consultation (Ellison et al. 2022).

[25] Residential treatment providers may offer a variety of evidence-based treatments to children in their care.

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APPENDIX 2A: Comparison of Federal Regulations for Children’s Residential Provider Types

TABLE 2A-1. Comparison of Federal Regulations for Children’s Residential Provider Types

Topic	Psychiatric residential treatment provider	Qualified residential treatment provider	Other residential providers
Service definition	A non-hospital facility that can provide inpatient psychiatric hospital services. Designed to offer a short-term, intense, focused mental health treatment program.	Type of child care institution as defined under the Family First Prevention Services Act (P.L. 115-123). Provides short-term, trauma-informed treatment. May also provide a placement and treatment for prenatal, postpartum, or parenting youth; a supervised independent living setting; and a placement for youth who have been or are at risk of becoming sex trafficking victims.	No federal regulations or requirements. Provider types typically include therapeutic boarding schools, wilderness programs, ranches, and boot camps; terms may vary by state. Programs vary but typically offer clinical, therapeutic, and rehabilitative services to youth.
Licensing and accreditation	Must be accredited by The Joint Commission, the Commission on Accreditation of Rehabilitation Facilities, the Council on Accreditation of Services for Families and Children, or by any other accrediting organization with comparable standards that is recognized by the state.	Must be licensed by the state as a CCI (42 USC § 672). Must be accredited by The Joint Commission, the Commission on Accreditation of Rehabilitation Facilities, the Council on Accreditation of Services for Families and Children, or another U.S. Department of Health and Human Services-approved organization.	No federal regulations or requirements.
Facility size	No size limit.	Publicly owned QRTPs can be no more than 25 beds to meet the statutory definition of a CCI (42 USC § 672). If more than 25 beds, they cannot claim Title IV-E funds. No size limit for private QRTPs.	No size limit unless the facility intends to seek Medicaid reimbursement (see Medicaid reimbursement row).

TABLE 2A-1. (continued)

Topic	Psychiatric residential treatment provider	Qualified residential treatment provider	Other residential providers
Age of eligible children	No minimum age. Maximum age is 21. Upon turning 22, individuals must be transitioned to community services or non-Medicaid inpatient services.	No minimum age. Maximum age depends on a state's age of foster care eligibility.	No federal regulations or requirements.
Length of stay	No length of stay limitation.	If longer than 30 days, requires an assessment. Within 60 days, requires review by the court. If an extended placement is necessary (6 to 12 months, depending on age), must submit documentation to the Children's Bureau, Administration for Children and Families in the U.S. Department of Health and Human Services.	No federal regulations or requirements.
Medicaid reimbursement	Provide care under the optional "Psych Under 21" benefit. May claim Medicaid for the total cost of care, including room and board. PRTFs must meet the conditions of participation, including limiting restraint and seclusion (42 CFR 441.150 et seq.). If the youth's Early and Periodic Screening, Diagnostic and Treatment (EPSDT) screen determines this service is necessary, it can be funded under Medicaid's EPSDT requirement, even if the service is not included in the state plan.	If they are not IMDs, QRTPs may claim Medicaid for behavioral health treatment and other medical costs, excluding room and board. Title IV-E pays maintenance costs, including room and board. QRTPs that are IMDs may not claim Medicaid, unless they also meet the requirements of a PRTF or they are covered under their state's Section 1115 SMI/SED demonstration. State Medicaid agencies determine whether a QRTP is an IMD. If billing Medicaid for allowable services under a Section 1915(i) state plan amendment, the QRTP must meet the home- and community-based setting requirements in accordance with 42 CFR 441.710(a)(1) and (2).	If they are not IMDs, other residential providers may claim Medicaid for behavioral health treatment and other medical costs, excluding room and board. Other residential providers that are IMDs may not claim Medicaid.

TABLE 2A-1. (continued)

Notes: CCI is child care institution. QRTP is qualified residential treatment program. PRTF is psychiatric residential treatment facility. IMD is institution for mental disease. SMI is serious mental illness. SED is serious emotional disturbance.

Source: MACPAC analysis of Baxter et al. 2023.

Chapter 3:

Access to Medications for Opioid Use Disorder in Medicaid

Access to Medications for Opioid Use Disorder in Medicaid

Key Points

- Opioid use disorder (OUD) is a chronic medical condition that disproportionately affects Medicaid beneficiaries who are more likely to experience health-related risk factors, which can put them at higher risk of overdose.
- Despite considerable policy efforts and recent declines in drug-related mortality, the number of opioid-related deaths in the United States remains high.
- Medications for opioid use disorder (MOUD)—methadone, buprenorphine, and extended-release injectable naltrexone—are effective treatments for OUD that can reduce the risk of overdose death and address socioeconomic costs associated with the opioid epidemic.
- In recent years, Congress and federal agencies have approved a variety of policies and funding to improve access to MOUD, including a requirement that state Medicaid agencies cover all forms of MOUD and associated counseling and behavioral therapies.
- While there has been improvement in rates of MOUD treatment over time, a substantial gap remains, with nearly 30 percent of beneficiaries with OUD not receiving MOUD. Moreover, there is considerable variation in MOUD treatment rates by states.
- MOUD use among Medicaid beneficiaries with OUD also varies across demographic groups, with the greatest disparities observed by age, eligibility group, and race and ethnicity.
- MACPAC identified a variety of factors that create barriers to MOUD and contribute to the treatment gap. Social stigma and limited provider availability are persistent challenges. Prior authorization for MOUD generally, and daily dosage caps for oral buprenorphine, are also commonly cited as barriers to timely and effective treatment.
- As part of the Commission’s continued focus on access to behavioral health care, MACPAC’s future work will examine the use of utilization management practices and how they affect MOUD access and treatment retention for Medicaid beneficiaries with OUD.

CHAPTER 3: Access to Medications for Opioid Use Disorder in Medicaid

Medicaid and the State Children's Health Insurance Program (CHIP) cover a substantial portion of the population with opioid use disorder (OUD) in the United States. In 2022, they were the primary source of coverage for nearly 40 percent of individuals age 12 to 64 with OUD, representing 1.9 million beneficiaries (MACPAC and SHADAC 2024).[1] OUD is a chronic medical condition involving complex interactions among brain circuits, genetics, environment, and social factors (ASAM 2019, NASEM 2019). Although rising rates of OUD were initially spurred by prescription medications, heroin and powerful synthetic opioids (e.g., illicit fentanyl) have become predominant and today account for most opioid misuse and related deaths (NCHS 2025, Volkow and Blanco 2020).

The importance of Medicaid's role in assisting with access to OUD treatment is underscored by the disproportionate share of drug overdose deaths among Medicaid beneficiaries relative to the general population. Medicaid beneficiaries, by virtue of their low income, are more likely to experience health-related risk factors such as unemployment and housing instability, which in turn can put them at higher risk for overdose (Grinspoon 2021, Pear et al. 2019, Yamamoto et al. 2019). In 2020, the drug overdose death rate was two times higher for Medicaid beneficiaries (54.6 per 100,000) compared to all U.S. residents (27.9 per 100,000). Medicaid beneficiaries accounted for nearly half of all overdose deaths, though they represented just a quarter of the U.S. population (Mark and Huber 2024).[2]

National data show a recent decline in drug-related mortality; however, the number of drug overdose deaths remains high. Between November 2023 and October 2024, approximately 84,000 people died from a drug overdose, most often involving the use of synthetic opioids such as illicit fentanyl (NCHS 2025). The latest national data show that although drug overdose death rates have decreased among white people, rates for other racial and ethnic groups generally have stayed the same or increased and are highest for Black and American Indian and Alaska Native people (Garnett and Miniño 2024).

Medications for opioid use disorder (MOUD) are an effective treatment for OUD that can reduce illicit opioid use and the risk of overdose death.[3] They have also been shown to reduce health care costs, loss of productivity, and involvement in the child welfare and criminal justice systems (SAMHSA 2021, NASEM 2019). The U.S. Food and Drug Administration (FDA) has approved three types of MOUD: methadone, buprenorphine, and extended-release injectable naltrexone. These medications are often offered in conjunction with counseling and other services (e.g., peer supports) to improve treatment retention and help patients manage their condition (SAMHSA 2021).

In recent years, Congress and federal agencies have approved a variety of policies and funding to improve access to MOUD. Some of these efforts have been specific to Medicaid, while others affect access to MOUD more broadly. Notably, Medicaid is now required to cover all forms of FDA-approved MOUD and associated counseling and behavioral therapies (§ 1905(a)(29) of the Social Security Act (the Act)). Congress also extended certain policies put into place to assist with access to MOUD during the COVID-19 public health emergency (PHE), such as additional flexibility to provide methadone take-home doses (SAMHSA 2024a).

Given these and other substantial federal policy changes and persistently high rates of opioid-related deaths, MACPAC undertook efforts to examine access to MOUD in Medicaid. This chapter presents findings from that work—drawing from the literature, stakeholder interviews, and an analysis of Medicaid claims data—and identifies areas for future Commission consideration.[4] It starts with background information about MOUD, followed by a discussion of recent Medicaid and non-Medicaid policies and funding that have affected access to MOUD. Next, we discuss MOUD coverage and present estimates of MOUD use, including how the benefit mandate, specifically additional coverage of methadone, affected utilization of MOUD. We then discuss three barriers to MOUD as identified through our work: social stigma; provider availability; and utilization management practices, including prior authorization. The chapter ends with a discussion of the Commission's plans to further investigate the use of utilization management practices and how they affect Medicaid beneficiaries' receipt of timely and effective care.

Overview of MOUD

Strong evidence demonstrates the effectiveness of MOUD—methadone and buprenorphine in particular. In randomized clinical trials, methadone, buprenorphine, and extended-release naltrexone were each found to be more effective in reducing illicit opioid use compared to no medication. Treatment with methadone and buprenorphine has also been shown to reduce risk of overdose death by nearly 50 percent. Moreover, MOUD can help address the socioeconomic costs associated with the opioid epidemic, such as lost productivity and increased child welfare involvement, by enabling individuals to maintain employment and fulfill their responsibilities as caregivers. Individuals taking MOUD are also less likely to use costly acute care settings or be involved in the criminal justice system relative to those with OUD who are not receiving medication treatment (SAMHSA 2021, NASEM 2019).

Important distinctions exist between the different types and formulations of MOUD as well as varying federal rules for prescribing and dispensing each medication (Table 3-1).

Methadone

Methadone is a controlled substance that has been used for decades to treat OUD.[5] It is an opioid agonist that binds to and activates the brain's opioid receptors, suppressing painful withdrawal symptoms and controlling opioid cravings in addition to blunting or blocking the effects of other opioids if taken.[6] Methadone for the treatment of OUD is taken orally and is generally dispensed only at federally regulated opioid treatment programs (OTPs). Typically, patients must travel to an OTP to receive medication daily or near daily, though over time they may be permitted to receive take-home doses. OTPs must be certified by the Substance Abuse and Mental Health Services Administration (SAMHSA) and accredited by an independent, SAMHSA-approved accrediting body. Federal law requires OTPs to provide comprehensive addiction care, including counseling, toxicology screens, and other services (SAMHSA 2024b).

Buprenorphine

Buprenorphine is a partial opioid agonist that reduces withdrawal symptoms and cravings and blunts or blocks the effects of other opioids. It is a controlled substance that, compared to methadone, produces a less intense opioid-like effect and poses less risk for clinically significant drug interactions (SAMHSA 2021). Buprenorphine can be taken orally daily or administered via weekly or monthly extended-release injections. To reduce the risk of misuse, some oral formulations of buprenorphine include the overdose-reversal drug naloxone, which can cause uncomfortable withdrawal symptoms if the medication is injected or snorted. Buprenorphine can be accessed in OTPs, but it is more commonly prescribed in office-based settings. Any provider licensed by the U.S. Drug Enforcement Administration (DEA) may prescribe buprenorphine, so long as they are also permitted to do so under state law. Branded products include oral formulations of buprenorphine-naloxone known as Suboxone and Zubsolv and buprenorphine extended-release injections called Sublocade and Brixadi (FDA 2024a).

Naltrexone

Naltrexone is an opioid agonist that binds to opioid receptors but does not activate them. It prevents relapse because an individual who is taking naltrexone and uses opioids will not experience the sought-after feeling of euphoria. Compared to other types of MOUD, naltrexone is less effective in reducing the risk of overdose mortality and is used less commonly for OUD treatment (OIG 2024, Wakeman et al. 2020). Oral and extended-release injectable forms of naltrexone are available, but only the extended-release form known by the brand name Vivitrol is FDA approved to treat OUD.[7] Patients must undergo opioid withdrawal and remain abstinent before initiating naltrexone, which is administered monthly. Naltrexone is not a controlled substance and can be prescribed and dispensed by any clinician with prescribing authority (SAMHSA 2024c).

TABLE 3-1. Medications for Opioid Use Disorder

Medication	Controlled substance		Dispensing		Route of administration		Frequency of administration		
	Yes	No	Pharmacy[1]	OTP	Oral	Injectable	Daily	Weekly	Monthly
Methadone	✓	–	–	✓	✓	–	✓	–	–
Buprenorphine	✓	–	✓	✓	✓	✓	✓	✓	✓
Naltrexone	–	✓	✓	✓	–[2]	✓	–	–	✓

Notes: OTP is opioid treatment program. A controlled substance is a drug or other substance that is highly regulated by the government because of its abuse and dependency potential.

✓ Check indicates that the medication meets the criterion.

– Dash indicates that the medication does not meet the criterion.

[1] Extended-release formulations of buprenorphine and naltrexone must be administered by a health care professional.

[2] The oral formulation of naltrexone is not approved by the U.S. Food and Drug Administration for the treatment of opioid use disorder.

Source: SAMHSA 2021

Although the standard of care for OUD includes counseling and other services that can support recovery, recent federal guidance emphasizes that treatment with MOUD should not be contingent upon someone receiving these additional services. There is evidence, for example, that patients benefit from buprenorphine treatment even when counseling services are not immediately available (HHS 2023a, NASEM 2019).

Medicaid Policies Affecting MOUD

In recent years, federal legislation and subregulatory guidance have established requirements as well as new options for states to increase access to MOUD in Medicaid.[8]

MOUD benefit mandate

The 2018 Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act (SUPPORT Act, P.L. 115-271) requires state Medicaid programs to cover all forms of FDA-approved MOUD and related counseling and behavioral therapies for five years beginning October 1, 2020.[9] As of fiscal year (FY) 2017, all state Medicaid programs covered some form of buprenorphine and naltrexone, whereas 13 states did not cover methadone for the treatment of OUD (MACPAC and Acumen 2024).[10] Congress later made the MOUD benefit mandate permanent with the passage of the Consolidated Appropriations Act, 2024 (P.L. 118-42).[11]

The Centers for Medicare & Medicaid Services (CMS) expected states to conduct provider outreach and enrollment to increase the MOUD provider workforce as they prepared to implement the benefit mandate in 2020. States could apply for an exception to the coverage mandate if implementing the benefit was not feasible due to a shortage of qualified providers or facilities serving Medicaid enrollees (CMS 2020). CMS approved exceptions for provider shortage in three states and four territories, primarily due to a lack of OTPs providing methadone.[12] Requests for exceptions due to provider shortage must be reapproved at least every five years (CMS 2024b).

The state officials, beneficiary advocates, and other stakeholders we interviewed generally expressed positive views of the MOUD benefit mandate and congressional action to make it permanent. Coverage is an essential component of access, and therefore, the benefit mandate was an important step toward better access to MOUD for Medicaid beneficiaries, particularly in states that added methadone coverage to comply with the mandate. Several stakeholders noted that in addition to ensuring payment for MOUD, the benefit mandate improved awareness of MOUD as an evidence-based treatment for OUD, which helped reduce stigma and more clearly establish MOUD as the standard of care.

Stakeholders noted that predictable and sustained funding for MOUD facilitates planning at the state and provider level. It also helps providers retain staff, which is critical given ongoing behavioral health workforce shortages. Moreover, a permanent MOUD benefit helps mainstream addiction treatment, which can assist with better integration of behavioral health and physical health care. Stakeholders noted that this comprehensive approach is important given the prevalence of serious physical health comorbidities (e.g., HIV, hepatitis C, cardiovascular disease) among beneficiaries with OUD and other types of substance use disorder (SUD).

Provider capacity demonstrations

The SUPPORT Act directed the Secretary of the U.S. Department of Health and Human Services, in consultation with CMS and other agencies, to conduct a demonstration project to increase the capacity of qualified Medicaid providers to deliver SUD treatment and recovery services. CMS awarded planning grants to 15 states and selected 5 of those states to participate in a three-year postplanning period beginning in the fall of 2021.[13]

Reports from the postplanning period indicate that the demonstration helped foster greater collaboration among state agencies and improved the capacity of their state Medicaid agencies to collect and share relevant data. All five states also reported increases in the number of Medicaid providers qualified to prescribe methadone and buprenorphine. However, states felt their efforts have been limited by a lack of administrative funding and uncertainty regarding the amount of federal funding available for demonstration activities.[14] The COVID-19 PHE also resulted in delayed implementation or cancellation of certain initiatives, as states had to set new priorities for resources to address the PHE (HHS 2024).

Section 1115 demonstrations

Stakeholders highlighted the importance of two demonstration opportunities that, among other goals, are designed to improve access to MOUD, including in institutional settings in which Medicaid is generally prohibited from paying for services.

SUD demonstrations. In 2017, CMS clarified how states can receive federal matching funds for services provided to beneficiaries receiving treatment for SUD in institutions for mental diseases (IMDs), which is otherwise generally prohibited under federal law. The demonstrations are intended to provide a full continuum of care to beneficiaries with SUD and OUD and to achieve specified milestones, including increased access to MOUD and a reduction in opioid-related deaths. Participating states must assess the availability of Medicaid-enrolled providers of medication-assisted treatment (MAT), including MOUD, and require residential treatment facilities to provide MOUD on site or assist with access off site (CMS 2017). As of March 2025, CMS approved Section 1115 demonstrations for SUD and OUD in 37 states, and 3 states have pending applications (KFF 2025).[15]

Reentry demonstrations. OUD and other SUDs are highly prevalent among individuals involved in the criminal justice system and contribute to poor health outcomes following incarceration (Maruschak et al. 2021). In 2023, CMS released guidance describing how states can receive federal matching funds for prerelease Medicaid services provided to incarcerated beneficiaries up to 90 days before their release, with the goal of improving care coordination and health outcomes as individuals reenter the community. At a minimum, states must cover prerelease MAT for all types of SUD, including OUD, as well as case management and a 30-day supply of prescription medications provided upon release, when clinically appropriate (CMS 2023a). As of March 2025, CMS approved Section 1115 reentry demonstrations in 19 states, and 9 states have pending applications (KFF 2025).[16]

State plan option for IMDs

In addition to the Section 1115 demonstration opportunity, the SUPPORT Act established an option for states to cover services for beneficiaries age 21 to 64 receiving withdrawal management or SUD treatment services in IMDs under the state plan. The authority was time limited until Congress permanently extended it under the Consolidated Appropriations Act, 2024. Among other requirements, eligible IMDs must offer at least two forms of MAT on site, including at least one FDA-approved partial agonist (buprenorphine) and one agonist (naltrexone). Eligible IMDs must also offer behavioral therapies alongside MAT (CMS 2019). Two states currently use this authority to cover short-term residential and inpatient SUD treatment (Houston 2023).

Health homes

States can establish Medicaid health homes under the state plan that integrate physical and behavioral health care and long-term services and supports for beneficiaries with OUD and other chronic conditions. States receive federal matching funds (90 percent) for health home services for eight quarters following approval of their state plan amendment, and SUD-focused health homes receive an additional two quarters of enhanced federal funding. Health home services for which enhanced federal matching funds are available are comprehensive care management, care coordination, health promotion, comprehensive transitional care and follow-up, patient and family support, and referral to community and social support services. As of 2024, seven states have SUD health homes, three of which are solely focused on beneficiaries with OUD. Several other states have health homes focused on a broader array of chronic conditions, which may include OUD (CMS 2024c).[17] Opioid health homes are typically MOUD providers (e.g., OTPs) that also offer health home services (CMS 2020).

Other Federal Policies Affecting MOUD

Federal agencies have taken a number of recent steps to improve access to MOUD, including actions to safely enable treatment during the COVID-19 PHE. These actions also eliminated previously documented barriers to MOUD, such as limited flexibility to provide methadone take-home doses. Additionally, Congress approved legislation to increase the number of providers eligible to prescribe buprenorphine and provided grant funding that states use to pay for infrastructure and services that are not covered by Medicaid but are integral to the provision of MOUD.

Methadone dispensing

During the COVID-19 PHE, SAMHSA allowed OTPs to dispense up to 28 days of take-home methadone doses for stable patients being treated for OUD and up to 14 days of take-home doses for less stable patients. These flexibilities were scheduled to end a year after the end of the PHE or upon publication of a final rule addressing them. In 2024, SAMHSA issued a final rule that permanently extended those methadone take-home dosing options.[18] The final rule also makes other updates to OTP regulations and eliminates certain barriers to treatment admission, including that patients have a history of at least one year of opioid addiction and that patients younger than age 18 have at least two unsuccessful attempts at treatment before accessing care at an OTP. The rule also prohibits OTPs from denying MOUD to patients who do not receive counseling (SAMHSA 2024a).

Stakeholders expressed positive views about these federal policy changes and noted that states may need to update their OTP regulations and Medicaid payment methodologies to align with federal rules and adopt the new flexibilities offered. For example, if a state's weekly bundled rate for methadone is left unchanged, there is a disincentive for OTPs to provide more than one week of take-home doses. Some states passed emergency legislation to align their regulations and payment methods with the new federal rule; however, others may not take full advantage of the opportunities provided under the new rule.

Buprenorphine initiation via telehealth

At the start of the PHE, the DEA began permitting patients to initiate buprenorphine via telehealth without first receiving an in-person medical evaluation (DEA 2020). Several stakeholders noted that this policy increased access to MOUD and that the use of audio-only visits for buprenorphine prescribing was particularly helpful in rural states, where patients often have to travel long distances to see a provider in person. After extending the policy several times on a short-term basis, DEA and SAMHSA published a final rule that permanently allows patients to receive up to a six-month supply of buprenorphine through a telehealth consultation with a provider, at which point the patient must complete an in-person visit to continue treatment (DEA 2025a).

Requirements for buprenorphine prescribers

The Consolidated Appropriations Act, 2023 (P.L. 117-328) permanently eliminated the requirement for providers to obtain a federal waiver (commonly referred to as a DATA-2000 or X-waiver) to prescribe buprenorphine for the treatment of OUD.[19] Any qualified provider with a standard DEA registration may now prescribe buprenorphine for OUD, as long as state scope-of-practice laws permit them to do so. The Consolidated Appropriations Act, 2023 also eliminated caps on the number of patients a prescriber can treat for OUD with buprenorphine at any given time. Providers applying for a new or renewed DEA registration must attest to having completed at least eight hours of training on OUD or other SUDs. Providers are not required to complete the training if they hold a current board certification in addiction medicine or addiction psychiatry or graduated within the past five years from a health professional education program (e.g., medical or advance practice nursing school) that required successful completion of an OUD or other SUD curriculum (SAMHSA 2024d).

Grant funds

Non-Medicaid grant funding has been a central component of state efforts to expand and sustain access to MOUD. MACPAC spoke to stakeholders about these funding sources, including the Substance Use Prevention, Treatment, and Recovery Services block grant and supplemental funding provided through the American Rescue Plan Act of 2021 (P.L. 117-2), before the U.S. Department of Health and Human Services announced that it would be terminating state grants and cooperative agreements funded by COVID-19 supplemental appropriations.[20] States described using these funds, as well as funding from State Targeted Response to the Opioid Crisis grants and State Opioid Response grants, to build infrastructure (e.g., to purchase vans for mobile MOUD treatment services), to pay for services that are not covered by their state's Medicaid program (e.g., harm reduction or peer support services), and to help MOUD providers remain financially viable when Medicaid reimbursement is not sufficient to fund the range of services provided.[21] States have also used grant funds to provide MOUD to justice-involved populations for whom Medicaid is not allowed to pay for services and for education and technical assistance to help providers obtain the federal waiver that until recently was required to prescribe buprenorphine.

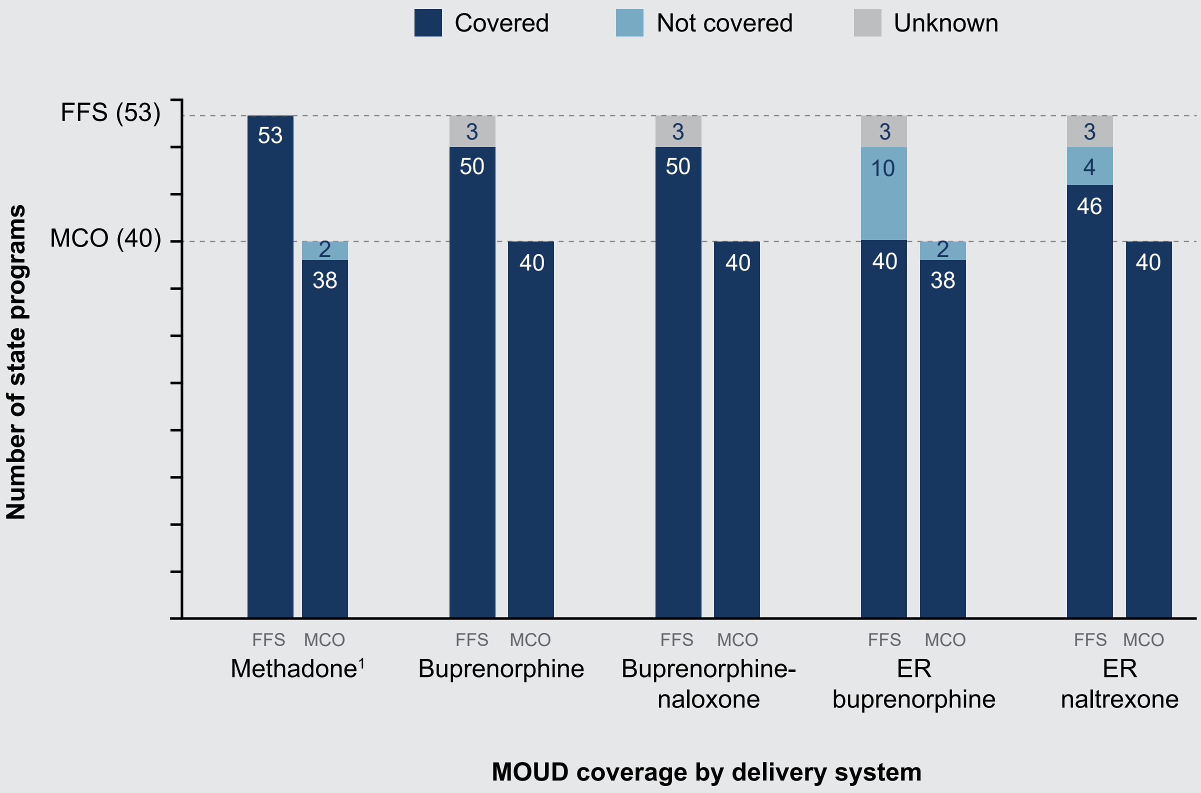
Grant funding has also supported community-based organizations that provide or refer Medicaid-eligible beneficiaries to MOUD, though they are not Medicaid-enrolled providers. For example, the Centers for Disease Control and Prevention provides funding for syringe services programs that, in addition to providing access to and disposal of sterile syringes and injection equipment, can offer an array of treatment and harm reduction services, including buprenorphine. These efforts and other community-based providers often provide services to people at high risk of an overdose who are typically hard to engage (e.g., unhoused individuals). They do this, for example, by employing peer recovery specialists with lived experience of SUD to conduct outreach to potential patients and by providing buprenorphine to individuals in non-traditional settings like parking lots and homeless encampments.

Coverage of MOUD

In a recent review of publicly available information, researchers were at times unable to identify evidence that Medicaid fee-for-service and managed care programs covered all forms of MOUD in every state (Figure 3-1).[22] The study, commissioned by SAMHSA, identified two states without documented managed care organization (MCO) coverage of methadone and two states without documented MCO coverage of extended-release buprenorphine. SAMHSA also did not find documentation of fee-for-service coverage of extended-release buprenorphine (10 states) and naltrexone (4 states). In two states and one territory, researchers were not able to identify whether fee for service covered any MOUD apart from methadone.[23]

Characterizing Medicaid coverage of MOUD can be challenging for several reasons. Every state (except

FIGURE 3-1. Medicaid Coverage of Medications for Opioid Use Disorder in Fee for Service and Managed Care, as Documented in Publicly Available Information, 2022–2023



Notes: FY is fiscal year. FFS is fee for service. MCO is managed care organization. ER buprenorphine is extended-release injectable buprenorphine. ER naltrexone is extended-release injectable naltrexone. MOUD is medications for opioid use disorder. This figure represents data on all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands based on a review of publicly available data sources.

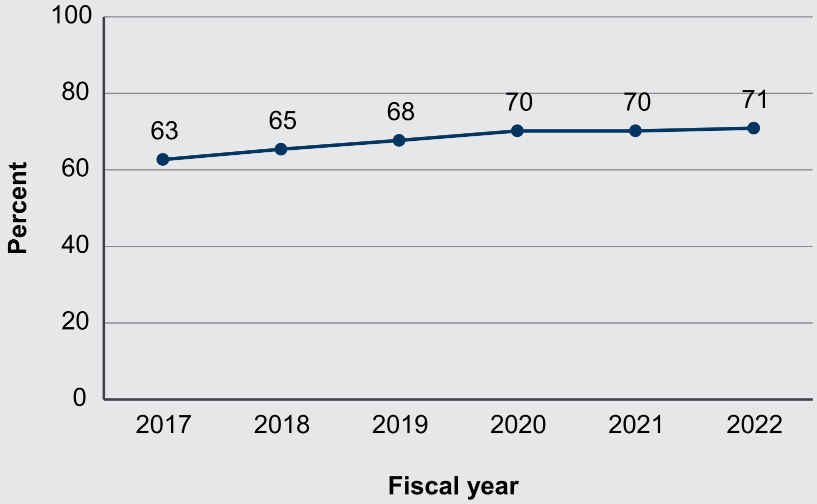
[1] The study identified South Dakota, the U.S. Virgin Islands, and Wyoming as covering methadone, though they were exempt from the MOUD benefit mandate due to a lack of Medicaid-enrolled opioid treatment programs (CMS 2024b).

Source: SAMHSA 2024e.

those that were exempt due to provider shortages) has amended their state plan to cover all forms of FDA-approved MOUD as a mandatory benefit, as required by the SUPPORT Act.[24] These medications are covered, although states and MCOs may control their use through prior authorization, clinical criteria, and other utilization management tools (CMS 2020).

Although every state complies with the MOUD benefit mandate, publicly available documentation of state and MCO coverage policies can be difficult to find. SAMHSA notes that although some states provide easily accessible formularies or comprehensive preferred drug lists, in other states, it is more difficult to identify MOUD coverage policies.[25] The authors observe that this lack of clarity can pose obstacles to the availability of medications by making it difficult for providers and beneficiaries to readily identify which forms of MOUD are covered without prior authorization and whether any other utilization management criteria apply (SAMHSA 2024e). However, in some instances, clinicians may have access to that information through electronic health records (ASAM 2021).

FIGURE 3-2. Share of Medicaid Beneficiaries Age 18–64 with Opioid Use Disorder Who Received Any Medication for Opioid Use Disorder in the United States, FY 2017–2022



Notes: FY is fiscal year. The figure shows the use of medications for opioid use disorder among individuals age 18 to 64 who were ever enrolled as a full-benefit, Medicaid-only beneficiary in a given fiscal year. Medications for opioid use disorder are methadone, buprenorphine, and extended-release injectable naltrexone. The analysis includes all 50 states and the District of Columbia, with the following exceptions: Illinois and New York were excluded for all years, and Maryland and Utah were excluded for FY 2017 due to data limitations.

Sources: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Documented Medicaid coverage of MOUD does not necessarily mean that access to or use of medications is widespread. The next section highlights findings from an analysis of Medicaid claims, which shows that the use of certain medications is extremely low or non-existent in some states, despite them being covered.

Utilization of MOUD

MACPAC contracted with Acumen LLC to examine MOUD use among Medicaid beneficiaries using data from the Transformed Medicaid Statistical Information System (T-MSIS). Specifically, we looked at national and state-level trends as well as variation in MOUD use by beneficiary demographic and health-related characteristics. We also assessed how the MOUD benefit mandate, specifically the addition of methadone coverage, affected utilization of MOUD.

The MOUD treatment rates presented in this section may differ from other available estimates due to differences in data sources and methodology. For information about our data sources and methodology, see Appendix 3A.

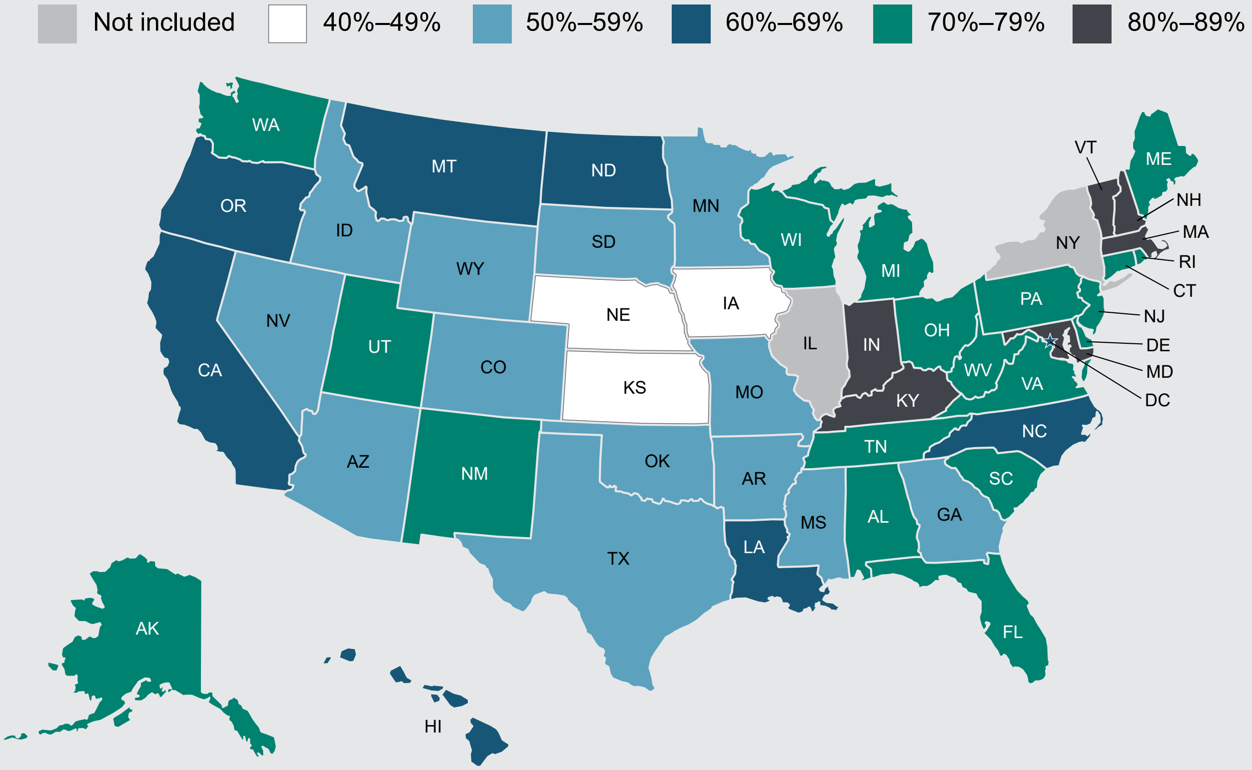
Any MOUD use

Although the share of Medicaid beneficiaries with OUD receiving MOUD has increased in recent years and is relatively high nationally, there is considerable variation across states.

