

Report to Congress on Medicaid and CHIP

JUNE 2021



MACPAC

Medicaid and CHIP Payment
and Access Commission

About MACPAC

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

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

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

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

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Commissioners

Melanie Bella, MBA, *Chair*
Kisha Davis, MD, MPH, *Vice
Chair*

Heidi L. Allen, PhD, MSW
Tricia Brooks, MBA
Brian Burwell

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APRN, CNM

Frederick Cerise, MD, MPH

Toby Douglas, MPP, MPH

Robert Duncan, MBA

Darin Gordon

Christopher Gorton, MD, MHSA

Dennis Heaphy, MPH, MEd, MDiv

Verlon Johnson, MPA

Stacey Lampkin, FSA, MAAA,
MPA

William Scanlon, PhD

Laura Herrera Scott, MD, MPH

Katherine Weno, DDS, JD

Anne L. Schwartz, PhD,
Executive Director

June 15, 2021

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

The Honorable Nancy Pelosi
Speaker of the House
The Capitol
Washington, DC 20515

Dear Madam Vice President and Madam Speaker:

On behalf of the Medicaid and CHIP Payment and Access Commission (MACPAC), I am pleased to submit the June 2021 *Report to Congress on Medicaid and CHIP*. This report includes chapters that address these issues: high-cost specialty drugs in the Medicaid program; access to mental health services for adults and children and adolescents enrolled in Medicaid and the State Children's Health Insurance Program (CHIP), and the integration of physical and behavioral health care through electronic health records (EHRs); the non-emergency medical transportation (NEMT) benefit in Medicaid; and state strategies for integrating care for people who are dually eligible for Medicaid and Medicare.

Chapter 1 addresses high-cost specialty drugs, which are increasingly driving Medicaid spending and creating financial pressure for states. The Commission recommends that Congress increase the minimum rebate percentage on drugs approved by the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway until the manufacturer has verified the clinical benefit. The Commission also recommends an increase in the additional inflationary rebate on drugs that receive approval from the FDA through the accelerated approval pathway. Once the FDA grants traditional approval, the Medicaid rebates would revert back to the standard amounts.

Chapter 2 focuses on the needs of adults with mental health conditions and the role of Medicaid in supporting crisis services. Medicaid beneficiaries with mental illness often have unmet needs and difficulty getting appropriate services. The Commission recommends that the Secretary of the U.S. Department of Health and Human Services (the Secretary) direct relevant agencies to issue guidance that addresses how Medicaid and CHIP can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises. The second recommendation calls on the Secretary to direct a coordinated effort to provide education, technical assistance, and planning support to expand access to such services.

Chapter 3 makes recommendations to address the unmet behavioral health needs of children enrolled in Medicaid and CHIP and avoid out-of-home placements. The Commission recommends that the Secretary direct relevant



agencies to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and CHIP. The second recommendation calls on the Secretary to direct a coordinated effort to provide education, technical assistance, and planning support to expand access to such services.

Chapter 4 looks at how EHRs can be used to strengthen clinical integration and improve patient care. EHR adoption remains low among behavioral health providers. The chapter discusses barriers to EHR adoption and concludes by identifying ways to strengthen EHR uptake among Medicaid's behavioral health providers. The Commission will continue examining how Medicaid policy can be used to support adoption among behavioral health providers.

Chapter 5 fulfills a congressionally mandated report on Medicaid's NEMT benefit. Federal law requires that state Medicaid programs ensure transportation to and from providers. We reviewed state policies, conducted interviews with stakeholders, analyzed administrative data, and held focus groups to examine beneficiaries' experiences using NEMT and state approaches to administering the benefit. While the share of Medicaid beneficiaries who use NEMT is relatively small, NEMT plays a vital role in facilitating access to care for those who rely on it. The chapter concludes with a discussion of how states are using technology to improve program performance and addressing concerns about program integrity.

The final chapter of the June report continues the Commission's work on integrating care for individuals who are dually eligible for Medicaid and Medicare. We explore ways that states can better integrate care through Medicare Advantage dual eligible special needs plans (D-SNPs) using existing contracting authority. The chapter describes why MACPAC is focused on D-SNPs, contracting strategies available to states, state ability to use these strategies, and MACPAC's plans for future work on federal policy that could give further momentum to state efforts. The Commission has recommended additional resources to help states design and implement integrated care models.

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,



Melanie Bella, MBA
Chair



Commission Members and Terms

Melanie Bella, MBA, *Chair*
Philadelphia, PA

Kisha Davis, MD, MPH, *Vice Chair*
Rockville, MD

Term Expires April 2022

Tricia Brooks, MBA
*Georgetown University Center for
Children and Families*
Bow, NH

Christopher Gorton, MD, MHSA
Germantown, MD

Brian Burwell
Ventech Solutions
Sudbury, MA

Dennis Heaphy, MPH, MEd, MDiv
Massachusetts Disability Policy Consortium
Boston, MA

Toby Douglas, MPP, MPH
Kaiser Permanente
Davis, CA

Stacey Lampkin, FSA, MAAA, MPA
Mercer Government Human Services Consulting
Tallahassee, FL

Term Expires April 2023

Martha Carter, DHSc, MBA, APRN, CNM
Independent Consultant
Culloden, WV

Darin Gordon
Gordon & Associates
Nashville, TN

Frederick Cerise, MD, MPH
Parkland Health and Hospital System
Dallas, TX

William Scanlon, PhD
Independent Consultant
Oak Hill, VA

Kisha Davis, MD, MPH
Aledade
Rockville, MD

Term Expires April 2024

Heidi L. Allen, PhD, MSW
Columbia University School of Social Work
New York, NY

Verlon Johnson, MPA
Client Network Services, Inc. (CNSI)
Olympia Fields, IL

Melanie Bella, MBA
Cityblock Health
Philadelphia, PA

Laura Herrera Scott, MD, MPH
Anthem
Towson, MD

Robert Duncan, MBA
Children's Wisconsin–Milwaukee Hospital
Sussex, WI

Katherine Weno, DDS, JD
Independent Public Health Consultant
Iowa City, IA

Commission Staff

Anne L. Schwartz, PhD, *Executive Director*

Allissa Jones, MTA, *Executive Assistant*

Communications

Caroline Broder, *Director of Communications*

Breshay Moore, *Communications Specialist*

Policy Directors

Moira Forbes, MBA, *Principal Policy Director*

Kristal Vardaman, PhD, MSPH

Joanne Jee, MPH,
Policy Director and Congressional Liaison

Principal Analysts

Kirstin Blom, MIPA,
Principal Analyst and Contracting Officer

Erin McMullen, MPP

Martha Heberlein, MA,
Principal Analyst and Research Advisor

Robert Nelb, MPH

Chris Park, MS,
Principal Analyst and Data Analytics Advisor

Senior Analysts

Kacey Buderl, MPA

Melinda Becker Roach, MS

Michelle KIELTY Millerick, MPH

Amy Zettle, MPP

Aaron Pervin, MPH

Analysts

Tamara Huson, MSPH

Ashley Semanskee, MPA

Linn Jennings, MS

Research Assistant

Jerry Mi

Operations and Finance

Jim Boissonnault, MA, *Chief Information Officer*

Kimberley Pringle, *Administrative Assistant*

Kevin Ochieng, *Senior IT Specialist*

Brian Robinson, CGFM, *Financial Analyst*

Ken Pezzella, CGFM, *Chief Financial Officer*

Eileen Wilkie, *Administrative Officer*

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Executive Summary: June 2021 Report to Congress on Medicaid and CHIP

MACPAC's June 2021 *Report to Congress on Medicaid and CHIP* addresses these issues: Medicaid payment policies for high-cost specialty drugs; access to mental health services; integrating physical and behavioral health care through electronic health records (EHRs); the non-emergency medical transportation (NEMT) benefit in Medicaid; and state strategies for integrating care for people who are dually eligible for Medicaid and Medicare.

CHAPTER 1: Addressing High-Cost Specialty Drugs

Chapter 1 looks at high-cost specialty drugs, which are increasingly driving Medicaid spending and creating financial pressure for states. From 2010 to 2015, net spending on specialty drugs in Medicaid almost doubled, growing from \$4.8 billion to \$9.9 billion, or 35 percent of total net drug spending.

In addition, the U.S. Food and Drug Administration (FDA) is approving more products through its accelerated approval pathway, a program that allows drugs to come to market faster than under the traditional process. Under this pathway, drugs can be approved based on surrogate endpoints that are likely to predict a clinical benefit but before the clinical benefit has been demonstrated.

States have expressed concern about paying high list prices when these products do not have a verified clinical benefit. The FDA requires that manufacturers conduct confirmatory trials to verify the clinical benefit of drugs receiving accelerated approval, but many of these trials are delayed and can take more than 10 years to complete.

MACPAC has been focusing on how to address states' concerns about the high and growing costs associated with specialty drugs, as well as how to

ensure that beneficiaries who could benefit from these new therapies still have access to them. To assist with these efforts, MACPAC worked with a contractor to conduct an analysis of the drug pipeline and convene a technical advisory panel of drug policy and pricing experts from academia, the private sector, state Medicaid and federal officials, beneficiary advocates, providers, health plans, and drug manufacturers. The goal was to bring together a diverse group of experts to help the Commission prioritize which drugs in the pipeline could have a significant effect on Medicaid over the next three to five years, identify what challenges these drugs present, and suggest new Medicaid payment and coverage policies that could help address these challenges.

In this chapter, we make the following recommendations:

- Congress should amend Section 1927(c)(1) of the Social Security Act to increase the minimum rebate percentage on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased rebate percentage would apply until the manufacturer has completed the postmarketing confirmatory trial and been granted traditional FDA approval. Once the FDA grants traditional approval, the minimum rebate percentage would revert back to the amount listed under Section 1927(c)(1)(B)(i).
- Congress should amend Section 1927(c)(2) of the Social Security Act to increase the additional inflationary rebate on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased inflationary rebate would go into effect if the manufacturer has not yet completed the postmarketing confirmatory trial and been granted traditional FDA approval

after a specified number of years. Once the FDA grants traditional approval, the inflationary rebate would revert back to the amount typically calculated under Section 1927(c)(2).

These changes would address states' concerns by reducing the net cost for the subset of drugs approved through the accelerated approval pathway, while preserving beneficiary access to these drugs under the terms of the Medicaid Drug Rebate Program. The Commission is not recommending a specific increase in the rebates but notes that the amount should provide a meaningful reduction in spending and provide a strong incentive to encourage completion of the confirmatory trial, but it should not be so large as to discourage development of drugs for conditions that disproportionately affect Medicaid beneficiaries. These recommendations do not alter the FDA accelerated approval pathway or change the obligation of states to cover accelerated approval drugs.

CHAPTER 2: Access to Mental Health Services for Adults Covered by Medicaid

Chapter 2 focuses on the needs of adults with mental health conditions and the role of Medicaid and the State Children's Health Insurance Program (CHIP) in supporting crisis services. Medicaid beneficiaries with mental illness often have unmet needs and difficulty getting access to appropriate services. In 2018, 50 percent of beneficiaries with serious mental illness reported that they needed but did not receive treatment. Access to treatment for Medicaid beneficiaries is affected by a variety of factors, including state coverage decisions. Beneficiaries may also have difficulty finding mental health providers who accept new patients.

The implementation of 9-8-8, the three-digit dialing code for the National Suicide Prevention Lifeline, is expected to increase demand for crisis services. States and localities are now grappling with how

to fund infrastructure changes to meet increased demand. Medicaid's role in supporting crisis services is critical, yet largely undefined. States have little guidance to implement crisis services in accordance with federal guidelines.