National estimates

In 2022, approximately 1.4 million Medicaid beneficiaries age 18 to 64 with OUD received some form of MOUD. The share of beneficiaries with OUD receiving MOUD increased from 63 percent in FY 2017 to 71 percent in FY 2022 (Figure 3-2). Access to MOUD was likely affected by several factors during this period, including federal and state initiatives to improve the availability of MOUD providers and the onset of the COVID-19 PHE in early 2020. Although there has been improvement in rates of MOUD treatment over time, a substantial gap remains, with nearly 30 percent of beneficiaries with OUD not receiving MOUD. We discuss stigma, provider shortages, and other factors that contribute to the treatment gap later in the chapter.

FIGURE 3-3. Share of Adult Medicaid Beneficiaries Age 18–64 with Opioid Use Disorder Who Received Any Medication for Opioid Use Disorder by State, FY 2022



Notes: FY is fiscal year. The figure shows use of medications for opioid use disorder among individuals age 18 to 64 who were ever enrolled as a full-benefit, Medicaid-only beneficiary in FY 2022. Medications for opioid use disorder are methadone, buprenorphine, and extended-release injectable naltrexone. Illinois and New York were excluded due to data limitations.

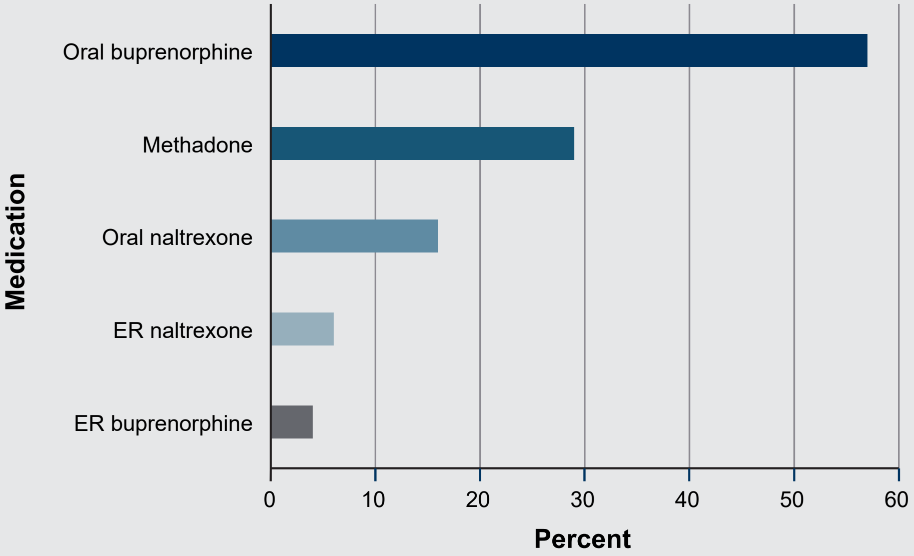
Source: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Our findings are generally consistent with those of other studies using T-MSIS data to analyze MOUD use among Medicaid beneficiaries with OUD (Saunders et al. 2024, HHS 2023b).[26] However, they are considerably higher than MOUD treatment rates observed in studies using national survey data. For example, our analysis of data from the 2022 National Survey on Drug Use and Health found that only 24 percent of beneficiaries with OUD received MOUD in the past year (MACPAC and SHADAC 2024).[27] This is partly because the National Survey on Drug Use and Health relies on self-reported data rather than diagnoses or claims for OUD-related services and therefore tends to identify more beneficiaries with OUD.[28]

State estimates

MOUD use among beneficiaries with OUD varies by state, ranging from 42 percent in Iowa to 84 percent in Vermont in FY 2022 (Figure 3-3). This is consistent with other studies that found wide variation in MOUD treatment rates across the states and likely reflects differences in the availability of MOUD providers, among other factors (KFF 2025, Clemans-Cope et al. 2019).

FIGURE 3-4. Share of Adult Medicaid Beneficiaries Age 18–64 with Opioid Use Disorder Receiving Medications for Opioid Use Disorder and Oral Naltrexone by Medication, FY 2022



Notes: FY is fiscal year. ER naltrexone is extended-release injectable naltrexone. ER buprenorphine is extended-release injectable buprenorphine. Medicaid beneficiaries may have had claims for more than one type of medication, and therefore, the sum of the percentages exceeds 100. Illinois and New York were excluded due to data limitations.

Source: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Use of specific medications

In FY 2022, Medicaid beneficiaries with OUD most commonly received an oral formulation of buprenorphine, followed by methadone, extended-release injectable naltrexone, and extended-release injectable buprenorphine (Figure 3-4). Roughly 16 percent of beneficiaries with OUD had a claim for oral naltrexone, though it is not FDA approved for the treatment of OUD and has not been found to be effective in clinical trials (Minozzi et al. 2011).[29] Off-label use of oral naltrexone for OUD is particularly common in states such as Iowa and Nebraska, where roughly half of beneficiaries receiving MOUD were treated with oral naltrexone.

Although use of extended-release injectable formulations is low overall, it is particularly low in certain states (Appendix 3B, Table 3B-1). In FY 2022, Arkansas, the District of Columbia, Idaho, South Dakota, Texas, and Wyoming each had 10 or fewer beneficiaries with claims for extended-release injectable buprenorphine.[30] Similarly, 10 or fewer beneficiaries were treated with extended-release injectable naltrexone in Mississippi, South Dakota, and Wyoming. Findings from our qualitative research suggest that low utilization of extended-release injectable formulations is likely the result of several factors, including a limited availability of providers administering these medications, utilization management policies intended to steer patients toward less costly oral formulations, and patient preference.

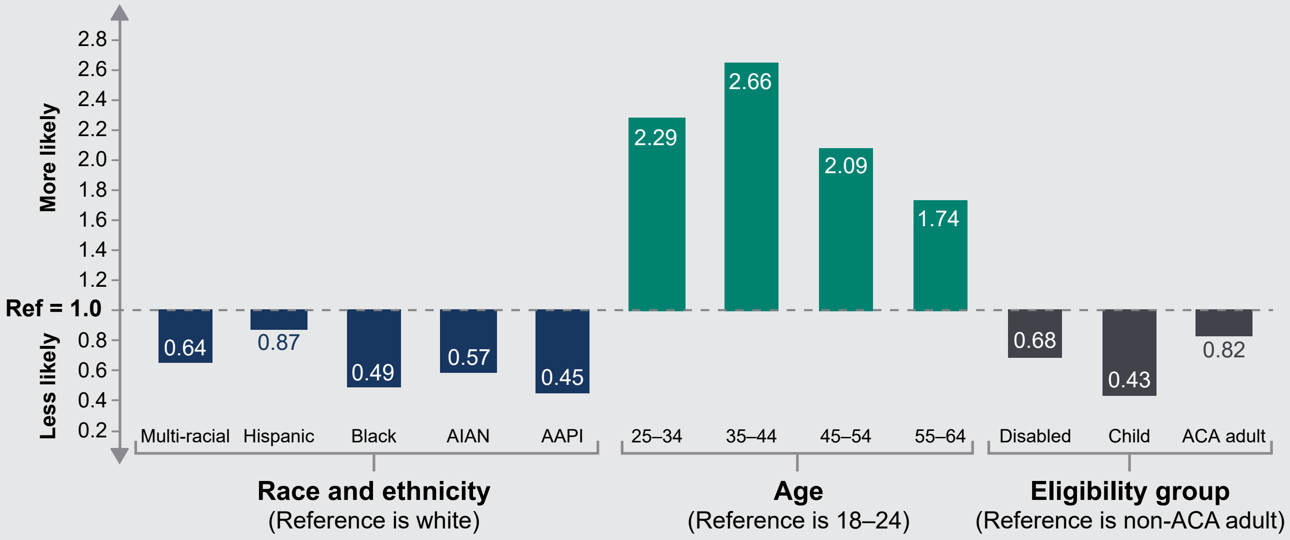
Use of methadone was particularly low in some states. In FY 2022, fewer than 1 in 5 beneficiaries receiving MOUD were treated with methadone in 17 states.[31] Relatively low use of methadone in some states may reflect limited availability of OTPs, which are the only providers authorized to dispense methadone under federal law (42 CFR Part 8). Although more stable patients may be permitted to receive take-home doses, beneficiaries typically must travel to an OTP to receive medication daily or near daily, which can pose barriers to access.

Variations in MOUD use among beneficiaries

Use of MOUD among Medicaid beneficiaries with OUD varied across demographic groups, with the greatest disparities observed by age, eligibility group, and race and ethnicity (Figure 3-5). In FY 2021, white beneficiaries were more likely than any other racial or ethnic group to receive MOUD. Rates of MOUD use were lowest among Black and Asian American and Pacific Islander beneficiaries with OUD, who were about half as likely to receive MOUD compared to their white counterparts. Other studies show similar disparities in the use of any MOUD as well as the type of MOUD received, with people of racial and ethnic minority groups being more likely to receive methadone and less likely to receive buprenorphine relative to white people with OUD (Nedjat et al. 2024).

Our analysis also found notable differences in MOUD use by age and eligibility group (Figure 3-5). Young adults age 18 to 24 were roughly two to three times less likely to receive MOUD than other adults younger than age 65. Conversely, MOUD use was most common among beneficiaries age 35 to 44. Examining MOUD use by eligibility group, we found that non-expansion adults with OUD were more likely to receive MOUD compared to beneficiaries with OUD in other eligibility groups.[32] Children and beneficiaries enrolled on the basis of a disability had the lowest odds of receiving MOUD, relative to non-expansion adults. This is consistent with other studies that have found lower odds of receiving MOUD for Medicaid beneficiaries with disabilities than for beneficiaries without disabilities (Thomas et al. 2023, MODRN 2021).

FIGURE 3-5. Odds of Beneficiaries with Opioid Use Disorder Receiving Any Medication for Opioid Use Disorder by Demographic Groups, FY 2021



Notes: FY is fiscal year. Black is Black, non-Hispanic. AIAN is American Indian and Alaska Native. AAPI is Asian American and Pacific Islander. ACA is Patient Protection and Affordable Care Act (P.L. 111-148). Odds ratios compare the likelihood of one group receiving any medication for opioid use disorder compared to that of another group, known as the "reference category," which is equal to one. White beneficiaries is the reference category to which other racial and ethnic groups are compared. Beneficiaries age 18 to 24 is the reference category for other age groups. Non-ACA adult is the reference category for other eligibility groups and represents adults who are not enrolled through the ACA Medicaid expansion. All associations reported are statistically significant (p < .001).

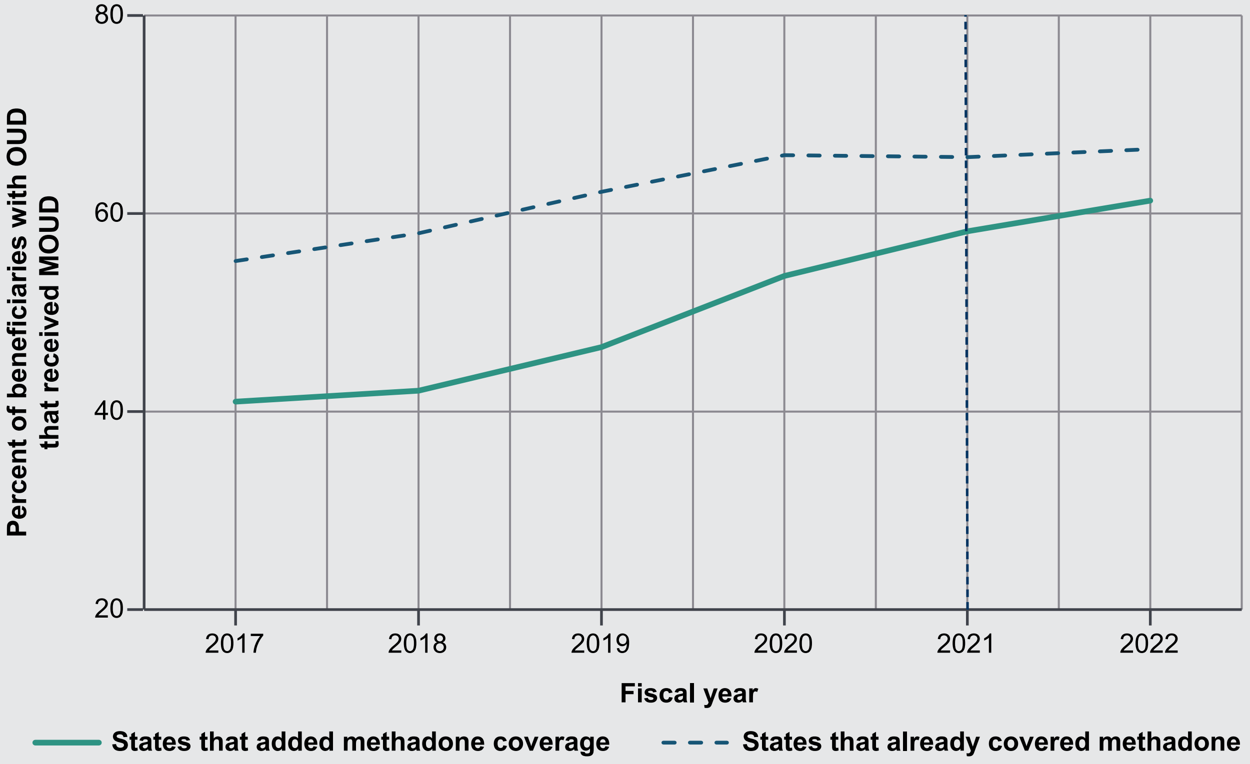
Source: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Effect of the MOUD benefit mandate

MACPAC sought to understand how the MOUD benefit mandate affected utilization of MOUD by evaluating the main outcome associated with the mandate: the addition of methadone coverage in states that had not previously covered it. In 2018, when Congress approved the MOUD benefit mandate, methadone was the only type of MOUD not covered in all states. Using Medicaid claims data, we identified 11 states that did not cover methadone at the time but subsequently added it.[33] Most of these states began coverage for methadone before FY 2021, as required, while others began covering methadone after the benefit mandate took effect in October 2020.

Our analysis shows that the percentage of beneficiaries with OUD using any form of MOUD increased more in states that added methadone coverage compared to those that had already covered all forms of MOUD (Figure 3-6). Overall, expanded methadone coverage was associated with an increase in MOUD use that was nearly 6 percentage points higher than the increase in MOUD use in states that already covered methadone. In other words, the addition of methadone coverage increased overall MOUD use and narrowed the gap in treatment rates between states that previously had not covered methadone and those that had.

FIGURE 3-6. Trends in Use of Medications for Opioid Use Disorder among Beneficiaries with Opioid Use Disorder in States that Added Methadone and States that Previously Covered Methadone, FYs 2017–2022



Notes: FY is fiscal year. OUD is opioid use disorder. MOUD is medications for opioid use disorder. This figure shows trends in MOUD use for states that added methadone coverage compared to similar states that already covered methadone during the study period. It excludes states with data quality issues and states that received an exemption to the federal requirement for states to cover all forms of MOUD (South Dakota and Wyoming), which took effect in FY 2021. MOUD are methadone, buprenorphine, and extended-release injectable naltrexone.

Source: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Limitations

Several limitations should be considered when assessing the results of this analysis. First, there were many other local, state, and federal policy changes addressing MOUD access during the study period, and therefore, changes in MOUD coverage and use cannot solely be attributed to the MOUD benefit mandate. The study period spans the height of the COVID-19 pandemic, during which treatment access was affected by social distancing requirements in addition to a number of new policies intended to mitigate access barriers (e.g., additional flexibility to offer buprenorphine via telehealth and methadone take-home doses). Although the factors motivating state decisions to add methadone coverage are beyond the scope of this analysis, it is likely that some states were already moving toward covering methadone independent of the federal policy change, while others added coverage to comply with the new requirement. Additionally, the analysis uses a broad definition of MOUD treatment: Beneficiaries are counted as having received MOUD if they had at least one MOUD claim. In that regard, the analysis measures access to MOUD rather than whether a beneficiary was engaged in more sustained, long-term treatment.

Barriers to MOUD

To examine factors that contribute to the MOUD treatment gap, MACPAC conducted a literature review and interviews with state Medicaid agency officials and MCO representatives as well as federal officials, beneficiary advocates, national associations, and other experts (Appendix 3A). Although there have been considerable federal, state, and local efforts to improve access to MOUD in recent years, social stigma and limited provider availability are persistent challenges. Prior authorization for MOUD generally, and daily dosage caps for oral buprenorphine, are also commonly cited as barriers to timely and effective treatment.

Stigma

Stakeholders reflected on the persistence of stigma and misinformation surrounding the use of methadone and buprenorphine, which tend to be labeled as so-called replacement drugs because they are themselves opioids and controlled substances. Consequently, there are abstinence-only treatment programs and facilities—often a step down from residential treatment (e.g., sober living or halfway houses)—that do not permit the use of methadone or buprenorphine and require patients to taper off these medications (Carroll et al. 2024, Facher 2024). This can cause severe harm and even overdose death for individuals who are receiving MOUD treatment and need or have been court ordered to stay in those settings as they transition back into the community. Moreover, stakeholders noted that abstinence-only policies may violate federal antidiscrimination laws such as the Americans with Disabilities Act (P.L. 101-336), which prohibits discrimination against individuals who are taking legally prescribed MOUD (DOJ 2022).[34] Courts and government agencies within the criminal legal system and family court systems have also prohibited or restricted the use of MOUD (LAC 2024).

Stigma can also reinforce structural barriers to MOUD, particularly for methadone. For example, 22 states have zoning laws that are more restrictive for OTPs than they are for other medical facilities, which can make it harder to identify new locations and ensure convenient access to OTPs. In some instances, state and pharmacy board regulations also limit access to methadone by requiring OTPs to obtain a license from the board of pharmacy or to have a pharmacist on staff. Additionally, some states require providers to obtain a certificate of need (i.e., a legal document demonstrating the need for new facility services that requires local approval) to establish an OTP. States regulations may pose such a barrier to entry that there is effectively a moratorium on new programs (Doyle 2022).

Stakeholders discussed how fear of running afoul of DEA regulations prevents some retail pharmacies from dispensing buprenorphine or increasing their buprenorphine supply, making it more difficult for patients to access the medication. Although federal regulations do not limit the quantity of buprenorphine a pharmacy can order, the DEA requires suppliers to monitor pharmacy orders of controlled substances through a centralized database, and suppliers have a legal duty to notify the DEA of pharmacy orders of opioid products that are atypically large or otherwise considered suspicious (DEA 2025b). Officials from one state Medicaid agency said pharmacies that run out of buprenorphine partway through the month are not replenishing their supply to avoid DEA scrutiny. Some pharmacies are still using years-old monthly quotas for stocking buprenorphine and are unwilling to increase their supply, even as they have seen the increased need for buprenorphine in the community.

Complex federal regulations regarding patient privacy can also contribute to stigma and dissuade providers from offering MOUD. Some stakeholders noted that federal rules governing confidentiality of SUD treatment records under 42 CFR Part 2 (Part 2) can make primary care providers hesitant to prescribe MOUD, out of concern that doing so will make their practices subject to additional federal regulatory requirements. Other stakeholders noted that Part 2 does not apply to the vast majority of primary care providers who prescribe MOUD; when Part 2 does apply, it serves an important function in promoting access to treatment and protecting individuals against stigma and discrimination. There is optimism that a recent federal rule aligning certain Part 2 requirements with Health Insurance Portability and Accountability Act (P.L. 104-191) rules could help mitigate some of these challenges, though some stakeholders suggested a continued need for education to reassure primary care providers and administrators.[35] The Commission has examined issues related to Part 2 in its prior work and issued recommendations in its June 2018 report to Congress calling for additional federal guidance and technical assistance to address the confusion among providers and other stakeholders (MACPAC 2018).[36] Since then, Congress and SAMHSA have funded a center of excellence to provide additional guidance and technical assistance on HIPAA, Part 2, and other behavioral health privacy topics (SAMHSA 2024g).

Stigma can be alleviated through efforts to change public perceptions about OUD and the medications used to treat it. By requiring states to cover MOUD, the SUPPORT Act helped establish it as the standard of care for MOUD and reduced stigma among policymakers and providers. To address stigma and provider hesitancy, state Medicaid programs and MCOs have conducted outreach to educate their providers and community leaders on the benefits of MOUD. For example, one state reported that a strong case for the evidence supporting methadone for OUD treatment has made OTPs a well-established part of their OUD treatment system. States have also worked to help providers understand complex federal regulations that may prevent them from getting involved in MOUD treatment. For example, one state Medicaid agency described working with its state's behavioral health agency to release informational bulletins and meet with providers to address concerns about pharmacies stocking and dispensing buprenorphine.

Provider availability

Stigma and a host of other factors contribute to the limited availability of MOUD providers. In 2022, 34 percent of U.S. counties did not have any OTPs or buprenorphine providers serving Medicaid enrollees. More than half of these counties (57 percent) did not have any MOUD providers, whereas the remaining counties had MOUD providers that did not see Medicaid patients. Most OTPs treated Medicaid enrollees, while most office-based buprenorphine providers did not (OIG 2024).[37] This is consistent with research showing less access to buprenorphine treatment in low-income areas with high concentrations of people with racial and ethnic minority backgrounds (Drake et al. 2024). Conversely, OTPs dispensing methadone tend to be located in low-income and urban communities with higher proportions of residents who belong to minority groups (Jehan et al. 2024).

Among other challenges, stakeholders cited the overall behavioral health workforce shortage as a key limiting factor. Efforts to recruit other provider types, such as primary care and obstetrics and gynecology providers, can be hindered by stigma and the complexity of treating patients with OUD. Those who are not addiction specialists may not have the training or support to care for patients with OUD, particularly those with polysubstance use, other health or mental health conditions, and social needs. To address these challenges, states report using State Opioid Response grant funding to recruit and provide ongoing support to office-based buprenorphine prescribers, including through investments in additional case management staff. States may also support teleconsultation models, such as Project ECHO, which offer MOUD providers regular access to guidance from addiction specialists.

Payment is another factor that can deter providers from offering MOUD or participating in Medicaid, though stakeholders we interviewed had varying perspectives on whether reimbursement rates were a barrier to increasing provider availability. Some MOUD providers do not accept Medicaid, and low Medicaid reimbursement rates can make them reluctant to participate. Moreover, many patients with OUD have complex needs that require more time or additional services (e.g., care coordination) that may not be adequately covered by Medicaid.

Stakeholders noted that the financial risks associated with offering injections of extended-release buprenorphine are of particular concern to many providers. There are costs associated with provider training, proper medication storage, and space to observe patients after injection. Moreover, extended-release buprenorphine is relatively expensive (up to $1,200 per dose) and must be administered within 45 days of delivery to the patient for whom it was prescribed. Providers who order the medication from a specialty pharmacy upon prescribing it risk assuming the cost of the medication if the patient does not return for their dose within that 45-day window. Although providers can avoid that risk by purchasing and stocking the medication, that so-called buy-and-bill approach requires a large up-front investment for the purchase of the medication, which may not be recouped unless all doses are administered.

Stakeholders described how federal, state, and local regulations limit the availability of methadone providers. As previously noted, methadone dispensing is limited to OTPs that are certified by SAMHSA, independently accredited, and compliant with a host of federal requirements. State and local restrictions such as zoning laws and certificate of need requirements create additional barriers to expanding OTPs in some states. Several states are trying to address these challenges through the use of mobile OTP units that can extend the reach of the OTP facilities with which they are affiliated. There are also federal efforts to expand the use of satellite medication units for dispensing methadone in alternate locations such as certified community behavioral health clinics, community mental health centers, and primary care clinics. Fixed units are locked medication storage containers, which are supervised by a nurse and associated with an OTP facility.

MOUD prescribing in the emergency department is another avenue for expanding access to MOUD. Some states have passed laws requiring emergency departments to prescribe MOUD or to provide a warm handoff to other providers who can initiate treatment. Stakeholders noted that integrating MOUD prescribing into routine emergency department practice can be difficult because providers may lack familiarity or training in providing these medications. However, some health systems have embraced opportunities to provide MOUD in emergency departments and to collaborate with other providers to ensure adequate support and continuity of care.

Utilization management

States and MCOs establish utilization management policies such as prior authorization to ensure the delivery of appropriate care and address other goals, such as controlling costs and reducing the potential for fraud, waste, and abuse. However, stakeholders noted that these approaches may delay or result in the denial of potentially life-saving care. Several stakeholders expressed concerns about the general use of prior authorization for MOUD as well as dosage limits for oral buprenorphine that cannot be overridden without prior approval.

Prior authorization

Many stakeholders we interviewed are supportive of removing prior authorization requirements for MOUD, which they contend delay patient care, create administrative hurdles for providers, and contribute to stigma. In the view of one addiction medicine specialist, treatment delays create the risk that patients waiting for medications will overdose or not reengage once their treatment is authorized. He and other interviewees emphasized the need to remove barriers and capitalize on every opportunity to engage individuals with OUD in treatment.

A few stakeholders highlighted the role of prior authorization in preventing medication diversion and ensuring beneficiaries receive high-quality care.[38] However, other interviewees emphasized that concerns about medication diversion are overstated, noting that eliminating prior authorization in many states has increased access to MOUD without notable increases in diversion. Moreover, MOUD that is diverted is most often used to avoid the painful effects of opioid withdrawal, not to get high. The lack of evidence that removal of prior authorization contributes to diversion and the fact that methadone and buprenorphine overdose rates have remained relatively flat over time raises questions about the basis for concerns about diversion of MOUD. One interviewee said, "The benefits of removing these barriers in terms of initiating treatment and maintaining people on treatment in an uninterrupted fashion outweigh any of these hypothetical risks that are not really grounded in the evidence." Moreover, several stakeholders noted that other effective methods are in place to prevent potential fraud, waste, and abuse, such as pharmacy edits that flag problematic prescribing practices (e.g., overprescribing) at the point of sale.

Buprenorphine prescribing limits

States may impose caps on the dosage of buprenorphine that can be prescribed on a single day to align with clinical standards and FDA labeling. In FY 2022, 73 percent of MCOs reported having a daily dosage limit of 24 mg for oral buprenorphine and buprenorphine-naloxone combination drugs (CMS 2023b). Often, providers cannot prescribe above this limit without receiving prior authorization. However, these policies do not reflect the evolving nature of the opioid crisis and the reality that individuals with OUD who use illicit fentanyl may need higher doses of buprenorphine to stabilize. Amid rising fentanyl use and related deaths, providers have struggled to secure coverage of 32 mg daily doses for patients who require a higher dose to stave off cravings and prevent opioid withdrawal. When higher doses are not approved, patients may have to accept a lower, less effective dose or pay for the extra quantity out of pocket.

Seeking to provide more patient-centered care and improve treatment retention, some states have raised the buprenorphine dosage cap to 32 mg per day. Additionally, the FDA recently began encouraging buprenorphine labeling changes to clarify that higher doses may be appropriate for some patients. The agency notes that current labeling has been misinterpreted as suggesting a maximum dosage of 16 or 24 mg per day, despite the absence of an explicit maximum dosage. The FDA's recommendations seek to clarify that daily doses of oral buprenorphine can be adjusted for each patient based on their individual therapeutic need and that daily doses higher than 24 mg per day may be required to keep patients in treatment and suppress opioid withdrawal (FDA 2024b).

Looking Ahead

Despite considerable policy efforts and recent declines in drug-related mortality, the number of opioid-related deaths in the United States remains alarmingly high. As part of its continued focus on access to behavioral health services for Medicaid beneficiaries, MACPAC will continue to examine factors affecting access to MOUD. Although many of the access challenges discussed in this chapter are not specific to Medicaid, utilization management, such as prior authorization, are typically within the program's purview. Building on its findings to date, MACPAC's future work will examine the use of these policies and their effects on timely and effective MOUD treatment.

Endnotes

[1] MACPAC contracted with the State Health Access Data Assistance Center to produce estimates of OUD prevalence and treatment based on an analysis of self-reported data from the National Survey on Drug Use and Health (NSDUH). The NSDUH is a federal survey of non-institutionalized individuals age 12 to 64 conducted annually in all 50 states and the District of Columbia. The 2022 NSDUH classified respondents as having an OUD if they met criteria in the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition, for having a heroin use disorder or a prescription pain use disorder. The definition of OUD therefore does not account for respondents' use of illegally made fentanyl, which may be mixed with heroin, substituted for heroin entirely, or sold as counterfeit prescription drugs (SAMHSA 2023).

[2] This study examined the prevalence of overdose deaths related to opioids as well as other drugs (e.g., cocaine) (Mark and Huber 2024).

[3] MOUD is a term that describes medications approved for the treatment of OUD. Medication-assisted treatment refers to MOUD and medications used to treat other substance use disorders.

[4] MACPAC contracted with Acumen LLC to interview state Medicaid agency officials in six states as well as state behavioral health agency officials and managed care organization representatives in a subset of those states. We also conducted interviews with federal officials, beneficiary advocates, national associations, and other experts.

Interviews were conducted between July and September 2024. See Appendix 3A for information on stakeholder interview methods.

[5] A controlled substance is a drug or other substance that is highly regulated by the government because of its abuse and dependency potential. Controlled substances with known medical use are available by prescription, whereas those without a known medical use (e.g., heroin) are illegal in the United States (DEA n.d.).

[6] Opioid agonists are substances that stimulate physiological activity at the cell receptors in the central nervous system that are normally stimulated by opioids (SAMHSA 2021).

[7] Oral naltrexone is approved for the treatment of alcohol use disorder.

[8] The discussion of recent Medicaid policies affecting access to MOUD is not exhaustive. Other policies and programs, such as federal mental health parity requirements and certified community behavioral health centers, are also intended to increase access to MOUD, among other goals (§ 1905(a)(31) of the Social Security Act, 42 CFR 438.3(n) and subpart K).

[9] Federal law defines the required MOUD benefit as including counseling services and behavioral therapy related to the drugs and biologics covered under the new mandatory benefit. States have flexibility to specify which counseling services and behavioral therapy are included in the mandatory benefit (CMS 2020).

[10] We identified states as covering methadone for the treatment of OUD if they had more than 10 beneficiaries with OUD who had methadone claims in a given fiscal year, because having a small number of beneficiaries with claims for methadone (10 or fewer) could indicate miscoding or other data quality issues.

[11] The MOUD benefit mandate does not apply to alternative benefit plans that do not align with the state plan. Consequently, some alternative benefit plans may not cover all forms of FDA-approved MOUD. All but four states that expanded Medicaid to low-income adults under the Patient Protection and Affordable Care Act (P.L. 111-148) provide that population with an alternative benefit plan that includes state plan benefits and therefore includes coverage for all forms of FDA-approved MOUD (CMS 2024a). States may also require other Medicaid populations to receive care through alternative benefit plans (Baumrucker 2018).

[12] The seven states and territories with approved exception requests are American Samoa, the Commonwealth of the Northern Mariana Islands, Guam, Hawaii, South Dakota, Wyoming, and the U.S. Virgin Islands (CMS 2024b).

[13] The states that received planning grants are Alabama, Connecticut, Delaware, District of Columbia, Illinois, Indiana, Kentucky, Maine, Michigan, Nevada, New Mexico, Rhode Island, Virginia, Washington, and West Virginia. The states selected to participate in the postplanning period are Connecticut, Delaware, Illinois, Nevada, and West Virginia (HHS 2024).

[14] Federal reimbursement for the postplanning period is based on a complex formula, and states reported difficulty predicting how much federal funding they would receive (HHS 2024).

[15] As of March 2025, CMS approved Section 1115 demonstrations for SUD and OUD in Alaska, California, Colorado, Connecticut, Delaware, District of Columbia, Idaho, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Utah, Vermont, Virginia, Washington, West Virginia, and Wisconsin. States with new pending applications are Alabama, Arizona, and Arkansas (KFF 2025).

[16] As of March 2025, CMS approved Section 1115 reentry demonstrations in Arizona, California, Colorado, Hawaii, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Montana, New Hampshire, New Mexico, North Carolina, Oregon, Pennsylvania, Utah, Vermont, Washington, and West Virginia. States with pending applications are Arkansas, Connecticut, District of Columbia, Louisiana, Minnesota, Nevada, New Jersey, New York, and Rhode Island (KFF 2025).

[17] The three states with opioid health homes are Maine, Rhode Island, and Vermont. States with SUD health homes are Maryland, Michigan, North Carolina, and Wisconsin (CMS 2024c).

[18] In the first 14 days of treatment, the take-home supply is limited to a maximum supply of seven days' worth of take-home medication. Between 15 and 30 days of treatment, the take-home supply maximum is 14 days. After 31 days, patients can receive a take-home supply up to 28 days (SAMHSA 2024a).

[19] The "X" designation comes from the unique DEA number starting with the letter "X" given to providers who obtained the waiver (Healy et al. 2023). DATA-2000 refers to the Drug Addiction Treatment Act of 2000, which created the exception and waiver process for certain providers seeking to prescribe buprenorphine for OUD.

[20] Citing the end of the PHE, on March 24, 2025, the U.S. Department of Health and Human Services (HHS) terminated $11.4 billion in state grants and cooperative agreements funded by COVID-19 supplemental appropriations, including supplemental Substance Use Prevention, Treatment, and Recovery Services block grant funding that had not yet expired (HHS 2025, Weixel 2025). A federal judge issued a temporary restraining order as the result of legal action brought by 22 states and the District of Columbia, which cited the provider cuts and elimination of SUD treatment and recovery services among other harms caused by the unexpected and abrupt terminations (order granting temporary restraining order, State of Colorado et al. v. U.S. Department of Health and Human Services et al., No. 1:25-cv-00121-MSM-LDA (D.R.I. 2025)). Future court rulings will determine whether HHS can ultimately move forward in rescinding the funds.

[21] State Targeted Response to the Opioid Crisis grants were authorized under the 21st Century Cures Act (P.L. 114-255) and the SUPPORT Act and funded through appropriations. Funding for State Opioid Response grants was first provided in the Consolidated Appropriations Act, 2018 (P.L. 115-141). The two programs were effectively merged under the Consolidated Appropriations Act, 2023, which amended the Cures Act by replacing the State Targeted Response to the Opioid Crisis authorization with an authorization for the State Opioid Response grants.

[22] To assess coverage, SAMHSA reviewed state-level Medicaid drug utilization data, state Medicaid fee-for-service and managed care organization formularies, state preferred drug lists, the national master Medicaid rebate agreement, and other sources such as state regulatory announcements and state plan amendments (SAMHSA 2024e).

[23] Researchers were unable to identify most fee-for-service MOUD coverage policies in Hawaii, Kansas, and the U.S. Virgin Islands (SAMHSA 2024e).

[24] In addition to the MOUD benefit mandate, state Medicaid programs generally must cover nearly all of a participating manufacturer's FDA-approved drugs when prescribed for a medically accepted indication under the Medicaid Drug Rebate Program (§ 1927 of the Social Security Act). Physician-administered drugs, such as extended-release injectable buprenorphine and naltrexone, may be included in the Medicaid Drug Rebate Program if payment for that drug is made separately from other services (i.e., it is not part of a bundled payment). Methadone for OUD is paid for as part of a bundled set of services delivered in an OTP and is therefore not covered under the Medicaid Drug Rebate Program.

[25] A preferred drug list provides a list of drugs that are considered preferred and that are generally covered without prior authorization. Preferred drug lists generally include lower-cost drugs such as generic versions or drugs for which the MCO or state has negotiated a rebate in exchange for preferred status (Ovsag et al. 2008). Preferred drug lists must be developed by a committee consisting of physicians, pharmacists, and other appropriate individuals appointed by the governor of the state (Section 1927(d)(4)(A) of the Social Security Act). For managed care, this list of preferred drugs is called a "formulary" (MACPAC 2024).

[26] T-MSIS collects Medicaid and CHIP data from states, territories, and the District of Columbia and is the largest national resource of beneficiary information (CMS 2025). Differences in methodology may explain differences in our results compared to those from other studies using T-MSIS to identify rates of MOUD use among Medicaid beneficiaries. For example, KFF's analysis includes youth, a population with lower use of MOUD, whereas ours does not (Saunders et al. 2024). Similarly, HHS includes the overdose-reversal drug naloxone in its definition of medications used to treat OUD, whereas ours includes only medications approved for long-term treatment of OUD (HHS 2023).

[27] Results from the 2022 NSDUH were the most recent data available at the time of our analysis.

[28] NSDUH reflects responses from people who may not have a clinically identified or diagnosed case of OUD; however, the survey may still underestimate the prevalence of OUD and other SUDs. This is because the NSDUH excludes people who do not have an address, such as those who are unhoused, institutionalized, or incarcerated—populations that tend to have higher rates of SUD (SAMHSA 2023).

[29] It is unlikely that these claims reflect treatment for a co-occurring alcohol use disorder, as the analysis excluded beneficiaries with claims for naltrexone associated with an alcohol use disorder diagnosis. See Appendix 3A for more information about our methodology.

[30] Arkansas had no claims for extended-release injectable buprenorphine.

[31] This does not include South Dakota and Wyoming, which received exceptions to the MOUD benefit mandate due to their lack of OTPs providing methadone to Medicaid beneficiaries.

[32] Non-expansion adults refers to adults who were not enrolled through the Patient Protection and Affordable Care Act Medicaid expansion.

[33] The 11 states that did not cover methadone and subsequently added coverage are Arkansas, Idaho, Kansas, Kentucky, Louisiana, Mississippi, Nebraska, North Dakota, Oklahoma, South Carolina, and Tennessee. We identified states as covering methadone if they had more than 10 beneficiaries with methadone claims in a given fiscal year, because having a small number of beneficiaries with claims for methadone (10 or fewer) could indicate miscoding or other data quality issues. South Dakota and Wyoming did not cover methadone when the SUPPORT Act was passed but were not included in this analysis because they received exceptions to the MOUD benefit mandate because they lacked Medicaid-enrolled OTPs.

[34] The Americans with Disabilities Act prohibits discrimination on the basis of disability, which is defined as a physical or mental impairment that substantially limits one or more major life activities. People with OUD often have a disability because they have a drug addiction that substantially limits on or more of their major life activities. The Americans with Disabilities Act also protects people who are in recovery who would be considered to have a disability in the absence of access to treatment or recovery services (DOJ 2022).

[35] On February 8, 2024, SAMHSA and the HHS Office for Civil Rights issued a final rule that aligns certain aspects of Part 2 requirements with Health Insurance Portability and Accountability Act privacy rules, as required by the Coronavirus Aid, Relief, and Economic Security Act (P.L. 116-136) (SAMHSA 2024f).

[36] In its June 2018 report to Congress, MACPAC recommended that the Secretary of the U.S. Department of Health and Human Services direct relevant agencies to issue joint subregulatory guidance that addresses Medicaid and CHIP provider and plan needs for clarification of key Part 2 provisions and direct a coordinated effort by relevant agencies to provide education and technical assistance on Part 2 (MACPAC 2018).

[37] Florida was excluded from the analysis due to data quality issues (OIG 2024).

[38] Medication diversion involves the diversion of drugs from legal and medically necessary uses toward those that are illegal and typically not medically authorized (CMS 2012). Legally dispensed methadone and buprenorphine are most commonly diverted to individuals with OUD to control opioid withdrawal and cravings (NIDA 2018).

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APPENDIX 3A: Methods

Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data

MACPAC contracted with Acumen LLC to examine medications for opioid use disorder (MOUD) use among Medicaid beneficiaries. The study population included Medicaid beneficiaries age 18 to 64 who were not dually enrolled in Medicare and Medicaid and who were validly enrolled in Medicaid and receiving full benefits for at least one month of the year. Beneficiaries age 17 and younger were generally excluded because treatment guidelines limit access to methadone for this population, and buprenorphine is indicated for individuals age 16 and older with opioid use disorder (OUD). Dually eligible beneficiaries, including beneficiaries older than age 65, were excluded because of the possibility that those with OUD could have received MOUD through Medicare.

Our analysis relied on Transformed Medicaid Statistical Information System (T-MSIS) data from fiscal years (FYs) 2017 through 2022, supplemented by the Centers for Medicare & Medicaid Services Race and Ethnicity Imputation file, which was available only for FYs 2017 through 2021. The file contains an indirectly estimated probability of each race and ethnicity category for each beneficiary and is used to impute missing race and ethnicity information. We used eligibility and claims data to identify Medicaid beneficiaries' demographic characteristics (with the exception of race and ethnicity), their MOUD utilization, and other health conditions. Due to data limitations, Illinois and New York were excluded for all years, and Maryland and Utah were excluded for FY 2017.

We identified beneficiaries with OUD using diagnosis and procedure codes according to methodology from the Centers for Medicare & Medicaid Services Chronic Conditions Data Warehouse, supplemented by clinical review. Oral naltrexone, which is approved by the U.S. Food and Drug Administration for alcohol use disorder and is sometimes prescribed off label for OUD, was included in the OUD definition to align with the Chronic Conditions Data Warehouse definition. However, beneficiaries with claims for oral naltrexone associated with an alcohol use disorder diagnosis were not classified as having OUD, because it was assumed that they were being treated for alcohol use disorder (rather than OUD). Claims for scans and laboratory tests were excluded to avoid overcounting beneficiaries with OUD based on scans or laboratory tests alone.

MOUD use was defined broadly to include beneficiaries who had at least one MOUD claim in a given year for methadone, buprenorphine, or extended-release injectable naltrexone. Oral naltrexone was not included in overall estimates of MOUD use because it is not indicated for the treatment of OUD. However, utilization of oral naltrexone was examined separately to provide insight into its off-label use.

We used descriptive analyses to show trends in MOUD use among Medicaid beneficiaries with OUD and multivariate logistic regression to assess whether MOUD use varied by beneficiary demographic and health-related characteristics.

To assess the effect of the MOUD benefit mandate, we used a quasi-experimental, synthetic difference-in-differences evaluation design to compare changes in MOUD use in the states that added methadone coverage to changes in MOUD use in similar states that covered methadone before the federal benefit mandate. A synthetic control was constructed for each treated state (the 11 states that added methadone coverage) such that the baseline trends in MOUD use were parallel between the treated states and synthetic comparison states. A final set of matching variables (e.g., Medicaid expansion status, rate of overdose death) was used to create the synthetic comparisons. We then compared the average difference in MOUD utilization in the pretreatment and posttreatment years for the treated and synthetic control states to estimate the treatment effect.

Stakeholder interviews

MACPAC contracted with Acumen to conduct 18 stakeholder interviews between July and September 2024. We interviewed state Medicaid agency officials in six states as well as state behavioral health agency officials and managed care organization representatives in a subset of those states. The states selected vary in their geographic location, share of the population living in rural areas, Medicaid expansion status, managed care organization penetration rate, and MOUD coverage changes that occurred around the time the benefit mandate took effect. MACPAC also conducted interviews with federal officials, beneficiary advocates, provider and state associations, and other national experts.

TABLE 3A-1. Interviewees by Type

Interviewee Type	Interviewees
Federal agency	Centers for Medicare & Medicaid Services Substance Abuse and Mental Health Services Administration
State Medicaid agency	Connecticut Georgia Idaho Louisiana South Dakota Tennessee
State behavioral health agency	Connecticut Idaho South Dakota
Managed care organization	BlueCare (Tennessee) Peach State (Georgia) Aetna Better Health (Louisiana) AmeriHealth Caritas Louisiana (Louisiana)
Other national expert	American Society of Addiction Medicine National Association of State Alcohol and Drug Abuse Directors Addiction Medicine Specialist and Researcher at the University of Colorado
Beneficiary advocate	Legal Action Center

APPENDIX 3B: Medications for Opioid Use Disorder Use by State and Medication

TABLE 3B-1. Number and Share of Medicaid Beneficiaries with at Least One Claim for Medications for Opioid Use Disorder by State and Medication, FY 2022

State	Number of beneficiaries with OUD	Methadone		Buprenorphine				Naltrexone			
		Oral		Oral		ER		Oral		ER	
		#	%	#	%	#	%	#	%	#	%
Alabama	9,396	2,504	32.2%	5,004	64.3%	48	0.6%	399	5.1%	24	0.3%
Alaska	7,405	1,157	18.0	3,615	56.3	655	10.2	1,184	18.4	862	13.4
Arizona	53,577	15,291	39.8	15,883	41.4	426	1.1	8,754	22.8	2,934	7.6
Arkansas	4,463	21	0.7	2,392	84.0	–	0.0	415	14.6	46	1.6
California	118,352	34,420	37.3	39,123	42.4	2,528	2.7	18,758	20.3	5,432	5.9
Colorado	35,361	4,372	17.4	11,813	47.0	1,007	4.0	8,438	33.6	2,621	10.4
Connecticut	35,878	15,867	54.0	9,929	33.8	636	2.2	4,195	14.3	1,358	4.6
Delaware	10,799	5,150	56.3	3,640	39.8	46	0.5	829	9.1	525	5.7
District of Columbia	3,300	823	30.8	1,334	50.0	*	0.3	547	20.5	139	5.2
Florida	28,605	9,682	42.8	10,856	48.0	135	0.6	2,613	11.6	306	1.4
Georgia	8,736	1,984	32.9	2,938	48.7	24	0.4	1,191	19.7	60	1.0
Hawaii	2,805	681	29.9	1,191	52.3	25	1.1	445	19.5	29	1.3
Idaho	7,910	192	3.3	3,617	62.1	*	0.1	2,026	34.8	241	4.1
Indiana	52,597	9,683	20.4	31,326	65.9	865	1.8	7,998	16.8	3,502	7.4
Iowa	8,815	1,610	22.8	2,083	29.5	137	1.9	3,535	50.1	158	2.2
Kansas	2,733	334	19.1	796	45.6	27	1.5	640	36.6	54	3.1
Kentucky	75,168	9,184	14.6	48,140	76.4	2,887	4.6	6,080	9.7	5,970	9.5
Louisiana	35,595	4,663	18.2	17,646	69.0	1,661	6.5	3,714	14.5	1,434	5.6
Maine	19,353	4,461	27.6	10,640	65.9	422	2.6	1,531	9.5	241	1.5
Maryland	59,356	23,693	47.0	25,089	49.8	1,698	3.4	3,561	7.1	2,047	4.1
Massachusetts	62,914	21,633	38.5	28,125	50.1	2,637	4.7	7,971	14.2	3,598	6.4
Michigan	52,073	9,498	22.3	24,892	58.3	2,374	5.6	6,879	16.1	4,098	9.6

TABLE 3B-1. (continued)

State	Number of beneficiaries with OUD	Methadone		Buprenorphine				Naltrexone			
		Oral		Oral		ER		Oral		ER	
		#	%	#	%	#	%	#	%	#	%
Minnesota	27,874	5,252	23.6%	10,588	47.6%	364	1.6%	7,170	32.3%	449	2.0%
Mississippi	3,718	127	5.3	1,944	81.7	22	0.9	319	13.4	*	0.3
Missouri	20,253	2,159	15.2	7,872	55.5	169	1.2	4,155	29.3	1,211	8.5
Montana	7,232	1,083	17.2	3,843	61.0	255	4.0	1,529	24.3	202	3.2
Nebraska	3,064	322	11.9	995	36.7	23	0.8	1,401	51.7	109	4.0
Nevada	13,645	2,713	31.2	4,137	47.6	60	0.7	2,082	23.9	311	3.6
New Hampshire	11,997	3,320	30.8	6,459	59.9	589	5.5	1,300	12.0	433	4.0
New Jersey	50,541	15,565	41.1	20,254	53.5	801	2.1	3,334	8.8	2,439	6.4
New Mexico	22,880	7,737	38.0	8,673	42.6	231	1.1	4,392	21.6	920	4.5
North Carolina	33,480	7,554	32.1	14,618	62.0	563	2.4	1,833	7.8	350	1.5
North Dakota	2,750	759	32.8	1,061	45.8	71	3.1	515	22.2	133	5.7
Ohio	108,918	14,772	16.5	62,851	70.2	3,392	3.8	13,436	15.0	9,257	10.3
Oklahoma	13,836	2,289	22.4	5,658	55.5	143	1.4	2,344	23.0	248	2.4
Oregon	34,746	7,517	26.8	15,447	55.0	886	3.2	6,221	22.2	648	2.3
Pennsylvania	111,642	18,884	20.9	61,397	67.9	9,282	10.3	9,145	10.1	6,442	7.1
Rhode Island	9,828	3,948	43.4	3,942	43.3	118	1.3	1,493	16.4	214	2.4
South Carolina	9,957	2,795	35.1	4,743	59.5	108	1.4	678	8.5	113	1.4
South Dakota	780	–	0.0	416	63.0	*	1.4	251	38.0	*	0.3
Tennessee	25,161	3,108	15.0	15,968	77.2	752	3.6	1,462	7.1	1,659	8.0
Texas	10,747	2,560	31.2	3,264	39.7	*	0.1	2,445	29.8	126	1.5
Utah	14,983	3,172	26.1	6,955	57.2	969	8.0	1,932	15.9	1,297	10.7
Vermont	10,085	3,177	35.0	5,832	64.3	172	1.9	730	8.1	110	1.2
Virginia	48,150	13,348	33.1	24,459	60.7	890	2.2	4,937	12.3	1,091	2.7
Washington	61,980	14,564	29.3	30,002	60.3	789	1.6	7,224	14.5	2,458	4.9
West Virginia	34,478	4,478	16.2	21,474	77.8	840	3.0	1,977	7.2	2,145	7.8
Wisconsin	27,789	7,838	34.4	11,259	49.4	823	3.6	4,311	18.9	2,077	9.1
Wyoming	455	–	0.0	240	71.0	*	0.3	100	29.6	*	2.1

TABLE 3B-1. (continued)

Notes: FY is fiscal year. OUD is opioid use disorder. ER buprenorphine is extended-release injectable buprenorphine. ER naltrexone is extended-release injectable naltrexone. The table shows the use of MOUD among individuals age 18 to 64 with OUD who were ever enrolled as a full-benefit, Medicaid-only beneficiary in FY 2022 as reported by states in the Transformed Medicaid Statistical Information System (T-MSIS). The first column reflects the person counts of Medicaid beneficiaries with OUD as identified using diagnosis and procedure codes in T-MSIS. Oral naltrexone is not approved by the U.S. Food and Drug Administration for OUD, though it is sometimes prescribed off label to individuals with OUD. Beneficiaries may have had claims for more than one type of medication, and therefore, the sum of the percentages may exceed 100 for some states. Illinois and New York were excluded due to data limitations.

* Asterisk indicates values 1 to 10.

– Dash indicates a value of zero.

Source: MACPAC and Acumen LLC, 2024, Analysis of Transformed Medicaid Statistical Information System (T-MSIS) Data.

Chapter 4:

Understanding the Program of All-Inclusive Care for the Elderly

Understanding the Program of All-Inclusive Care for the Elderly

Key Points

- The Program of All-Inclusive Care for the Elderly (PACE) is a provider-led, home- and community-based approach to care that provides Medicaid and Medicare coverage to individuals who are age 55 or older and require a nursing facility level of care, but can live safely in the community. Most states offer PACE programs, with enrollment of more than 83,000 individuals in 2025.
- PACE participants generally receive all medical and non-medical services from an interdisciplinary team of providers.
- Most PACE enrollees are dually eligible for Medicaid and Medicare. State Medicaid agencies, federal officials, PACE organizations, and consumer advocates largely agreed that PACE represents the most fully-integrated form of care available to dually eligible individuals.
- PACE is financed through capitated per member per month payments from state Medicaid agencies and Medicare Parts A, B, and D.
- We identified two key areas of complexity in administering PACE: unclear delineation of oversight responsibilities and a lack of data on service utilization. Oversight responsibilities, particularly for states, are unclear in federal statute and regulation.
- PACE organizations, state Medicaid agencies, and federal officials have difficulty capturing service utilization data due to the nature of PACE. Although states can require PACE organizations to report additional data, they face challenges reviewing the data due to issues of data quality and limited staff capacity.

CHAPTER 4: Understanding the Program of All-Inclusive Care for the Elderly

The Program of All-Inclusive Care for the Elderly (PACE) is a provider-led, home- and community-based approach to care that provides Medicaid and Medicare coverage to individuals who are age 55 or older and require a nursing facility level of care (NFLOC) but can live safely in the community. Most PACE enrollees are dually eligible for Medicaid and Medicare, and PACE provides a fully integrated coverage option for Medicare beneficiaries, in addition to other offerings such as the Medicare Advantage (MA) fully integrated dual eligible special needs plans (FIDE SNPs). Although PACE began as a demonstration program in California, it was made permanent in 1997. It is an optional offering for states under their Medicaid program, and enrollment is voluntary for participants.

The Commission has had a long-standing interest in integrated care for dually eligible individuals because of its potential to address misaligned incentives between Medicaid and Medicare and to improve health outcomes for beneficiaries, including many with complex care needs. PACE features, such as an interdisciplinary care team and a flexible and comprehensive benefit structure, make this care approach unique among integrated care programs and well positioned for the Commission's exploration. This chapter addresses how PACE is designed, administered, and overseen by states and the federal government. This chapter begins with an overview of the PACE model, including the statutory and regulatory framework that governs the program. It then describes our interview findings grouped across several elements of the model: eligibility and enrollment, provider application and procurement, service delivery, grievances and disenrollment, federal and state oversight, and payment. This chapter concludes by looking ahead.

Overview

In 2023, more than 13 million people were dually enrolled in Medicaid and Medicare, with about 70 percent eligible for full Medicaid benefits, referred to as "full-benefit dually eligible beneficiaries," and the remainder eligible for Medicaid assistance with Medicare premiums and in some cases cost sharing, referred to as "partial-benefit dually eligible beneficiaries." Of the full-benefit dually eligible population, approximately 1.3 million received care through the three options that provide fully integrated coverage: MA FIDE SNPs, Medicare-Medicaid Plans, and the PACE (CMS 2024a).[1]

As of April 2025, more than 83,000 individuals were enrolled in PACE across 33 states and the District of Columbia, with many states contracting with multiple PACE organizations (Figure 4-1) (NPA 2025). Participants in PACE generally receive both medical and non-medical services from a single interdisciplinary team (IDT) of providers, both at a PACE center and in their homes. The IDT provides all services covered by Medicaid and Medicare, either directly or through other contracted providers, as well as any additional services determined necessary, without any limitations, cost sharing, or deductibles (42 CFR 460.90).

PACE organizations receive capitated per member per month payments from state Medicaid agencies and Medicare Parts A, B, and D, in addition to any premiums from participants. The small subset of PACE enrollees who are not eligible for Medicaid pay a premium equal to the Medicaid capitated rate plus a premium for Medicare Part D drugs. Medicaid-only and dually eligible PACE enrollees do not pay any premiums (42 CFR 460.186, CMS 2011a). States must develop a Medicaid capitation rate for PACE enrollees based on the cost of Medicaid state plan services for the state's comparable nursing facility-eligible population. Generally, states base the capitation amount for each Medicaid beneficiary enrolling in PACE on a blend of the cost of nursing facility and community-based care for the frail elderly in the area as well as Medicaid managed care data in those states where applicable (CMS 2011a). Combined federal and state Medicaid spending on PACE services totaled $3.9 billion in fiscal year (FY) 2023 (Figure 4-5) (CMS 2023).

PACE originated in San Francisco, California, in 1971 when On Lok Senior Health Services established an adult PACE center as a way to provide culturally competent care to the elders of immigrant families in a community-based alternative to nursing facility care (On Lok 2023). It first was a state pilot program and then operated as a Centers for Medicare & Medicaid Services (CMS, known at the time as the "Health Care Financing Administration") demonstration program throughout the 1980s and 1990s; Congress codified what became known as "PACE" as a permanent Medicare program and Medicaid state plan option (§ 1894 and § 1934 of the Social Security Act) as part of the Balanced Budget Act of 1997 (P.L. 105-33). This legislation established the first form of integrated care in the nation (MACPAC 2020). In the law, Congress outlined five key principles of the PACE model that the Secretary of U.S. Department of Health and Human Services (HHS) may not modify or waive:

- the focus on frail elderly qualifying individuals who require the level of care provided in a nursing facility;
- the delivery of comprehensive, integrated acute and long-term care services;
- the IDT approach to care management and service delivery;
- capitated, integrated financing that allows the provider to pool payments received from public and private programs and individuals; and
- the assumption by the provider of full financial risk.

The Balanced Budget Act of 1997 required CMS to develop additional regulations addressing eligibility, administrative requirements, application procedures, services, payment, participant rights, and quality assurance under the PACE model. These regulations were first proposed in CMS rulemaking in 1999, finalized in 2006, and updated in 2019 (CMS 2019, 2006). CMS also includes updates to PACE regulations in annual MA and Part D rules (CMS 2024b).

Research suggests that PACE participants generally have better health outcomes compared to similar groups. Several studies have found that PACE participants experience reduced mortality rates and nursing facility use when compared to non-PACE individuals, including people who are dually eligible, residents of nursing facilities, and people enrolled in home- and community-based services (HCBS) waivers, despite having a higher mortality risk and being more likely to be medically needy (Segelman et al. 2017, Ghosh et al. 2015, JEN Associates 2015, Wieland et al. 2010). Both studies that compare PACE participants to similar populations and follow cohorts of PACE enrollees for extended periods of time have documented PACE's ability to reduce hospitalizations and potentially avoidable hospitalizations (Feng at al. 2021, Meunier et al. 2016, Segelman et al. 2014, Meret-Hanke 2011, Beauchamp et al. 2008).[2] One recent study conducted for HHS found that despite being the oldest, having the greatest number of comorbidities, and having the highest mortality rates on average, PACE enrollees were less likely to be hospitalized, less likely to visit the emergency department, less likely to use institutional care, and no more likely to die compared to enrollees in FIDE SNPs, dual eligible special needs plans (D-SNPs), and non-integrated MA plans (Feng et al. 2021). Although more limited, research also suggests that the PACE model's unique IDT component is better suited to provide behavioral and culturally competent health care, leading to improved mental health outcomes and interactions with providers (Travers et al. 2022, Vouri et al. 2015, Ginsburg and Eng 2009).

Analytic Approach

To better understand the PACE model design, administration of the model, and how states and the federal government oversee it, we contracted with the Center for Health Care Strategies to conduct interviews with PACE subject matter experts. We spoke with key state officials, PACE organizations, consumer advocates, and one state PACE association across five states and the District of Columbia. We also interviewed federal stakeholders from the Center for Medicaid and CHIP Services (CMCS) and the Center for Medicare within CMS, the Office of the Assistant Secretary for Planning and Evaluation (ASPE), and the National PACE Association (NPA). We selected five states (California, Louisiana, Massachusetts, Michigan, and Pennsylvania) and the District of Columbia that vary in geography, political leanings, integrated care offerings, and PACE program maturity. This chapter describes PACE as it is operated as of our interviews in 2024, although we acknowledge that announced reorganization efforts of HHS may introduce changes (HHS 2025).

Key Findings

Our interviews with PACE stakeholders highlighted key findings across six aspects of the model: eligibility and enrollment, provider application and procurement, service delivery, grievances and disenrollment, federal and state oversight, and financing. Interviewees shared details about the experiences of PACE participants and how the PACE model provides community-based care for those with complex care needs. We also heard about the challenges that providers encounter in establishing and operating PACE programs and that federal and state agencies face in overseeing them. Federal officials, state officials, PACE organizations, and consumer advocates all largely agreed that PACE represents the most fully integrated form of care available to dually eligible individuals and identified two key areas of complexity for federal and state regulators: unclear delineation of oversight responsibilities and a lack of data on service utilization. Oversight responsibilities, particularly for states, are unclear in federal statute and regulation. Furthermore, although data exist on service utilization by PACE beneficiaries, PACE organizations, state Medicaid agencies, and federal officials face challenges in capturing that data due to the nature of PACE and a lack of established encounter data codes.

Eligibility and enrollment

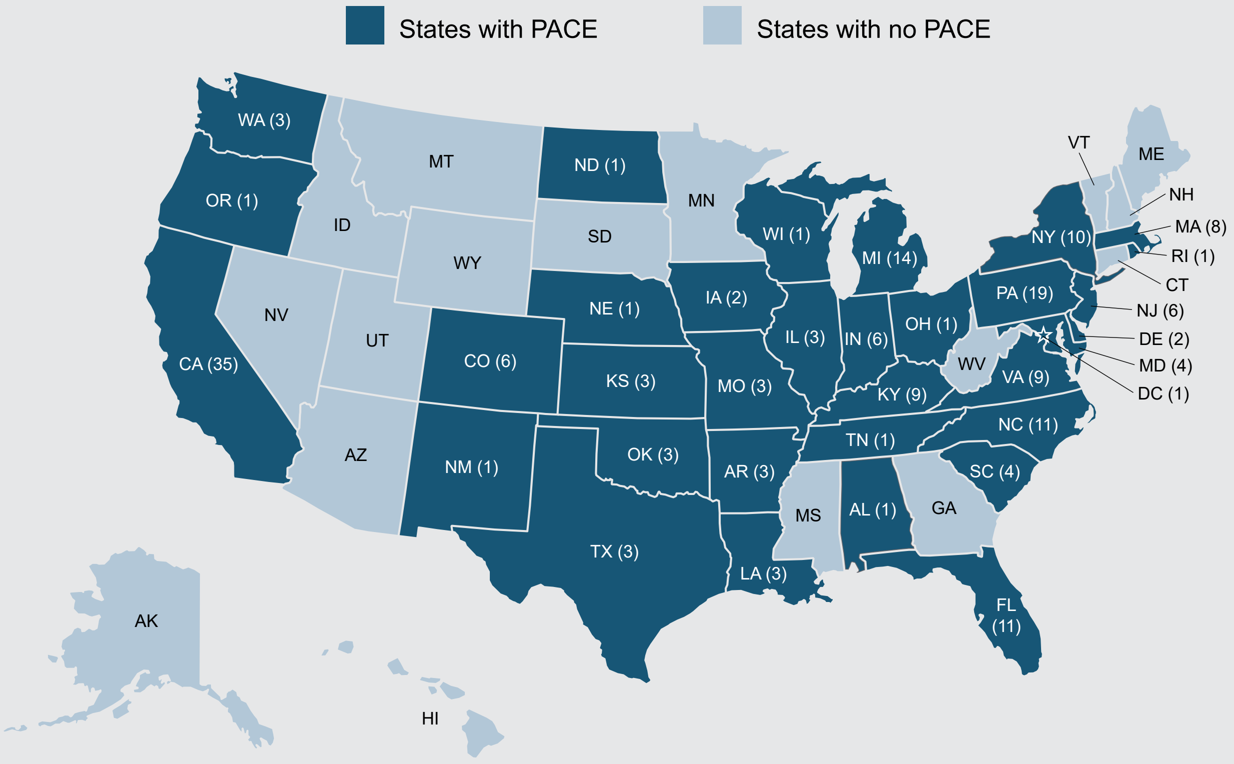
To be eligible for PACE, an individual must be 55 years or older, meet the NFLOC requirement in their respective state, live within the service area of a PACE organization, and be able to live safely in the community at the time of enrollment.[3] States and PACE organizations may include additional eligibility criteria in the three-way PACE program agreements that are signed with CMS that do not modify the basic eligibility criteria specified in regulation, though it is not clear to what extent this is done (§ 1894(a)(5)(D) and § 1934(a)(5)(D) of the Social Security Act). Importantly, eligibility for PACE is not restricted to dually eligible individuals. A PACE enrollee may be eligible for Medicaid, Medicare, both, or neither (42 CFR 460.150(d)). However, most PACE enrollees, 80 percent, are dually eligible for Medicaid and Medicare (CMS 2024c). Once eligibility is determined, enrollment in PACE is effective the first day of the month after the date the PACE organization receives the participant's signed enrollment agreement and continues until the participant's death, regardless of changes in health, unless the participant voluntarily disenrolls or is disenrolled by the PACE organization.

States must evaluate PACE enrollees annually to ensure they continue to meet the state Medicaid NFLOC requirement, with two exceptions. If the state determines that a participant's condition is not likely to improve, they may waive the annual recertification requirement (42 CFR 460.160(b)(1)). Additionally, under "deemed continued eligibility," the state may allow a participant who no longer meets the state Medicaid NFLOC requirement to remain enrolled in PACE upon determining that the participant would likely meet the NFLOC within six months of not being enrolled in the program (42 CFR 460.160(b)(2)).

As of April 2025, 83,533 individuals were enrolled in PACE across 33 states and the District of Columbia (Figure 4-1) (NPA 2025). That same month, 67,851 Medicare beneficiaries were enrolled in 190 PACE organizations (CMS 2025a, 2025b). CMS monthly enrollment data exclude Medicaid-only beneficiaries, who make up 20 percent of enrollees (CMS 2024c). Less than 1 percent of PACE enrollees are Medicare-only beneficiaries (NPA 2023). Many states contract with multiple PACE organizations. Among the five states that shared PACE enrollment data with us, the median PACE organization enrollment was 320 participants in August 2024.

PACE enrollment is lower than enrollment in other integrated care options, but the number of PACE participants has steadily increased in recent years. Enrollment in PACE among dually eligible and Medicaid-only beneficiaries has grown by 62 percent, from 39,653 in 2016 to 64,253 in 2022 (Figure 4-2) (CMS 2024c). Although dually eligible beneficiaries have consistently made up a larger portion of PACE enrollees, Medicaid-only beneficiaries have experienced a higher rate of growth (120 percent compared to 52 percent). By comparison, more than 245,000 individuals were enrolled in Medicare-Medicaid Plans, and more than 367,000 were enrolled in FIDE SNPs in April 2025 (CMS 2025c, ICRC 2025).

FIGURE 4-1. Program of All-Inclusive Care for the Elderly Organizations by State, April 2025



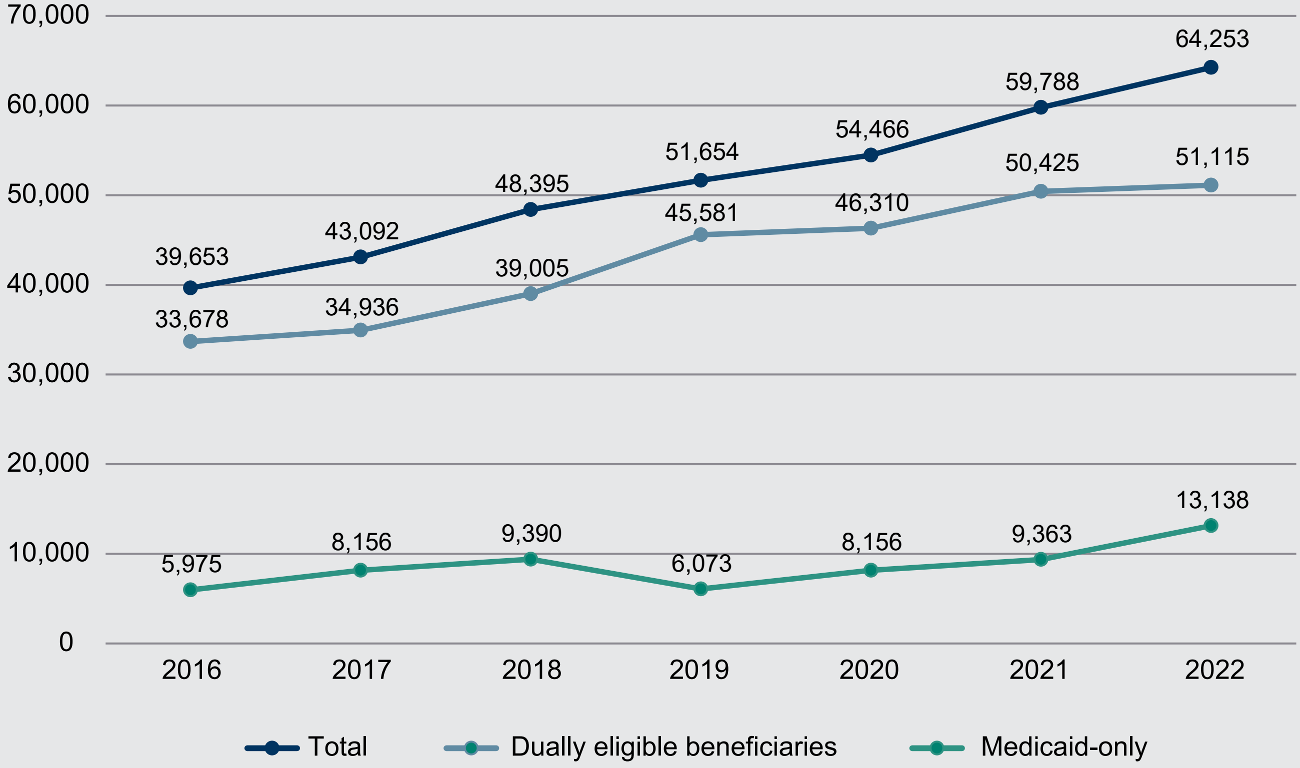
Notes: PACE is Program of All-Inclusive Care for the Elderly. Number in parentheses indicates the number of PACE organizations operating within a state.

Source: CMS 2025b.

PACE organizations that we interviewed shared that most enrollment comes from word-of-mouth referrals, senior housing expositions, and senior center referrals. PACE organizations in multiple states told us state Medicaid agencies were not always including PACE when providing potential beneficiaries with options counseling and case management services. PACE organizations market their services within guidelines set by federal regulations, which include but are not limited to requirements for accurate information, languages offered, and approval from CMS and the state (42 CFR 460.82). New PACE organizations or established PACE organizations expanding their service area cannot advertise until CMS and states grant approval (CMS 2022a). Some organizations also engage in formal marketing through community events, though one PACE organization told us it does not market at all due to approaching an enrollment cap set by the state.

PACE organizations described encountering community providers who were hesitant to refer individuals to PACE for fear of losing their patient, since PACE participants can receive care only from PACE providers, unless the PACE organization contracts with community-based providers to provide services. These stakeholders also noted long eligibility and enrollment timelines, hindering hospitals from referring patients at discharge. Several PACE organizations expressed frustration that individuals may require nursing facility care while their enrollment into PACE is in process, making it less likely the participant would ultimately complete their enrollment in PACE.