In this chapter, we make the following recommendations:

- The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to issue joint subregulatory guidance that addresses how Medicaid and the State Children's Health Insurance Program can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises.
- The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to provide education and technical assistance on the implementation of a behavioral health crisis continuum that coordinates and responds to people in crisis in real time. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of crisis services.

The Commission plans to continue its work examining the needs of beneficiaries with behavioral health conditions, especially for those who report involvement with the criminal justice system.

CHAPTER 3: Access to Behavioral Health Services for Children and Adolescents Covered by Medicaid and CHIP

Chapter 3 makes recommendations to address the unmet behavioral health needs of children enrolled in Medicaid and CHIP and avoid out-of-home placements. Behavioral health disorders usually begin in childhood or adolescence and can have long-term implications for health and well-being.

In 2018, only 54.1 percent of non-institutionalized youth enrolled in Medicaid or CHIP who experienced a major depressive episode received mental health treatment. While home- and community-based services for children and adolescents with significant mental health conditions can prevent institutional placement, these services are often unavailable or difficult to access. For those with significant mental health conditions, the inability to access intensive home- and community-based behavioral health services can result in avoidable out-of-home placements and involvement with the foster care and juvenile justice systems.

In this chapter, we make the following recommendations:

- The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program.
- The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, the Substance Abuse and

Mental Health Services Administration, and the Administration for Children and Families to provide education and technical assistance to states on improving access to home- and community-based behavioral health services for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of these services.

CHAPTER 4: Integrating Clinical Care through Greater Use of Electronic Health Records for Behavioral Health

Chapter 4 looks at how EHRs can be used to strengthen clinical integration and improve patient care. This is of particular concern in Medicaid, given that Medicaid beneficiaries suffer from higher rates of substance use disorder (SUD) and mental health conditions than those with private insurance. They also experience other chronic conditions at higher rates than their privately insured peers.

Adopting certified electronic health record technology is one strategy to improve communication between behavioral and physical health providers, and to provide better integrated care for beneficiaries. However, EHR adoption remains low among behavioral health providers.

Behavioral health providers were largely left out of federal efforts to encourage the use of health information technology and EHRs. Barriers to EHR adoption among behavioral health providers include limited funds to invest in hardware, software, and training. In addition, many EHRs do not meet the needs of providers who work with beneficiaries in SUD treatment programs.

In the coming year, the Commission will continue examining how federal Medicaid policy can be used to support EHR adoption among behavioral health providers.

CHAPTER 5: Mandated Report on Non-Emergency Medical Transportation

Chapter 5 responds to a mandate from Congress that MACPAC report on Medicaid's NEMT benefit. Federal law requires that state Medicaid programs ensure transportation to and from providers. NEMT was initially described in regulation as an administrative requirement. Congress clarified that NEMT is a statutorily required benefit in the Consolidated Appropriations Act of 2021 (P.L. 116-260).

MACPAC reviewed state policies, conducted interviews with stakeholders, analyzed administrative data, and held focus groups to examine beneficiaries' experiences using NEMT and state approaches to administering the benefit. The NEMT benefit includes a broad range of transportation services and is available to all full-benefit beneficiaries.

States may manage the benefit directly, contract with a third-party broker, or provide services under Medicaid managed care contracts. Although federal policy encourages coordination across federally assisted transportation programs, in most states, NEMT is not well coordinated with other programs.

Our analysis found that in fiscal year (FY) 2018, there were over 60 million NEMT ride-days. State and federal spending on NEMT was \$2.6 billion, excluding managed care payments to providers. Although the share of Medicaid beneficiaries who use NEMT is relatively small, with less than 5 percent of beneficiaries using the service in FY 2018, NEMT plays a vital role in facilitating access to care for those who rely on the transportation. The most frequent users of NEMT include beneficiaries who are eligible for Medicaid on the basis of disability or age and those with certain conditions, including end-stage renal disease, intellectual or developmental disabilities, and behavioral health conditions.

NEMT program performance varies across and within states. The chapter concludes with a discussion of how states are using technology to improve program performance and how they are addressing concerns about program integrity.

Changes in health care delivery during the COVID-19 pandemic may reduce the need for NEMT services in certain circumstances. However, the extent to which beneficiary need for NEMT is changing remains unclear. As states consider how to address policy goals, such as reducing racial disparities and increasing COVID-19 vaccination rates, they may want to consider the role of NEMT in promoting access to care.

CHAPTER 6: Improving Integration for Dually Eligible Beneficiaries: Strategies for State Contracts with Dual Eligible Special Needs Plans

Chapter 6 continues the Commission's work on integrating care for the 12.3 million individuals who are dually eligible for Medicaid and Medicare. People who are eligible for both programs often experience fragmented care and poor health outcomes because their benefits are not coordinated. Integrated care models, designed to address coordination challenges, can improve the beneficiary experience and may reduce federal and state spending. However, only about 10 percent of dually eligible beneficiaries are enrolled in integrated care.

In this chapter, we focus on ways states can use their contracts with Medicare Advantage dual eligible special needs plans (D-SNPs) to promote greater integration and increase enrollment in integrated plans. D-SNPs, designed to meet the specific needs of dually eligible beneficiaries, enroll over 3 million beneficiaries and are available in 43 states and the District of Columbia.

The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) requires all D-SNPs to have contracts with the states in which they operate, sets minimum integration standards, and gives states the authority to impose additional requirements on D-SNPs. MACPAC identified ways states can exercise their MIPPA authority to improve the integration of Medicaid and Medicare services and to help states implement the strategies.

There are certain MIPPA strategies that all states can deploy. For example, states can contract directly with D-SNPs to cover Medicaid benefits, ensuring the D-SNPs are responsible for coverage of both Medicaid and Medicare benefits for their members. This strategy may be particularly useful for states without Medicaid managed care for dually eligible beneficiaries. Other strategies are easiest to implement in states with experience using Medicaid managed care.

Few states have fully exercised their MIPPA authority. This may be due to limited state experience using Medicaid managed care for dually eligible beneficiaries, a lack of Medicare expertise, and competing priorities. States that have maximized MIPPA authority, including Arizona, Idaho, and Tennessee, have enrolled a large share of their dually eligible beneficiaries in integrated care.

Over the next year, the Commission will explore how federal policy could promote use of MIPPA strategies and other approaches to integration, acknowledging that state efforts to integrate care are at different stages.

Chapter 1:

Addressing High-Cost Specialty Drugs

Addressing High-Cost Specialty Drugs

Recommendations

1.1 Congress should amend Section 1927(c)(1) of the Social Security Act to increase the minimum rebate percentage on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased rebate percentage would apply until the manufacturer has completed the postmarketing confirmatory trial and been granted traditional FDA approval. Once the FDA grants traditional approval, the minimum rebate percentage would revert back to the amount listed under Section 1927(c)(1)(B)(i).

1.2 Congress should amend Section 1927(c)(2) of the Social Security Act to increase the additional inflationary rebate on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased inflationary rebate would go into effect if the manufacturer has not yet completed the postmarketing confirmatory trial and been granted traditional FDA approval after a specified number of years. Once the FDA grants traditional approval, the inflationary rebate would revert back to the amount typically calculated under Section 1927(c)(2).

Key Points

- State Medicaid officials have expressed concern about paying high prices for accelerated approval drugs. These are drugs approved by the FDA based on whether they have an effect on a surrogate endpoint that is reasonably likely to predict a clinical benefit. This is different from traditional approval, which requires verification of the clinical benefit.
- Under the Medicaid Drug Rebate Program (MDRP), all FDA-approved drugs must be covered, including those approved under both the traditional and accelerated pathways. While manufacturers are required to conduct postmarketing confirmatory trials to verify that an accelerated approval drug achieves a clinical benefit, these trials are often delayed.
- Increasing the Medicaid rebates on accelerated approval drugs until the clinical benefit has been verified strikes a balance between addressing state concerns about paying high prices for these products while maintaining access for beneficiaries. MACPAC's recommendations make no changes to the obligation to cover these drugs.
- In this chapter, MACPAC also considers coverage and payment policies for cell and gene therapies, a subset of specialty drugs that are receiving significant attention due to their high costs and potential as durable or curable treatments.
- A new national drug benefit for cell and gene therapies could allow for new coverage, payment, or rebate requirements without disrupting the structure of the MDRP for all other outpatient drugs. This chapter looks at the issues that would need to be considered in designing such a benefit.

CHAPTER 1: Addressing High-Cost Specialty Drugs

In fiscal year (FY) 2019, Medicaid spent approximately \$66.7 billion on outpatient prescription drugs and collected \$37.1 billion in rebates, resulting in net drug spending of \$29.6 billion, or about 5 percent of benefit spending that year (MACPAC 2020a). Drug spending trends have been fairly moderate over the past few years, with annual increases between 1.4 and 4.7 percent from calendar year (CY) 2016 to CY 2019. However, the Centers for Medicare & Medicaid Services (CMS) Office of the Actuary projects Medicaid drug spending to increase between 5 and 6 percent annually over the next several years (OACT 2020).

Medicaid drug spending trends are increasingly being driven by high-cost specialty drugs.¹ From 2010 to 2015, net spending on specialty drugs in Medicaid almost doubled, growing from \$4.8 billion (25 percent of total net drug spending) to \$9.9 billion (35 percent of total net drug spending) (CBO 2019).² According to Magellan Rx Management, a leading Medicaid pharmacy benefit administrator, the net cost per claim for traditional drugs in fee-for-service (FFS) Medicaid fell by 0.4 percent from 2018 to 2019, while the net cost per claim for specialty drugs increased 8.6 percent over the same period. In 2019, specialty drugs accounted for 48.5 percent of FFS pharmacy spending but only 1.3 percent of drug utilization (Magellan 2020).

State Medicaid officials have expressed concern about the fiscal pressures created by the introduction of new specialty drugs. The launch prices for specialty drugs continue to grow, with one gene therapy for spinal muscular atrophy costing as much as \$2.1 million per course of treatment. The introduction of each new drug can add substantial costs to the Medicaid budget.

Looking forward, nearly 8,000 products are in development across all stages of the

pharmaceutical pipeline, and many of these products are specialty drugs, including nearly 400 cell and gene therapies (PhRMA 2021, 2020). While some of these therapies are expected to deliver long-term clinical benefits and could be potentially curative, the high up-front cost of specialty drugs can create significant pressure on state budgets. Additionally, many of these therapies are indicated for conditions that affect small populations—a situation that creates uncertainty about the number of individuals who might seek treatment in any given year and the potential for volatility in annual budgets of both states and health plans.

In addition, the U.S. Food and Drug Administration (FDA) is approving more products through its accelerated approval pathway, a program that allows drugs to come to market faster than under the traditional process. Under this pathway, drugs can be approved based on surrogate endpoints that are likely to predict a clinical benefit but before the clinical benefit has been demonstrated. In 2020, the FDA approved 53 novel therapies, including 12 drugs (23 percent) under the accelerated approval pathway (FDA 2021a).

States have expressed concern about paying high list prices when these products do not have a verified clinical benefit. The FDA requires that manufacturers conduct confirmatory trials to verify the clinical benefit of drugs receiving accelerated approval, but many of these trials are delayed and can take more than 10 years to complete (Chen 2018, Naci et al. 2017).

MACPAC has consistently heard from states that the utilization management tools permitted under Medicaid law are ineffective in containing costs for high-cost specialty drugs (Brown 2017). Although states have started to develop some innovative strategies to deal with particular high-cost specialty drugs, such as a subscription model to pay for hepatitis C drugs, they are seeking new tools, some of which may require new authorities, to address high-cost specialty drugs more broadly (Gee 2018, Jeffrey 2018). In a recent survey, over two-thirds of states responded that developing policies and

strategies related to new high-cost therapies was a top priority (Gifford et al. 2020).

As a result, MACPAC has been focusing on how to address concerns about the high and growing costs associated with specialty drugs, while also ensuring that beneficiaries who could benefit from these new therapies still have access to them. To assist in the Commission's efforts, MACPAC worked with a contractor to conduct an analysis of the drug pipeline and convene a technical advisory panel (TAP) of drug policy and pricing experts from academia and the private sector, state Medicaid and federal officials, beneficiary advocates, providers, health plans, and drug manufacturers. The goal was to bring together a diverse group of experts to help the Commission prioritize which drugs in the pipeline could have a significant effect on Medicaid over the next three to five years, identify what challenges these drugs present, and suggest new Medicaid payment and coverage policies that could help address these challenges. As a part of this work, we identified a discrete, but important, first step to address state concerns: increasing the rebate on accelerated approval drugs until the clinical benefit has been confirmed.

This chapter presents the Commission's recommendations on increasing the statutory Medicaid rebates on drugs receiving accelerated approval until the clinical benefit has been verified. Specifically:

- Congress should amend Section 1927(c)(1) of the Social Security Act to increase the minimum rebate percentage on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased rebate percentage would apply until the manufacturer has completed the postmarketing confirmatory trial and been granted traditional FDA approval. Once the FDA grants traditional approval, the minimum rebate percentage would revert back to the amount listed under Section 1927(c)(1)(B)(i).
- Congress should amend Section 1927(c)(2) of the Social Security Act to increase the additional inflationary rebate on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased inflationary rebate would go into effect if the manufacturer has not yet completed the postmarketing confirmatory trial and been granted traditional FDA approval after a specified number of years. Once the FDA grants traditional approval, the inflationary rebate would revert back to the amount typically calculated under Section 1927(c)(2).

These changes would address states' concerns by reducing the net cost for the subset of drugs approved through the accelerated approval pathway, while preserving beneficiary access to these drugs under the terms of the Medicaid Drug Rebate Program (MDRP). The Commission is not recommending a specific increase in the rebates but notes that the amount needs to be significant enough to provide a meaningful reduction in spending and provide a strong incentive to encourage completion of the confirmatory trial, but not so large as to discourage development of drugs for conditions that disproportionately affect Medicaid beneficiaries. These recommendations do not alter the FDA accelerated approval pathway or change the obligation of states to cover accelerated approval drugs.

This chapter begins with an overview of the MDRP. It continues by detailing the findings from MACPAC's TAP. It then discusses the accelerated approval pathway and the concerns that the use of surrogate endpoints in the approval process creates for payers. The chapter then presents the rationale for the Commission's recommendations for Congress to increase the rebates on accelerated approval drugs until the clinical benefit has been verified.

The TAP also discussed issues related to cell and gene therapies and provided the Commission with a framework for developing a new benefit for

coverage and payment of these therapies. The Commission discussed these ideas in its public meetings and decided that while it was premature to make recommendations, it would be useful to share an analysis of the key design options and the potential trade-offs that would need to be considered when developing such a benefit in this report. Our analysis also considers implications for certain stakeholders. The chapter concludes by discussing considerations for a national drug registry and outlining the Commission's future work in this area.

Medicaid Drug Rebate Program

The Medicaid Drug Rebate Program was created under the Omnibus Budget Reconciliation Act of 1990 (P.L. 101-508) with the purpose of ensuring that Medicaid pays a net price that is consistent with the lowest or best price that manufacturers charge other payers for the drug. Under the program, a drug manufacturer must enter into a Medicaid national drug rebate agreement with the Secretary of the U.S. Department of Health and Human Services (the Secretary) in order for states to receive federal funding for using the manufacturer's products (§ 1927(a)(1) of the Social Security Act (the Act)).³ In exchange for the rebates, state Medicaid programs generally must cover all of a participating manufacturer's drugs when prescribed for a medically accepted indication, although the states may limit the use of some drugs through preferred drug lists (PDLs), prior authorization, and quantity limits.⁴

Coverage and access

Under the MDRP, a drug meets the definition of a covered outpatient drug if its manufacturer has in place a rebate agreement with the Secretary and the drug has been approved by the FDA (§ 1927(k) of the Act). This means that a state is generally required to cover all of a participating

manufacturer's products as soon as they have been approved by the FDA and enter the market—that is, when they are available for sale by the manufacturer in the state.⁵ Although a state can use prior authorization, clinical criteria, or other utilization management tools to manage the use of a particular drug, the effect of these limitations “should not result in the denial of access to effective, clinically appropriate, and medically necessary treatments” (CMS 2015, p. 3).

Medicaid's requirement to cover essentially all FDA-approved drugs makes the program unique among payers. In general, plans sold on health insurance exchanges and Medicare Part D plans have minimum requirements for drug coverage, but they are allowed to exclude coverage for some drugs.⁶ Likewise, self-insured plans, large group plans, and grandfathered health plans not subject to essential health benefit requirements can exclude coverage for some drugs. This Medicaid coverage requirement limits states' ability to manage utilization and spending and to negotiate rebates with manufacturers compared with other payers.

Statutory rebates

Medicaid drug rebates are calculated based on average manufacturer price (AMP). AMP is defined as the average price paid to the manufacturer for the drug in the United States by wholesalers for drugs distributed to retail community pharmacies and by retail community pharmacies that purchase drugs directly from the manufacturer (§ 1927(k)(1) of the Act).⁷

The rebate formula for single source and innovator multiple source drugs (i.e., brand-name drugs) differs from the formula for non-innovator multiple source drugs (i.e., generic drugs).⁸ For purposes of simplicity, this chapter refers to single source and innovator multiple source drugs as brand drugs and refers to non-innovator multiple source drugs as generic drugs or generics.

The rebate amount for covered outpatient drugs has two components: a basic rebate amount and

an additional inflationary component. For most brand drugs, the basic rebate amount is equal to either 23.1 percent of AMP or AMP minus best price, whichever is greater.⁹ Best price is statutorily defined as the lowest price available to any wholesaler, retailer, provider, or paying entity, excluding certain governmental payers (§ 1927(c)(1)(C) of the Act).¹⁰ For generic drugs, the basic rebate amount is calculated as 13 percent of AMP with no best price provision.

An additional rebate based on an inflationary component is added if the increase in a drug's AMP exceeds the increase in the Consumer Price Index for All Urban Consumers (CPI-U) over time. The inflationary component is equal to the amount that the drug's current quarter AMP exceeds its baseline AMP trended to the current period by the CPI-U.¹¹ This inflationary rebate is designed to limit the increase in the net price of any drug to the rate of inflation.

Until January 1, 2024, the total rebate amount (the sum of the basic and inflationary components) cannot exceed 100 percent of AMP (§ 1927(c)(2)(D) of the Act). The American Rescue Plan Act of 2021 (ARP, P.L. 117-2) removes this cap on Medicaid rebates beginning January 1, 2024 (§ 9816 of ARP).

Supplemental rebates

A state can negotiate with manufacturers to obtain supplemental rebates, which manufacturers provide to ensure that their products are placed on the state's PDL. As of December 2020, almost all states (46 states and the District of Columbia) were receiving supplemental rebates in addition to mandated federal rebates (CMS 2020).¹² Preferred drugs typically face fewer utilization management requirements (e.g., prior authorization) than therapeutically equivalent drugs that are not on the list, and this results in a shift in market share to the preferred drugs. Some states pursue supplemental rebate agreements on their own, while others have joined multistate coalitions for negotiation purposes (CMS 2020).

Developing New Models

To assist in the Commission's examination of the effects of high-cost specialty drugs on Medicaid, as noted above, MACPAC worked with a contractor to conduct an analysis of the drug pipeline and convene a TAP to examine these issues more closely. The TAP included drug policy and pricing experts from academia and the private sector, state Medicaid and federal officials, beneficiary advocates, providers, health plans, and drug manufacturers. Over the course of three meetings, the panel prioritized which drugs in the pipeline could have a significant effect on Medicaid, what challenges these drugs present, and what changes to Medicaid payment and coverage policies could help address these challenges.

Drug pipeline

MACPAC's contractor analyzed all specialty drugs currently in Phase I-III trials or drugs under FDA review.¹³ Given the number of drugs in the pipeline, the analysis prioritized later-stage products that are likely to have the greatest effect on Medicaid in the next three to five years based on expected cost and patient population (NORC 2020).

The pipeline analysis highlighted three types of high-cost specialty drugs that will have a significant or disproportionate effect on Medicaid:

- High-cost pediatric drugs. Because more than two out of every five children are Medicaid beneficiaries, high-cost pediatric products are of particular importance for Medicaid (MACPAC 2020b). Several high-cost cell and gene therapies with pediatric indications in the pipeline could generate high total spending even with relatively few eligible patients. Currently, 186 drugs with pediatric indications are in development across all clinical trial phases. Among them are 45 cell or gene therapies, which are indicated to treat children with sickle cell disease, leukemia/lymphoma, muscular dystrophy, and achromatopsia. In addition to gene

therapies, several specialty drugs for cystic fibrosis are in the pipeline. A large proportion of children with these conditions are expected to be covered by Medicaid because these conditions are often qualifying disabilities for Medicaid eligibility.

- **Adult gene and cell therapies.** Even though Medicaid is not likely to be the largest payer for gene and cell therapies indicated for adults, any utilization of these high-cost products may strain Medicaid budgets. Focusing specifically on therapies nearing FDA approval, 61 gene and cell therapies indicated for adults are in Phase III or later (e.g., a new drug application has been submitted). Among these therapies, 24 are indicated for various types of cancers. Products for hemophilia, autoimmune diseases, diabetes, and cardiovascular disease could also have significant Medicaid utilization. For example, four hemophilia gene therapies in Phase III trials are expected to launch in the next few years. Another hemophilia A product is currently under FDA review but will require two more years of clinical trial data prior to approval. It is expected to have a launch price between \$2 million and \$3 million.
- **Other specialty drugs.** Beyond cell and gene therapies, Medicaid drug spending will be driven by specialty products with moderately high prices, significant utilization, and higher incremental costs relative to the current treatments. Currently, 282 specialty drugs are in Phase III clinical trials or under FDA review. The three therapeutic areas with the largest number of drugs in development are oncology (78 products), autoimmune diseases (33 products), and COVID-19 treatments (19 products). Other therapeutic areas with a number of drugs in development are those that treat genetic disorders, hematologic conditions, and infectious diseases.

Challenges for state Medicaid programs

After reviewing the findings from the pipeline analysis, the TAP participants broadly agreed that three types of drugs should be prioritized for further discussion and model development given their potential effect on Medicaid. They include: (1) cell and gene therapies for adults and children, (2) drugs approved through the accelerated approval pathway, and (3) specialty high-cost drugs for highly sensitive populations. Each of these drug types have attributes that make them challenging to manage under the MDRP, described briefly below:

- **High up-front costs.** Products with extremely high list prices and a short duration of use create sudden spikes in Medicaid spending, rather than consistent monthly costs. Gene and cell therapies can have list prices of more than \$1 million per course of treatment. Though such products have the potential to reduce other medical spending over a beneficiary's lifetime, these high up-front costs are difficult to manage for states, which operate within annual budgets.
- **Budget volatility.** Many extremely high-cost specialty drugs are indicated for conditions that affect a small population, which creates uncertainty about the number of individuals who will seek treatment in any given year. As a result, their effects on state spending can be extremely variable from year to year and make it difficult to predict and manage annual pharmacy costs. Unexpected increases in drug spending can also be challenging for Medicaid managed care plans that have annual capitated contracts, which cannot easily accommodate sudden increases in spending (e.g., the rapid, new spending that occurred when new hepatitis C medications launched at the end of 2013).
- **Uncertain long-term benefit.** While some of these drugs may lead to reductions in other medical spending for beneficiaries, these

reductions may take many years to materialize. Moreover, some therapies for conditions with few treatment options may have significant clinical benefits but never realize savings that offset the drug purchase price. Additionally, Medicaid-funded treatments may yield future cost savings for other payers, such as commercial insurers or Medicare.