FIGURE 4-2. Program of All-Inclusive Care for the Elderly Enrollment, FYs 2016–2022



Notes: FY is fiscal year. This figure excludes Medicare-only beneficiaries.

Source: MACPAC, 2025, analysis of CMS Medicaid Managed Care Enrollment reports for 2016 through 2022.

One state we spoke with that employs independent enrollment brokers for their Medicaid managed care coverage said that the brokers raise awareness about PACE and assist with enrollment. One PACE organization noted that these brokers conduct eligibility determinations for PACE in addition to those conducted by the state and provider. The broker-initiated process includes required steps such as individual counseling that precedes the eligibility determination. By using independent enrollment brokers to document PACE organizations' enrollment denials, this state was better able to observe how some PACE organizations may selectively enroll participants, meaning they avoid enrolling individuals whom they believe may be high cost. Consumer advocates confirmed this practice, noting that PACE organizations sometimes use the eligibility criterion about being able to live safely in the community to exclude high-cost, high-need individuals. States are responsible for establishing the process by which PACE organizations determine who can live safely in the community, but state officials (including those who shared concerns about favorable selection) noted the language is often broad and open to interpretation by PACE organizations (42 CFR 460.152(a)(4)). When asked about these concerns, one federal official emphasized that states are responsible for enforcing enrollment requirements as they see fit.

Provider application and procurement

To become a PACE organization, expand a PACE service area, or add a PACE center, an entity must submit complete applications for both the PACE program and Medicare Part D program to CMS (42 CFR 423.458, 42 CFR 460.12). The applications must include assurances from the state Medicaid agency confirming the entity's qualifications and the state's willingness to enter into the agreement with the PACE organization and CMS (42 CFR 460.12(b)). The applications must also describe the proposed service area, which CMS, in consultation with the state, may alter to avoid overlapping service areas. CMS and the state will approve expansions only after the organization has completed a successful initial trial period audit and, if applicable, addressed any necessary corrective actions (42 CFR 460.12(d)).

States use varied approaches for identifying and selecting PACE organizations, with some issuing requests for proposals (RFPs), others requiring letters of intent, and one directly reaching out to potential providers. Additionally, many states require PACE organizations to meet state licensing requirements, such as obtaining adult day care or PACE-specific licenses. PACE organizations also described the challenges that applicants face navigating the dual state and federal application process, which can take years to complete due to multiple reviews by states and CMS and limited quarterly application submission windows. Although most states expressed interest in expanding PACE statewide, challenges, particularly workforce shortages and concerns about organizations' financial viability, limit expansion in rural areas.

State procurement of PACE organizations. States we interviewed differed in their approaches to procuring new PACE organizations, particularly with the use of RFPs to select PACE organizations to submit applications. Half of the states we spoke with reported using an RFP process to identify potential PACE organizations. Instead of an RFP, two states require potential PACE organizations to submit a letter of intent to begin the state application process. Officials from the final state said that they identify and directly reach out to potential PACE organizations, such as health systems and community organizations, based on service area and areas of unmet need.

In addition to requiring applications to the state as a PACE organization, some states also require that the organization apply to different state licensing boards as a clinical provider. For example, one state we spoke with requires PACE organizations to obtain the state's adult day care license, while another requires that PACE applicants apply to receive the state's separate PACE license. According to an interview with NPA, of the 33 states and the District of Columbia operating PACE programs, 18 require additional licenses beyond the requirements in federal regulation, such as to operate a primary care clinic or for home health.

Application challenges for providers. The federal PACE application process requires applicants to comply with regulations and secure state approval for entering into a three-way program agreement between the PACE organization, the state, and CMS. Federal officials told us that the Division of Medicare Advantage Operations under the Center for Medicare leads the review of PACE applications, with input on specific portions of the application from other CMS divisions, namely the Office of Program Operations & Local Engagement (OPOLE) and CMCS. The Division of Benefit Purchasing and Monitoring under the Center for Medicare also processes the corresponding PACE Medicare Part D Application. Prospective PACE organizations submit their applications through CMS's Health Plan Management System (HPMS).

The calendar year 2025 MA and Part D final rule introduced stricter application requirements, such as submitting the state assurance form, and a review of past performance during the federal application process (CMS 2024a). If the state assurance form is not submitted with the application, the Center for Medicare will consider the application incomplete and will not review the application (42 CFR 460.12(b)(3), 42 CFR 460.20).

Federal officials we spoke with cited incomplete state assurances, inaccurate service area maps, unclear organizational charts, and insufficient descriptions of eligibility determination and disenrollment processes as some common issues with PACE applications.[4] Federal officials explained that delays or incomplete state assurances often occur because PACE organizations frequently submit their applications to CMS while still completing their facilities, obtaining state licensing approvals, and fulfilling state readiness reviews. The PACE organizations we interviewed emphasized that the state and federal review and approval process can take several years and substantial financial resources. For example, states may require PACE organizations to hire all staff as part of the state readiness review, but since there is no federal deadline for states to conduct the state readiness review, PACE organizations can be fully staffed for extended periods of time without serving any participants (Harootunian 2022). One organization shared that it invested approximately $15 million by the time its PACE center opened.

PACE organizations highlighted the limited quarterly submission window for federal applications as a major barrier, with only one day per quarter available to submit applications for both new organizations and service area expansions (CMS 2025d). They said it complicates the process, especially for larger organizations seeking to expand into multiple areas. The state PACE association we spoke with, however, acknowledged that these submission limits help ensure PACE program quality and sustainable growth. One state noticed an increase in for-profit PACE organizations responding to this single-submission requirement by partnering with subsidiary organizations on applications. Since the lead applicant is the subsidiary organization, the for-profit parent organization is able to submit multiple, separate applications concurrently under different “H-numbers,” which is how CMS labels plan contracts. A for-profit PACE organization we spoke with in that state acknowledged using this tactic to expand more rapidly, especially as the organization looks to establish PACE programs in other states. Officials in that state said that this strategy creates administrative challenges and that they are considering whether to tighten requirements on PACE applicant organizations to try to control the growth of for-profit subsidiaries with unique H-numbers entering the market.[5]

State interest in expanding PACE. All but one state we interviewed expressed interest in expanding their PACE programs to additional areas, with many aiming for statewide expansion. One state has doubled the number of zip codes covered by PACE organizations in the past two years, allowing the expansion of PACE organizations’ service areas after the COVID-19 public health emergency (PHE) and allowing some PACE organizations to overlap service areas with other PACE organizations’ service areas to promote consumer choice.[6] Another state official mentioned that health systems and community organizations often inquired when the state might be expanding the PACE program.

State officials highlighted several challenges with expanding PACE into rural areas. For instance, one state shared that after issuing a request for applications in rural counties, no PACE organizations submitted bids. When the state surveyed PACE organizations about the lack of bids, the organizations cited concerns about finding an adequate workforce and the financial feasibility of operating in rural areas. PACE organizations must make substantial up-front investments to establish a PACE center and expressed concern there would not be enough eligible enrollees in rural areas to make the program financially viable. Additionally, states noted challenges that PACE organizations face in building a sufficient provider network in rural areas, where certain federally required provider types may be scarce or unavailable.

State program goals. State officials described limited authority to tailor the program’s design to meet state goals. Some state officials found certain PACE regulations at odds with expansion of the program, noting that regulatory inflexibility can be a barrier to growing PACE in line with state goals for integrated care. Section 903 of the Medicare, Medicaid, and SCHIP Benefits Improvement and Protection Act of 2000 (P.L. 106-554) allows CMS to waive or modify certain regulatory aspects of the model to give PACE organizations more operational flexibility (CMS 2024d). Five core model elements cannot be waived: a focus on frail older adults requiring NFLOC; the delivery of comprehensive, integrated acute and long-term care services; an IDT approach to care management and service delivery; capitated, integrated financing that allows the provider to pool payments; and the assumption of full financial risk (42 CFR 460.26(c)). Organizations submit waiver requests to the state administering agency, which must forward them to CMS, either indicating agreement with the request or noting concerns (CMS 2005). One state cited the current approval process for PACE organization waivers as a challenge because states may not be able to ensure uniformity of the PACE model within a state so that all eligible beneficiaries can access the same standard PACE model. That state described one instance in which an official said they submitted waivers seeking increased telehealth flexibilities on behalf of several PACE organizations. The state official said they also asked CMS if waivers approved for one PACE organization could be automatically applied to all PACE programs in the state, but they said CMS declined to do this, instead requiring that individual organizations submit the request themselves.

Service delivery

PACE features an IDT of providers who assess participants' needs, develop care plans, and provide continuous care in the community. PACE organizations must offer a wide range of services, including Medicare- and Medicaid-covered services, without benefit limitations on the amount, duration, or scope of services provided (42 CFR 460.90). Stakeholders noted that PACE's comprehensive and flexible benefit design allows participants to live independently in the community, and many considered it more robust than other integrated care models.

IDT. As a community-based alternative to institutional care, the goal of PACE is to delay, if not prevent, nursing facility and hospital use for as long as possible (CMS 2011b). To achieve this, PACE organizations use an IDT. Each member of the IDT must be employed or contracted by the PACE organization and provide or arrange for care to be provided to participants 24 hours a day, 365 days a year across all care settings. Under the regulations, the IDT must be composed of at least 11 providers: (1) primary care provider, (2) registered nurse, (3) master's level social worker, (4) physical therapist, (5) occupational therapist, (6) recreational therapist or activity coordinator, (7) dietitian, (8) PACE center manager, (9) home care coordinator, (10) personal care attendant, and (11) driver (42 CFR 460.102). The IDT provides or arranges to provide PACE participants with all Medicare- and Medicaid-covered services as well as other services beyond those programs that they deem necessary, regardless of payment source (42 CFR 460.92).

PACE benefit. PACE offers a comprehensive benefit package with flexibilities that other plans serving dually eligible individuals lack. Common benefits offered include a broad range of services such as adult day care, dentistry, laboratory and x-ray services, meals, and transportation. The only services expressly excluded from PACE coverage are cosmetic surgery, experimental procedures, and services furnished outside the country (42 CFR 460.96).[7] Typical Medicaid and Medicare benefit limitations and conditions on the amount, duration, scope of services, deductibles, copayments, coinsurance, and other cost sharing do not apply to PACE (42 CFR 460.90). For example, a Medicaid state plan may limit how often an individual can receive new dentures to every five years. However, in PACE, if a participant requests and is determined to need dentures before that five-year time period is over, the PACE organization would be required to cover them. PACE organizations must also have written contracts with each outside organization, agency, or provider for additional services that are not provided directly by the IDT, including at least 26 medical specialties, such as cardiology and dermatology (42 CFR 460.70).

Interviewees largely agreed that PACE, as designed, provides enrollees with a broad array of comprehensive benefits. Federal officials and consumer advocates highlighted that PACE centers offer socialization opportunities to those at risk of isolation and reduce barriers to accessing care by having nearly all care services provided in one location. Stakeholders also noted that the PACE design helps address social needs such as meals, transportation, and home modifications. Several PACE organizations mentioned being able to provide culturally competent care by hiring multilingual staff, providing social programming, and using alternative care sites.[8] One consumer advocate mentioned that PACE centers offer respite for family caregivers, especially for those caring for individuals with dementia or other high-care needs.

PACE center. Each PACE organization must operate a PACE center, which is a facility in which the IDT coordinates and provides most services, including primary care, therapy, social activities, personal care, and meals (42 CFR 460.98(d)).[9] Although important, center attendance is not mandatory. Instead, the IDT determines how often each participant should attend as part of developing their care plan (42 CFR 460.98(f)). The IDT is required to work with participants and their caregivers to develop and regularly update the care plan to meet all of a participant's medical, physical, emotional, and social needs (42 CFR 460.106).

PACE organizations also have the option to provide services in the participant's home and alternative community settings as needed (42 CFR 460.98(b)(2)). An estimated 95 percent of PACE participants live at home (NPA 2019). If a participant enters institutional care, such as a nursing facility, they remain enrolled in PACE, and the costs are covered by the PACE organization. The broad flexibility PACE organizations have in care delivery allows them to provide a tailored mix of medical and nonmedical services across the full spectrum of care settings by the IDT or contracted providers that can help older adults remain in the community.[10]

Consumer advocates identified a few challenges with PACE from the enrollee perspective, particularly regarding the amount of home-based care provided. In some states, PACE offers fewer home services compared to other Medicaid-managed long-term services and supports or HCBS programs. Although PACE must provide all Medicaid-covered services in a state's approved plan (42 CFR 460.92(a)(2)), there are no federal requirements for the quantity of home-based care, since the IDT determines participant care plans (42 CFR 460.90(a)). Consumer advocates said that few states require standardized home care needs assessments for PACE, allowing organizations to instead choose their own instrument and method to determine hours of home care, which can result in participants at different PACE organizations in a state receiving varying levels of support despite having similar needs.[11] Additionally, consumer advocates shared that some PACE organizations may struggle to balance fidelity to integrated care provided in the PACE center with participant preferences to receive services in the home, particularly after the PHE. In one state, the lack of access to local hospitals and specialists led a PACE organization to serve more homebound enrollees, prompting both the state and the organization to adjust service delivery and clinical policies. Advocates also noted that PACE organizations may struggle to support enrollees at home without a substantial unpaid support system, usually provided by family caregivers. Federal officials said that PACE organizations are responsible for providing care 24 hours a day, 7 days a week, and although reliance on family caregiving is permitted, the needs of PACE participants often exceed the level of care unpaid caregivers can safely provide.

All of the PACE organizations we interviewed use participant and caregiver satisfaction surveys to gather enrollee feedback, as PACE organizations are required to develop, implement, and maintain quality-improvement programs that measure participant and caregiver satisfaction (42 CFR 460.134). Survey results are used by the PACE organization only to improve services and are not shared with CMS, though CMS may review quality-improvement measures during audits. PACE organizations must also establish a participant advisory committee (PAC) to discuss enrollees' concerns, with the majority of the committee's membership made up of participants and their representatives (42 CFR 460.62(b)). All PACE organization interviewees shared that they use PACs to identify issues and make continuous improvements to their organizations, such as updating the layout of a PACE center for better functionality.

Grievances and disenrollment

If a PACE participant is not satisfied with their care, they may take several actions, such as submitting a grievance, requesting a service and appealing any denials, or disenrolling from the program entirely. PACE organizations must have formal grievance, service determination request (SDR), and appeals processes in place to address participant disagreements with decisions regarding their care. States monitor PACE program disenrollment through various methods, including requiring providers to report disenrollments to Medicaid agencies and providing financial rewards to organizations with low voluntary disenrollment rates. Common reasons for disenrollment include participant death and relocation.

Grievances and appeals. A grievance is a verbal or written complaint that a PACE participant may use to express dissatisfaction with the quality of care provided or the services delivered, regardless of whether the participant requests any corrective action (42 CFR 460.120(b)). A PACE participant or their representative may make an SDR for the IDT to provide, modify, or continue a service (42 CFR 460.121(b)). If the SDR is denied by the IDT, a participant may appeal the decision (42 CFR 460.122).

PACE organizations must have a formal written grievance process to address and resolve medical and nonmedical complaints from participants, family members, designated representatives, and caregivers within 30 days (42 CFR 460.120(g)). Additionally, PACE organizations must notify participants of their rights to submit grievances, provide continuous care during the grievance process, document and track grievances, and analyze the information for quality improvement (42 CFR 460.120). PACE organizations must have a similar formal written appeals process, the first step of which is making an SDR, to address noncoverage or nonpayment of services (42 CFR 460.122). They are also required to notify participants in writing of additional appeal rights under Medicare, Medicaid, or both; help the participant decide which option to pursue if both apply; and send the appeal to the correct external entity (42 CFR 460.124).

States we spoke with use different processes for monitoring grievances and appeals from PACE enrollees. One state has a specific ombudsman program for PACE, while others rely on general long-term care or health care ombudsman programs to monitor for grievances. In some states, grievances are submitted to the state PACE office or the licensing department, while one state we spoke with offers a hotline for PACE grievances. Enrollees with Medicaid can also use the general Medicaid state fair hearing appeals process, which varies by state and takes 30 to 60 days (42 CFR 460.124).

Consumer advocates highlighted that PACE denial notifications are often vague and lack clear explanations, making it difficult for enrollees to understand the reasons for service denials and to file appeals. For example, one consumer advocate noted that the reason for denial is often listed as a reference to the federal PACE statute or regulations (42 CFR 460) or because the IDT determined a service was not medically necessary. One element of PACE that can make it difficult for enrollees to appeal denials is that the PACE organization acts as both the health care provider and plan (42 CFR 455.410). One consumer advocate mentioned this can be particularly challenging when participants need to gather additional medical opinions and submit evidence to appeal a service denial, since all the providers work for the PACE organization. Recent federal regulations (42 CFR 460.120) now require PACE organizations to have formal grievance processes and resolve complaints within 30 days. Consumer advocacy organizations we interviewed told us they had not heard of many PACE enrollees filing appeals or submitting grievances, which may be due to the small size of the PACE program.

Disenrollment. A PACE participant may voluntarily disenroll from the program at any time, with disenrollment taking effect on the first day of the subsequent month (42 CFR 460.162(a)). Since PACE participants must receive all their Medicaid and Medicare services from PACE or contracted providers, enrolling in an MA plan, Original Medicare Part D, Medicaid prepayment plans, or optional benefits such as a Section 1915(c) HCBS waiver or Medicare hospice benefit would count as a voluntary disenrollment (42 CFR 460.154(i)). Involuntary disenrollment can occur for a number of reasons, including failing to pay premiums, engaging in disruptive or threatening behavior, moving outside the PACE program service area, or no longer meeting the state Medicaid NFLOC requirement and not being deemed eligible to continue in the program (42 CFR 460.164).

All states interviewed actively monitor their PACE programs for voluntary and involuntary participant disenrollment through a variety of methods. One state requires PACE organizations to submit a form that codes the reasons for a participant's disenrollment, as well as any areas of dissatisfaction and the participant's contact information, to the state Medicaid agency. This state noted that it has had limited success reaching participants that disenroll from PACE. Another awards PACE organizations with low voluntary disenrollment rates an annual bonus to encourage participant continuity. States and PACE organizations also stressed that participant disenrollment of either kind is not common, given the small census of programs and generally high satisfaction of participants. Consumer advocates we interviewed, including an organization that serves as the state's ombudsman program, shared that they had not heard of many PACE disenrollments.

When disenrollments do occur, PACE organizations must make referrals and share medical records with new providers as well as collaborate with CMS and the state administering agency to ensure participants enroll seamlessly in other applicable programs (42 CFR 460.168). Consumer advocates expressed concern that federal transition of care regulations for PACE do not adequately hold PACE organizations accountable and are not as comprehensive as transition of care requirements for Medicaid managed care plans (specifically at 42 CFR 438.62).

Stakeholders listed several reasons why PACE participants may disenroll. State officials and PACE organizations listed participant death and relocation out of a program's service area as the most common reasons for disenrollment.[12] They also cited the intensity of the PACE program's care model as a reason for voluntary disenrollment. One PACE organization described their program as high touch, requiring enrollees to frequently meet with providers and attend the PACE center, which they said could be overwhelming for some individuals.[13] These stakeholders also noted seeing a rise in voluntary disenrollments as more MA plans offer plan debit card benefits as supplemental offerings. Plan debit cards are particularly attractive to older adults with fixed or limited incomes, such as PACE participants who may not understand that they are disenrolling from PACE by enrolling in another health plan. Consumer advocates also highlighted PACE's closed network model, mentioning that some individuals choose to disenroll because they find that the PACE organization, or their preferred primary care or specialist providers, will not contract with each other. However, PACE organizations we spoke with frequently sign single-case contracts with participants' preferred providers.

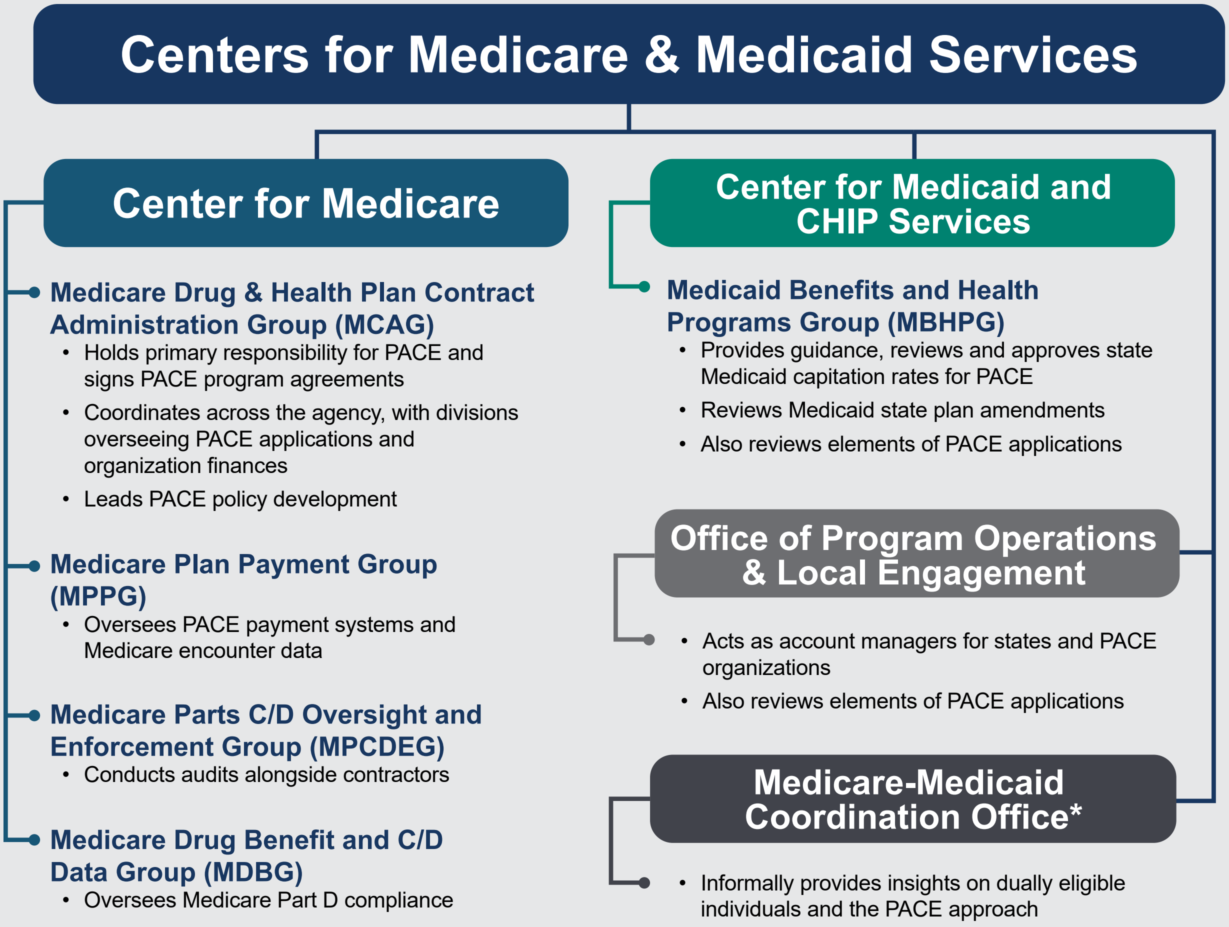
Officials in two states noted that some PACE organizations have limited nursing facility options in their provider network, leading to disenrollment when enrollees are unwilling to move to available facilities. Federal officials confirmed in interviews that there are no nursing facility network adequacy requirements for PACE organizations. States and providers also mentioned tension between families that may wish to move an enrollee into a nursing facility and IDTs that determine the enrollee is still best served in the community. Federal officials at CMS and ASPE acknowledged that voluntary disenrollments often occur when enrollees transition to nursing facilities. Officials from ASPE suggested examining provider networks, payment issues, or the rise of MA institutional special needs plans as potential causes. They emphasized that these disenrollments appear to reflect enrollee preferences rather than PACE organizations trying to avoid paying for nursing facility care, though they recommended states increase their monitoring.

Federal and state oversight

Federal statute and regulation outline shared oversight of PACE with federal and state officials responsible for overseeing different PACE processes. However, an oversight structure that some stakeholders described as overly complex and without clear ownership can create confusion, and the state's expected role in oversight is not always explicit. Structural challenges in reporting utilization and quality data also complicate efforts to oversee PACE organizations. Stakeholders said that current data reporting required of PACE organizations is minimal, and although some PACE organizations said that they share more extensive data with their PACE associations and with their ownership, other PACE organizations may consider reporting requirements burdensome. Nearly all stakeholders, including federal and state officials, PACE organizations, and consumer advocates, also expressed interest in the development of a standardized national PACE quality measure set that would allow for comparisons within and across states. Yet, these measures have proven challenging to develop because of the diversity of PACE programs and their small population size.

Complex oversight structure. As a Medicaid and Medicare program, PACE oversight activities span a number of divisions and offices within CMS (Figure 4-3). Although PACE is not an MA product, federal oversight of PACE relies on the same oversight infrastructure that supports MA. Officials said the Center for Medicare holds the primary responsibility for PACE oversight at CMS, coordinating the oversight and monitoring of PACE with all other CMS groups.[14]

FIGURE 4-3. Program of All-Inclusive Care for the Elderly Oversight Apparatus within the Centers for Medicare & Medicaid Services



Centers for Medicare & Medicaid Services

Center for Medicare

Medicare Drug & Health Plan Contract Administration Group (MCAG)
- Holds primary responsibility for PACE and signs PACE program agreements
- Coordinates across the agency, with divisions overseeing PACE applications and organization finances
- Leads PACE policy development

Medicare Plan Payment Group (MPPG)
- Oversees PACE payment systems and Medicare encounter data

Medicare Parts C/D Oversight and Enforcement Group (MPCDEG)
- Conducts audits alongside contractors

Medicare Drug Benefit and C/D Data Group (MDBG)
- Oversees Medicare Part D compliance

Center for Medicaid and CHIP Services

Medicaid Benefits and Health Programs Group (MBHPG)
- Provides guidance, reviews and approves state Medicaid capitation rates for PACE
- Reviews Medicaid state plan amendments
- Also reviews elements of PACE applications

Office of Program Operations & Local Engagement
- Acts as account managers for states and PACE organizations
- Also reviews elements of PACE applications

Medicare-Medicaid Coordination Office*
- Informally provides insights on dually eligible individuals and the PACE approach

Notes: PACE is Program of All-Inclusive Care for the Elderly. * The Medicare-Medicaid Coordination Office is officially known as the "Federal Coordinated Health Care Office."

Source: MACPAC interviews, 2024.

Federal oversight consists of PACE organization audits and review of quality data reporting. PACE organizations are required to undergo annual audits with on-site elements during their initial three contract years of operation (§ 1894(e)(4)(A)(i) and § 1934(e)(4)(A)(i) of the Act). After the trial period, CMS audits move to a remote basis, and the frequency of audits is determined based on risk factors that CMS identifies.[15] Federal officials said that audits focus primarily on areas impacting participant access to services (Figure 4-4). Federal officials described audits as resource intensive for CMS, but they said that the audit results are useful for identifying specific challenges with PACE organization performance as well as for informing policymaking.[16] PACE organizations are also required to submit quality data to HPMS. PACE organizations are required to submit data on 23 medical and non-medical elements on a quarterly cadence, comprising basic safety and utilization information such as reported falls, medication administration errors, and emergency room visits (CMS 2024e). In addition to audits, account managers from OPOLE review each

PACE organization's data to determine if there are any concerning utilization patterns or quality outcomes, such as disenrollments and adverse events, and then meet with organizations quarterly to discuss the data reports. Federal officials said these meetings act as opportunities for CMS to potentially identify any upcoming areas of non-compliance and learn more about how PACE organizations are using their data for process improvement. OPOLE works with MCAG to issue compliance actions for failures that have had considerable negative participant impact.

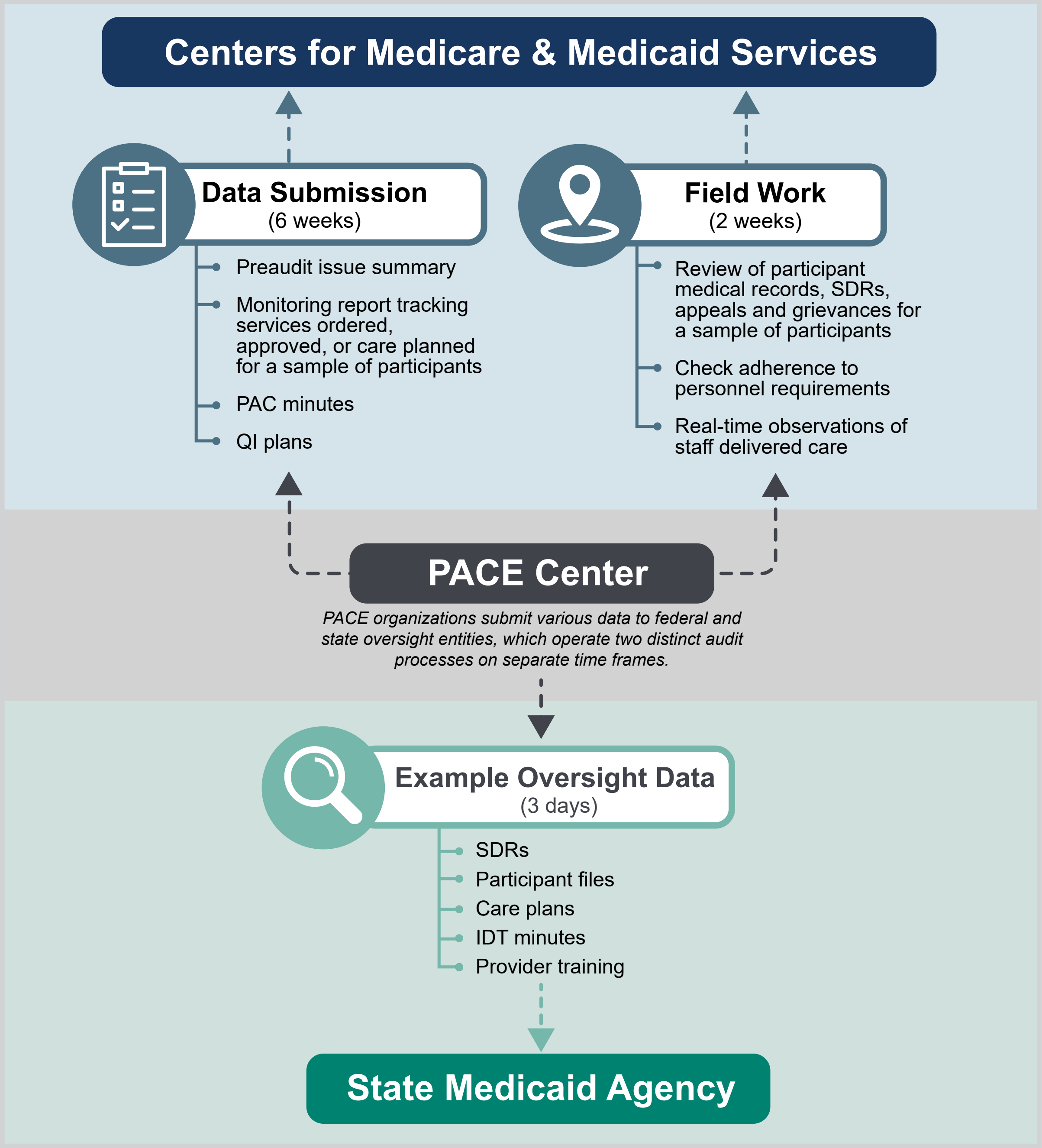
Several stakeholders raised concerns with the structure of PACE oversight, describing a fragmented system that they said makes it difficult to determine where responsibility for oversight of PACE enrollee experiences and outcomes lies. One state official criticized how CMS oversees PACE at length, describing the program as "homeless" within the agency because of how oversight is split among many separate divisions. This organizational confusion results in PACE organizations and states receiving conflicting information. For example, the state official said they were told by CMS that PACE organizations could offer participants plan debit cards, similar to those offered by MA plans that many stakeholders said draw dually eligible beneficiaries away from the PACE program; yet, a PACE provider in another state said in an interview that CMS informed them that cash cards would count as income for the participant and could affect their financial eligibility for Medicaid.[17] Even though federal responsibility for PACE is divided, the state official said that CMS is "too involved" in day-to-day management of PACE sites, taking on a larger role than the agency does with D-SNPs because PACE organizations also act as providers.

Others underscored the difficulty of understanding how oversight activities connected to PACE organization performance. Audit results are public, but several stakeholders said these reports are often difficult to parse and focus more on corrective actions issued than general performance, which federal officials attributed to the sensitive nature of audits. Federal officials said the agency is transparent with the audited organizations about identified issues.[18] Consumer advocates also said PACE regulations lack specific beneficiary protections to be overseen, such as network adequacy standards or defined limits on wait times for accessing services like HCBS, that are available to other Medicaid HCBS users.[19]

State role. States' oversight approaches varied. Regulations describing federal and state monitoring under 42 CFR 460 subpart K do not clearly differentiate roles for CMS and states, only stating that CMS monitoring is "in cooperation with the state administering agency." Our interviews found that audits are the primary tool used by states for oversight, with the cadence and level of audit review varying depending on the number of PACE organizations in the state (Figure 4-4). State officials said they typically check for PACE provider compliance with federal regulations without duplicating what is done by CMS. One state official said that they conduct routine audits triannually for the state's mature PACE organizations but annual audits, similar to CMS, during an organization's first three years of operations. For three states, officials said that they visit PACE centers and manually pull information from electronic medical records, patient files, and SDRs to validate whether participants were receiving all the services they were authorized to receive. Officials in one of those states described their audit process as a three-day site visit. Those state officials said their audits consist of checking whether level of care determinations are being completed appropriately, if care plans include the necessary medical and social components, and whether personnel have received required training. Another state focuses its oversight activities on assisting PACE organizations in improving processes. For example, the state official said they randomly sample minutes from the IDT meetings to see what was discussed, examine patient files to see if those issues were addressed, and—eventually, though the official said this is not currently in practice—speak with participants about how the issue was resolved.

Although not always part of the audit process, state officials mentioned that their oversight also relies on minutes from PACE organizations' PACs to identify potential issues.[20] An official in one state noted that state engagement with PACE organizations occurs regularly outside of audits as well, such as in biweekly site visits and calls.

FIGURE 4-4. Federal and State Medicaid Agency Audit Reporting Requirements for Program of All-Inclusive Care for the Elderly



Notes: PAC is participant advisory committee. QI is quality improvement. PACE is Program of All-Inclusive Care for the Elderly. SDR is service determination request. IDT is interdisciplinary team. Centers for Medicare & Medicaid Services audits of PACE centers include an initial data submission period followed by field work, which requires an on-site visit for PACE centers in their trial period. Listed data elements required for state audits represent examples provided through interviews with state officials, but requirements vary by state. The estimated duration for each audit step is included in parentheses.

Sources: MACPAC interviews with state officials and review of CMS audit protocol, CMS 2022b.