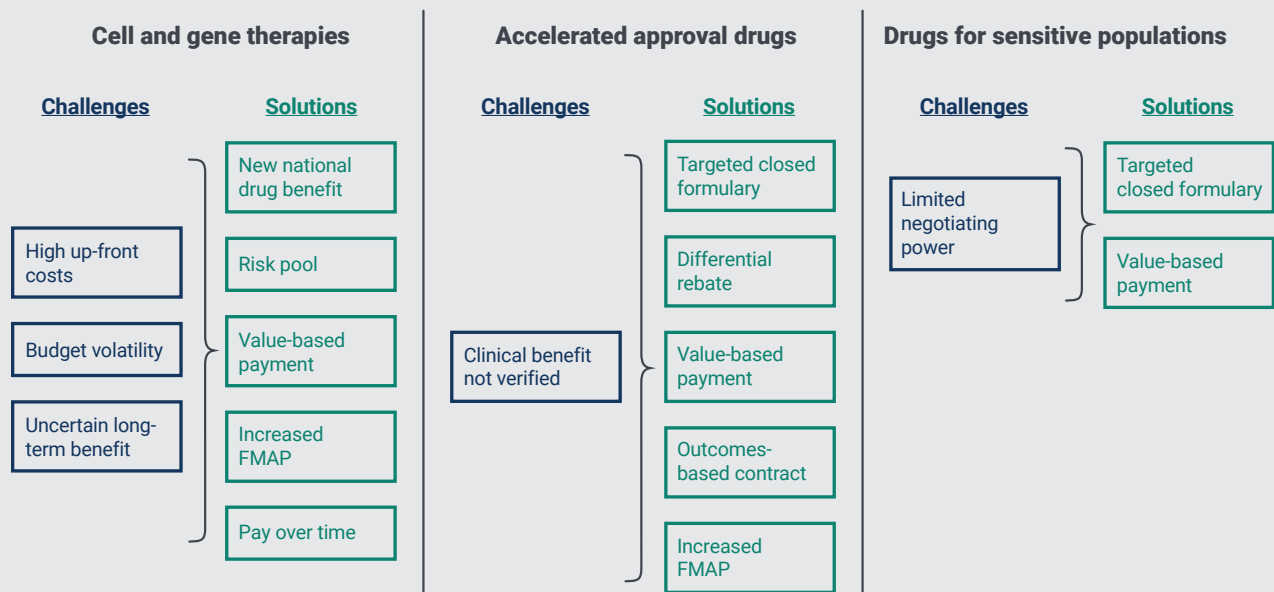
- Clinical benefit not verified. Traditional FDA approval requires that a clinical benefit be shown before approval can be granted. The accelerated approval pathway allows for drugs to be approved based on surrogate or intermediate clinical endpoints that are likely to predict a clinical benefit, even though the clinical benefit has yet to be verified. Payers have expressed concern that the launch prices of these drugs do not reflect that the clinical benefit has not yet been verified. Moreover, while the FDA requires

drug manufacturers to conduct postmarketing trials to verify the clinical benefit, these trials are often delayed and payers may be covering drugs for several years that ultimately do not confer a clinical benefit.

- Limited negotiating power. State Medicaid programs have limited ability to negotiate rebates for drugs that have no or limited therapeutic competition, or for conditions for which most or all of the drugs in a particular class (e.g., HIV/AIDS treatments) fall under broad federal or state mandates to cover these drugs with little to no restrictions (e.g., no preferred drug list).

TAP participants identified the specific challenges to Medicaid associated with each of the three priority drug types and mapped potential models to address those challenges (Figure 1-1).

FIGURE 1-1. Drug Types, Challenges, and Solutions



Note: FMAP is federal medical assistance percentage.

Source: NORC and MACPAC, 2021, findings from Technical Advisory Panel.

Models considered by the TAP included:

- new national drug benefit: coverage outside of the MDRP in which the federal government would purchase certain high-cost products, such as cell and gene therapies;
- risk pool: multistate or national purchasing pool for high-cost drugs that treat small patient populations;
- value-based payment: payment based on a third-party assessment of the drug's value;
- increased federal medical assistance percentage (FMAP): higher federal match for a specific set of high-cost therapies;
- pay over time: amortize payments for high-cost, short-duration therapies over a longer period of time;
- outcomes-based contract: higher rebates if the drug does not achieve a specified clinical outcome;
- differential mandatory rebates: higher mandatory rebates for certain products; and
- targeted closed formularies: allow states to deny coverage for certain drugs.

These models are not mutually exclusive and could be combined.

For accelerated approval drugs, the TAP participants briefly discussed allowing states to implement a commercial-style closed formulary that would allow them to exclude coverage of accelerated approval drugs while the clinical benefit has yet to be verified. Many participants had concerns that a closed formulary would limit access to beneficiaries and that other options could address the issue without removing Medicaid's coverage requirement.

They also discussed setting a price based on an independent assessment of value or developing mandatory outcomes-based contracts for Medicaid. The participants agreed that it would be difficult to assess value or to identify appropriate outcome

targets until the specific level of clinical benefit was known and verified. These models could be useful once the clinical benefit has been verified, but they would not address the challenges that payers face while the manufacturer is conducting the confirmatory trial. Moreover, states already face substantial challenges in implementing value- or outcomes-based models (Gifford et al. 2020).¹⁴

Participants also discussed increasing the FMAP but decided against this option; while an increased federal match would decrease state spending, it would shift costs to the federal government and not decrease overall Medicaid spending.

Given these concerns, the TAP participants identified a differential rebate on accelerated approval drugs as the best option because it strikes a balance between reducing Medicaid costs while still maintaining access.

With respect to cell and gene therapies, the TAP explored a wide variety of payment and rebate models that could be used to address the challenges of the high up-front costs, budget volatility, and uncertainty about long-term benefits. Because of the small size of the target population for many of these products, panel participants discussed the need to aggregate the populations to create a more predictable pool of patients, to smooth risk by reducing annual state or plan-to-plan variation in spending, and to increase leverage in negotiations with manufacturers. This could be accomplished through a new national benefit or a national risk pool.

On pricing, participants agreed that volume-based rebates would not be sufficient to reduce costs and that other mechanisms would be necessary to reduce the price of these therapies. They discussed setting prices based on an independent assessment of value, allowing states to pay for the drugs over time, or using outcomes-based contracts. Additionally, due to the extremely high cost of these products and the potential for long-term benefits to accrue to other payers, many participants thought that the federal government could increase the FMAP or cover the cost of these therapies completely.

Ultimately, the TAP noted, and the Commission agreed, that creating a new benefit for cell and gene therapies had the most potential because it would aggregate the population into a more predictable risk pool and allow for new coverage, payment, or rebate requirements without disrupting the existing structure of the MDRP for all other outpatient drugs. Some combination of the other models could be implemented under the new benefit without creating unintended consequences for coverage of or rebates on other drugs.

The third area the TAP identified as a priority was drugs used to treat sensitive populations. This category includes drugs that treat debilitating conditions for which few to no treatment options exist (e.g., spinal muscular atrophy), as well as more manageable conditions, such as HIV/AIDS. Historically, states have had limited ability to manage these drug classes and as a result have limited negotiating power with manufacturers. Participants discussed the idea of a targeted closed formulary in which states would have narrow exclusionary capabilities based on sound clinical criteria. Formularies could be developed to ensure access to a minimum number of products. Additionally, narrow exclusions of certain products, such as line extensions and combination products, would allow states to provide broad access to all the chemical entities but give them additional leverage in supplemental rebate negotiations with manufacturers. Participants also discussed the idea of developing a value-based payment policy using an independent assessment. However, the panel had difficulty narrowing down the options and ultimately did not settle on any particular model. Many TAP participants noted that states may not be able to fully use any new tools or models due to existing state laws. For example, some states have laws requiring coverage of all HIV/AIDS drugs with minimal or no restrictions.

The findings from the TAP were helpful in informing the Commission's work. After deliberating on the various policy options and key design considerations that came from the TAP, the Commission decided to make recommendations

for a differential rebate on accelerated approval drugs. In the Commission's view, the creation of a new drug benefit for cell and gene therapies has potential. However, we are not ready to make a recommendation on this model at this time. We discuss both of these models in greater detail below.

Accelerated Approval

The FDA has programs that expedite development and review of new drugs that address an unmet medical need for a serious or life-threatening condition. The accelerated approval pathway allows the FDA to grant approval more quickly than the traditional approach because it allows approval based on whether the drug has an effect on a surrogate endpoint that is reasonably likely to predict a clinical benefit (§ 506(c) of the Federal Food, Drug, and Cosmetic Act).¹⁵ A surrogate endpoint is a marker—a laboratory measurement, radiographic image, physical sign, or other measure—that is thought to predict clinical benefit, but is not itself a measure of clinical benefit (FDA 2014). Surrogate endpoints are essentially a proxy for a clinical benefit. For example, tumor shrinkage in certain cancer types has been considered reasonably likely to predict improvement in overall survival and is a commonly used surrogate endpoint in the accelerated approval of cancer drugs (Chen 2018, FDA 2014).

When the FDA approves a drug through the accelerated approval pathway, it requires manufacturers to conduct additional postmarketing studies (sometimes called Phase IV studies) to verify that the drug achieves a clinical benefit (21 CFR 314.510, 21 CFR 601.41, FDA 2014).¹⁶

Risk of surrogate endpoints

The FDA has acknowledged that using surrogate endpoints creates a risk that patients could be exposed to a drug that later was shown not to provide an actual clinical benefit. It has also noted that because accelerated approval may rely on

smaller or shorter clinical trials than used under traditional approval, this pathway may result in less information about the occurrence of rare or delayed adverse events (FDA 2014). A common criticism is whether surrogate endpoints are actually predictive of a clinical benefit and thus, better health outcomes. For example, studies have called into question whether tumor shrinkage, a common surrogate endpoint, is sufficiently correlated with better survival rates (Chen 2018, Pietrangelo 2017). Critics point to these risks when raising concerns that the accelerated approval pathway results in less effective and potentially dangerous drugs entering the market (Chen 2018, CMS 2017, Kesselheim and Avorn 2016).

Critics also point out that some drugs granted accelerated approval have been rejected by the FDA's European counterpart, the European Medicines Agency (EMA). For example, the FDA approved both Folutyn, used to treat peripheral T-cell lymphoma, and Exondys 51, used to treat Duchenne muscular dystrophy, through the accelerated approval pathway, while the EMA denied these applications (Chen 2018; EMA 2018, 2012; Pollack 2016). Disagreement on the approval of a particular drug can occur even within the FDA. Some FDA staff members thought that the evidence presented for Exondys 51 did not demonstrate that the drug was reasonably likely to produce a clinical benefit. They appealed the approval decision, but the approval was upheld (Box 1-1).

Delay in postmarketing confirmatory trials

As noted above, the FDA requires manufacturers to conduct postmarketing studies to verify and describe the clinical benefit. These trials must be completed with due diligence (21 CFR 314.510 and 601.41). The FDA has interpreted due diligence to mean that such trials must be conducted promptly to facilitate the determination of whether a clinical benefit has been verified as soon as possible (FDA 2014). However, there are not clear standards on how long these postmarketing studies should take,

and they are often delayed. One analysis found that results from confirmatory trials for over half of indications granted accelerated approval between 2009 and 2013 were not available after a median of five years of follow-up (Naci et al. 2017). Some confirmatory trials can take 10 years or longer (Chen 2018). By comparison, the FDA states it normally takes an average of one to four years for Phase III clinical trials under the traditional pathway (FDA 2018).

Some practical reasons exist for delays in the postmarketing trials. For example, finding and recruiting patients willing to participate in drug trials among the small populations affected by rare diseases can be challenging. However, there is also a concern that drug manufacturers do not have the same financial incentives to complete these trials as they do with Phase III clinical trials under the traditional pathway. This concern exists because accelerated approval products generate revenue, and a negative finding from a confirmatory trial could reduce those revenues and even result in the drug being pulled from the market (Chen 2018).

BOX 1-1. Controversial Approval of Exondys 51

In 2016, the FDA granted accelerated approval to Exondys 51 (eteplirsen), a treatment for Duchenne muscular dystrophy (DMD) in patients who have a confirmed mutation in the dystrophin gene that can be treated by skipping exon 51 (FDA 2016a). Exondys 51 costs about \$300,000 per year but can run up to \$1 million annually based on a patient's weight (Thomas 2017).

The drug's approval was controversial. The FDA's advisory committee of external experts voted against granting accelerated approval. The advisory committee members who voted no commented that the applicant did not provide substantial evidence that the drug is reasonably likely to produce a clinical benefit (FDA 2016b). The director of the Center for Drug Evaluation and Research overrode the committee's recommendation and granted accelerated approval to Exondys 51. Some FDA staff expressed concern and appealed the approval decision to the FDA commissioner, who ultimately upheld the approval decision (FDA 2016c). Because of the controversy surrounding Exondys 51's approval, many commercial payers declined to cover the drug or only covered it in limited circumstances (Thomas 2017).

In 2018, Sarepta Therapeutics, the manufacturer of Exondys 51, sought accelerated approval for Vyondys 53 (golodirsen), a similar drug that would treat DMD in patients who have a confirmed mutation in the dystrophin gene that can be treated by skipping exon 53. The initial approval was denied, and as a part of the complete response letter, the FDA pointed out that the manufacturer had yet to initiate the required confirmatory trial for Exondys 51 two years and 11 months after its approval. The complete response letter noted that if the manufacturer had begun the trial, additional evidence could have been available to assess the likelihood that small amounts of truncated dystrophin would lead to a clinical benefit (FDA 2019a). The manufacturer appealed the decision, and Vyondys 53 was granted accelerated approval in December 2019 (FDA 2019b). Subsequently, in February 2021, the FDA granted Sarepta accelerated approval for Amondys 45 to treat patients amenable to exon 45 skipping (FDA 2021b). Three drugs have been approved based on the same surrogate endpoint that created significant disagreement within the FDA and without any additional evidence to demonstrate the relationship between the surrogate endpoint and the clinical benefit.

As part of the original approval letter for Exondys 51, Sarepta agreed to a timeline in which the postmarketing confirmatory trial would be completed in 2020 with a final report submission in 2021 (FDA 2016a). Information from the U.S. National Library of Medicine's clinical trial database indicates that the confirmatory trial for Exondys 51 started in July 2020 and is estimated to be complete in February 2026, a delay of five to six years from the initial timeline agreed upon in the original approval letter (ClinicalTrials.gov, NCT03992430, FDA 2016a).

State concerns

The MDRP requires states to generally cover all of a participating manufacturer's products as soon as they have been approved by the FDA and enter the market. This coverage requirement includes drugs approved under the accelerated approval pathway (CMS 2018a). State Medicaid officials have expressed concern about the requirement that Medicaid cover these drugs when additional studies are still needed to verify their clinical benefit (CMS 2019, 2017). In particular, they have shared concerns about paying high list prices when these products do not have a verified clinical benefit, and in some cases, may cause harm to vulnerable patients. They are wary about paying for therapies that ultimately do not demonstrate a clinical benefit, as was the case with Makena. This drug, used to reduce the risk of preterm birth, received accelerated approval in 2011. In October 2020, the FDA proposed that the drug be pulled from the market because the postmarketing study failed to show clinical benefit (FDA 2020a).¹⁷

In addition, the length of time taken to complete some confirmatory trials means that states may be paying for high-cost treatments for several years before the benefit is verified. The case of Exondys 51 makes this clear. In the initial terms of its approval in 2016, the confirmatory trial for Exondys 51 was to be completed by 2020 (FDA 2016a). The manufacturer recently indicated the trial began in 2020 and is not estimated to be complete until 2026, meaning that state Medicaid programs will be required to cover this drug for 10 years without confirmation of its clinical effectiveness (ClinicalTrials.gov, NCT03992430).

State Medicaid officials are particularly concerned about these issues given that the number of drugs approved through the accelerated approval pathway has been increasing. Over the five-year period of 2015 to 2019, 31 drugs (14.1 percent of all approved drugs during that period) were approved through the accelerated approval pathway. By comparison, the same number of drugs received accelerated approval in the 10-year period of 2005 to 2014, and

they represented 11.5 percent of all drugs approved in that time frame (FDA 2020b).

Commission Recommendations

In this report, the Commission recommends two changes to the Medicaid Drug Rebate Program. It is important to note that should Congress make these changes, Recommendation 1.1 is the primary recommendation and does not require the adoption of Recommendation 1.2. Recommendation 1.2 should only be adopted in conjunction with Recommendation 1.1. The rationale and implications of these recommendations are described below.

Recommendation 1.1

Congress should amend Section 1927(c)(1) of the Social Security Act to increase the minimum rebate percentage on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased rebate percentage would apply until the manufacturer has completed the postmarketing confirmatory trial and been granted traditional FDA approval. Once the FDA grants traditional approval, the minimum rebate percentage would revert back to the amount listed under Section 1927(c)(1)(B)(i).

Recommendation 1.2

Congress should amend Section 1927(c)(2) of the Social Security Act to increase the additional inflationary rebate on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased inflationary rebate would go into effect if the manufacturer has not yet completed the postmarketing confirmatory trial and been granted traditional FDA approval after a specified number of years. Once the FDA grants

traditional approval, the inflationary rebate would revert back to the amount typically calculated under Section 1927(c)(2).

Rationale

We recommend that Congress increase the statutory rebates on drugs receiving accelerated approval to lower the net price of these products until the manufacturer completes its postmarketing confirmatory trial and verifies the clinical benefit of the drug. This increased rebate would apply to all products approved through the accelerated approval pathway that have not yet completed confirmatory trials.¹⁸ Given that the FDA has an existing process to convert an accelerated approval to a traditional approval, once confirmatory trials are completed and the FDA grants traditional approval, the higher rebates would be removed and existing rebates under the MDRP (e.g., 23.1 percent of AMP) would apply (FDA 2020c).¹⁹

Changing the rebates under the MDRP strikes a balance between addressing state concerns of paying high prices for products that do not have a verified clinical benefit while maintaining Medicaid coverage for these products. Because accelerated approval drugs meet the definition of covered outpatient drugs under the MDRP, states would still be required to cover these products. The increased rebates would allow states to pay less until the manufacturer verifies the clinical benefit of the drug.

Increasing the minimum rebate would lower the net price and would help account for the risk that the product might not achieve the anticipated clinical benefit. The higher minimum rebate would also create a financial incentive for manufacturers to complete confirmatory trials in a timely manner.

An increase in the inflationary rebate would help mitigate any large increases in list price that could occur before the manufacturer completed the confirmatory trial. This increase would not go into effect for a specified number of years (e.g., five years) to provide manufacturers with a reasonable amount of time to complete the confirmatory trial but would penalize lengthy delays. In short, it would

provide an additional incentive for manufacturers to demonstrate the effectiveness of their products in a timely manner. Because this increase would be tied to the inflationary rebate, it would not be applied if the manufacturer did not increase the price faster than inflation.

Once the FDA grants traditional approval, the rebate amounts would revert back to the standard amounts calculated under the MDRP. This would effectively serve to increase the net price for the manufacturer once it had verified the drug's clinical benefit.

The Commission is not recommending a specific increase in the minimum or inflationary rebate, nor the specific number of years after which the increased inflationary rebate would apply. We consider these decisions to be matters for Congress as we do not have empirical data to make these determinations. But the Commission notes that the rebate amount needs to be significant enough to provide a meaningful reduction in Medicaid spending and to provide a strong incentive for drug manufacturers to complete confirmatory trials. When asked about the rebate amount, most TAP participants suggested that the increase in the minimum rebate for accelerated approval drugs should be higher than the 8 percentage point increase in the minimum rebate provided under the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended). However, too high a rebate could discourage manufacturers from investing in the development of drugs for conditions that disproportionately affect Medicaid beneficiaries.

Manufacturers have commented that they oppose this policy and argue that additional Medicaid rebates may discourage research and development or delay the market availability of drugs for serious conditions that may disproportionately affect Medicaid beneficiaries. They argue that accelerated approval drugs are not approved under lower evidentiary standards and point to FDA guidance that states “drugs granted accelerated approval must meet the same statutory standards for safety and efficacy as those granted traditional approval”

(FDA 2014). However, as noted previously, the FDA has also acknowledged that using surrogate endpoints under the accelerated approval pathway creates a risk that patients could be exposed to a drug that ultimately is shown not to provide an actual clinical benefit (FDA 2014). The recommendations do not dispute the FDA's decision to approve the drug; rather, the Commission is focused on how Medicaid pricing can be used to lower the net price to account for the fact that clinical benefit is not verified.

In terms of the effect of increased rebates on manufacturer behavior, it is important to note that manufacturers take several factors into account, including Medicaid rebates, when making decisions on drug development and product launch. First, Medicaid is not the sole payer for these drugs, so an increased rebate would not necessarily have a significant influence on a manufacturer's decision to pursue this pathway or drug development. For example, in 2010, the ACA increased the minimum rebate on brand drugs from 15.1 percent of AMP to 23.1 percent of AMP. While we do not know whether this caused any manufacturer to forgo a drug candidate, no decline occurred in drug development in the aggregate. A record number of drugs have been approved since the ACA increase in the Medicaid rebate. For example, an average of 25.5 new drugs were approved per year between 2000 and 2009, compared with an average of 37.8 new drugs approved per year between 2010 and 2019 (FDA 2020b).

Second, manufacturers would still benefit from the accelerated approval pathway as it would provide earlier access to the market and allow their drugs to generate revenue and establish market share while their confirmatory trials are underway. Manufacturers would need to weigh the cost of the additional rebates with the benefit of early market access, which could allow manufacturers to establish their products before competitors enter the market. Finally, an increased rebate would create a financial incentive for manufacturers to complete the confirmatory trial in a timely manner. The reset of the rebate back to the standard

amount once the drug converts to traditional FDA approval would equate to an increase in the net price to Medicaid and, therefore, in revenue to the manufacturer.