Our interviews confirmed that there are few domains for which state Medicaid agencies have primary oversight responsibility. For example, states must review and approve that involuntary disenrollments are in line with regulation (42 CFR 460.164(f)) and process external appeals through the state fair hearing process (42 CFR 460.124(b)). States are also tacitly responsible—as the entities that set the criteria by which PACE organizations evaluate whether a participant can be considered capable of living safely in the community at the time of enrollment (42 CFR 460.150(c)(2))—for overseeing whether PACE organizations abuse the assessment process to select participants who may be healthier or lower cost. However, states may also form two-way agreements with PACE organizations to include additional requirements to those explicitly required by federal regulation or the three-way program agreement. In an interview with MACPAC, NPA estimated that about half of states may use two-way agreements with PACE organizations. Four states in our study included additional requirements in their two-way agreements, but officials said that those agreements tend to be relatively pro forma, either emphasizing that the state also has an interest in ensuring PACE organization compliance with federal regulations or specifying how data should be reported for state systems. However, one state requires PACE organizations to submit additional financial reports and to comply with other guidance documents the state may release, while another state official said their state was in the process of revising its two-way agreement for the first time since 2015 to include additional reporting requirements and detail the state auditing process.[21]

State officials made clear in interviews that they do not wish to duplicate what one state official described as an extremely burdensome federal audit for PACE organizations, leaving it to CMS to ensure compliance with federal regulations.[22] One federal official agreed that compliance with federal regulations is CMS's purview, emphasizing that there should not be any overlap between the CMS and state audits. CMS invites states to attend quarterly calls between OPOLE and PACE organizations that occur outside of the audit process. Although states do not have direct access to the CMS data reports discussed on these calls, federal officials said that states tend to actively participate in these meetings, although they noted that engagement varies by state. Meanwhile, federal officials said that they rely on their state partners to raise issues that they have identified with enrollment or through grievances made to the state Medicaid agency, as CMS lacks line of sight on those processes. Additionally, many states require PACE organizations to conduct and report satisfaction surveys with participants. Federal officials said they view these surveys as tools PACE organizations can use to improve internal processes, and although CMS does not review the results, officials noted they may inform quality improvement plans that PACE organizations do discuss with CMS.

Limited utilization data reporting. Stakeholders described minimal data reporting required by federal and state entities for oversight, and in nearly all cases, reporting requirements focused on process measures rather than quality outcomes. Interviewees noted challenges with reporting PACE data that ranged from technical difficulties in defining and reporting Medicaid encounters to a lack of staff capacity to process data to inform oversight, which make comparisons across PACE organizations impractical and hamper state Medicaid agency efforts to provide their legislatures with evidence to support the continued growth of PACE.

In addition to submitting limited utilization data to HPMS for quality oversight, PACE organizations must submit data on certain Medicare encounters to CMS. Federal officials said that PACE Medicare encounter data are based primarily on claims for services provided outside the PACE center, which differs from MA plans that must report encounters for all covered services.[23] Among states interviewed, only one state currently requires PACE organizations to submit Medicaid encounters, while two other states are working with organizations to develop such requirements.[24] Yet another state once required PACE organizations to submit Medicaid encounters, but the state official said they dropped the requirement due to challenges those organizations faced in reporting accurate data. Identifying encounters in a PACE center is challenging because, unlike with traditional providers, a participant may encounter various members of their IDT while at the center, each potentially offering a mix of what could be Medicare-covered or Medicaid-covered services. Interviewees said that the high-touch nature of PACE would likely generate a huge volume of claims data that could overwhelm small PACE organizations, regardless of what approach they took to defining encounters.

Several PACE organizations voiced concerns with encounter data reporting requirements, particularly for purposes of oversight and reimbursement. Although some states have figured out how to work with organizations to report accurate data, NPA officials said they are concerned that some states simply apply existing managed care reporting systems to their PACE program without adapting them to properly capture actual services and expenses. A state PACE association concurred with that assessment, and officials said that encounter codes for managed care plans do not adequately document the services provided to PACE enrollees. The state association shared that it is working with its counterparts in the state Medicaid agency to improve data collection to better capture services and supports for non-medical social needs. A number of PACE organizations and NPA said that there is a lack of consistency in how PACE organizations within a state report on the same data due to the broadness of federal and state reporting instructions, which can make comparison difficult. That said, we also heard from several PACE organizations that they can report encounter data and currently do so for their associations, but the states may not be requesting it.[25]

Given the spectrum of ownership in PACE, from large organizations with sites in several states to small local community-based organizations, interviewees said PACE organizations vary in their level of sophistication with regard to reporting data. At least one PACE organization official voiced frustration with the administrative burden of meeting various complex reporting requests. The PACE official said as their organization has grown, it was forced to start acting more like a health plan rather than as a provider delivering patient care, likening the experience to running two companies at once. Some PACE organizations we interviewed described challenges with their providers meeting all CMS reporting requirements and guidelines, with one organization saying the process—with strict timelines and the need for extensive documentation—is “arduous” for PACE organization providers who do not experience similar requirements in other delivery systems.[26] The PACE organization representative added that they hire local providers, who require constant training on reporting requirements and PACE and continue to struggle to report as expected.

Consumer advocates said that federal and state agencies could require a greater range of data to be collected and publicly shared to improve oversight. Advocates recommended a number of potential data elements, including but not limited to authorized services versus services used; percentage of requested services approved by the IDT; enrollee experiences during transitions in care; and stratification of data by race, sex, insurance type, and PACE organization ownership type.[27]

Measuring quality. Stakeholders said that quality is difficult to measure in PACE given the limited reported data available. Even where some measures exist, the lack of standardization means that PACE organizations are largely measured against the yardstick of their prior performance. PACE organizations must establish quality improvement programs and meet or exceed minimum levels of performance established by CMS and states (42 CFR 460.134(c)). Federal officials said that CMS audits include four elements, one of which is compliance and quality improvement. As part of the audit, CMS conducts an interview to review a PACE organization’s quality data to ensure all required data are collected and analyzed and that measures are taken to improve performance when necessary. However, CMS collects quality data only if it finds evidence of non-compliance. The officials emphasized that CMS audits and reporting requirements do allow the agency to spot issues and see improvement in quality over time for individual PACE organizations. However, one federal official indicated that the data elements produced by existing reporting requirements have limited utility, remarking that some within CMS do not find the HPMS quality data helpful in understanding PACE performance.

Most states do not require substantial reporting on quality, although regulation grants them authority to require a range of data reporting, including on quality (42 CFR 460.130(d)). Some officials said they are attempting to familiarize PACE organizations with reporting this type of data, while others said they lack the capacity to review the quality data they currently require. An official in one state said it focuses on five components of quality but noted that these components are essentially used to check whether a provider is correctly completing a required process. Another state requires PACE organizations to submit a quarterly quality report, but officials in that state said the reports are not yet complete enough to use, and state staff capacity to oversee them is limited. An official in another state said the state has a PACE site with ongoing quality issues and requires some quality measures in its two-way agreement, but the state does not have the capacity to review the data. And yet another state meets with PACE organizations about their quality plans, but it does not request data on quality.[28] Instead, most states require participant and caregiver experience surveys, such as the Integrated Satisfaction Measurement for PACE survey or Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Survey (Box 4-1). Several states and consumer advocates said they rely on those surveys as a proxy for quality, and one federal expert voiced appreciation for the surveys while noting that the PACE program's small size makes it difficult to measure participant experience in broader surveys of dually integrated beneficiary satisfaction.

Nearly every interviewee supported or recommended the creation of national quality measures for PACE, and several stakeholders described past and ongoing efforts aimed at developing them. Officials said CMS previously undertook a project to develop quality standards, but the agency was stymied by questions of whether measures would be comparable across PACE organizations nationally. Measures would need to be applicable for PACE programs of various sizes and with different patient mixes, and officials said the utility of publishing such measures was less clear for participants as few have a choice of PACE organizations in their community. However, another federal expert said they are interested in standardized quality measures to compare PACE program performance by ownership type in light of the rapid growth of for-profit PACE organizations. Officials in one state, which had previously told MACPAC about its efforts to develop standardized quality measures for PACE, echoed that national quality measures are needed to understand the level of care PACE organizations are providing.[29] New York, which was not included in this study, has also investigated the development of PACE-specific quality measures (New York DOH 2022). PACE organizations also expressed a desire to have more uniformity in quality measures—and regulations—across states, which they said would allow organizations to expand across state borders more easily, potentially covering otherwise difficult-to-service rural areas. NPA noted that it is developing a PACE provider recognition program, which would include a standard quality measure set that it would use to evaluate providers (APIQ 2023).

BOX 4-1. Measuring Participant Satisfaction in the Program of All-Inclusive Care for the Elderly

States rely on a number of survey tools to evaluate Program of All-Inclusive Care for the Elderly (PACE) performance, often using participant satisfaction as a proxy. A commonly used instrument directly designed for the PACE population is the Integrated Satisfaction Measurement for PACE survey. This instrument, developed in 2009 in collaboration with the California PACE Association, is used across 32 states covering nearly 75 percent of PACE centers. PACE participants provide responses on their satisfaction with key PACE domains, including activities, meals, transportation, and care teams; states may also survey participant caregivers or PACE center staff (Vital Research 2023). Another method through which states may capture PACE quality is the Consumer Assessment of Healthcare Providers and Systems Home and Community-Based Survey, which includes questions related to unmet need, satisfaction, and caregiver supports (AHRQ 2024). A third survey instrument, the National Core Indicators—Aging and Disabilities, may also include PACE participants and breaks out responses on questions relating to access and satisfaction by home- and community-based service program type. Currently, only two states include PACE participants in this survey (NCI-AD 2024).

Financing

As an integrated care approach, PACE organizations receive capitated payments from Medicaid and Medicare. These capitation payments do not fluctuate with changes in a participant's health status but must account for the frailty of PACE enrollees compared to the general Medicaid or Medicare populations.[30] PACE organizations must accept these payments as full reimbursement for both Medicaid and Medicare participants, meaning providers cannot charge participants deductibles, copayments, or coinsurance (42 CFR 460.182(c), 42 CFR 460.90). Unlike other integrated models, PACE organizations fully braid these financing streams into a single fund to provide all necessary services to PACE participants. This means the PACE organization does not have to delineate which services are covered by Medicare or Medicaid and bill for their respective services provided by the IDT; rather, PACE providers do not bill at all for services provided through the PACE program, and the PACE organization operates with full financial risk.

Due to a lack of high-quality data, published studies have largely been unable to estimate the effects of integrated care, including PACE, on Medicaid spending (Barrie Smith et al. 2021). Research on PACE's impact on Medicaid spending is mixed. Some studies reported an increase in Medicaid spending under PACE, while others identified savings to Medicaid from enrolling frail adults in PACE who would have otherwise received more expensive care in institutional settings (Ghosh et al. 2015, Wieland et al. 2013, Foster et al. 2007).

BOX 4-2. Other Sources of Program of All-Inclusive Care for the Elderly Financing

Program of All-Inclusive Care for the Elderly (PACE) organizations receive a blend of monthly capitated payments from Medicare Parts A, B, and D and any premiums from participants, in addition to capitated payments by state Medicaid agencies.

Medicare Parts A and B. The Centers for Medicare & Medicaid Services (CMS) pays PACE organizations using county-level benchmarks (Skopec 2024). Unlike Medicare Advantage plans, PACE organizations do not submit bids but rather receive the benchmark amount for the counties served. Medicare payments to PACE organizations are risk adjusted, and organizations also receive a frailty adjustment (CMS 2011a).

Medicare Part D. PACE organizations must submit bids as Medicare Part D plan sponsors with separate plan benefit packages for dually eligible participants, for whom PACE organizations receive additional amounts to cover where Medicare Part D low-income subsidies do not fully cover participant costs, and for Medicare-only participants (CMS 2011a). CMS pays PACE organizations monthly with payments comprising Medicare Part D premiums paid on behalf of participants, reinsurance subsidies, and low-income subsidies (CMS 2024f).

Premiums. PACE organizations may not collect premiums from dually eligible or Medicaid-only participants, who comprise the majority of program participants. PACE organizations may collect Medicare Part D premiums and a premium to cover the Medicaid capitation payment from Medicare-only participants and any participants who pay privately (42 CFR 460.186).

Post-eligibility treatment of income. PACE organizations may collect payment from Medicaid-covered participants related to their liability in spending down income to meet Medicaid financial eligibility or as part of post-eligibility treatment of income (CMS 2011a). Some states do use this option for PACE.

The methodologies for Medicaid and Medicare capitation payments to PACE organizations differ.[31] Generally, states base the capitation rate for each Medicaid participant on a blend of the cost of nursing home and community-based care for the elderly in the area as well as Medicaid managed care data in those states where applicable to account for the frailty of the PACE population (CMS 2011a). Medicaid rates must be less than the amount that would otherwise have been paid (AWOP) for a comparable population age 55 or older meeting NFLOC criteria not enrolled in PACE (42 CFR 460.182). Although each state uses different methods to determine their Medicaid AWOPs and capitation rates for PACE, approximately half of states set the capitation rates as a fixed percentage of the AWOP (e.g., 95 percent of the AWOP). States can create multiple rate cells based on participant age, sex, geographic region, eligibility category, or Medicare status to more accurately project the AWOP (CMS 2025e). However, states cannot use separate institutional and community rate cells, as they can in some Medicaid payments to D-SNPs (MACPAC 2013). Separate Medicaid rates are determined for dually eligible and Medicaid-only PACE participants. Among our case study states, Medicaid capitation payments for full-benefit dually eligible individuals ranged from approximately $2,800 per member per month to $7,700 per member per month; this range reflects the various factors that the rate comprises, such as local cost of living and health care costs, as well as local policies, budgetary constraints, and negotiated agreements between state Medicaid agencies and PACE organizations (Skopec 2024). Rates for Medicaid-only participants are normally higher than rates for dually eligible beneficiaries to account for services that are usually covered by the Medicare capitation payment (Stitt and Higgins 2021). For example, in one state we spoke with, the highest capitation payment made for Medicaid-only participants was about $2,800 per member per month more than the highest capitation payment made for full-benefit dually eligible participants in 2022.

Combined federal and state Medicaid spending on PACE services totaled $3.9 billion in FY 2023. Fifty-six percent ($2.2 billion) of that spending came from the federal share of Medicaid costs, while another 5 percent ($183 million) came from the federal share of relief associated with the COVID-19 PHE. The remaining 40 percent, or $1.5 billion, came from the 32 states and the District of Columbia with PACE programs last year (CMS 2023). Aggregate Medicare spending data on PACE are not available. For more information on other sources of PACE financing, see Box 4-2.

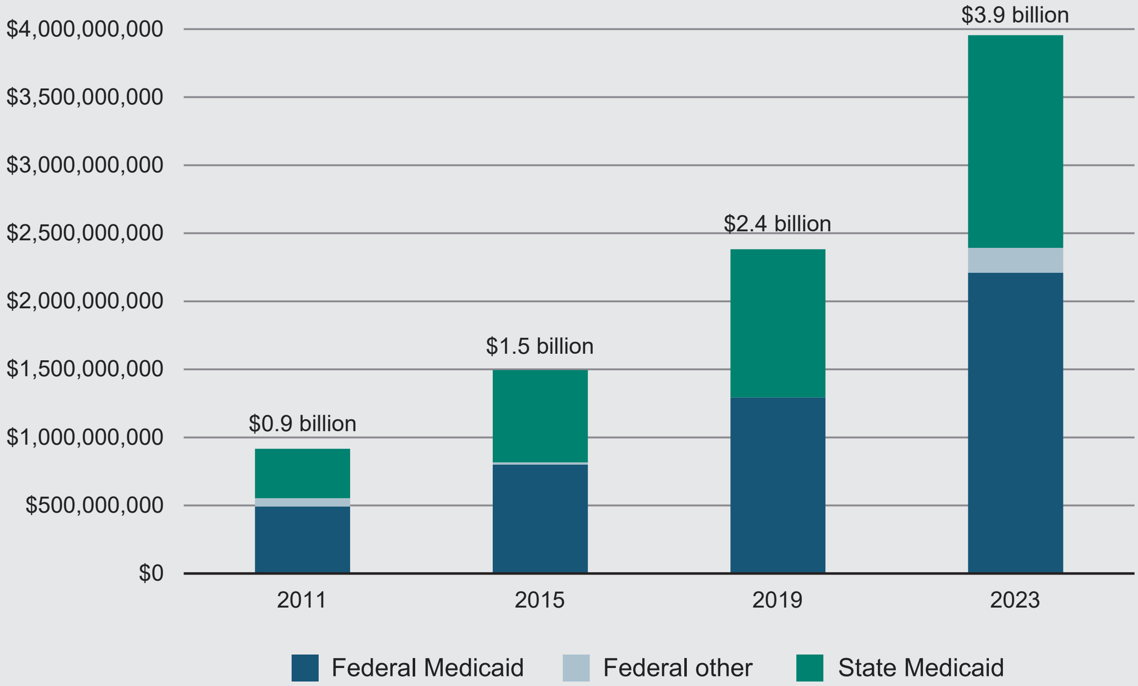
Medicaid spending on PACE has increased substantially in recent years as the federal government and states have moved to increase the use of HCBS relative to institutional care. Over the past two decades, spending on PACE has grown from $0.9 billion in 2011 to $3.9 billion in 2023 (Figure 4-5).

Interviews with federal and state officials revealed few specifics about how states approach developing their PACE capitation rates, although several states said they rely on the same third-party actuaries that develop rates for their Medicaid managed care programs. States attempt to develop their capitation rates using comparable populations, but the PACE population's unique needs paired with the lack of reliable data on PACE organizations' utilization and costs raises concerns about how well Medicaid capitation rates match the services provided. One federal official shared that substantial variation in the quality of encounter and claims data at the state level makes it difficult to assess the adequacy of PACE payments relative to PACE expenses and that differing state rate-setting methodologies and comparison populations can result in either lower or higher Medicaid spending on PACE compared to alternative care settings as well as between PACE organizations. California is unique among the states we interviewed in developing its PACE capitation rates using utilization and experience data (CMS 2018). However, states varied in how often they update PACE capitation rates as state budgets constrain the availability of funds from the legislature for both service expansions and capitation rate increases. And overall, PACE organizations said they lack the clarity from states on how Medicaid capitation rates are established.

Medicaid capitation rate development. CMCS provides states with guidance on rate setting, in addition to reviewing rates developed by states (42 CFR 460.182). The agency issued an updated Medicaid capitation rate setting guide effective January 1, 2025, which replaces the previous version from 2015 and requires thorough documentation of how states developed the AWOP and subsequent rates (CMS 2025e). Federal statute does not require PACE Medicaid capitation rates to be actuarially sound, unlike other managed care rates under 42 CFR 438. Guidance from CMS instructs states to ensure consistency of their rate methodology with the AWOP and the rate description in their state plan (CMS 2025e). Most states rely on third-party actuaries to develop their Medicaid capitation rates for PACE. Officials shared that actuaries in several of the states we spoke with use past-year utilization data for the state's fee-for-service and managed care populations to inform PACE rates. Officials in one state said its capitation rates are set as a percentage of fee for service, though they noted the need for this approach to change as the state has less fee-for-service data to use as its dually eligible population increasingly receives coverage through managed care.[32] Several states mentioned relying on utilization data regarding nursing facility placements and hospital stays, although one state said that some PACE organizations have objected to including nursing facility utilization in developing the PACE capitation rate because PACE is not an institutional model. Federal officials said that CMCS contracts with an actuary to ensure that the costs used by a state to develop their AWOP are based on appropriate populations and allowable costs. In developing capitation rates, actuaries are bound by their profession to adhere to actuarial standards of practice regardless of whether the rates are required by law to be actuarially sound. One federal official discussed the difficulties of collecting and interpreting PACE cost data and associated challenges of analyzing the cost effectiveness of PACE compared to other integrated care models.

States varied in how regularly their rates are reviewed and updated. Officials in most states we interviewed said that rates are reviewed on an annual basis.[33] Federal officials said that most states update rates annually, but in interviews officials from three states described rates that had not been adjusted in years.[34]

FIGURE 4-5. Federal and State Program of All-Inclusive Care for the Elderly Expenditures, FYs 2011–2023



Notes: FY is fiscal year. "Federal Other" includes funds from the American Recovery and Reinvestment Act of 2009 (P.L. 111-5), Balancing Incentive Program, and American Rescue Plan Act of 2021 (P.L. 117-2) that the Centers for Medicare & Medicaid Services includes with federal medical assistance percentage (FMAP) reporting.

Source: CMS-64 data from FY 2011 to FY 2023 (CMS 2023).

For PACE organizations in one state, a PACE provider said that rates had not been increased in 15 years.[35] Officials across multiple states emphasized that rate increases depend entirely on the state budget, since the PACE program comprises a small portion of Medicaid funding allotted by the state legislature. One state official noted that rates in their state, which previously increased PACE rates two years earlier, may increase substantially pending state budget discussions active at the time of our interview. However, that official expressed frustration that the state Medicaid agency currently lacks the necessary data about PACE costs and performance to press the legislature for higher rates.[36]

As the only state in our study to develop rates using PACE utilization and experience data, officials in California said in an interview that the state shifted to that payment methodology in 2018 to better match Medicaid payments to PACE organization risk. State officials said that an experience-based payment methodology more directly paid PACE organizations for their projected costs rather than setting a statewide percentage of the AWOP.[37] However, some PACE stakeholders highlighted that the state uses experience-based payment only for PACE organizations rated as "fully credible," meaning that organizations must meet a member-month threshold with sufficient enrollment over a two-year period (CMS 2018). For organizations that do not meet this threshold, PACE representatives said that organizations receive a blended rate based on the experience of PACE organizations in the same county or region, or using an adjacent, nearby, or similar county or region, within the state. California officials added that they regularly engage PACE organizations in an effort to be transparent about how the state uses submitted data to develop rates, but they said they still receive feedback from the PACE organizations on transparency and lack of methodological understanding.[38] Some PACE organizations we spoke with disagreed that the state's rate-setting process has been transparent.

State requirements around PACE organizations submitting Medicaid encounter data among our interviewed states were uncommon, even among states with Medicaid managed care and other mature integrated care models. California's PACE capitation rate setting may most closely reflect that of other managed care models because it pays PACE organizations within a rate range, developed based on experience data reported by organizations, while staying below the AWOP. Some PACE organizations said in interviews that current encounter reporting systems cannot be used for reimbursement due to a lack of PACE-specific encounter codes. Among states in our study, officials in two states said they develop their AWOP using similar populations in those states' integrated D-SNPs.

PACE organizations voiced mixed views on Medicaid rate-setting methodologies, and they said that they found state processes for developing PACE capitation rates to be unclear. PACE Medicaid capitation rates are risk-based payments made prospectively to cover the projected Medicaid expenses of the enrolled PACE participant, usually based on the average cost of a comparable population in alternative settings. This may result in financial gains or losses to the PACE organization when actual expenses vary from the capitation rate. One PACE organization said their organization faced a financial loss in the past year due to housing costs for participants who no longer have family supports. Meanwhile, another PACE organization said that Medicaid capitation rates in its state have failed to keep up with inflation and changes to patient acuity. PACE stakeholders in California voiced the most substantial complaints about the adequacy of Medicaid capitation rates. Most PACE organizations we interviewed that operate in the state said that because PACE organizations can use the capitation payments to provide services not covered under Medicaid or Medicare but determined necessary by the IDT, current encounter reporting does not accurately capture organizational costs. However, one PACE organization acknowledged that it benefits from cost savings when services it provides can generate reductions in hospitalizations and nursing facility placements.

State Medicaid capitation rates to PACE organizations can vary widely based on factors such as local cost of living and health care costs, and most states do not provide public data on capitation rates or how they are calculated. Officials in one state said that PACE organizations benefit from a capitation rate that blends nursing facility and community populations, noting that these organizations receive a capitation rate that assumes a level of nursing facility placements that officials said PACE organizations rarely meet. However, an official in another state remarked that PACE reimbursement may always appear insufficient to providers when compared with rates received in nursing facilities and through other HCBS since PACE capitation rates are statutorily required to be below those rates.

Looking Ahead

Although its market presence remains small compared to other integrated care approaches, enrollment, spending, and interest in PACE have grown substantially over the past decade. As demonstrated in our interviews, stakeholders largely view PACE as a comprehensive and effective approach for integrating a full spectrum of medical, social, and supportive services for individuals age 55 and older with complex health needs, most of whom are dually eligible. More than 25 years after PACE became a permanent Medicaid and Medicare program, there remains ample room to explore the program as part of the Commission's long-standing interest in policies affecting dually eligible beneficiaries.

Endnotes

[1] FIDE SNPs are MA plans that limit enrollment to dually eligible beneficiaries, offer fully integrated coverage, and are typically responsible for all Medicaid and Medicare benefits. Medicare-Medicaid Plans operate under a three-way contract with the Centers for Medicare & Medicaid Services (CMS), the state, and the plan to provide all Medicaid and Medicare benefits (MACPAC 2022).

[2] The control populations used for PACE participants in these studies are varied, with evaluations matching PACE enrollees to people enrolled in home- and community-based services (HCBS) 1915(c) waivers, new nursing home entrants, and other non-PACE dually eligible individuals across states (Ghosh et al. 2015, JEN Associates 2015, Segelman et al. 2014, Wieland et al. 2010, Beauchamp et al. 2008). One important limitation to note is that ineligible populations, such as HCBS waiver users who do not meet NFLOC requirements or nursing home entrants who cannot safely remain in their home, make less comparable control groups.

[3] To be eligible for PACE, an individual must meet the NFLOC requirement established in the state's Medicaid plan (42 CFR 460.150(b)(2)). The NFLOC is a proxy for the comparative frailty of PACE enrollees, a factor that the Balanced Budget Act of 1997 required that states incorporate into PACE capitation rates (MACPAC 2013).

[4] One state described an instance in which a PACE organization's application was marked incomplete because the PACE center did not yet have a street address. This was because the town had not yet named the new street on which the PACE center was located. An official from this state said that CMS is often too strict with PACE applications, leading to delays in approving and operationalizing new programs.

[5] Federal officials confirmed that the use of multiple H-numbers also creates administrative challenges for CMS as audits are conducted on the contract level.

[6] Although two states do permit PACE organizations to operate in some of the same areas, the majority of states do not allow PACE organizations to compete in the same service area (42 CFR 460.12(c)(2)).

[7] Services furnished outside the country may be allowed as indicated at 42 CFR 424.122 and 42 CFR 424.124 or through the state's Medicaid state plan. Surgery to improve the function of a body part after an injury and reconstruction after a mastectomy are included.

[8] PACE organizations we spoke with reported serving diverse populations. Two PACE organizations serve primarily Black populations, with program censuses of 93 percent and 100 percent Black participants. Another organization noted its sizeable Hispanic and Vietnamese populations. The state association we interviewed shared that across the state, 44 percent of PACE enrollees identified as Hispanic, 21 percent as white, 19 percent as Asian, 8 percent as other, 7 percent as Black, and 1 percent as American Indian.

[9] PACE organizations must have at least one PACE center within or next to its designated service area, which may be defined by county, zip code, street boundaries, census tract, block, or tribal jurisdictional area and which is established in the program agreement signed by the PACE organization, state, and CMS (42 CFR 460.32, 42 CFR 460.98(e)(1)).

[10] Surveys and qualitative interviews conducted in one study suggest that PACE programs were able to make substantial service delivery changes in response to the PHE. The majority of respondents increased the amount of in-home care provided to compensate for the reduction

in center-based direct care, with home-based staff delivering services such as nursing; primary care; personal and home health care; physical, occupational, and speech therapy; and medication administration, along with various other health care and social support services (Perry et al. 2024).

[11] At least one state official said in an interview that their state's two-way agreement specifies that PACE organizations must use a community-based assessment for all HCBS in the state.

[12] One state interviewed requires PACE organizations to assist with participant transfers between PACE organizations via subregulatory guidance. An official said that the state had seen several nursing facilities and assisted living facilities close and that the state would prefer participants who have elected to enroll in PACE to be able to remain in PACE rather than dropping into fee for service. This state manually reviews and approves each participant transfer to ensure PACE organizations are not poaching participants who live in areas served by multiple providers.

[13] Frequency of PACE center attendance is determined by the IDT, but participants may refuse to partake in PACE center activities if they wish while still receiving services from the center.

[14] Medicare and Medicaid oversight are required for any PACE program, regardless of participant makeup, given its status as a program under both Sections 1894 and 1934 of the Social Security Act.

[15] Federal officials pointed to the PHE as the initial reason for conducting audits virtually. However, the officials said they have continued to conduct most audits after the trial period—during which audits are statutorily required to be conducted on site—virtually because they said it reduces burden for PACE organizations. One PACE organization interviewee said their site is heavily documenting all of its processes in anticipation of a future audit as the PACE organization has not been audited by CMS in the last six years.

[16] CMS officials noted that two recent rounds of rulemaking related to PACE arose due to audits that identified the need for certain safeguards.

[17] PACE programs may be able to offer plan debit cards without affecting participants' financial eligibility for Medicaid, but they must follow different marketing guidelines than MA plans (ATI Advisory 2024).

[18] Officials in one state, which has had turnover in its office that oversees PACE, said they struggle to interpret CMS audit reports and would prefer those results to be shared automatically with the state rather than over calls with the PACE organization.

[19] Federal regulations do require general time frames for arranging and providing services, which became effective in 2025, and will be included in oversight efforts going forward (42 CFR 460.98(c)(2)).

[20] State officials described PACs as a useful source for uncovering issues within and trending across PACE organizations. However, they also noted that typical complaints are about the quality of the food or transportation, similar to those voiced in other integrated care models.

[21] An official in a different state said it was updating its two-way agreement for the first time since 2014 and distinguished the length and complexity of the PACE agreement—which they said was about 14 pages—from that of the state's agreement with its integrated MA dual eligible special needs plans, which extends hundreds of pages.

[22] This state official said they believe the CMS audit is sufficient and that the state should audit only in response to critical incidents.

[23] PACE Medicare encounter claims are usually generated by specialty services delivered outside the PACE center, such as audiology, cardiology, dentistry, and other specialty services listed in 42 CFR 460.70.

[24] One state official said they looked to encounter reporting procedures developed by New York and Colorado for a model to adapt for their own state. Although the official said they are working to have all integrated care offerings in the state reporting in a similar way to allow for insights, such as trends in nursing facility utilization, they added that they would not recommend comparing PACE to D-SNPs using encounters because services are less clear-cut in PACE. For example, the official said that transportation in PACE is often far more involved than a similar transportation benefit offered through a D-SNP because drivers for PACE may end up assisting a participant inside and then aiding them in a related task within their home.

[25] One PACE organization official noted that it collects and reports encounter data to its parent organization, which requires it in support of a grant the organization receives. The state in which this organization operates does not collect Medicaid encounter data.

[26] Current quarterly data reporting requirements give PACE organizations 45 days after the end of the reporting quarter to submit data to CMS (CMS 2024e).

[27] Federal regulations require that the IDT document all recommendations for care or services as well as the reasons for not approving or providing those services (42 CFR 460.102(d)(iii)). State officials said they review SDRs and will, in some cases, walk through service request denials with the IDT as part of their audit.

[28] PACE organizations must use a set of outcome measures for internal quality-improvement activities (42 CFR 460.136).

[29] Although this state requires PACE organizations to submit an annual quality-improvement report, officials said that it primarily relies on participant satisfaction surveys as a proxy for quality.

[30] Although some states include a risk adjustment component in their Medicaid rates, most use a flat rate for all participants receiving Medicaid (Stitt and Higgins 2021). In prior examinations of Medicaid capitation rates for integrated care plans, MACPAC found that few states used risk adjustment in PACE due to the limitations of risk adjustment models for long-term services and supports. Wisconsin and New York risk adjusted for PACE services by combining the PACE and D-SNP rate-setting efforts and using the long-term services and supports risk adjustment process for both programs (MACPAC 2013).

[31] Currently, federal officials said that PACE organizations use a legacy diagnosis reporting system as the basis for reimbursement while CMS helps familiarize organizations with submitting service-level encounter data, although the agency uses the encounter data it receives to assist in calculating costs. However, utilization data are not as complete as they would be from an MA plan.

[32] This state does not currently enroll dually eligible individuals in Medicaid managed care.

[33] Medicaid capitation rates can be renegotiated annually (42 CFR 460.182).

[34] In contrast, one state official said their state updates capitation rates annually and has even issued mid-year capitation rate updates as needed, which CMS permits under specific circumstances, such as legislation mandates, on a case-by-case basis.

[35] The PACE organization speculated that capitation rates were finally increased because PACE organizations in the state were beginning to struggle to demonstrate financial soundness to CMS. State officials confirmed that the capitation rate was increased for 2024 and will likely be increased again for the coming rate year.

[36] A PACE organization in one state said it saw a 10 percent cut in its capitation rate one year due to state budget constraints, which they said created vulnerability for their organization.

[37] One PACE organization in the state said that California is still statutorily limited in its payment rates by the AWOP. Therefore, some PACE sites in the state may near that ceiling with their experience-based rates.

[38] Although state officials said that reimbursement is calculated based on reported costs, they also noted that the state's contracted actuary also considers whether reported costs are reasonable. The officials said that some PACE organizations may report extraordinary costs that the state does not find reasonable.

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Chapter 5:

Self-Direction for Home- and Community-Based Services

Self-Direction for Home- and Community-Based Services

Key Points

- Self-direction is a beneficiary-controlled home- and community-based services (HCBS) delivery model that allows the individual to have decision making authority over their HCBS and directly manage their services with assistance.
- States can decide to offer employer authority, a model in which the beneficiary chooses who provides their care and services, or budget authority, a model in which the beneficiary has choice over how their monthly budget is distributed among allowable goods and services in their person-centered service plan, or both.
- States must establish a system of information and assistance, including financial management services (FMS), to support beneficiaries in managing their self-directed care. A range of entities provide information and assistance supports, and the roles of these entities may be difficult to distinguish from one another.
- States have broad flexibility when designing their self-direction programs including: selecting the Medicaid HCBS authorities for administering self-direction; determining which HCBS populations will be offered self-direction options; selecting which services can be self-directed; electing budget authority, employer authority, or both; and allowing family members to be paid caregivers.
- States use a variety of program-specific methods for quality reporting, monitoring, and oversight. States leverage information and assistance roles and FMS agencies to support data collection for these efforts. Data collection processes can vary across state operating agencies.
- Limited data reporting and analysis capacities in self-direction may hinder state and national efforts to ensure quality and conduct effective monitoring and oversight.

CHAPTER 5:

Self-Direction for Home- and Community-Based Services

Medicaid home- and community-based services (HCBS) are designed to allow people with the need for long-term services and supports (LTSS) to live in their homes or a home-like setting in the community. Self-direction is a beneficiary-controlled HCBS delivery model that allows the individual to choose their service providers and have control over the amount, duration, and scope of services and supports in their person-centered service plan (PCSP) (42 CFR 441.740, Murray et al. 2024, ACL 2014).[1] In self-direction, the beneficiary can either hire HCBS workers directly, referred to as "employer authority"; set their workers' hourly wages or purchase approved goods and services that help the beneficiary remain in a home- or community-based setting, referred to as "budget authority"; or both (CMS 2024a).[2] Medicaid is the primary payer of self-directed HCBS, supporting 66 percent of all self-directed services in 2019, although other sources, such as state general revenues, may also pay for self-direction (Edwards-Orr et al. 2020).

Compared with traditional, agency-directed HCBS, self-direction offers beneficiaries increased autonomy in how their HCBS are delivered, as the individuals providing care or services are accountable to the beneficiary or the beneficiary's representative. In an agency-directed model, the service provider coordinates care for the beneficiary, generally establishing a care schedule, assigning an HCBS worker to a beneficiary, managing the HCBS worker, and determining the HCBS worker's wage (DDA 2025, ADMH 2022). In a self-directed model, the beneficiary manages aspects of their care, deciding how, when, and by whom their services are provided (CMS 2024b, Crisp 2017). The flexibility that beneficiaries have in self-direction allows them to tailor care and services to their specific needs, preferences, and routines.