It is possible that increasing rebates would create an incentive to launch drugs at higher prices or attempt to shift costs to other payers. However, the extent to which manufacturers may be able to raise prices is unclear. Some economists believe that manufacturers already have the incentive to launch drugs at the maximum price the market will bear, regardless of the level of Medicaid rebates (Kaltenboeck and Bach 2018, Kesselheim et al. 2016). Even if manufacturers can raise prices to offset much of the cost of the increased rebates, they would still have an incentive to complete the confirmatory trial in a timely manner because conversion to traditional approval would lead to additional revenue.

Beneficiary advocates have also expressed concerns that access to innovative therapies could be decreased if manufacturers reduce research and development in, or delay the availability of, new therapies that treat serious conditions. In particular, advocates have expressed concern that manufacturers could reduce investment in rare conditions as manufacturers may be more sensitive to price changes for drugs that treat small populations or indications.

However, increasing the rebate on accelerated approval drugs could potentially increase beneficiary access to these products once they enter the market, particularly relative to other proposed policies. Due to their concerns about paying high prices when accelerated approval drugs do not have a verified clinical benefit, states are seeking to limit coverage of these products, which could reduce beneficiary access. Beneficiary advocates have expressed concerns that access to many of these accelerated approval drugs has been limited because some states have implemented restrictive coverage and prior authorization criteria.

Additionally, Massachusetts and Tennessee have requested Section 1115 demonstration waivers that would allow the state to implement a closed formulary, meaning that the state would not have to cover all FDA-approved drugs under the MDRP and could choose to exclude certain drugs or classes of drugs. These states specifically requested authority to exclude coverage of accelerated approval drugs because state officials believe the high prices of these drugs do not lead to prudent fiscal administration when the clinical benefit has yet to be verified (CMS 2019, 2017).²⁰ Earlier this year, CMS approved Tennessee's request to implement a closed formulary while still receiving the MDRP rebates—the first time this has been allowed (CMS 2021). Although Tennessee's demonstration approval was authorized as part of its modified block grant financing structure, this approval could provide a legal framework for other states to seek a closed formulary to exclude coverage of accelerated approval drugs.

Implications

Federal spending. The increased rebate would reduce net spending for accelerated approval products. Because the recommendations do not include specific amounts for the rebate increase, the Congressional Budget Office (CBO) provided estimates assuming a 10 percentage point increase for the minimum rebate and a 20 percent increase in the inflationary rebate if the confirmatory trial had not been completed after five years. Assuming these rebate changes would be implemented in FY 2022, the CBO estimates that these recommendations would decrease federal spending by \$0 to \$50 million in the first year and \$0 to \$1 billion in the first five years, compared with the current law baseline. To provide context for these savings, the CBO estimated that gross Medicaid spending (i.e., before rebates) on accelerated approval drugs in FY 2019 was approximately \$1 billion, including both federal and state spending.

States. State spending would decrease because states would receive the non-federal share of the increase in rebate amounts. This change

theoretically could affect supplemental rebates; however, it is unlikely that states would receive significant supplemental rebates on these products because they are unlikely to have much competition. States would still be required to offer coverage for these products.

Enrollees. Because this rebate would be implemented under the MDRP, coverage of accelerated approval drugs would not change. Beneficiaries would still have access to accelerated approval drugs once they entered the market. If manufacturers decided to forgo the accelerated approval pathway, beneficiaries might have to wait longer for those drugs to come to market. However, beneficiary access to these products could improve if states were willing to reduce prior authorization criteria because the net price of these drugs would be reduced.

Drug manufacturers. Manufacturers would be required to pay larger Medicaid rebates on any of their products going through the accelerated approval pathway. Manufacturers would need to decide whether to bring their products to the market early under the accelerated approval pathway and incur the added cost of the increased rebate or to wait to complete Phase III trials and pursue the traditional approval pathway to pay the standard MDRP rebate.

A New Benefit for Cell and Gene Therapies

Cell and gene therapies are a subset of specialty drugs that are receiving significant attention due to their high costs and potential as durable (i.e., having long-term benefit) or curable treatments. For example, Zolgensma, a one-time intravenous infusion indicated to treat spinal muscular atrophy, has a list price of \$2.1 million.

Our pipeline analysis identified 45 cell or gene therapies indicated for pediatric populations and 61 therapies indicated for adults in Phase III or later

(e.g., a new drug application submitted). Because more than two out of every five children in the U.S. are Medicaid beneficiaries, high-cost pediatric products are of particular importance for Medicaid (MACPAC 2020b). While Medicaid is not likely to be the largest payer for gene and cell therapies indicated for adults, any use of these high-cost products may strain Medicaid budgets.

Cell and gene therapies tend to have extremely high up-front costs. Additionally, many of these therapies are indicated for conditions that affect a small population, creating uncertainty at the state and plan level about the number of individuals who might seek treatment in any given year. This combination of utilization uncertainty and high cost can cause significant budget volatility, which can be especially challenging for smaller states to manage using existing tools.

In addition to the high up-front costs, states have questions about the long-term benefit of covering these therapies. Because little data are available to assess the durability of these therapies, some stakeholders question whether these products will produce the long-term benefits suggested by manufacturers. Further, states recognize that if these products do deliver lasting benefits, they will be paying for treatments that may ultimately accrue benefits to other payers.

New benefit for cell and gene therapies

The TAP discussed how a new national drug benefit for cell and gene therapies could address the high up-front costs, budget volatility, and uncertainty in the long-term benefit that cell and gene therapies present. A new benefit would allow for new coverage, payment, or rebate requirements without disrupting the existing structure of the MDRP for all other outpatient drugs. One option would be to create a centralized, national coverage pool for these products. A federally administered program would allow standardization of coverage and payment rules across states and plans. Additionally, the model could be designed to ensure that coverage and payment rules are the same

regardless of setting. Currently, coverage, payment, and rebate requirements for drugs may differ depending on whether the drug is administered in the inpatient or outpatient setting and how payment is made.²¹

This model could be designed to address several concerns. For example, by increasing federal funding for these products and pooling patients nationally to increase utilization predictability, it could help address states' concerns about high up-front costs and budget volatility. It could also be designed with more flexible coverage than exists under current Medicaid drug coverage rules. A federal program would consolidate purchasing power, improving the ability to negotiate with manufacturers. Furthermore, the program could require Medicaid rebates or create new mandated rebates to guarantee a certain level of discount.

At this time, the Commission is not ready to make a recommendation on a new benefit for cell and gene therapies; rather, our goal for this chapter is to highlight the design choices and implications that would need to be considered.

Key design considerations

Establishing a new benefit for cell and gene therapies would require substantial statutory and regulatory changes at the federal and state levels. In thinking about the design options, policymakers need to consider both the overarching goals and the specific policy parameters, including which therapies to include and how to balance beneficiary access with efforts to control spending. In this section, we draw out these policy and design issues (Table 1.1).

TABLE 1-1. Design Options and Considerations for New Cell and Gene Therapy Benefit

Design element	Options and considerations
State participation	<ul style="list-style-type: none"> • Mandatory or optional for states • Multipayer model including Medicare and commercial insurers
Inclusion criteria	<ul style="list-style-type: none"> • Cover all cell and gene therapies or a subset of therapies • Base coverage on condition (i.e., all drugs for a certain condition, including drugs that are not cell and gene therapies) or only cover cell and gene therapies • Cover only cost of drug or all costs associated with administration of therapy (e.g., hospital stay)
Price	<ul style="list-style-type: none"> • Mandatory rebates similar to Medicaid Drug Rebate Program • Value-based price based on independent assessment of value • Outcomes-based contract • Combination of pricing models
Supply chain	<ul style="list-style-type: none"> • Incorporate a third party to manage and distribute the supply of the drug regardless of setting • Maintain rebate model to minimize supply chain disruptions
Scale and duration	<ul style="list-style-type: none"> • Demonstration versus permanent model • Permanent or temporary coverage in new benefit depending on amount of competition
Funding	<ul style="list-style-type: none"> • Increase federal funding • Require payer contributions if multipayer model

Source: NORC and MACPAC, 2021, findings from Technical Advisory Panel.

Below we discuss each design element and the potential considerations and tradeoffs of each option in more detail.

State participation. Participation in a new benefit for cell and gene therapies could be mandatory or optional for state Medicaid programs. Mandatory participation would create a larger risk pool, which would improve the ability to reduce up-front costs and smooth out budget volatility. Pooling risk across all states would reduce annual state or plan-to-plan variation in spending by creating a more predictable pool of treated patients. A bigger pool would also increase leverage to negotiate prices with manufacturers. However, mandatory

approaches to Medicaid policy inevitably lead to pushback from some stakeholders. If state participation was optional, it would be important to entice larger states into the pool to help spread risk and increase negotiating leverage. Large states have less incentive to opt into multistate pools because they tend to have more negotiating power than smaller states and are more likely to benefit from supplemental rebates. However, the new benefit would still be attractive to larger states if it included a pricing structure that provided a lower net price for cell and gene therapies that have limited or no competition for which manufacturers are not likely to provide meaningful supplemental rebates.

Another option would be to expand the benefit to include other payers, such as Medicare, the Department of Veterans Affairs, state or federal employees, and commercial insurers. A multipayer pool would help address state concerns about bearing the cost of gene and cell therapies that end up showing durability and prevent future disability and reduce long-term treatment costs that could accrue to another payer. Furthermore, it could increase coverage for patients to the extent that commercial insurers currently have an incentive to limit coverage for these products or to shift their members into Medicaid prior to treatment to avoid costs. A multipayer pool could reduce selection bias across payers and plans.

Inclusion criteria. Creating a new benefit would require decisions about which therapies would be included and for whom, and which additional services should be considered part of the benefit. For example, the benefit could be limited to those cell and gene therapies that are expected to have durable benefits versus those that may only have short-term benefits (e.g., blood transfusion). CMS or another federal entity would need to establish a process to define evidence of durability that would dictate inclusion in the model and adjust the criteria over time if necessary.

Therapies could also be selected for inclusion based on price. For example, the benefit could be structured to target only the highest-cost therapies (e.g., over \$1 million per treatment) or those with a certain amount of expected total spending (e.g., \$1 billion). However, a price or spending threshold could create a price floor, discouraging price competition if manufacturers target that amount when setting the list price to ensure inclusion in the new benefit.

A separate benefit for cell and gene therapies could create financial incentives for states to shift utilization toward those therapies, particularly if the benefit is fully federally funded. Condition-based inclusion criteria could address these concerns about encouraging use of a gene therapy over other alternatives. For example, the benefit could include all drugs for a certain clinical condition

(e.g., hemophilia). Even so, this could create difficult choices on which conditions to include. Some selection issues could be addressed by implementing strong clinical criteria to qualify for cell and gene therapy. To address beneficiary concerns about access, CMS and states could work with professional clinical societies or an independent expert panel (e.g., convened by the National Academies) to establish appropriate qualification criteria for treatment.

Many cell and gene therapy regimens include additional services, such as an inpatient hospital stay. The benefit could be structured to include only the cost of the drug or to cover a patient's entire cost of care. If the latter, additional decisions would be required to define the bundle of services provided as part of the normal course of treatment and whether payment should be standardized for all the other services.

Price. A key feature of a new cell and gene therapy benefit would be to allow for new payment and rebate models without disrupting the existing structure of the MDRP for all other outpatient drugs.

By consolidating gene and cell therapies into a separate drug benefit, the federal government would have increased negotiating leverage and may be able to obtain larger rebates. Under the current MDRP requirements, states argue that they lack the leverage to negotiate supplemental rebates on cell and gene therapies. These products do not have clinical alternatives and cannot be excluded from coverage. If these treatments are carved out and separated from the MDRP, manufacturers may be more likely to negotiate if all state volume is aggregated into a single pool. However, the federal government would only have significant negotiating leverage if exclusion of coverage is a possibility under the new benefit. Many stakeholders and beneficiary groups would have strong concerns about changing Medicaid rules to exclude coverage and limiting access to these treatments.