States have considerable flexibility when designing and administering self-direction programs, which has led to an array of different approaches to operating this model both across and within states. States choose which federal authorities to use, which LTSS subpopulations to serve, what services to offer in self-direction, whether or not to allow beneficiaries to have budget or employer authority, and under some authorities whether to allow family members to serve as paid caregivers. States also rely on numerous entities to support the self-directed functions that sustain these programs, including beneficiary advocacy organizations, case management entities, information and assistance support professionals, financial management services (FMS) agencies, managed care organizations (MCOs), and support brokerages.[3]

To understand the statutory and regulatory framework governing self-direction and identify existing data on the model, MACPAC conducted a literature review and interviews with federal and state officials, national subject matter experts, and stakeholders.[4] This chapter synthesizes the findings from MACPAC's work and provides a comprehensive overview of the self-directed HCBS delivery model. The chapter begins with an overview of self-directed HCBS, including the range of federal HCBS authorities that states use to offer self-direction, the statutory and regulatory framework governing the model, and the multitude of actors states may designate to support program administration. Next, we introduce findings that identify variation in the design and administration of self-directed HCBS and administrative complexity in self-direction. The chapter concludes with next steps to further the Commission's work.

Medicaid Coverage of Self-Directed HCBS

The guiding tenet of self-direction is that HCBS beneficiaries are capable of determining the types of assistance they need to independently reside in their communities (HSRI 2024). This approach differs from agency-directed care when an agency or health care provider takes on the responsibility of managing the care process. Self-direction is a beneficiary-controlled HCBS delivery model that allows the individual, with help to the extent available and necessary from trusted representatives (usually family or friends), to "have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports” (CMS 2024a). In self-direction, a state can choose to offer employer authority, a model in which the beneficiary chooses who provides their care and services, and budget authority, a model in which the beneficiary has choice over how their monthly budget is distributed among allowable goods and services in their PCSP, or both (42 CFR 441.440, 441.740, Murray et al. 2024, Murray 2024, ACL 2014). Self-directing beneficiaries, or their representatives, can hire, oversee, and terminate paid caregivers, who can be family members, friends, or other acquaintances.

States offer and finance self-direction through an array of HCBS waiver and state plan authorities, including through Sections 1915(c), 1915(i), 1915(j), 1915(k), 1905(a)(24), and 1115 authorities (Appendix 5A). These Medicaid authorities operate under different guidelines, but the Centers for Medicare & Medicaid Services (CMS) has published regulations specifying common requirements across all self-direction models. These models must include a person-centered planning process, a PCSP, information and assistance supports, FMS, a quality assurance and continuous improvement system, and an individualized needs assessment to determine benefit allocations (e.g., authorized aide hours or an individualized budget) (42 CFR 441.474, CMS 2024a).[5] These guidelines support beneficiaries who self-direct, or their representatives, in managing their LTSS.

Self-direction models are available in all 50 states and the District of Columbia, and enrollment has grown substantially over the past decade (Murray et al. 2024, O’Malley Watts et al. 2022). In 2023, more than 1.5 million individuals self-directed their HCBS through programs funded primarily by Medicaid but also through state general revenues, the Veterans Health Administration, and the Older Americans Act (P.L. 89-73, as amended) (Murray et al. 2024). This marks a 23 percent increase in enrollment since 2019 and an 87 percent increase since 2013 (Murray et al. 2024).

States often serve several populations across different Medicaid waiver and state plan programs, including but not limited to older adults, people with physical disabilities or intellectual or developmental disabilities (I/DD), and people with HIV/AIDS (Srinivasan et al. 2024). In a 2023 review of self-direction programs that are funded primarily by Medicaid but also by state general revenue, the Veterans Health Administration, the Older Americans Act, and some other funding streams, 50 states offered self-direction to adults older than age 65 and adults with physical disabilities, and more than half offered self-direction for adults with I/DD, adults with a traumatic brain injury, children with physical disabilities, children with I/DD, and children with traumatic brain injury (Murray et al. 2024).[6] Only a few states (14 percent) have self-direction programs specifically for adults with serious mental illness (SMI) and children with serious emotional disturbance (SEM) (Murray et al. 2024).[7]

Origins of self-direction

Today’s self-directed HCBS programs can be traced back to the 1950s when the U.S. Department of Veterans Affairs pioneered a participant-directed long-term care program: The Aid and Attendance Program (CMS 2024c, Grana and Yamashiro 1987). This program enabled veterans with service-related disabilities to hire personal attendants through a cash benefit (NCD 2013, Grana and Yamashiro 1987). Soon after its inception, the program was redesigned and repurposed to serve a larger population of veterans who needed LTSS after the completion of their military service (VA 2024). This veteran-directed care program is an early example of self-direction, which would be unavailable for civilians until states began offering consumer direction of the Medicaid personal care services benefit option through their state plan in the early 1990s (CMS 2025, 2024a).[8, 9] This optional benefit gives Medicaid beneficiaries increased autonomy over the provision of their personal care services but does not fully convey employer authority to the beneficiary, nor does it provide budget authority (§ 1905(a)(24) of the Social Security Act, CMS 2024a, EOA 2007). During the 1980s and early 1990s, some states incorporated employer authority self-directed services into their Section 1915(c) HCBS waiver programs, authorizing case managers to allow HCBS program participants to employ individual providers, including family members other than spouses or parents of minor children (ASPE 2010).

Cash and Counseling Demonstration and Evaluation. In 1995, the Robert Wood Johnson Foundation partnered with the Office of the Assistant Secretary for Planning and Evaluation and began planning the Cash and Counseling Demonstration and Evaluation (EOA 2007, Doty 1998).[10] Authorized under Section 1115 of the Social Security Act (the Act), the purpose of the Cash and Counseling Demonstration and Evaluation was to assess the feasibility, advantages, and disadvantages of self-direction in the financing and delivery of personal assistance services (PAS) and home care services for Medicaid beneficiaries (Doty 1998). Under the demonstration, Medicaid beneficiaries eligible for PAS and HCBS in three states, Arkansas, Florida, and New Jersey, volunteered to receive a cash allowance with counseling services in lieu of traditional, agency-directed services and supports (Mahoney and Simone 2016, EOA 2007).[11] Beneficiaries in the Cash and Counseling Demonstration and Evaluation reported higher satisfaction and quality of life as well as fewer unmet needs for assistance and fewer adverse health consequences such as bedsores and contractures compared with those receiving agency-directed services (Brown et al. 2007, Dale et al. 2004).

In addition to beneficiary satisfaction, the Cash and Counseling Demonstration and Evaluation assessed the effects on Medicaid costs for demonstration-covered services (Brown et al. 2007, Dale et al. 2004). Overall, personal care and HCBS costs under the Cash and Counseling Demonstration and Evaluation per month of benefits received was higher across all three states and all age groups receiving services when compared with agency-provided services (Brown et al. 2007). Researchers attributed the cost differential in two of the states, Arkansas and New Jersey, to unmet care needs among beneficiaries in the traditional system (Brown et al. 2007, Dale et al. 2004). For example, in Arkansas, nearly one-quarter of beneficiaries who should have been receiving agency-directed services did not receive any personal care services during the first year of the demonstration program (Dale et al. 2004). Among beneficiaries of agency-directed services who did receive personal care services in Arkansas during that first year, they received only 68 percent of the total hours of care for which they were qualified (Dale et al. 2004). However, if all recipients had received the expected number of hours as defined in their care plans, the average personal care expenditures in the Cash and Counseling Demonstration and Evaluation after one year would have been slightly less than the average expenditures for agency-directed personal care services (Dale et al. 2004).

Furthermore, the observed increased costs in the Cash and Counseling Demonstration and Evaluation were partially offset by savings on other Medicaid services (e.g., nursing facility services and home health) (Brown et al. 2007, Dale et al. 2004). In the second demonstration year, the difference in total Medicaid costs between self-directed and agency-directed PAS in Arkansas was statistically insignificant (5 percent), including the offsets (Dale et al. 2004). In Florida, the cost differential between beneficiaries in the Cash and Counseling Demonstration and Evaluation and those receiving agency-provided services was primarily due to a mandate to increase funding for waiver services to beneficiaries with disabilities, which occurred during the Cash and Counseling Demonstration and Evaluation's inception (Brown et al. 2007). Ultimately, the availability of funds and prescription to increase spending for the state's disability population led to a reevaluation of beneficiaries' initial spending plans when beginning the Cash and Counseling Demonstration and Evaluation, which often increased their allowance amounts (Brown et al. 2007).

After the Cash and Counseling Demonstration and Evaluation's success, 11 additional states received replication grants from the Robert Wood Johnson Foundation, and 1 state received a grant from the Retirement Research Fund and implemented budget authority self-directed services programs, mostly under Section 1915(c) HCBS waiver authority, between 2004 and 2009 (Simon-Rusinowitz et al. 2014). By 2011, the demonstration states had more than 20,000 beneficiaries enrolled (Simon-Rusinowitz et al. 2014).

Federal requirements governing self-direction

States have a range of options to choose from in Title XIX of the Act when designing their self-direction programs. These federal Medicaid authorities dictate the instrumental features of a state's program, such as eligibility, contracting, and payment structures (Bradley et al. 2001). This section provides an overview of the federal requirements that shape the landscape of the self-directed HCBS delivery model (Appendix 5B).

In statute, self-directed HCBS are defined as "services for the individual which are planned and purchased under the direction and control of such individual or the individual's authorized representative, including the amount, duration, scope, provider, and location of such services" (42 USC § 1396n). Regardless of the Medicaid HCBS authority under which a state authorizes self-direction, all models must meet the following federal requirements:

- person-centered planning process;
- PCSP;
- individualized budget;
- information and assistance in support of self-direction;
- FMS; and
- quality assurances and continuous improvement system.

In self-direction, the beneficiary leads the person-centered planning process. The PCSP focuses on identifying the beneficiary's strengths, preferences, needs, and desired outcomes, while also preparing for contingencies like service interruptions and addressing potential risks (CMS 2024a). The PCSP is a written document outlining the specific services and supports the individual will receive to meet their needs and stay in the community. States offering budget authority develop an individualized budget for the beneficiary based on this plan. States must define how to calculate these budgets and monitor expenditures (CMS 2024a).

States provide information and assistance supports, which include counseling, training, and FMS, for individuals who choose to self-direct their care (CMS 2024a). A support broker or consultant helps individuals navigate the self-direction process, from identifying personnel needs to ensuring services are properly managed (42 CFR 441.450(c), CMS 2024a). FMS agencies assist with managing budgets, handling payroll, paying taxes, and tracking expenses (CMS 2024a). Although some individuals may manage these tasks themselves, most rely on FMS agencies for support. Finally, each state Medicaid agency must maintain a system for quality assurance and improvement, identifying and addressing issues to ensure services are effective. Although quality requirements may vary by state, all states are responsible for monitoring both system performance and individual outcomes (CMS 2024a). Some aspects of self-direction are also found in the broader HCBS system, such as beneficiary choice and control, person-centered planning, the PCSP, and the quality assurance and continuous improvement system. Other elements, such as an individualized budget, individuals determining HCBS worker qualifications and wages, and the availability of information and assistance supports, are unique to self-direction (Murray 2024).

Medicaid authorities. Medicaid coverage of self-directed HCBS is authorized under the Act, and as of 2023, nearly all states provide self-direction under Section 1915(c) waivers, and one-third offer self-direction via the state plan (Murray et al. 2024). Under the Act, states have several authorities they can leverage to administer self-directed HCBS, and requirements under these authorities impact a state's self-direction program design (42 USC § 1396n, Murray 2024). For example, states can offer budget authority under Section 1115 demonstrations and Section 1915(c), 1915(i), 1915(j), and 1915(k) Medicaid authorities (Murray 2024). However, budget authority is not available for Section 1905(a)(24) state plan personal care services unless the state plan option is paired with the Section 1915(j) self-directed PAS state plan authority (Murray 2024). States must consider these variations when designing and administering their self-directed programs (Murray 2024) (Appendix 5A).

Section 1915(c) authority is the most common authority through which state agencies offer self-directed HCBS, with 46 states using at least one Section 1915(c) waiver for this purpose in 2023 (Murray et al. 2024). Section 1915(c) waivers allow state agencies to provide self-directed HCBS for individuals with institutional level of care needs (42 USC § 1396n). These waivers cover a broad range of nonmedical, social, and supportive services, such as case management, personal care, and respite care, to help individuals live independently in the community.[12]

Other Medicaid authorities that states use to offer self-direction include Section 1115 demonstration authority as well as Sections 1915(i), 1915(j), 1915(k), and 1905(a)(24) state plan options.[13] Section 1115 demonstrations allow states to conduct pilot projects, including those promoting self-direction in managed care (O'Malley Watts et al. 2017). Section 1915(i) enables states to provide self-directed services for individuals who meet needs-based criteria that are less stringent than what is required for an institutional level of care (O'Malley Watts et al. 2022). Section 1915(j) allows for self-direction of state plan personal care services and Section 1915(c) waiver services, with provisions for beneficiaries to hire legally responsible relatives or purchase items to support independence (CMS 2024d, Colello 2022). The Section 1915(k) Community First Choice state plan option enables states to provide attendant services for individuals meeting state institutional care criteria, with a 6 percentage point increase in federal matching funds for service expenditures (Colello 2022, CMS 2020). Finally, Section 1905(a)(24) allows states to offer personal care services under a self-directed model, though without budget authority or the ability to hire family members (Murray et al. 2024, MACPAC 2023) (Appendix 5A).[14]

Employer authority and budget authority

When states design their self-direction programs, they can choose to offer beneficiaries employer authority, budget authority, or both. Employer authority allows beneficiaries to choose and manage their direct care workers, while budget authority lets beneficiaries choose how their monthly budget is distributed among allowable goods and services, such as caregiver pay and items that increase independence or substitute for human assistance (42 CFR 441.740, Murray 2024, Srinivasan et al. 2024). States may elect whether to allow employer or budget authority for specific services (CMS 2024b).

Employer authority. Beneficiaries use employer authority to recruit, identify, hire, terminate, train, schedule, supervise, and evaluate the HCBS worker (42 CFR 441.450(j)). Beneficiaries undertake these activities either on their own or with assistance from their representatives, information and assistance support entities, FMS agencies, and MCOs. When a beneficiary has employer authority, they assume the employer responsibilities rather than a provider agency (CMS 2024b). This responsibility includes recruiting, hiring (conducting interviews, performing background checks, and checking references), setting work schedules, identifying training needs, assigning tasks, supervising, evaluating performance, and terminating employees, when required (CMS 2024b). Employer authority is allowable under all Medicaid HCBS authorities.

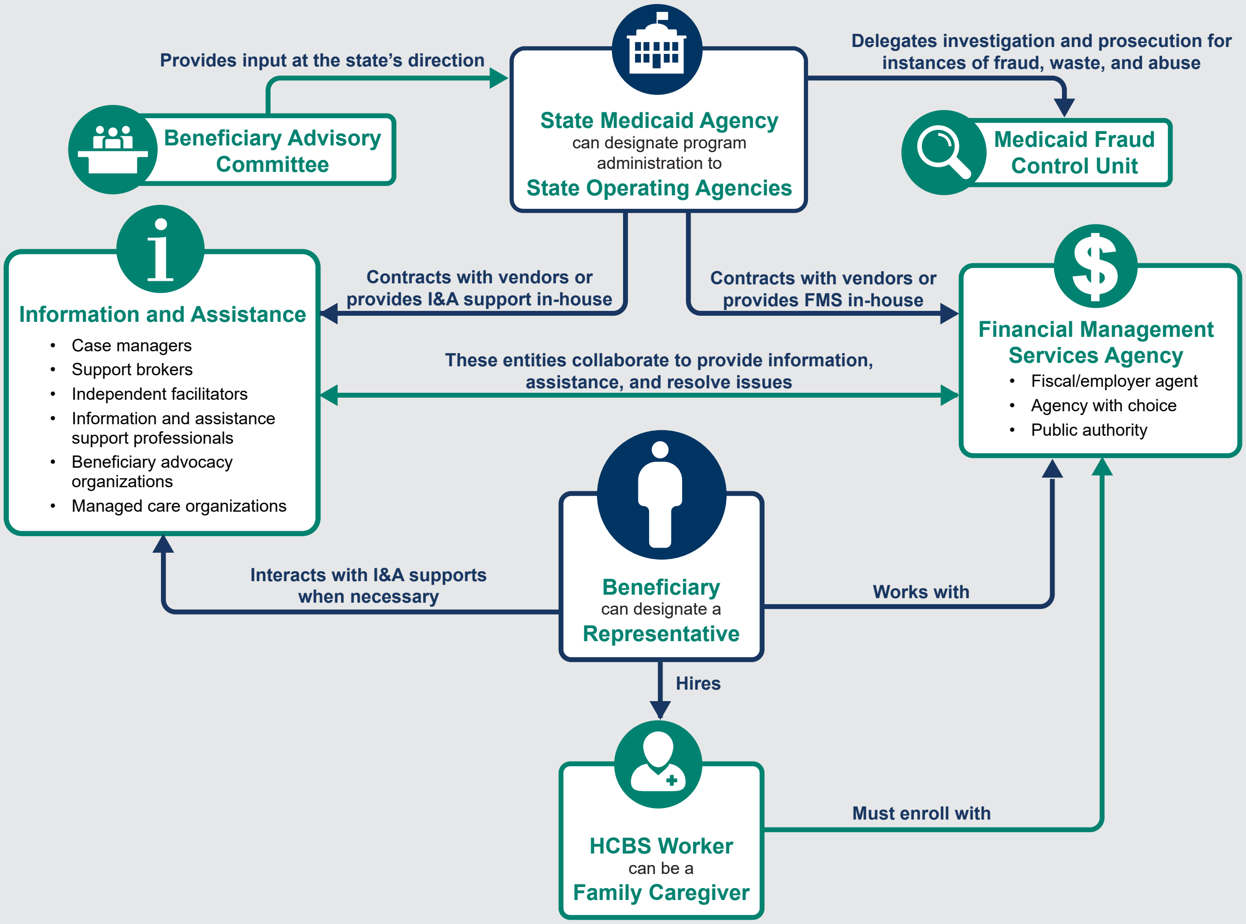
Budget authority. Beneficiaries use budget authority to purchase services and supports; determine the amount paid for a service, support, or item; and review, as well as approve, invoices (42 CFR 441.450(j)). For example, a beneficiary with budget authority can set the wage for their HCBS worker. States have also introduced flexibilities that allow beneficiaries to allocate their service funds toward goods and services that promote independence, such as assistive technology or home modifications (Teshale et al. 2021).

Most HCBS authorities allow states to offer budget authority (Appendix 5A). In 2023, 44 states had established at least one self-direction program that included budget authority, and all 10 states with the largest reported growth in enrollment in self-direction allowed budget authority (Murray et al. 2024). Among the 44 states using budget authority, 35 states allowed beneficiaries to purchase goods and services (Murray et al. 2024).

Key Stakeholders in Program Administration

Self-direction programs include a range of entities that support the beneficiary in managing their care (Figure 5-1). Under self-direction, the beneficiary is typically the legal employer or coemployer of their own staff, and most beneficiaries choose to hire family members, friends, or other people they know to provide their necessary care services (CMS 2007). The state Medicaid agency is responsible for ensuring that a program operates in line with federal regulations, and it can delegate its authority to another entity, such as another state agency, with an agreement specifying the delegated tasks. When another state agency manages a self-direction program, it is referred to as the "operating agency," and the Medicaid agency supervises its operations. States may also employ information and assistance providers or use FMS agencies to provide support services and fulfill administrative responsibilities that are required as part of self-direction (CMS 2024b).

FIGURE 5-1. Key Stakeholders in Self-Direction



Notes: I&A is information and assistance. FMS is financial management services. HCBS is home- and community-based services.

Sources: MACPAC compilation based on review of Sections 1915(c), 1915(i), 1915(j), 1915(k), and 1905(a) of the Social Security Act and the 2024 Section 1915(c) waiver technical guide. We also reviewed relevant regulatory guidance at 42 CFR 441 as well as evidence collected through interviews with experts.

Beneficiary

The beneficiary is the individual who is eligible for and enrolled in the Medicaid program (CMS 2024b). In a self-direction model, individuals have the opportunity, and the responsibility, to oversee all aspects of service delivery through a person-centered planning process. This oversight could involve employer responsibilities, such as recruiting, hiring, training, and supervising providers, as well as determining the qualifications required for HCBS workers beyond federal and state standards.[15] Additionally, beneficiaries may have financial responsibilities under budget authority, enabling them to manage how Medicaid funds within their budget are allocated and, in some cases, determine the rates for specific HCBS workers within the limits established by the program (CMS 2024e). States are required to support or arrange for the provision of supports that help beneficiaries develop a PCSP and individualized budget, manage and execute services, and carry out employer and budget responsibilities (CMS 2024e). These responsibilities and supports allow beneficiaries to be the primary judges of the quality of the services they direct (CMS 2024e).

Representative

If a beneficiary is unable or unwilling to self-direct their HCBS, they can choose a representative to assist (ICRC 2017). A representative cannot be paid or serve as the beneficiary's HCBS worker (ICRC 2017). Typically, a representative is a family member or close friend who helps the individual make decisions based on their preferences. Although beneficiaries continue to control how and when their services are delivered, representatives can provide support with tasks that individuals may find challenging, such as reviewing and approving time sheets, addressing worker performance issues, or reminding workers to arrive on time. In some cases, a representative may handle all of these tasks on behalf of the individual.

HCBS worker

The beneficiary chooses HCBS workers to provide the services outlined in the PCSP. Under certain Medicaid authorities, state Medicaid agencies may require background checks and may establish education, certification, or licensing requirements for caregivers hired under self-direction, but specific requirements vary by state and by the Medicaid authority used to allow self-direction (Teshale et al. 2021).[16] HCBS workers hired through self-direction can include many different kinds of providers, such as direct support professionals, personal care aides, home health aides, and certified nursing assistants (MACPAC 2022).[17] Beneficiaries may hire HCBS workers whom they already know in the community or from agencies with the help of support brokers (CMS 2024a). Some states also maintain and publish HCBS worker registries to help beneficiaries find qualified workers (CMS 2023).

Family caregivers. Under certain Medicaid authorities, states determine who can be an HCBS worker in self-direction. Some of the authorities convey authority to the individuals to establish provider qualifications and determine who can be an HCBS worker. Under most authorities, states have the flexibility to allow family members to provide HCBS, which includes legally responsible individuals, with the exception of Section 1905(a)(24) state plan personal care services, unless the state operates a concurrent Section 1915(j) state plan authority (Teshale et al. 2021) (Appendix 5A).

A legally responsible individual is any person who has a duty under state law to care for another person, such as the parent of a minor child or a spouse (CMS 2024b). When acting as an HCBS worker, the legally responsible individual must offer services that go beyond what is typically expected from a spouse or parent, referred to as "extraordinary care" (CMS 2024b).[18]

State

The state Medicaid agency must maintain a system for quality assurance and improvement, identifying and addressing issues to ensure services are effective (CMS 2024a). The state must also make available information and assistance supports and FMS (CMS 2024a). The state Medicaid agency can delegate the tasks of operating the self-direction program to other state operating agencies, such as the departments overseeing services for people with disabilities, mental health services, and aging services.

States are required to have Medicaid fraud control units as a part of their Medicaid state plans under the Act (42 CFR 1007.3). Medicaid fraud control units operate independent of the state Medicaid agency and the operating agencies and investigate claims of fraud and abuse in the state's Medicaid program, including services provided through self-direction (42 CFR 1007.9).

Beneficiary advisory board. Some states have a beneficiary advisory board that provides input to state policymakers on discrete self-directed HCBS topics. The beneficiary advisory board is typically composed of beneficiaries and their family members (DDS 2025a, Wisconsin DHS 2025). A few of the states that we interviewed mentioned leveraging a beneficiary advisory board, although they are not present in all states. Under Section 1915(k) authority, states are required to establish a Development and Implementation Council to consult and collaborate with the state in the development and implementation of the state's Community First Choice benefit (42 CFR 441.575).[19]

Information and assistance supports

Information and assistance supports must be available to beneficiaries who are self-directing their HCBS, but the amount and frequency of assistance may vary depending on beneficiary preference (42 CFR 441.464, CMS 2024a). CMS defines information and assistance in self-direction as a system that is "responsive to an individual's needs and desires for assistance in developing a PCSP and budget plan, managing the individual's services and workers and performing the responsibilities of an employer" (CMS 2024a). In practice, information and assistance supports encompass a wide range of services:

- information on how a self-directed service option works;
- education on individual rights and responsibilities;
- access to resources supporting self-direction;
- counseling and coaching;
- training beneficiaries and assisting with issues; and
- access to an independent advocacy system available in the state (CMS 2024a).

The broad definition of information and assistance provides flexibility to states when they design beneficiary supports. Through interviews with state officials, stakeholders, and subject matter experts, we found that many entities may provide information and assistance: case managers, support brokers, independent facilitators, area agencies on aging (AAAs), beneficiary advocacy organizations, information and assistance support professionals, and FMS agencies. The state can perform these information and assistance roles or contract with vendors. All of these roles or entities are not present in every state and may overlap with other information and assistance supports available to self-directing beneficiaries. Below is an overview of each role and its function in providing information and assistance in support of self-directed HCBS.

Case managers. The states we interviewed indicated that the case manager shares information about self-direction options with beneficiaries and helps them enroll in self-directed HCBS. According to interviewees, case managers assist with care planning, coordination, and assessment; support beneficiaries with resources and counseling; and train them in their employer responsibilities. In other cases, case managers refer the beneficiary to other information and assistance supports roles (e.g., a support broker or an information and assistance support professional) that provide these supports (CMS 2024b). Case managers have regular check-ins with beneficiaries and help them complete paperwork. Although case managers form a part of the information and assistance support system in self-direction, a case manager's role may be broader than serving self-direction users exclusively, extending to beneficiaries receiving HCBS in a traditional service delivery model.

Support brokers. A support broker (also referred to as a "counselor," "consultant," "coach," "independent facilitator," or "information and assistance specialist") is generally selected by the beneficiary and takes direction from them (CMS 2024b, Mahoney et al. 2021). A support broker helps beneficiaries navigate the self-direction process, from identifying personnel needs to ensuring services are properly managed (CMS 2024a, Mahoney et al. 2021). Support brokers monitor service delivery and help address concerns regarding quality or safety, liaising between the individual and their FMS agency or performing other information and assistance supports functions (CMS 2024a). Compared with a case manager, state officials shared that the support broker generally provides more day-to-day supports and handles payment and time sheet issues, but both functions work closely with each other.

Independent facilitators. In addition to a support broker, some states have independent facilitators.[20] According to state officials and advocacy organizations, the independent facilitator liaises between the support broker and FMS agency. The role is intended to reduce the workload for support brokers and focuses on helping beneficiaries with administrative tasks like time sheets and troubleshooting as issues arise. They can also support HCBS worker recruitment.

Information and assistance support professionals. States may designate information and assistance support professionals as a separate entity to assist in developing the PCSP and the individual service budget and to manage services and employer responsibilities, according to subject matter experts (CMS 2024a). None of the state agencies we interviewed indicated that they designate a separate entity to provide only information and assistance support.

FMS agencies. According to interviewees, in addition to their primary role as a fiscal intermediary, FMS agencies may also provide information and assistance supports. For example, we heard that FMS agencies commonly provide support brokerage services. Some states delegate support brokerage services to FMS agencies and provide payment for those services, while other FMS agencies are providing these services more informally.

AAAs and Aging and Disability Resource Centers. Interviewees shared that AAAs and Aging and Disability Resource Centers (ADRCs) provide options counseling, self-direction program referrals, and in some instances case management and waiver service coordination. AAAs are funded outside of Title XIX through the Older Americans Act. However, they can be funded by Medicaid in support of self-direction through a contractual agreement. States or vendors contract with AAAs to provide information and assistance supports, but sometimes AAAs provide informal supports as well. AAAs may work closely with other entities providing information and assistance and FMS agencies.

Beneficiary advocacy organizations. Advocacy organizations provide resources and education to beneficiaries on self-direction and advise state agencies through input from beneficiaries and community members with lived experience, according to interviewees. They may help support beneficiaries or connect them to additional resources if issues arise when self-directing. They can also advocate for beneficiaries when their service hours or budget allotment are adjusted.

FMS

Under most authorities, beneficiaries cannot receive direct cash payments, so the FMS agency acts as a fiscal intermediary between the Medicaid program, beneficiary, and HCBS worker (§§ 1115, 1905(a)(24), 1915(c), and 1915(i) of the Act). FMS agencies receive funds from the state and use those funds to pay the beneficiary's HCBS worker for services rendered in accordance with their PCSP (42 CFR 441.454, 441.545, CMS 2024f) (Appendix 5A). In addition to handling payroll, FMS agencies must assist beneficiaries in understanding their billing and documentation responsibilities, perfoming tax and employment benefits services, purchasing goods and services, and monitoring the beneficiary's self-directed budget (42 CFR 441.484, CMS 2024g). Although some beneficiaries choose to manage some of these tasks themselves or with their authorized representative, most rely on an FMS agency for support (CMS 2024a).

In self-direction programs with budget authority, the FMS agency monitors and reports on individual beneficiaries' expenditures (42 CFR 441.484, Murray 2024). FMS agencies must verify that spending on goods and services and payment rates are approved in the PCSP before issuing payment (Murray 2024). Additionally, FMS agencies must track a beneficiary's expenditures and notify the beneficiary and other relevant third-party administrators, such as a case manager or support broker, when funds are being expended too rapidly or are being underused (42 CFR 441.484, Murray 2024).

States can choose from different FMS agency models and may choose more than one model. The primary models are the fiscal/employer agent (F/EA) model and the agency with choice (AwC) model (CMS 2024b, 2024g). Although less common, one state in our case study uses a public authority to provide training for HCBS workers and manage criminal background checks while the state pays the workers (CMS 2024g).

F/EA. Under this model, the beneficiary is the common law employer (i.e., employer of record or legally responsible employer) of the HCBS worker. Of the FMS models, this one places the greatest level of responsibility and risk on the beneficiary. They are directly liable for performing employment-related tasks, including hiring, supervising, and firing their employees (CMS 2024b). The FMS agency supports the beneficiary in fulfilling their employer-related obligations by processing payroll and taxes. The agency can either be nested within the state (i.e., government F/EA) or be a contracted entity (i.e., a vendor F/EA), but both perform the same functions (CMS 2024b). All the states we spoke with selected a vendor F/EA model, which is the most common of the two approaches (CMS 2024b, Murphy et al. 2011).

AwC. In the AwC model, the FMS agency is the common law employer (i.e., employer of record or legally responsible employer) of the HCBS worker, and the beneficiary is considered their coemployer (i.e., managing employer) (CMS 2024b). In this model, the beneficiary manages the worker in their day-to-day activities, but the FMS agency is responsible for all of the employment-related functions for the beneficiary's workers. In addition to processing payroll and taxes, under the AwC model, provider agencies can help a beneficiary find an HCBS worker, help with interviewing and hiring processes, and train and manage the HCBS worker (DDS 2025b). Under this model, the FMS agency can offer beneficiaries a list of HCBS workers to choose from who are already enrolled with the FMS agency.

Public authority. Public authority is considered a multiple-employer model with three different employers (CMS 2024h). In this model, the beneficiary is the employer for hiring, supervising, and firing their HCBS worker (CMS 2024h). The state is responsible for processing payroll in this model, and the public authority or workforce council (usually at the county level) works with unions to negotiate the wages, benefits, and working conditions for HCBS workers and serves as the employer of record. The public authority also generally maintains an HCBS worker registry that is available to beneficiaries.

MCO

Through our interviews, including with MCOs, we found that the role of an MCO in self-direction may be similar to some of the information and assistance supports functions. MCOs perform functional needs assessments and assess a beneficiary's ability to self-direct based on the waiver requirements (42 CFR 438.208(c)(3)(ii)). In some states, the MCO uses these assessments to determine the services and service hours that a beneficiary can self-direct, ensuring they stay within state spending caps. Additionally, MCOs process service authorizations, perform back-end claims payment and encounter filing with the state, and provide case management and service coordination. The MCOs we interviewed shared that they also engaged in quality monitoring and oversight: monitoring compliance with electronic visit verification (EVV) and reporting critical incidents and suspicious activity.

When self-directed HCBS are administered in a managed care environment, the MCO collaborates with other information and assistance roles and FMS agencies to support self-direction. For example, once the beneficiary has been assessed and has developed their PCSP, the MCO can share this information with the FMS agency to help with the beneficiary's enrollment processes. In addition to collaboration during the beneficiary enrollment process, MCO case managers work closely with FMS agencies to support beneficiaries and identify issues quickly. One MCO we interviewed shared that they established a daily feed with an FMS agency to share authorizations, which allows them to rapidly address provider payment challenges caused by authorization issues.

State Design Considerations

States have broad flexibility when designing their self-direction programs, including (1) selecting specific HCBS authorities for administering self-direction; (2) determining which HCBS populations to offer self-direction options; (3) selecting which services can be self-directed; (4) electing budget authority, employer authority, or both; and (5) allowing family members to be paid caregivers.

Medicaid HCBS authorities

States select administrative authorities based on their policy and programmatic goals as well as the authorities the state uses to operate its existing agency-directed HCBS programs. Federal officials shared that self-direction is currently available in more than half of all Section 1915(c) waivers, or about 150 waivers. In general, state officials said they prefer Section 1915(c) waivers for their flexibility in serving specific populations, setting enrollment limits, limiting availability based on geography, and selecting which services can be self-directed. Federal officials highlighted that these flexibilities help states better manage the costs of operating self-directed HCBS programs. One state Medicaid agency mentioned that Section 1915(c) waivers provide a more defined framework for self-direction and that the flexibilities to set enrollment caps and tailor the model to specific populations made it easier for the state to manage costs and conduct oversight. Although less common, some of the states we interviewed used other authorities such as Section 1915(k) authority, which offers an enhanced federal match, or Section 1115 demonstrations due to the flexibility to target different eligibility groups.[21]

Populations that self-direct

Self-direction programs serve different populations in each state. An inventory that included 80 percent of all self-directed LTSS programs funded through Medicaid or state revenues between 2010 and 2011 found that about 60 percent (129 programs) of the identified self-directed programs (212 programs) served two or more LTSS subpopulations (Sciegaj et al. 2014). Few programs targeted a single population in this inventory, and the majority of programs served older adults (Sciegaj et al. 2014).

A more recent analysis conducted by AARP found that all 50 states and the District of Columbia have options to self-direct for adults older than age 65 and adults with physical disabilities (Murray et al. 2024). More than 90 percent of states offer self-direction for adults with I/DD and adults with traumatic brain injury (Murray et al. 2024). In contrast, self-direction for adults with SMI is less available across states, with less than half (24 states) offering self-direction for this population (Murray et al. 2024). However, some states are working toward incorporating more self-direction for behavioral health needs. For example, Texas is working to expand self-direction to individuals with SMI (Texas HHSC 2021).