The program could also implement mandatory rebates similar to those in the MDRP to guarantee a

certain level of price reduction. These rebates could be set at a fixed percentage (e.g., a percentage of AMP) or could be tied to a mandatory outcomes-based contract so that the rebate would bring the net price down if the drug did not achieve the desired outcome. A uniform national benefit would streamline the development of an outcomes-based contract for the manufacturer, compared with negotiating with 51 separate state programs. If the benefit were extended to include other payers, collection of outcomes data could be simplified and beneficiary outcomes could be tracked more easily over time even if they switched payers or plans.

Alternatively, the federal government could set a value-based price, similar to a maximum allowable cost or upper payment limit. The value-based price would tie payment to an independent analysis of the product's value—a departure from current models, which anchor payment to the manufacturer-determined list price. The value assessment could come from an international pricing methodology or an organization such as the Institute for Clinical and Economic Review. Some stakeholders have concerns about using an international reference price and suggest that tying the price to an assessment from an organization based in the United States would be more acceptable because it would reflect existing U.S. priorities related to innovation and value. Other stakeholders would likely oppose this option entirely and argue that an upper price limit would disincentivize innovation and investment. Another concern is that setting a value-based price for Medicaid would cause manufacturers to raise prices in the commercial market. However, some argue that a federally supported value-based price could establish a strong benchmark that other payers would use for negotiation and that the ability to cost shift may be limited.

It is possible that such pricing models, while introducing new complexities, would not necessarily lead to a lower net price than is currently achieved through the existing MDRP. Combining new approaches with the existing minimum and inflationary rebate formulas of the MDRP could ensure that the new benefit would achieve a similar

or lower net price. For example, the total rebate for cell and gene therapies could be the lower of the MDRP rebate amount or the difference between AMP and a value-based price. Alternatively, the federal government could establish a mandatory outcomes-based contract for any drugs covered under the benefit to lower the price below the MDRP amount if the product does not achieve the anticipated outcome.

A new benefit separate from the MDRP also could be beneficial to manufacturers and commercial payers. For example, any best price established for the new benefit could be defined in a different way to better account for new pricing and rebate models than the MDRP currently allows. Separating cell and gene therapies into a new benefit could provide more flexibility for manufacturers and commercial payers to develop new models but limit any unintended consequences that a definitional change to best price under the MDRP could have on other drugs.

Supply chain. A new pricing model could disrupt the existing supply chain. Currently, states pay providers, not manufacturers, for drug acquisition costs. As a result, the federal government and the states would not set a value-based price for the product directly with the manufacturer. Rather, a value-based price would establish the payment to providers, who would then be forced to negotiate with manufacturers to ensure that their acquisition costs would be lower than the program payment rate. This traditional buy-and-bill process would put pressure on providers because manufacturers would not be required to sell their products to providers at the value-based price.

To address these concerns, a new benefit could incorporate a third party, such as a specialty pharmacy, to manage and distribute the supply of the drug, regardless of whether the therapy was administered in inpatient or outpatient settings. The specialty pharmacy model would reduce pressure on providers to acquire the product below the value-based price. But it would also eliminate existing revenue that providers make on the spread that can occur under the traditional buy-and-bill process.

A rebate model, particularly one like the MDRP, would not disrupt the existing supply chain. Providers could still operate under the buy-and-bill model, while the states would receive the rebate from the manufacturer to lower the net price.

Scale and duration. A new benefit for cell and gene therapies would require significant statutory changes, and it would require significant operational changes, time, and effort for drug manufacturers, states, and providers to implement. To minimize disruption and test whether the model works as intended, policymakers could start small, for example, as a demonstration, or only include a small number of therapies. A smaller scale would allow policymakers to learn from the model's outcomes in the early years and help them assess the overall effect on beneficiary access and other market dynamics.

Another consideration is whether this new benefit should permanently cover cell and gene therapies. The model could include a mechanism to determine whether at some point, coverage and payment for certain drugs would revert to prior models, for example, if generics were developed or if other sufficient competition became available. CMS would need to conduct routine evaluations of outcomes and beneficiary access, and assessments of whether drugs should move in or out of the benefit.

Funding. Financing for a new cell and gene therapy benefit could be shared between the federal government and states, as is currently the case in Medicaid, or fully financed by the federal government. Full federal funding would address the budget volatility within and across states. Furthermore, full federal funding could standardize coverage across all states, and could consolidate and streamline the implementation of new pricing structures (e.g., value-based pricing), financing models (e.g., pay over time), or outcomes-based contracts. However, this option would shift spending to the federal government and could increase incentives for states to try to shift utilization to cell and gene therapies from other potentially cheaper

treatments for which the state would share in the cost. Another option would be to increase the FMAP for the cell and gene therapy benefit. This option would help alleviate some of the budget pressure on the states but still leave some financial incentive for states to manage the use of these therapies.

Under a multipayer model, the financing could operate similar to a risk pool. Each payer could contribute to the financing by paying a fixed amount (e.g., per member per month). Similar to the Medicaid model, the federal government could contribute more funding to reduce the cost to each payer.

Stakeholder implications

Depending on how the new drug benefit is designed, it could have varying effects on beneficiaries, manufacturers, and providers.

Beneficiaries. If the model removed the coverage requirement, beneficiary access could be limited. Conversely, this model could improve access to gene and cell therapies by creating a unified approach to coverage and payment, rather than the variation in approaches that state Medicaid programs use today. Additionally, to protect beneficiary access, CMS could implement a strong patient appeal process to address concerns about patients' ability to navigate a federal program.

Manufacturers. Manufacturers would likely favor keeping the MDRP's mandatory coverage requirement to ensure drug access for Medicaid beneficiaries. While manufacturers have indicated that they are receptive to ways to better link drug price to effectiveness and value, they value the existing pricing model and would prefer incorporating outcomes-based contracts into the model to arrive at a value-based net price. In particular, they would not want to see a pricing model that penalizes cell and gene therapy manufacturers relative to manufacturers of traditional products. Similarly, they view a price ceiling or a rate-setting approach based on a third-party evaluation as politically untenable, but

they could see using a third-party evaluation as a starting point for negotiation. If the new benefit for cell and gene therapies allowed for more restrictive coverage or lower net prices than under the MDRP, manufacturers could be concerned that the coverage or pricing models would eventually be expanded to other drugs as a way to reduce Medicaid costs.

Providers. Because cell and gene therapies are administered by providers, concern could arise that a new benefit could increase the administrative burden by separating the authorization processes for drugs and any ancillary services. However, given that the process for obtaining approval for a cell or gene therapy already has many hurdles, an additional prior authorization requirement would not necessarily affect physician decisions.

Providers may also have concerns that this model would require separate claims systems for the drug and the associated medical services, thus fragmenting data that would be needed to conduct retrospective reviews. This fragmentation in coverage and payment systems may already be happening to some extent in states that either carve out certain therapies from managed care contracts or separate payment for the drug from the associated medical services in the inpatient setting. It would be important to have integrated data systems so providers and researchers would have a complete view of the patient's medical history.

Another concern is the potential for lost revenue if the buy-and-bill process was eliminated. However, most cell and gene therapies currently are distributed through specialty pharmacies or a select number of centers of excellence, so the buy-and-bill process is not typical for gene and cell therapies at this point and may not be a major source of revenue for most providers.

Consideration for a National Registry

One limitation of models that seek to link a drug's price to its effectiveness and value is that they require data collection to demonstrate that specific appropriate and meaningful outcomes have been achieved. The TAP discussed at length the need for improved outcomes data, and the administrative burden and costs of data collection. Such challenges concern all payers but may be particularly notable for Medicaid due to the churn of beneficiaries in and out of the program, as well as the potential need to coordinate data collection across several different Medicaid managed care plans. Given the significant amount of public funding being used to cover specialty drugs in Medicaid, the TAP suggested that the federal government consider creating a national data registry to track outcomes for patients taking these products. Such data could be used to support coverage and payment decisions. Participants suggested that CMS could work with the FDA and the National Institutes of Health to develop a national registry to collect and share data with states and Medicaid managed care plans; the registry could also be expanded to include other payers.

A national registry could have several benefits. It could provide real-world evidence to the FDA and payers for multiple purposes, including postmarketing evaluation of clinical efficacy and safety of accelerated approval drugs, value assessments of cell and gene therapies, and long-term outcomes tracking as beneficiaries move across states and Medicaid managed care plans, or to other payers, such as Medicare or private insurance. A national registry could also be beneficial to drug manufacturers as it could centralize outcomes data and allow for greater standardization and adoption of outcomes-based contracts. In addition, it could reduce the cost of postmarketing clinical trials if the FDA incorporated real-world evidence from the registry data into its evaluation of clinical efficacy and safety.

Next Steps

The Commission will continue to focus attention on the merits of a new benefit for cell and gene therapies, including how to address tradeoffs. For example, the Commission will want to gather more evidence and input on the strengths and weaknesses of the various options that could be used to establish a net price for such a benefit. In doing so, we plan to reach out to various stakeholders for input on the framework and monitor the development of new proposals for alternative coverage or payment models for cell and gene therapies.

Endnotes

¹ There is no single definition of specialty drugs, and researchers and industry stakeholders may use different criteria in identifying specialty drugs. Some rely solely on price, while others include other characteristics, such as treating a chronic, complex, or rare disease, requiring special handling in the supply chain, being initiated or maintained by a specialist, being administered by a professional, or being distributed through non-traditional channels such as a specialty pharmacy (CBO 2019).

² For its analysis, CBO identified the specialty drugs that were on the market in 2015 using a definition developed by IQVIA (formerly known as IMS Health). This definition encompasses drugs that treat a chronic, complex, or rare condition and that have at least four of the following seven characteristics: (1) cost at least \$6,000 per year, (2) be initiated or maintained by a specialist, (3) be administered by a health care professional, (4) require special handling in the supply chain, (5) be associated with a patient payment assistance program, (6) be distributed through non-traditional channels (such as a specialty pharmacy), or (7) require monitoring or counseling either because of significant side effects or because of the type of disease being treated. The list of specialty drugs on the market in 2015 was purchased from IQVIA and is proprietary (CBO 2019).

³ In addition to executing a Medicaid drug rebate agreement as a condition for Medicaid coverage of their products, drug manufacturers must enter into an agreement that meets the requirements of Section 340B of the Public Health Service Act (P.L. 102-585) and a master agreement with the Secretary of Veterans Affairs (§ 1927(a)(1) of the Act). Additionally, the manufacturer must enter into a Medicaid drug rebate agreement in order for payment to be made under Medicare Part B. A drug not covered under a rebate agreement may be eligible for federal Medicaid funding in limited circumstances if the state has determined that the drug is essential to the health of its beneficiaries.

⁴ A medically accepted indication means any use for a covered outpatient drug that is approved under the Federal Food, Drug, and Cosmetic Act (P.L. 75-717) or that is supported by one or more citations included or approved for inclusion in one of the following three compendia: American Hospital Formulary Service Drug Information, United States Pharmacopeia-Drug Information, or the DRUGDEX Information System (§ 1927(k)(6) of the Act).

⁵ A drug manufacturer must have a signed Medicaid drug rebate agreement in place in order for its products to be covered by Medicaid. If a manufacturer does not have a rebate agreement with the Secretary, a state does not have to cover that manufacturer's products until the rebate agreement is effective.