Across case study states, we found that many beneficiaries succeed in self-directing their HCBS with an appropriate level of supports and a contingency plan. State officials, researchers, consumer advocates, and other stakeholders identified certain beneficiaries who may require additional supports to be able to self-direct effectively, including people with few natural supports, those experiencing homelessness, those who have low technological literacy or lack access to technology, those who live in rural areas, and those with low English proficiency.[22] Interviewees emphasized that these populations can still effectively self-direct their HCBS with the appropriate supports and plans in place. For example, one interviewee shared that individuals with dementia may still be able to self-direct but need a contingency plan for when they can no longer safely direct their services. Conversely, interviewees noted that beneficiaries with strong natural supports, such as older adults with adult children or strong social networks, are generally well equipped to successfully self-direct their HCBS with fewer additional supports.[23]

Self-directed services

State agencies have the flexibility to select which services are available for self-direction. Nationwide, the most commonly self-directed services include personal care, transportation, and respite (ASD 2023). Case study states most commonly offered the following services under their self-directed HCBS programs: respite; personal care assistance; personal care; homemaker; peer support; transportation; skilled nursing; private duty nursing; supported employment; equipment, technology, and modifications; and individual goods and services. Several researchers and state officials said that states are more likely to allow personal care services, such as bathing and dressing, to be self-directed due to their intimate nature. Forty states offered self-direction for home-based services in at least one of their waivers, and 22 states offered self-directed day services in at least one of their waivers (MACPAC 2024). No state offering round-the-clock services under a Section 1915(c) waiver offered a self-direction option for that service (MACPAC 2024).

The National Core Indicators–Aging and Disabilities Adult Consumer Survey, which gathers data on experience of care from older adults and individuals with disabilities, found that 91 percent of the surveyed self-direction participants felt they had the amount of control they desired over their services in the 2023–2024 survey (HSRI and ADvancing States 2025). Additionally, in the 2022–2023 survey year, just under 80 percent of surveyed self-direction participants felt that the services and supports they wanted to self-direct were always available, and in the 2023–2024 survey year, this share increased to 84 percent (HSRI and ADvancing States 2025, 2024).

Interviewees identified two approaches states generally take to determine which services to offer under self-direction: (1) choose from the services available under the state's traditional service delivery model, or (2) develop a new suite of self-directed services, often in response to advocacy. Two states we spoke with offer the same services across both agency and self-directed models for their I/DD population. Officials from one state noted that a benefit of this approach is that a beneficiary can receive care from an agency during the day, while a family caregiver works another job, and then receive self-directed services in the evening when the caregiver is home, blending both traditional and self-directed HCBS. In contrast, a national advocacy organization described the second approach as developing a "separate parallel ecosystem of self-direction." In these cases, state agencies said that stakeholder input influenced which services were allowed to be self-directed.

Additionally, two state Medicaid agencies shared that they consider the level of training or licensing required to provide specific services when defining which services can be self-directed. One state shared that they avoid offering self-direction for services that necessitate complex certification or licensing requirements for HCBS workers. Another agreed, sharing that some services require more extensive training for workers, so they preferred to offer only less-complex services such as respite, personal attendant, personal assistance, and community transportation under the self-directed model.

Budget and employer authorities

A notable flexibility that states might draw on as they design self-directed HCBS programs is whether to offer beneficiaries employer authority, budget authority, or both. Under employer authority, beneficiaries receive help to recruit, hire, and supervise HCBS workers. Beneficiaries act as common law employers or coemployers of these HCBS workers, rather than provider agencies assuming full employer responsibilities. Under budget authority, beneficiaries are responsible for managing individualized budgets set by the state Medicaid or operating agencies or a delegated entity. These agencies determine how to use budget authority in their program design, such as permitting beneficiaries to make decisions about purchasing goods and services authorized in PCSPs and manage the funds in their individualized budget, which may include shifting funds between services (CMS 2024b). Interviewees said employer authority tends to be easier for self-directed beneficiaries to understand and requires fewer state administrative resources than budget authority. However, offering both budget authority and employer authority options gives beneficiaries more choices and control.

Employer authority. States can allow beneficiaries to function as either common law employers or coemployers of their HCBS worker. Under the common law employer approach, beneficiaries are considered legally responsible employers of hired workers (CMS 2024b). Two state operating agencies emphasized the importance of ensuring self-directing beneficiaries understand their responsibilities and their risks when they are common law employers. For example, beneficiaries, who are functioning as employers, and their fiscal agents are jointly liable for employer taxes, including state, federal, and local taxes. Another state agency added that navigating state labor laws and ensuring an adequate level of knowledge and understanding of employer burden can be a challenge for beneficiaries who are self-directing, but FMS agencies and support brokers can assist beneficiaries in managing these employer-related responsibilities.

Under the coemployment approach, beneficiaries are supported by an agency that functions as the common law employer for workers recruited by beneficiaries. In this model, the beneficiary shares employer responsibilities, acting as the managing employer that provides on-the-job instruction and oversight (CMS 2024b). The coemployer model emerged in one state because state officials found it difficult to engage self-directing beneficiaries under the common law employer model: beneficiaries wanted more control of services but did not want all of the employer responsibilities. Similarly, a beneficiary advocacy organization in a different state said coemployment might be the right model for beneficiaries who do not want the full array of employer responsibilities.[24]

Even within a single self-directed HCBS program, states' selection of employer authority might vary by service and credentialing considerations. State agencies might offer employer authority based on what is practical for a given service. For example, a state Medicaid agency decided against allowing employer authority for home modifications due to concerns around verifying employee credentials for that service. Similarly, a national advocacy organization described how states consider which services can be delegated to non-licensed workers under self-direction to fill gaps in the traditional service delivery system. For example, a state operating agency found that employer authority is useful for homemaker, personal care, or transportation services but potentially less effective for clinical therapeutic intervention services, which require the beneficiary to hire a specialized or licensed provider.

Budget authority. Stakeholders noted that budget authority has become an increasingly popular option among both states and beneficiaries. Researchers and state officials agreed that budget authority provides beneficiaries with the most choice. Another researcher also highlighted that states with the largest increase in self-direction enrollment from 2019 to 2023 are those that allow budget authority.

When states implement budget authority, they must establish a process for determining individualized budgets, which can vary across and within states. CMS officials indicated that the process should be based on the needs and preferences outlined in the PCSP and level of care assessments (CMS 2024b). One state agency official shared plans to implement a standardized assessment tool across its self-direction programs to measure what services are needed and how frequently and analyze the data to develop individualized budgets. Another state Medicaid official noted it updated its budget determination process to ensure consistency across self-directed beneficiaries with similar care needs. Two states shared that since using budget authority can be complex for self-direction beneficiaries, they simplified their budget determination process by establishing minimum and maximum HCBS worker wages for specific self-directed services. Subject matter experts and state Medicaid agency officials cautioned that allowing self-directed beneficiaries to set wages for workers could create disparities between self-directed and agency-directed services.

Interviewees raised other challenges associated with the complexities of offering budget authority for self-directed services. One state Medicaid official noted that paying different rates for the same service can be difficult because their administrative systems normally associate a single service type with a single rate, not the variation permitted in self-direction. Other states and stakeholders noted that changes in care or budget assessments often lead to new budgets for consumers.

Family caregivers

States have the authority to determine who can provide HCBS under self-direction programs. In many cases, states offer the flexibility to allow family members, which may include legally responsible individuals such as spouses or parents of minor children, to deliver care under certain conditions (Teshale et al. 2021). Allowing family members to be paid caregivers is a benefit of the self-direction model, and many interviewees noted that it has helped address the national workforce shortage. However, interviewees also noted that it can be challenging to establish safeguards around family caregiving that ensure the provision of care while preserving the self-directing beneficiary's choice and control.

All case study states allowed for paid family caregivers in at least one of their self-direction programs. One state historically had not allowed family caregivers to provide services but received CMS approval to lift this restriction after feedback from families in the state. Another state allows family caregivers to be paid employees for most services, except for the live-in caregiver service. A third state we spoke with allows family caregivers to be paid employees but does not permit legally responsible family members to be paid.

State officials and consumer advocates shared that decisions to allow family caregivers to be paid employees are influenced by advocacy as well as recent caregiving flexibilities implemented during the public health emergency. These stakeholders discussed how employment of family caregivers can help address the national HCBS workforce shortage. They also noted that family caregiving can help provide culturally competent care. One state highlighted that allowing family caregivers to be paid employees allows their self-direction programs to reach diverse cultures and geographic areas in the state.

However, some researchers and state officials raised concerns about whether beneficiaries receive appropriate care when family caregivers are involved. One state Medicaid agency explained that it set strict standards around the hiring of family caregivers when beneficiaries direct their own services but does not set the same standards for family members employed under AwC. In that case, the AwC entity is responsible for overseeing the caregiver's performance. Another agency in that state noted the challenges of balancing program integrity with the need to preserve beneficiary choice and control. Finally, an MCO raised concerns about beneficiaries' reluctance to report critical incidents involving family caregivers. We also heard concerns about the lack of available data on family caregivers that can complicate state efforts to monitor self-directed care.

Issues around family caregivers often centered around compensation, beneficiary choice, and safety. One state shared that determining a family caregiver's compensation can create interpersonal tensions between family members. Additionally, we heard from some interviewees that decision making in self-direction may include family members in addition to the beneficiary, which can be an issue when that family member is also the caregiver.[25] Federal and state officials described this scenario as a potential conflict of interest, distinct from regulatory conflict of interest requirements, in which family members may feel they know what the beneficiary wants and potentially undermine the beneficiary's control and choice.[26] Finally, one state raised a concern about ensuring that family caregivers do not work more than 40 hours per week to avoid overworking and potentially causing a safety issue for the beneficiary and caregiver. The state's data and payrolling system tracks family caregiver hours across multiple beneficiaries to address this issue.

Considerations for State Administration

Through our interviews, we found that states have ample flexibility in administering their self-direction programs. Most of the states we interviewed administered their programs across multiple state operating agencies, with only one state hosting all of their self-direction programs under the state Medicaid agency. When administering information and assistance supports, states vary in how they define and structure the functions and in their collaboration across these entities. The roles of information and assistance support entities often overlap and may be difficult to clearly distinguish from one another.

Interviewees shared that FMS agencies may have a range of responsibilities, which vary by state and potentially even within a single state. States also employ different contracting strategies, and one state shared that two of its operating agencies provide FMS through its regional offices. Among states that contract with FMS agencies, state Medicaid and operating agencies can hold multiple FMS agency contracts to enhance beneficiary choice or only one FMS agency contract for a more streamlined approach.

State officials shared a variety of program-specific methods that states use for quality reporting, monitoring, and oversight in discussions around information and assistance supports, FMS provision, and managed care. Primarily, we found that states leverage information and assistance roles and FMS agencies to support those efforts. However, existing systems are generally not designed to stratify the data by self-directed and agency-directed beneficiaries. Limited data reporting and analysis capacities in self-direction may hinder state and national efforts to ensure quality and conduct effective monitoring and oversight.

Collaboration across programs

Some states administer self-directed HCBS solely through the state Medicaid agency, while others delegate program administration across multiple state agencies. Among the states we interviewed, the majority administer self-direction across multiple agencies. For example, one state we spoke with administers seven different self-direction programs across three agencies: the state Medicaid agency, the state's agency for developmental disabilities, and the department of aging (Box 5-1). This multiagency structure can lead to variation in how the different self-direction programs are administered within a state, an observation that multiple state officials noted. For example, some state operating agencies have different fiscal intermediaries than the state Medicaid agency.

The variation in how different state agencies administer self-direction requires collaboration across those agencies, something that generally works smoothly but can produce some challenges. In one state, officials noted that their self-direction programs are population specific; therefore, each is administered slightly differently, which requires collaboration across operating agencies. Officials in another state Medicaid agency emphasized the extensive collaboration and involvement in program administration across all the state's operating agencies. However, officials in a third state Medicaid agency said they experienced challenges working with operating agencies and getting responses in a timely manner when the state Medicaid agency needed to act quickly to implement new CMS requirements. They shared that any policy or operational changes that the state Medicaid agency wants to make require extensive negotiation and coordination with the operating agencies.

BOX 5-1. Self-Direction Case Study State: Ohio

Ohio operates Section 1915(c) waivers, which allow for self-directed home- and community-based services (HCBS), offering both budget and employer authority for a range of services and allowing family caregivers to be paid. The Ohio Department of Medicaid (ODM), Ohio Department of Aging (ODA), and Ohio Department of Developmental Disabilities (DODD) operate and oversee these programs for approximately 2,000 beneficiaries (Murray et al. 2024). This system is illustrated in the figure below.

ODM has jurisdiction over the Section 1915(c) Integrated Care Delivery System Waiver (or MyCare Ohio Waiver) and operates it in coordination with ODA, which gives beneficiaries dually eligible for Medicare and Medicaid who are age 65 and older and beneficiaries age 18 to 64 with physical disabilities the ability to self-direct their services through a managed care delivery system that is available in certain counties.

In addition, ODM has a new self-direction benefit under the Section 1915(c) Ohio Home Care Waiver program that is designed for beneficiaries younger than age 60 with physical disabilities or unstable medical conditions. Depending on the waiver, beneficiaries receive their case management through a case management entity or one that contracts with Area Agencies on Aging (AAAs) or through a managed care organization or one that contracts with AAAs.

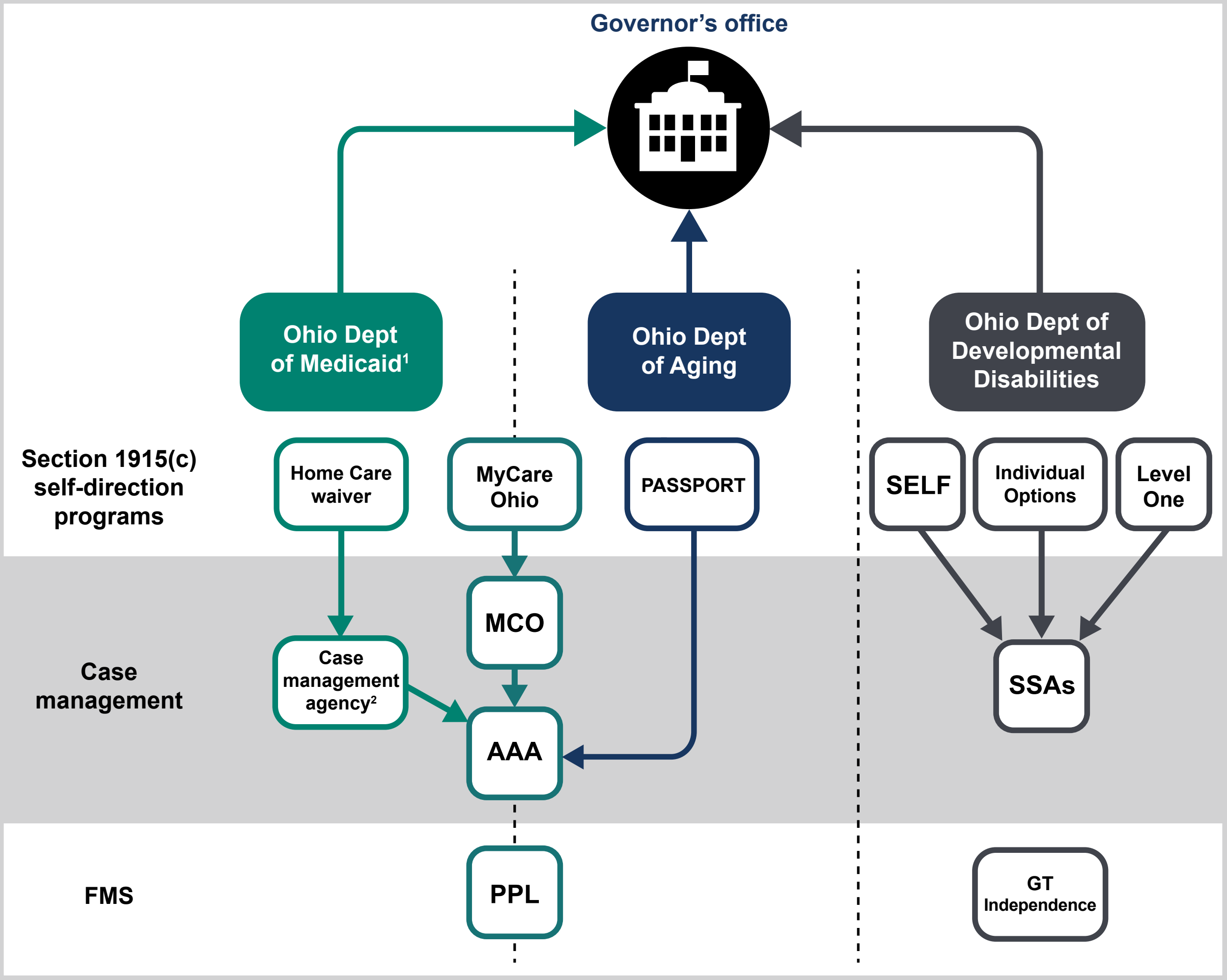
ODA also operates an HCBS waiver program—the Section 1915(c) PASSPORT waiver—which covers self-direction for beneficiaries with physical disabilities (age 60 to 64) and beneficiaries age 65 and older who may be dually eligible but are not enrolled in the Section 1915(c) MyCare Ohio Waiver. Similar to the programs under ODM, beneficiaries in the PASSPORT waiver program receive case management through AAAs. ODA and ODM share a contract with the same financial management services (FMS) agency for their FMS in these programs, Public Partnerships LLC.

Although each waiver program has distinct rules and requirements, many members naturally age out of the Section 1915(c) Home Care waiver or become dually eligible while on the PASSPORT waiver and transition into the Section 1915(c) MyCare Ohio waiver. The waivers are designed to help with this progression. For example, the services available through MyCare Ohio are inclusive of all the services offered under the Home Care waiver and PASSPORT. In addition, beneficiaries transitioning from either waiver to MyCare Ohio can retain their previous caregivers to support continuity of care.

Separately, DODD operates three Section 1915(c) waivers that offer self-direction for beneficiaries with intellectual and developmental disabilities—the Self Empowered Life Funding (SELF), Level One, and Individual Options waiver programs. These programs offer different services for self-direction, different levels of employer and budget authority, and varying budget determination methodologies. For example, the Section 1915(c) SELF waiver program, which is restricted to beneficiaries who want to self-direct, offers the greatest breadth of self-directed services, allowing the purchase of goods and services within an individualized budget. The Level One waiver program also allows for the purchase of goods and services but offers fewer services for self-direction. The Section 1915(c) Individual Options Waiver is the most restrictive, only offering transportation and self-directed homemaker/personal care services. Both the Section 1915(c) SELF waiver and Level One waiver have the same established budget amounts for individual services, while the Section 1915(c) Individual Options waiver uses an assessment process to develop personalized budgets for beneficiaries. Regardless of the waiver, case management services are provided via services and supports administrators at the county boards of developmental disabilities, and FMS are provided through a vendor, GT Independence.

Source: Murray et al. 2024.

BOX 5-1. (continued)



Notes: Dept is department. MyCare Ohio is Integrated Care Delivery System waiver. SELF is Self Empowered Life Funding waiver. MCO is managed care organization. AAA is area agency on aging. SSA is services and support administrator. FMS is financial management services. PPL is Public Partnerships LLC.

[1] ODM also offers limited self-direction in the OhioRISE waiver for beneficiaries younger than age 20 with serious emotional disturbance, which is not pictured in this graphic since it is limited to self-directing secondary flex funds through budget authority.

[2] ODM contracts with two case management agencies for the Ohio Home Care Waiver. One case management agency contracts with AAAs to provide case management, and the other provides the service themselves and not through AAAs.

Sources: Interview with Ohio state officials and a review of Ohio's Section 1915(c) waivers.

Information and assistance entities

State agencies must establish roles and responsibilities for state staff and third-party entities that provide information and assistance to Medicaid beneficiaries in support of self-direction. States either perform these functions directly or contract them out to third-party entities. Third-party entities can include MCOs and FMS agencies or state-supported HCBS providers such as AAAs and ADRCs. States may enlist multiple third-party entities to support their self-direction programs or limit the number of support entities, and both approaches have benefits and challenges. When working with third-party entities, state agencies define their expectations through vendor contract requirements. Several interviewees noted that state agencies may require that third-party entities, such as MCOs, FMS agencies, and AAAs, contract with each other to facilitate collaboration. Researchers, federal officials, national advocacy organizations, and national associations mentioned substantial variation in the level of collaboration and interactions between third-party entities in self-direction programs both within and across states.

State agencies vary in how they structure and define the roles of third-party entities in their information and assistance support systems. Information and assistance support entities can include information and assistance support professionals, case management entities, support brokerages, AAAs, beneficiary advocacy organizations, FMS agencies, and MCOs. Interviewees noted that their roles often overlap and may be difficult to clearly distinguish from one another.

Defining roles and structuring information and assistance supports. In setting up a system of information and assistance supports for beneficiaries using self-direction, state agencies may establish multiple distinct roles that various third-party entities fulfill or establish a stand-alone service that does not necessarily overlap with other roles. Stakeholders had different views on how to set up a system of information and assistance supports. Some expressed a preference for a more streamlined approach with stand-alone roles, while others preferred a layered system in which gaps are covered by allowing more than one entity to fulfill the same role. Regardless of the approach, stakeholders agreed that establishing clearly defined roles and responsibilities for third-party entities is critical.

The states in our case studies all established multiple roles in their information and assistance systems, and state officials generally noted that this approach works well; other stakeholders noted some challenges. Advocacy organizations shared that providing information and assistance supports through multiple independent entities diffuses responsibilities and causes roles to overlap unnecessarily. For example, some self-direction programs include an additional support broker role, which interviewees noted can provide self-direction-specific information and can also overlap with other roles, such as that of case managers.

A national advocacy organization shared that states typically choose entities to provide information and assistance based on existing structures and entities that beneficiaries are already familiar with, such as AAAs and ADRCs. These entities provide resources and education to beneficiaries in self-direction. State officials in one case study state primarily used AAAs to provide information and assistance supports for beneficiaries in one of their self-direction programs. According to an FMS agency we interviewed, AAAs can help them reach communities or regions with lower rates of self-directed HCBS referrals and enrollment. Leveraging these trusted organizations that are part of the service infrastructure for older adults and people with disabilities and that already have connections to community resources could help beneficiaries navigate the complicated self-direction landscape.

Among interviewees, findings around whether states should rely on existing entities to provide information and assistance supports were mixed. According to subject matter experts, beneficiaries who rely on existing entities to provide information and assistance may receive more streamlined information than through support brokerages or FMS agencies that are not already part of the broader service array for the HCBS population. In contrast, advocates noted that when multiple entities, in addition to existing ones, provide information and assistance support, beneficiaries may receive inconsistent or disparate information. Despite the advantage of leveraging existing networks, interviewees from two states noted that relying on established entities for options counseling can pose a challenge as they generally have less knowledge of self-direction compared with their understanding of the agency-delivery model, sometimes creating a bias toward agency-delivered services.

Since existing entities in a state may have less program-specific knowledge and large caseloads, some state agencies establish a support broker role that is specific to self-direction. By focusing solely on the self-direction programs available in a state, according to interviewees, the support broker helps beneficiaries navigate self-direction. The services a support broker provides vary by state and program, ranging from providing information and assistance to beneficiaries on the services that are available for self-direction to tailored, one-on-one coaching on managing HCBS workers. Some states offer support brokerage functions as a waiver service paid out of beneficiaries' direct budgets; other states provide this support as an administrative function. An FMS agency shared that when support brokerage services are offered as a waiver service rather than an administrative service, uptake may be lower because the payment for the support broker comes out of a beneficiary's individualized budget.

Although support brokers generally have more program-specific knowledge than other information and assistance support entities that serve the general HCBS population, there are challenges. According to interviewees, adding another role diffuses responsibility in the information and assistance supports system and increases variation in the quality of supports across different entities. For example, interviewees noted major variation in support brokers' training and the resulting quality of services that they provide. A support brokerage in one of the case study states noted that although they are required by the state Medicaid agency to have trainings for support brokers, their contracts with the Medicaid agency do not include specific training standards. As a result, each support brokerage in the state trains their employees differently. This variation in training can lead to variation in service quality but also allows these entities increased flexibility to design their trainings to meet internal standards for quality service delivery.

Across the case study states, the support broker roles were the least routinely defined, and case management entities and beneficiary advocacy organizations shared that they often perform the role of a support broker, providing coaching for beneficiaries in self-direction. Support brokers have program-specific knowledge that other information and assistance support professionals may not. As a result, other information and assistance support entities may struggle to provide these supports in addition to performing their other roles. These challenges with the support broker role are apparent across the different models that state agencies select to structure support broker services: (1) contracting with independent support brokers as a designated role, (2) establishing a support brokerage role nested within the FMS agency, and (3) incorporating the support brokerage services under case management.

Under the first model, in which the independent support broker is a designated role, one subject matter expert shared that although independent support brokers typically spend considerable time with beneficiaries, they add another entity to the information and assistance supports system, which requires information sharing across entities to be effective. A separate support brokerage entity is less streamlined and can diffuse responsibility across the information and assistance support system, such as the responsibility for supporting beneficiaries in acting as an employer. This expert also observed a trend toward more agency-based support brokerage approaches, since ensuring quality and removing underperforming support brokers is easier in an agency-based model. An interview with an FMS agency that serves multiple states corroborated this finding, sharing that support brokerage services were rarely a stand-alone support in the states they served.

In the second model, states pay the FMS agencies a separate fee to provide support broker services. An FMS agency interviewee shared that they prefer to host the support brokerage function within the FMS agency since FMS agencies have extensive knowledge of the self-directed program compared to independent support brokers. A state Medicaid agency agreed that it is helpful to have the support broker function within the FMS agency's scope because care coordinators or case managers may not have the capacity to provide these supports. The FMS agency representatives also noted that it is not always clear what services and supports a support broker is providing in states where that function is separate from the FMS agency. In these cases, the FMS agencies often find themselves educating the support brokers or providing some of these supports without explicit compensation. Despite potential advantages to this model, a subject matter expert noted that an FMS agency's support brokerage services are generally provided virtually or via phone conversations, which may reduce accessibility for some beneficiaries with low technological literacy or limited internet access.

In the third model, case managers provide the support broker services, but attitudes about this model were mixed. One state Medicaid agency shared that they have consultants who are expected to provide both case management and support brokerage services. However, stakeholders disagreed with state officials on this model's effectiveness. One advocacy organization in the same state shared that their staff often have to educate case managers on various aspects of the self-direction model. An MCO responsible for providing case management in a different state shared a similar challenge with integrating the case management and support broker roles. The MCO shared that their case managers struggle to perform both roles simultaneously and suggested establishing designated support brokers. In another state where case managers perform some support brokerage functions, state officials shared that they did not think it would be more effective for an external entity to perform those duties.

Collaboration across the information and assistance support system. Researchers, federal officials, national advocacy organizations, and national associations mentioned varying levels of collaboration in self-direction among information and assistance entities. One researcher described interactions between third-party entities as often minimal and of poor quality. The interviewee said that the most effective collaboration typically begins in response to an adverse event, adding that high turnover rates of third-party employees inhibit well-coordinated operations. In contrast, a state Medicaid agency official highlighted contracting requirements among information and assistance entities, FMS agencies, and MCOs as a tool to help with collaboration.

MCOs regularly interact with other information and assistance support entities and with FMS agencies. For example, one MCO shared that they collaborate with the combined support brokerage and FMS function through biweekly meetings. The MCO has access to the support broker portal, so they can see real-time notes, and employ a liason team to document interactions between the MCO and the FMS agency. During biweekly meetings, the MCO and the FMS agency escalate concerns and troubleshoot compliance issues. The FMS agency also shares files and data with the MCO, including records of beneficiaries completing trainings, which are a prerequisite for MCOs to authorize care for a beneficiary. The MCO then transfers their authorizations back to the FMS agency. The FMS agency also shares EVV data and claims data with the MCO and escalates potential fraud, waste, and abuse issues with the MCO. However, MCOs shared that there are challenges to collaborating directly with an FMS agency, since both the FMS agency and the MCO can, in some cases, contract exclusively with the state agency and not with each other. However, MCOs can mitigate this issue by maintaining continuous communication with partners and with the state. Both MCOs we spoke with said they have regularly scheduled standing meetings with their state Medicaid agency, describing these collaborative relationships as helpful to the operation of their self-directed programs.

State approaches to FMS

States may choose to have one, multiple, or no FMS agencies. For example, according to one of the FMS agency interviewees, one state they work in has about 200 FMS agency contracts, while another state we interviewed has only one (Texas HHSC 2025). State decisions regarding FMS structure, such as the choice to contract with one or multiple agencies or to allow MCOs to hold FMS contracts, represent a trade-off between minimizing administrative oversight and allowing beneficiary choice. One state agency noted that it can be challenging to establish a standardized and streamlined approach to the information and assistance that multiple FMS agencies provide. This challenge highlights a need for a more centralized system, especially when multiple information and assistance entities are collaborating. An MCO working in a state with only one FMS agency identified benefits to this approach, stating that it is easier to collaborate with other MCOs in the state and troubleshoot similar challenges with just one FMS agency. However, the MCO noted that this approach has trade-offs. For example, increasing competition among multiple FMS agencies within the state could result in higher-quality FMS. Another MCO and some state officials noted that having multiple FMS agencies in a state gives beneficiaries more opportunities to match their needs with services—for example, choosing an FMS agency that offers more beneficiary supports.[27]

One state we interviewed only uses an FMS agency for some of its self-direction programs, whereas others operate via a county-based model. The state Medicaid agency and an operating agency we spoke with in that state both prefer the latter model. In particular, officials with the state Medicaid agency said that its data system operated by the counties functions like an FMS agency, and thus, they do not need a separate FMS agency.

Quality reporting, monitoring, and oversight

Over the course of discussions around information and assistance supports, FMS provision, and managed care, we identified a variety of methods that states use to administer their self-direction programs through quality reporting, monitoring, and oversight. However, data are limited, and states primarily rely on information and assistance entities and FMS agencies to support these functions. At the federal level, it is not possible to identify total spending and enrollment that is specific to self-directing Medicaid beneficiaries. At the state level, officials rely on information from contracted entities to support their oversight processes, but poor data systems infrastructure and limited interoperability can pose challenges.

Entities supporting monitoring and oversight. States rely on information from contracted entities for their oversight and monitoring processes. One subject matter expert suggested that FMS agencies play a major role in monitoring and overseeing the total service hours a beneficiary receives and in reporting this information to the state. For example, three FMS agencies that serve multiple states and state agency officials said that FMS agencies share data with the state to support oversight activities, including authorizations and claims data, summary notes from service visits, and payment information. FMS agencies also noted that they develop data dashboards for states. This data sharing supports quality reporting, monitoring, and oversight. Another state Medicaid agency highlighted that their FMS agency developed system flags to notify them when an HCBS worker is being paid over an established threshold, either signaling that they may be working too many hours and the beneficiary needs additional training to effectively manage their service hour allotment or prompting investigations to ensure beneficiaries are receiving the services outlined in their PCSPs.

States also rely on other information and assistance support functions and internal processes to support quality reporting, monitoring, and oversight. For example, one state shared that it receives weekly utilization reports that its support brokers and regional offices monitor.[28] Other states identified internal quality monitoring processes that ensure HCBS workers are up to date on any required state certifications or licensing. However, state officials may face challenges to these existing quality reporting, monitoring, and oversight processes as their self-direction models grow. State officials noted that adapting to substantial increases in enrollment strained their monitoring and oversight capabilities.

Data systems. At the federal level, stratifying self-directing Medicaid beneficiaries from the broader HCBS population can be a challenge. Subject matter experts shared that they cannot comprehensively identify spending in self-direction or Medicaid-specific enrollment. CMS does not require personal identifiers for beneficiaries self-directing their services in the Transformed Medicaid Statistical Information System (T-MSIS), which further limits analysis (Doty 2025, Srinivasan et al. 2024).

Among states, reporting and monitoring capabilities may present challenges to effective data collection efforts in self-direction. Several interviewees cited poor data systems infrastructure and limited interoperability among entities as key barriers to administration of self-direction programs. Also, in one state, officials noted that data collection processes vary across operating agencies. One state Medicaid agency said they need a robust data infrastructure to validate hours for reimbursement accurately. Another state Medicaid agency struggled with stratifying self-directing beneficiaries in data analysis and reporting. One MCO that supports self-direction program monitoring identified an inability to directly access the FMS agency's EVV data system portal as a major delay in their monitoring processes. Due to the delays in transferring the FMS agency's EVV data to the MCO, they said that it can be weeks or months before they know that a beneficiary is not getting their prescribed care.

Many interviewees referenced EVV as a method to ensure quality and conduct program monitoring and oversight in self-direction, but EVV systems are new, and a few states are still in the implementation phase. After an audit by the Office of Inspector General at the U.S. Department of Health and Human Services found that self-directed personal care services were particularly susceptible to fraud, through the enactment of the 21st Century Cures Act (P.L. 114-255), federal officials implemented EVV requirements (OIG 2015, 2012). EVV is a tool for states to detect and address potential instances of fraud, waste, and abuse (CMS 2018).[29] Subject matter experts, state interviewees, and federal officials specifically identified the global positioning system tracking requirement as well as required check-ins and checkouts in EVV as some of the most challenging aspects of the system for HCBS workers to implement. Still, multiple stakeholders have found EVV to be useful in monitoring for instances of fraud, waste, and abuse. One MCO noted that global positioning system data in EVV are especially useful in flagging potential fraud. For example, if a service is logged as being provided in an out-of-state location, the MCO would pull records, question, and exchange files to ensure program integrity.

Given some of the challenges states face in effective monitoring, some interviewees acknowledged the future implications of the CMS final rule on ensuring access to Medicaid services and the requirements it established in supporting quality monitoring of self-direction programs (CMS 2024h). In the final rule, states must report on the length of time it takes for a self-directing beneficiary to receive services from the day that they were enrolled in the program (42 CFR 441.311(d)(2), CMS 2024h). Officials from one state Medicaid agency said that the final rule will help assist with quality reporting, monitoring, and oversight through this requirement. The final rule also includes provisions on rate transparency and reporting requirements that directly impact certain self-directed services, including homemaker, home health aide, personal care, and habilitation services (Appendix 5B) (CMS 2024h). Officials from the same state Medicaid agency also said that the final rule will help them create more standardized program administration processes across the different state operating agencies. Federal officials said that states will need to ensure that self-directing HCBS beneficiaries and their HCBS workers understand that these requirements, such as critical incident reporting requirements, are applicable to them.

Looking Ahead

Self-direction of HCBS continues to evolve as a model that can offer Medicaid beneficiaries choice while alleviating the burdens of the national HCBS workforce shortage. This study identifies considerations that states can take into account when they design and administer these programs. State agencies implement flexible statutory and regulatory requirements differently, depending on Medicaid authority, HCBS subpopulation, budget authority, employer authority, and other factors. The variation reflects the flexibility states have to tailor their self-directed HCBS programs to meet their programmatic priorities.

Endnotes

[1] A PCSP is a document describing the services and supports that are important for the individual to meet the needs identified in the functional assessment as well as what is important to the individual with regard to preferences for the delivery of HCBS (42 CFR 441.301(c)(2)).

[2] Sometimes the budget authority model is referred to as the "Cash and Counseling" model. In this study, we reviewed self-direction programs that offer employ authority, budget authority, or both.

[3] States are mandated through 42 CFR 441.740(e) to offer the following functions in support of self-direction for their applicable programs: information and assistance; FMS; and voluntary training on how to select, manage, and dismiss providers.

[4] Mathematica, in partnership with MACPAC, conducted interviews with representatives from the Direct Care Workforce Strategies Center, National Council on Aging; Center for Medicaid and CHIP Services, Division of LTSS; National Academy for State Health Policy; Applied Self-Direction; AARP; Pennsylvania State University; Alabama Medicaid Agency; Alabama Department of Mental Health, Developmental Disabilities Division; California Department of Health Care Services; California Department of Social Services; California Department of Developmental Services; MassHealth; Massachusetts Department of Developmental Services; Ohio Department of Medicaid; Ohio Department of Developmental Disabilities; Ohio Department of Aging; Tennessee Division of TennCare; Tennessee Department of Intellectual and Developmental Disabilities; Wisconsin Department of Health Services, Division of Medicaid Services; The Arc of Massachusetts; CareSource; Community Living Alliance; Consumer Direct Care Network; GT Independence; Justice in Aging; Lutheran Social Services Connections; Massachusetts Regional Self-Direction Managers (regional offices); Public Partnerships LLC; San Diego County IHSS Office; Top of Alabama Regional Council of Governments; Wellpoint; and Wisconsin Board for People with Developmental Disabilities.

[5] The individualized budget is required only when a beneficiary has budget authority.

[6] These data do not include self-directed programs that exclusively offer respite.

[7] Slightly less than half of states have self-direction programs available for adults with SMI and children with SED; however, this program count appears larger than it is because state plan Medicaid authorities do not allow for population targeting (Murray et al. 2024). Therefore, although someone with SMI or SED could potentially qualify for such self-direction programs, they often do not meet the institutional level of care or functional needs requirements to be eligible, as the nature of their disability is different.

[8] Offering personal care services has been a state plan option since the mid-1970s, when it was established administratively under the authority of the Secretary of Health and Human Services (ASPE 2010). However, it was not formally added to the list of services in the Medicaid statute until 1993 (ASPE 2010).

[9] Consumer direction is outlined in the state Medicaid manual at Section 4480: “A State may employ a consumer-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of the personal care services and, if necessary, fire the provider. The State Medicaid Agency maintains responsibility for ensuring the provider meets State provider qualifications . . . and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the State may either provide personal care services without consumer direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services” (CMS 2025).

[10] The Robert Wood Johnson Foundation sponsored another demonstration program separate from, but philosophically related to, the Cash and Counseling Demonstration and Evaluation. From 1994 to 2001, the Robert Wood Johnson Foundation gave grants to local and state government agencies initially in New Hampshire and subsequently in 18 other states for “self-determination” projects targeting adults with I/DD. Conceptually, self-determination is not quite the same as self-direction, but, over time, the two have come to be seen as closely intertwined. The self-determination projects emphasized a person-centered planning process that encompassed not just the development of a Medicaid-funded service plan but sought to identify the goals, preferences, and developmental potential of individuals with I/DD to enable them to experience meaningful and fulfilling lives (Conroy et al. 2002).

[11] Originally, the Office of the Assistant Secretary for Planning and Evaluation and the Robert Wood Johnson Foundation selected four states to participate in the Cash and Counseling Demonstration and Evaluation. However, in 1999, New York left the demonstration due to difficulties in recruiting (Mahoney and Simone 2016).

[12] When this authority is paired with Section 1915(a) or Section 1915(b) authority, states can offer self-direction within managed care systems (CMS 2024i, Doty et al. 2010).

[13] Section 1115 demonstrations are authorized by the Balanced Budget Act of 1997 (P.L. 105-33), while the Section 1915(i) and Section 1915(k) Community First Choice state plan options were established by the Deficit Reduction Act of 2005 (P.L. 109-171) and the Patient Protection and Affordable Care Act (P.L. 111-148, as amended), respectively.

[14] Under Section 1905(a)(24) state plan personal care services, a state may employ a self-directed service delivery model to provide personal care services under the personal care optional benefit to individuals in need of personal assistance, including persons with cognitive impairments, who have the ability and desire to manage their own care. In such cases, the Medicaid beneficiary may hire their own provider, train the provider according to their personal preferences, supervise and direct the provision of the personal care services, and, if necessary, fire the provider. The state Medicaid agency maintains responsibility for ensuring the provider meets state provider qualifications and for monitoring service delivery. Where an individual does not have the ability or desire to manage their own care, the state may either provide personal care services without self-direction or may permit family members or other individuals to direct the provider on behalf of the individual receiving the services.

[15] The federal government sets certain conditions of participation for personnel who provide certain services. For example, home health aides must have a minimum of 75 training hours (42 CFR 484.80). States may establish additional standards for personnel who provide such services, such as home health aides (42 CFR 484.80). In self-direction, the beneficiary can define further training and certification requirements for these personnel who provide HCBS beyond federal and state minimum standards (CMS 2024b). Regulations at 42 CFR 440.70(d) specify that home health agencies participating in the Medicaid program must also meet the Medicare conditions of participation, which are set forth in regulations at 42 CFR 484 (CMS 2017).

[16] In addition to training and certification requirements for HCBS workers that a state deems appropriate, in self-direction, the beneficiary or representative must identify the specific training needed to meet their needs for assistance as part of the PCSP (CMS 2024b). A state may not allow the HCBS worker qualifications to be solely specified in the PCSP or by the participant and must establish the essential minimum qualifications that an HCBS worker must meet to be deemed qualified and ensure the requirements are met when HCBS are provided (CMS 2024b).

[17] Direct support professionals are a type of HCBS worker that supports people with disabilities to remain engaged with their community and provides caregiving and support with activities of daily living (ODEP 2025). Job development staff or job coaches are an example of direct support professionals (ODEP 2025).

[18] Section 1915(c) waiver technical guidance from CMS defines “extraordinary care” as care that exceeds the range of activities that a legally responsible individual would ordinarily perform in the household on behalf of a person without a disability or chronic illness of the same age and that is necessary to ensure the health and welfare of the participant and avoid institutionalization (CMS 2024b). For example, a legally responsible individual supporting a teenage child enrolled in a waiver with activities of daily living such as bathing and dressing could constitute extraordinary care, as teenage children without a disability or chronic illness do not typically require such support. States that do allow legally responsible individuals to provide personal care or similar services must specify the situations in which payment may be approved for the delivery of exceptional care and describe how the state ensures that services provided by this individual are in the participant’s best interest (CMS 2024b).

[19] The regulations at 42 CFR 441.575 specifically require that the majority of the Development and Implementation Council members be composed of individuals with disabilities, elderly individuals, and their representatives. The regulations require the state to consult and collaborate with the council when developing and implementing a state plan amendment to provide Community First Choice services and supports.

[20] Through interviews with state officials, we found that some states may refer to their support brokers as “independent facilitators.” This definition is focusing on independent facilitators in states that have separate support broker and independent facilitator functions.

[21] Several states operate self-direction programs across multiple HCBS authorities. Some states shared that operating multiple authorities can present administrative challenges. Another state plans to phase out legacy Section 1915(c)-only waivers and enroll all self-directed beneficiaries in programs operating under both Section 1915(c) and 1915(j) to improve program flexibilities.

[22] Natural supports are unpaid supports that are provided voluntarily to the individual in lieu of HCBS state plan or waiver services and supports (42 CFR 441.301, 441.725). Individuals who provide natural supports may include but are not limited to family members, neighbors, friends, and other personal associations and relationships.

[23] Federal officials noted that self-direction is not as prevalent for the older adult population, as many individuals receive

residential or assisted living services, so they have limited opportunities for self-direction.

[24] Under the Fair Labor Standards Act, the AwC FMS agency can be considered a third-party employer and be required to pay overtime (Appendix 5B).

[25] A beneficiary's paid provider is not allowed to also serve as the beneficiary's representative who makes decisions for, or in coordination with, the beneficiary (42 CFR 441.505, 441.480).

[26] Section 1915(c), 1915(i), 1915(j), and 1915(k) authorities have conflict of interest requirements in place to ensure the independence of individuals performing case management or assessment functions from those who provide HCBS to participants (42 CFR 431.301(c)(1)(vi), 441.468(d), 441.555(c), 441.730(b)).

[27] FMS agencies may offer some additional supports to compete with other FMS agencies in a state for clients.

[28] Regional offices are state-run centers that oversee self-direction programs in their area and communicate with information and assistance support entities and FMS agencies. In some cases, they may hold contracts with FMS agencies or information and assistance support entities. A state agency, such as the state Medicaid agency or operating agency, oversees the regional offices.

[29] Section 1903(l)(5)(A) of the Act (42 USC 1396) defines EVV as "a system under which visits conducted as part of such [personal care and home health care] services are electronically verified with respect to (i) the type of service performed; (ii) the individual receiving the service; (iii) the date of the service; (iv) the location of service delivery; (v) the individual providing the service; and (vi) the time the service begins and ends."

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APPENDIX 5A: Statutory Authorities Used for Self-Directed Medicaid Home- and Community-Based Services

States cover self-directed Medicaid home- and community-based services through one or more statutory authorities, including waivers and state plan options (Table 5A-1).

TABLE 5A-1. Statutory Authorities for Self-Directed Medicaid Home- and Community-Based Services

Type of authority	Authority	Description	Budget authority	Employer authority	Permits payment of relatives	Permits payment of legally responsible individuals	Total states using authority for self-direction
Waiver	Section 1915(c)	Allows states to offer a wide range of home- and community-based services (HCBS) to individuals who meet an institutional level of care. Also allows states to forgo certain Medicaid requirements to target HCBS benefits to specific populations, cap the number of beneficiaries who receive these benefits, and create waiting lists for people who cannot be served under the enrollment cap.	Yes, but no direct cash payments.	Yes	Yes	Yes	46
	Section 1115	Not specific to HCBS, Section 1115 demonstration authority is a broad authority that allows states to test new delivery models that advance the goals of the Medicaid program.	Yes, but no direct cash payments.	Subject to specific requirements in approved demonstration	Yes	Yes	14

TABLE 5A-1. (continued)

Type of authority	Authority	Description	Budget authority	Employer authority	Permits payment of relatives	Permits payment of legally responsible individuals	Total states using authority for self-direction
State plan	Section 1905(a)(24)	Allows states to cover personal care services but does not give beneficiaries using self-direction the authority to manage their own individual service budget.	No	Yes	No	No	–
	Section 1915(i)	Allows states to offer HCBS to people who need less than an institutional level of care, the typical standard for Medicaid coverage of HCBS. States can also establish specific criteria for people to receive services under this authority.	Yes, but no direct cash payments.	Yes	Yes	Yes	4
	Section 1915(j)	Gives authority for self-directed personal assistance services (PAS), providing beneficiaries with the ability to hire and direct their own PAS attendant. States may also give beneficiaries the authority to manage their own individual service budget. This authority is used in conjunction with state plan PAS or other HCBS authorities such as Section 1915(c) waivers.	Yes, required. Cash payments are allowed to beneficiaries.	Yes	Yes	Yes	7
	Section 1915(k)	Known as Community First Choice (CFC), this option provides states with a 6 percentage point increase in the federal medical assistance percentage (FMAP) for PAS.	Yes, cash payments are allowed to beneficiaries.	Yes	Yes	Yes	8

TABLE 5A-1. (continued)

Notes: Under self-direction, beneficiaries, or their representatives if applicable, have decision making authority and responsibility for managing all aspects of their service delivery in a person-centered planning process with the assistance of a system of available supports.

– Dash indicates data were not available on that authority.

Sources: CMS 2024; Murray et al. 2024; Sections 1115, 1905(a)(24), 1915(c), 1915(i), 1915(j), and 1915(k) of the Social Security Act; 42 CFR 440.70(b).

APPENDIX 5B: Final Rules and Guidance

The Centers for Medicare & Medicaid Services (CMS) has issued a variety of final rules and guidance documents that establishes a comprehensive regulatory framework through which states administer their Medicaid self-directed home- and community-based services (HCBS). These rules and accompanying guidance have a direct impact on self-direction program design and administration and intend to enhance choice, control, and flexibility for beneficiaries self-directing their services.

Revised Section 1915(c) waiver application (2004–2007). CMS refined the criteria and guidance to states surrounding self-direction in its Section 1915(c) HCBS waiver application and instructions, technical guide, and review criteria (CMS 2024a). These modifications were designed to encourage states to include self-direction across their HCBS waiver programs (CMS 2009a). Revisions pertaining to self-direction included the incorporation of employer authority and budget authority into the application as well as requirements for the inclusion of information and assistance supports (CMS 2024a). These changes to the waiver application ultimately replaced the Independence Plus framework, which states previously had to use when implementing self-direction under a Section 1115 demonstration or a Section 1915(c) waiver, streamlining the waiver application and review process (CMS 2024a, 2002).

Federal guidance on the implementation of Section 6087 of the Deficit Reduction Act of 2005 (P.L. 109-171) (2007). In this state Medicaid directors' letter, CMS provides guidance on state requirements for administering self-directed personal assistance services (PAS) via a Section 1915(j) state plan authority (CMS 2007). These guidelines include an overview of payment methodology options under Section 1915(j) authority, minimum state assurances, reporting requirements, and state flexibilities regarding eligibility, conditions for disenrollment, and options for individual budget authority (CMS 2007). The guidance emphasizes that self-direction participants in a Section 1915(j) state plan or Section 1915(c) waiver program have access to counseling on self-directed options before enrollment in addition to a support system that can "inform, counsel, train, and assist participants with their employer-related responsibilities, including managing their workers and budgets and performing their fiscal and tax responsibilities" (CMS 2007). The guidance also directs states to submit an annual report on the total number of enrollees self-directing their services under Section 1915(j) state plan authority as well as total expenditures (CMS 2007). States must also conduct an evaluation every three years that compares beneficiaries' health and wellness in this state plan option with those who elected not to participate in self-directed PAS (CMS 2007). Although self-directed PAS under Section 1915(j) authority is a state plan option, the guidance clarifies that it does not need to be available throughout the entire state, and the state may limit the population eligible to self-direct and the number of individuals self-directing (CMS 2007). Last, the state may allow beneficiaries to have budget authority under this state plan option, and beneficiaries are not required to use a financial management services (FMS) agency if they are using the cash option (CMS 2007).

Self-directed PAS program state plan option, final rule (2008). Through this final rule, CMS provides guidance to states in administering self-directed PAS under Section 1915(j) of the Social Security Act, as authorized by the Deficit Reduction Act of 2005 (CMS 2008a). This rule establishes the framework for self-directed PAS, including requirements for person-centered planning, a risk management system, using budget authority, and using FMS (CMS 2008a).

Specifically, the final rule implemented a series of requirements that states must meet before pursuing self-directed PAS under this provision. First, states must have an existing personal care services benefit or be operating an HCBS waiver program before implementing self-directed PAS under this state plan option (CMS 2008a, 2008b). Second, all enrollment in the program must be voluntary, and for beneficiaries who choose to later disenroll from the program, a traditional, agency-delivered HCBS option must be available (CMS 2008a, 2008b). Last, states need to have quality assurances and other safeguards that ensure the health and welfare of beneficiaries participating in the self-direction state plan option (CMS 2008a, 2008b). These must also include a support system to provide “sufficient information, training, counseling, and assistance to participants” so they may manage their budgets and services (CMS 2008b). Key components of this support system include support brokers or consultants and FMS agencies (CMS 2008a).

Federal guidance on the implementation of Section 6087 of the Deficit Reduction Act of 2005. In a second state Medicaid directors’ letter on the optional choice to self-direct PAS, CMS provides additional clarification on beneficiaries’ use of their individual budget authority for “permissible purchases” (CMS 2009b). This guidance also applies to the purchase of “individual directed goods and services” under a Section 1915(c) waiver. The key criterion beneficiaries must adhere to when purchasing these goods and services with their individual budget authority is that “the purchase be related to a need or goal identified in the participant’s State-approved person-centered service plan” (CMS 2009b). The guidance directs states to make available supports brokers or consultants for self-direction participants under these authorities to provide appropriate information, counseling, training, and assistance, as needed or desired by participants, to enable participants to effectively direct the service planning and budget planning process, develop their service plans and individualized budget plans, and manage and direct their service and budget plans (CMS 2009b). State Medicaid agencies must also design procedures for effective oversight of spending on goods and services, including an annual reassessment of participants, which incorporates their use of goods and services to supplant human assistance needs (CMS 2009b).

Community First Choice option, final rule (2012). This final rule implements the Community First Choice state plan option under Section 1915(k) of the Social Security Act, as authorized under the Patient Protection and Affordable Care Act (P.L. 111-148, as amended) (CMS 2012a). The Community First Choice state plan option provides home- and community-based attendant services and supports at a 6 percentage point increase in the federal medical assistance percentage (FMAP) (CMS 2012a). Among other major provisions, this rule expands opportunities for self-direction, allowing beneficiaries to select and manage their attendant services and supports (CMS 2012a). The final rule mandates that states use a person-centered service plan that is based on a functional needs assessment (CMS 2012a). The person-centered service plan must also allow attendant services to be provided in either a traditional service-delivery model or a self-directed model within a defined service budget (CMS 2012a). Additionally, the final rule clarifies definitions of self-direction and the “self-directed model with service budget,” also referred to as “individual budget authority” (CMS 2012a).

HCBS, final rule (HCBS Settings Rule of 2014). This final rule defines and describes state plan Section 1915(i) HCBS, offering new flexibilities for providing services for the elderly and people with disabilities (CMS 2014a). In addition to establishing requirements around the qualities of settings eligible for Medicaid reimbursements under HCBS programs, including settings requirements for Community First Choice, the rule requires states to implement person-centered planning processes, which are critical for self-direction programs (CMS 2014a). The rule amends Section 1915(i) of the Social Security Act outlining minimum supports for self-direction participants, including information and assistance, FMS supports, and the availability of an independent advocate to assist with access to and oversight of self-directed HCBS (CMS 2012b). Last, it defines both employer authority and budget authority (CMS 2014a, 2012b).

Self-direction and the implementation of the Fair Labor Standards Act regulation changes (2014). Pursuant to changes in the Fair Labor Standards Act, states operating self-direction models with a “third party joint employer” must ensure that direct care workers’ (DCWs) work meets the minimum wage and overtime requirements (CMS 2014b). This guidance provides an overview of the “economic realities test,” so states may determine which of their self-directed programs are impacted by the regulatory changes in the Fair Labor Standards Act. The guidance also identifies reimbursement options for third parties when a DCW provides services to multiple beneficiaries (CMS 2014b). For example, reimbursing a DCW for overtime or travel when split across multiple self-directing beneficiaries may be challenging (CMS 2014b). Additionally, these costs may not be deducted from an individual beneficiary’s budget or the administrative costs for a third party (CMS 2014b). The reimbursement frameworks include both a capitated and fee-for-service approach.

Medicaid and CHIP managed care, final rule (2016). This rule updates regulations governing Medicaid managed care, including specific provisions that impact self-directed HCBS. The rule encourages states to include self-direction within their managed care system (CMS 2016). It also bolsters existing principles of self-direction by mandating person-centered planning for all managed long-term services and supports beneficiaries (including those in self-direction) and including consumer protections and supports (CMS 2016). These protections require managed care organizations to provide beneficiaries with clear information about self-direction options, access to adequate networks of qualified providers, and a robust grievance and appeals process (CMS 2016). It also mandates separation between the roles of care planning and service delivery to ensure beneficiaries have guidance and support in directing their services that are free from potential conflicts of interest (CMS 2016).

Ensuring access to Medicaid services, final rule (2024). This rule aims to ensure access to Medicaid services, and its provisions regarding rate transparency and reporting requirements directly impact self-directed homemaker, home health aide, personal care, and habilitation services (CMS 2024b). The rule mandates that at least 80 percent of all Medicaid payments must be spent on compensation to direct care workers for homemaker services, home health aide services, and personal care services (CMS 2024b). States must report on the percentage of payments for homemaker, home health aide, personal care, and habilitation services that are spent on compensation for DCWs at the provider level (CMS 2024b). For self-direction, the state must report separately on the compensation for self-directed services but exclude payment data for self-directed services for which individuals have budget authority (CMS 2024b). Last, the reporting and payment adequacy requirements apply only to services provided through Section 1915(c) waivers; Section 1915(j), 1915(k), and 1915(i) state plan authorities; and managed care delivery systems authorized under Section 1115(a), but they do not apply to Section 1905(a) state plan services (CMS 2024b).

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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 quarternary 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.

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 the Centers for Medicare & Medicaid Services. 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 of business administration from Virginia Commonwealth University.

Jennifer L. Gerstorff, FSA, MAAA, is a partner consulting actuary at Mercer, where she focuses on Medicaid and other government programs. Over the course of her consulting career, she has served as lead actuary for several state Medicaid agencies. In addition to supporting state agencies through her consulting work, Ms. Gerstorff actively volunteers with the Society of Actuaries and American Academy of Actuaries work groups, participating in research efforts, developing content for continuing education opportunities, and facilitating monthly public interest group discussions with Medicaid actuaries and other industry experts. She received her bachelor in applied mathematics from Columbus State University.

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.

April Hartman, MD, FAAP, is a board-certified general pediatrician with over 25 years of clinical experience in both rural and urban settings. She serves as professor and division chief of general pediatric and adolescent medicine at the Medical College of Georgia at Augusta University. She currently chairs the Medicaid Task Force for the Georgia Chapter of the American Academy of Pediatrics; serves as president of the Board of Directors for Child Enrichment, Inc.; and is the medical liaison for Resilient Communities of East Georgia. Dr. Hartman earned her medical degree from Meharry Medical College in Nashville, Tennessee.

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 is also a dually eligible Medicaid and Medicare beneficiary enrolled in One Care, a plan operating in Massachusetts under the CMS Financial Alignment Initiative. Mr. Heaphy is engaged in activities that advance equitable whole person-centered care for beneficiaries in Massachusetts and nationally. He is cofounder of Disability Advocates Advancing Our Healthcare Rights (DAAHR), a statewide coalition in Massachusetts. DAAHR was instrumental in advancing measurable innovations that give consumers voice in One Care. Examples include creating a consumer-led implementation council that guides the ongoing development and implementation of One Care, an independent living long-term services and supports coordinator role on care teams, and an independent One Care ombudsman. Previously, he worked as project coordinator for the Americans with Disabilities Act for the Massachusetts Department of Public Health (MDPH) and remains active on various MDPH committees that advance health equity. In addition to policy work in Massachusetts, Mr. Heaphy is on the advisory committee of the National Center for Complex Health & Social Needs and the Founders Council of the United States of Care. He is a board member of Health Law Advocates, a Massachusetts-based nonprofit legal group representing low-income individuals. He received his master of public health and master of divinity from Boston University and master of education from Harvard University.

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 the Centers for Medicare & Medicaid Services, 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 and chair of the New Mexico Medical Insurance Pool. Ms. Ingram earned her bachelor's degree from the University of Puget Sound and her master of business administration from New Mexico State University.

Anne Karl, JD, is a partner at Manatt Health with 15 years of experience in health care. She advises states and providers across the country on a wide range of Medicaid and CHIP issues. Ms. Karl has expertise with complex Medicaid payment and financing issues. She also leads teams that support states as they develop, negotiate, and implement Medicaid 1115 waivers. Ms. Karl received her law degree from Yale Law School.

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.

Adrienne McFadden, MD, JD, is vice president and chief medical officer of Medicaid at Elevance Health, where she serves as the strategic clinical thought leader for the Medicaid line of business. After beginning her career in emergency medicine, Dr. McFadden has held multiple executive and senior leadership roles in health care, digital health, and public health. Dr. McFadden received her medical and law degrees from Duke University.

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.

Jami Snyder, MA, is the president and chief executive officer of JSN Strategies, LLC, where she provides health care-related consulting services to a range of public and private sector clients. Previously, she was the Arizona cabinet member charged with overseeing the state's Medicaid program. During her tenure, Ms. Snyder spearheaded efforts to stabilize the state's health care delivery system during the public health emergency and advance the agency's Whole Person Care Initiative. Ms. Snyder also served as the Medicaid director in Texas and as the president of the National Association of Medicaid Directors. Ms. Snyder holds a master's degree in political science from Arizona State University.

Biographies of Staff

Annie Andrianasolo, MBA, is the chief administrative officer. Most recently, Andrianasolo managed the chief executive officer's office at the Pharmaceutical Research and Manufacturers of America. Andrianasolo previously worked for various nonprofit organizations, including the Public Health Institute, the Minneapolis Foundation, and the World Bank. Andrianasolo holds a bachelor of arts in economics from the University of the District of Columbia and a master of business administration from Johns Hopkins University.

Gabby Ballweg is an analyst. Before joining MACPAC, Ballweg worked as the project coordinator for the Wisconsin Community Health Empowerment Fund and interned at Action on Smoking and Health. Ballweg graduated from the University of Wisconsin, Madison, with a bachelor of science in biology and political science.

Kirstin Blom, MIPA, is a policy director. Before joining MACPAC, Blom was an analyst in health care financing at the Congressional Research Service. Before that, Blom worked as a principal analyst at the Congressional Budget Office, estimating the federal budgetary effects of proposed legislation affecting the Medicaid program. Blom has also been an analyst for the Medicaid program in Wisconsin and for the U.S. Government Accountability Office. Blom 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, Broder led strategic communications for a variety of health policy organizations and foundations, developing and implementing communications strategies to reach both the public and policymakers. Broder has extensive experience working with researchers across multiple disciplines to translate and communicate information for the public. Earlier positions include working as a reporter covering health and technology policy issues. Broder holds a bachelor of science in journalism from Ohio University.

Drew Gerber, MPH, is an analyst. Before joining MACPAC, Gerber consulted with the Minnesota Department of Human Services on long-term services and supports financing options and served as project manager for the University of Minnesota's COVID-19 modeling effort. Gerber holds a master of public health in health policy from the University of Minnesota and a bachelor of science in journalism and global health from Northwestern University.

Tamara Huson, MSPH, is the contracting officer and a senior analyst. Before joining MACPAC, Huson worked as a research assistant in the Department of Health Policy and Management at The University of North Carolina. Huson also worked for the American Cancer Society and completed internships with the North Carolina General Assembly and the Foundation for Health Leadership and Innovation. 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.

Joanne Jee, MPH, is a policy director. Before joining MACPAC, Jee was a program director at the National Academy for State Health Policy, focused on children's coverage issues. Jee also has been a senior analyst at the U.S. Government Accountability Office, a program manager at The Lewin Group, and a legislative analyst in the U.S. Department of Health and Human Services Office of Legislation. Jee has a master of public health from the University of California, Los Angeles, and a bachelor of science in human development from the University of California, Davis.

Linn Jennings, MS, is a senior analyst. Before joining MACPAC, Jennings worked as a senior data and reporting analyst at Texas Health and Human Services in the Women, Infants, and Children program and as a budget and policy analyst at the Wisconsin Department of Health in the Division of Medicaid. Jennings holds a master of science in population health sciences with a concentration in health services research from the University of Wisconsin, Madison, and a bachelor of arts in environmental studies from Mount Holyoke College.

Patrick Jones, MPP, is an analyst. Before joining MACPAC, Jones served as a consultant at Koné Consulting, LLC, supporting multiple projects related to human services and the Medicaid program. Jones received a master of public policy from Georgetown University's McCourt School of Public Policy and a bachelor of arts from Bard College.

Carolyn Kaneko is the graphic designer. Before joining MACPAC, Kaneko was design lead at the Artist Group, handling a wide variety of marketing projects. Kaneko's experience includes managing publication projects at all stages of design production and collaborating in the development of marketing strategies. Kaneko holds a bachelor of arts in art from Salisbury University with a concentration in graphic design.

Kate Massey, MPA, is the executive director. Before joining MACPAC, Massey was senior deputy director for the Behavioral and Physical Health and Aging Services Administration with the Michigan Department of Health and Human Services. Massey has nearly 20 years of operational and policy expertise in Medicaid, Medicare, the State Children's Health Insurance Program (CHIP), and private market health insurance. Massey previously served as chief executive officer for Magellan Complete Care of Virginia. Before that, Massey served as vice president for Medicaid and Medicare and government relations for Kaiser Permanente of the Mid-Atlantic States, overseeing the launch of two Medicaid managed care organizations in Virginia and Maryland. Massey also has worked for Amerigroup, establishing its Public Policy Institute and serving as executive director. Earlier positions include working for the Office of Management and Budget, where Massey led a team focused on Medicaid, CHIP, and private health insurance market programs. Massey also served as unit chief of the Low-Income Health Programs and Prescription Drugs Unit in the Congressional Budget Office. Massey has a master of public affairs from the Lyndon B. Johnson College of Public Policy at the University of Texas at Austin and a bachelor of arts from Bard College.

Madelyn Mustaine, MPA, is a research assistant. Before joining MACPAC, Mustaine was an intern at AcademyHealth's Evidence-Informed State Health Policy Institute and a research assistant at Indiana University. Mustaine graduated from Indiana University with a bachelor of science in public affairs and a master of public affairs, concentrating in policy analysis and health policy.

Nick Ngo is the chief information officer. Before joining MACPAC, Ngo was deputy director of information resources management for the Merit Systems Protection Board for 30 years. Ngo began his career in the federal government as a computer programmer with the U.S. Department of the Interior. Ngo graduated from George Mason University with a bachelor of science in computer science.

Audrey Nuamah, MPH, is a senior analyst. Before joining MACPAC, Nuamah worked as a program officer at the Center for Health Care Strategies, working with state agencies and provider organizations. Before that, Nuamah worked for the commissioner of health at the New York State Department of Health. Nuamah holds a master of public health with a concentration in health policy and management from Columbia University Mailman School of Public Health and a bachelor of arts in health and societies from the University of Pennsylvania.

Kevin Ochieng is the senior IT specialist. Before joining MACPAC, Ochieng was a systems analyst and desk-side support specialist at American Institutes for Research, and before that, an IT consultant at Robert Half Technology, focused on IT system administration, user support, network support, and PC deployment. Previously, Ochieng served as an academic program specialist at the University of Maryland University College. Ochieng has a bachelor of science in computer science and mathematics from Washington Adventist University.

Brian O'Gara is an analyst. Before joining MACPAC, O'Gara was a health policy analyst at the Bipartisan Policy Center, with a focus on improving and expanding access to high-quality long-term services and supports. O'Gara graduated from American University with a bachelor of arts in political science and public health.

Chris Park, MS, is the data analytics advisor and policy director. Park focuses on issues related to managed care payment and Medicaid drug policy and has lead responsibility for MACStats. Before joining MACPAC, Park was a senior consultant at The Lewin Group, providing quantitative analysis and technical assistance on Medicaid policy issues, including managed care capitation rate setting, pharmacy reimbursement, and cost-containment initiatives. Park holds a master of science in health policy and management from the Harvard T. H. Chan School of Public Health and a bachelor of science in chemistry from the University of Virginia.

Steve Pereyra is the financial management analyst. Before joining MACPAC, Pereyra worked as a finance associate for the nonprofit OAR, handling various accounting responsibilities and administering the donations database. Pereyra graduated from Old Dominion University with a bachelor of science in business administration.

Ken Pezzella is the chief financial officer. Pezzella has more than 20 years of federal financial management and accounting experience in both the public and private sectors. Pezzella also has broad operations and business experience and is a proud veteran of the U.S. Coast Guard. Pezzella holds a bachelor of science in accounting from Strayer University and is a certified government financial manager.

Melinda Becker Roach, MS, is a principal analyst. Before joining MACPAC, Roach was a program director at the National Governors Association (NGA) Center for Best Practices as well as NGA's legislative director for health and human services. Roach previously served as a legislative advisor on personal staff in the U.S. House of Representatives. Roach holds a master of science in health policy and management from the Harvard T. H. Chan School of Public Health and a bachelor of arts in history from Duke University.

Katherine Rogers, MPH, PhD, is the deputy director. Before joining MACPAC, Dr. Rogers served as long-term care director for the Medicaid program in Washington, DC, overseeing day-to-day operations in the Medicaid long-term care system as well as the launch of two new integrated Medicare-Medicaid programs. Before that, Dr. Rogers worked on programs serving people who are eligible for Medicare and Medicaid, long-term care users, and other complex populations in both nonprofit and government roles. Dr. Rogers holds degrees from The George Washington University, the University of Pennsylvania, and Cornell University.

Holly Saltrelli, MPP, is a principal analyst. Most recently, Saltrelli was a director at Guidehouse, leading the independent evaluation of a state's Section 1115 waiver and providing technical assistance to state Medicaid employees on the unwinding of the public health emergency. Saltrelli has worked with the Centers for Medicare & Medicaid Services, health plans, and health care providers to assess value-based payment strategies and conduct data-driven research, including previous roles at FTI Consulting and The Lewin Group. Saltrelli received a bachelor of arts from Amherst College and a master of public policy from Georgetown University.

Sheila Shaheed, MSPH, is an analyst. Before joining MACPAC, Shaheed worked as a health policy analyst and coordinator at CapView Strategies, where Shaheed focused on both the Medicare and Medicaid programs and included projects pertaining to payment and delivery system reform, value-based care, and coverage and access issues. Shaheed holds a bachelor of science from Howard University and a master of science in public health from the Johns Hopkins Bloomberg School of Public Health.

JoAnn Martinez-Shriver, JD, MPH, is a principal analyst. Before joining MACPAC, Martinez-Shriver was a senior advisor and deputy assistant secretary for legislation on oversight at the U.S. Department of Education and the U.S. Department of Health and Human Services. Martinez-Shriver previously served as a senior analyst at the U.S. Government Accountability Office, studying and drafting numerous reports on Medicaid and CHIP as well as other health policy-related topics. Martinez-Shriver holds a juris doctor from The George Washington University Law School, a master of public health from The George Washington University Milken Institute School of Public Health, and a bachelor of arts in political science from the University of California, Los Angeles.

Janice Llanos-Velazquez, MPH, is a principal data analyst. Before joining MACPAC, Llanos-Velazquez was a researcher at Mathematica analyzing Medicaid and CHIP enrollment and administrative data to inform program monitoring and help clients make data-driven decisions. Before Mathematica, Llanos-Velazquez worked for Washington, DC's Department of Health Care Finance, initially working as an analyst on children's health services and then transitioning to a data analyst role with a portfolio including analytic products related to enrollment and eligibility, maternal and child health, long-term services and supports, and other topics. Llanos-Velazquez received a master of public health from The George Washington University Milken Institute School of Public Health and a bachelor of science in biochemistry from Virginia Tech.

Asher Wang is an analyst. Before joining MACPAC, Wang worked as a policy research assistant at the Duke-Margolis Institute for Health Policy. Wang has worked on issues focused on health care payment and delivery reform, including state Medicaid strategies to advance accountable care for safety net providers. Wang received a bachelor of arts from Yale University.

Ava Williams, MA, is an analyst. Before joining MACPAC, Williams worked as a research assistant focusing on suicide demographics in Miami-Dade County. Williams has a master of arts in forensic psychology from The George Washington University and a bachelor of science in psychology from Nova Southeastern University.

Erica Williams is the human resources specialist. Before joining MACPAC, Williams was the human resources information system coordinator and licensure coordinator of a regional health system. Before this, Williams worked for a nonprofit organization as a human resource generalist. Williams graduated from Delaware State University with a bachelor of arts in special education and psychology.

Kiswana Williams is the executive assistant. Before joining MACPAC, Williams had extensive experience in providing administrative assistance to a variety of organizations in government contracting, law, and real estate. Williams also has experience coordinating large meetings with executive leadership. Williams holds a bachelor of science in business administration from the University of Maryland, College Park.

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Medicaid and CHIP Policy

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