⁶ For Medicare Part D formularies, each drug category or class must include at least two drugs (regardless of the classification system utilized). Part D plan formularies must include all or substantially all drugs for the following six protected classes: immunosuppressants (for prophylaxis of organ transplant rejection), antidepressants, antipsychotics, anticonvulsants, antiretrovirals, and antineoplastics (CMS 2016a). Exchange plans must cover one drug in every United States Pharmacopeia category and class, or the same number of drugs in each category and class as the state benchmark plan (45 CFR 156.122(a)(1)).

⁷ The covered outpatient drug rule finalized in 2016 includes a separate definition of AMP for the so-called 5i drugs—inhalation, infusion, instilled, implanted, or injectable drugs. These drugs are not generally sold through the same distribution channels as other drugs, so the AMP for 5i drugs includes sales of a type not included in AMP calculations of non-5i drugs.

⁸ Generally, an innovator drug is a drug produced or distributed under a new drug application approved by the FDA. Single source drugs are innovator drugs manufactured by only one company and innovator multiple source drugs are innovator drugs that have at least one generic equivalent available. Non-innovator multiple source drugs are multiple source drugs that are not innovator drugs—generally, these are drugs that have been approved by the FDA under an abbreviated new drug application.

⁹ For blood clotting factor drugs and drugs approved by the FDA exclusively for pediatric indications, the rebate percentage is 17.1 percent of AMP, instead of 23.1 percent of AMP.

¹⁰ Best price excludes certain governmental payers, such as the Indian Health Service, Department of Veterans Affairs, Department of Defense, Public Health Service (including 340B), Federal Supply Schedule, and Medicare Part D plans.

¹¹ The baseline AMP is the AMP during the quarter before the Medicaid Drug Rebate Program was started or, for new drugs, the first full quarter after the drug's market date. For generic drugs marketed on or before April 1, 2013, the baseline AMP is equal to the AMP for the third quarter of 2014, and the baseline CPI-U is the CPI-U for September 2014. For generic drugs marketed after April 1, 2013, the baseline AMP is equal to the AMP for the fifth full calendar quarter after which the drug is marketed as a drug other than a brand drug, and the baseline CPI-U is equal to the CPI-U for the last month of the baseline AMP quarter (CMS 2016b).

¹² In accordance with Section 2501(c) of the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended), 24 states—Arizona, Arkansas, California, Delaware, Florida, Illinois, Iowa, Kansas, Kentucky, Louisiana, Massachusetts, Michigan, Minnesota, Nebraska, New Hampshire, New York, North Dakota, Ohio, Oregon, Pennsylvania, Texas, Virginia, Washington, and West Virginia—are expanding supplemental rebate collections to include drugs dispensed to beneficiaries who receive drugs through a managed care organization (MCO). Minnesota limits its collection of supplemental rebates for MCO enrollees to direct-acting antivirals for the treatment of hepatitis C (CMS 2020).

¹³ Phase I trials are conducted in a small group of people to determine safety (e.g., dosing range) and identify side

effects. Phase II trials involve a few hundred people with the disease or condition for which the drug is being developed and are designed to test for efficacy and additional safety data. The size of the trial usually is not large enough to show whether the drug is beneficial. Phase III trials are large studies of people with the disease or condition and are designed to demonstrate the efficacy of the drug compared with commonly used treatments and to monitor for adverse reactions. The FDA grants approval after the successful completion of Phase III trials. Phase IV trials include postmarketing requirements or commitments carried out after the drug has been approved by the FDA (FDA 2018).

¹⁴ Oklahoma received a state plan amendment in 2018 to allow the state to negotiate outcomes-based contracts with manufacturers through a supplemental rebate agreement. In 2019, Oklahoma's Medicaid pharmacy director stated that the agency dedicated an enormous amount of time to enter into contracts, meeting with 27 companies (more than three meetings with most of the companies), only to successfully negotiate four contracts. In addition, she acknowledged that defining outcomes that are sufficient indicators of efficacy has been a challenge. The manufacturer frequently wanted to use a clinical or laboratory measure that is not available in the state's claims data (Murad 2019).

¹⁵ In order to qualify for accelerated approval, a drug must treat a serious condition, generally provide a meaningful advantage over available therapies, and demonstrate an effect on a surrogate endpoint that is reasonably likely to predict a clinical benefit or on a clinical endpoint that can be measured earlier than irreversible morbidity or mortality (IMM) that is reasonably likely to predict an effect on IMM or other clinical benefit (i.e., an intermediate clinical endpoint) (FDA 2014).

¹⁶ Section 506(c)(2) of the Federal Food, Drug, and Cosmetic Act states that approval under the accelerated approval pathway may require the sponsor to conduct appropriate postapproval studies to verify and describe the predicted effect on irreversible morbidity or mortality or other clinical benefit. This could allow the FDA to grant accelerated approval without requiring a confirmatory trial. However, the FDA, through regulations and guidance, has indicated that accelerated approval will be subject to the requirement that the manufacturer study the drug further to verify the clinical benefit (21 CFR 314.510, 21 CFR 601.41, FDA 2014). The

confirmatory trial does not have to be a separate trial and may be a continuation of an ongoing trial. We are not aware of any example where accelerated approval was granted without a requirement for a confirmatory trial.

¹⁷ The manufacturer has requested a hearing, after which the FDA commissioner will decide whether to withdraw approval of Makena and its approved generic equivalents. Makena and its approved generic equivalents will remain on the market until the manufacturers decide to remove the drugs or the FDA commissioner mandates their removal.

¹⁸ The FDA may grant accelerated approval for new indications after a drug has been initially approved (including under traditional approval). Because Medicaid rebates are determined at the national drug code (NDC) level and pricing generally does not differ based on indication, the increased rebate would not apply if the drug has received traditional approval for at least one indication for that particular NDC.

¹⁹ The FDA uses the terms traditional, full, and normal approval interchangeably when discussing the conversion from accelerated approval. The conversion does not require another new drug application (NDA) but is typically executed as a supplement NDA that indicates the manufacturer has fulfilled its commitment under 21 CFR 314.510 or 21 CFR 601.41 to verify the clinical benefit.

²⁰ In 2017, Massachusetts submitted a Section 1115 demonstration waiver that explicitly requested authority to not cover some drugs granted accelerated approval because they “have not yet demonstrated clinical benefit” and “can be particularly costly” (CMS 2017). This portion of the Section 1115 demonstration waiver request was denied by CMS in 2018 (CMS 2018b). In 2019, Tennessee submitted a Section 1115 demonstration waiver amendment that requested authority to implement a closed formulary and specifically highlighted accelerated approval drugs as an area where it wanted flexibility “to exclude these new drugs from its formulary until market prices are consistent with prudent fiscal administration or the state determines that sufficient data exist regarding the cost effectiveness of the drug” (CMS 2019). Earlier this year, CMS approved the state’s request to implement a closed formulary while still receiving the MDRP rebates as part of the state’s modified block grant financing structure. This is the first time CMS has allowed a state to exclude coverage and still receive the MDRP rebates (CMS 2021).

²¹ The definition of covered outpatient drugs under the MDRP excludes drugs that are billed as part of a bundled service within certain settings (e.g., drugs provided as part of a clinic visit or hospital stay and paid for as part of those services (§ 1927(k)(3) of the Act). This means that if a drug is provided as part of services received in one of the settings listed in the statute and is paid as part of those services (i.e., there is not direct payment for the drug), it is not subject to a rebate. However, if a state authorizes and makes a direct payment for the drug separately from the service in one of those settings, it can claim a rebate for that drug. Because certain cell and gene therapies can be administered in both the inpatient and outpatient settings, the coverage requirements and applicability of Medicaid rebates under the MDRP may be different depending on the setting and payment methodology.

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Commission Vote on Recommendations

In MACPAC’s authorizing language in Section 1900 of the Social Security Act, Congress requires the Commission to review Medicaid and CHIP 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, fulfills 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 on high-cost specialty drugs. 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 Recommendations 1.1 and 1.2 on April 9, 2021.

High-Cost Specialty Drugs

1.1 Congress should amend Section 1927(c)(1) of the Social Security Act to increase the minimum rebate percentage on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased rebate percentage would apply until the manufacturer has completed the postmarketing confirmatory trial and been granted traditional FDA approval. Once the FDA grants traditional approval, the minimum rebate percentage would revert back to the amount listed under Section 1927(c)(1)(B)(i).

Yes: Bella, Brooks, Burwell, Carter, Cerise, Davis, Douglas, George, Gordon, Gorton, Lampkin, Milligan, Retchin, Scanlon, Szilagyi, Weno

16	Yes
1	No

No: Barker

1.2 Congress should amend Section 1927(c)(2) of the Social Security Act to increase the additional inflationary rebate on drugs that receive approval from the U.S. Food and Drug Administration (FDA) through the accelerated approval pathway under Section 506(c) of the Federal Food, Drug, and Cosmetic Act. This increased inflationary rebate would go into effect if the manufacturer has not yet completed the postmarketing confirmatory trial and been granted traditional FDA approval after a specified number of years. Once the FDA grants traditional approval, the inflationary rebate would revert back to the amount typically calculated under Section 1927(c)(2).

Yes: Bella, Brooks, Burwell, Carter, Cerise, Davis, Douglas, George, Gordon, Gorton, Lampkin, Milligan, Retchin, Scanlon, Szilagyi, Weno

16	Yes
1	No

No: Barker

Chapter 2:

Access to Mental Health Services for Adults Covered by Medicaid

Access to Mental Health Services for Adults Covered by Medicaid

Recommendations

- 2.1 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to issue joint subregulatory guidance that addresses how Medicaid and the State Children's Health Insurance Program can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises.
- 2.2 The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to provide education and technical assistance on the implementation of a behavioral health crisis continuum that coordinates and responds to people in crisis in real time. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of crisis services.

Key Points

- Many Medicaid beneficiaries with mental health conditions have difficulty accessing treatment. In 2018, 50 percent of beneficiaries with serious mental illness reported that they needed but did not receive treatment.
- Access to treatment is affected by a variety of factors including the extent to which states cover services and the willingness of providers to accept new Medicaid patients.
- Limited access to care has serious consequences for beneficiaries with mental illness. They are more likely than their privately insured peers to receive inpatient treatment and to report involvement with the criminal justice system.
- Crisis services can help reduce inappropriate use of psychiatric hospital beds and facilitate access to ongoing care. They can also divert individuals from the criminal justice system.
- Implementation of 9-8-8, the three-digit dialing code for the National Suicide Prevention Lifeline, is expected to increase demand for crisis services as well as mental health services more broadly. States and localities are now grappling with how to fund infrastructure changes that will be needed to cover increased demand.
- Medicaid programs can play a critical role in financing crisis services but states have little guidance on how to implement crisis services in accordance with federal guidelines.
- The Commission recommends that the Secretary of Health and Human Services (HHS) provide additional subregulatory guidance to states to address how Medicaid and CHIP can be used to fund a crisis continuum for beneficiaries with behavioral health conditions. The Commission also recommends that HHS provide technical assistance to states to support planning and cross-agency coordination.
- Looking forward, the Commission plans to further examine the needs of beneficiaries who report involvement with the criminal justice system.

CHAPTER 2: Access to Mental Health Services for Adults Covered by Medicaid

In 2018, roughly one in five non-institutionalized adults age 18–64 had a mental illness, and about half of all Americans will experience mental illness in their lifetime (SHADAC 2020, Kessler et al. 2007). Some are living with mild to moderate conditions while others have serious mental illness (SHADAC 2020).

Regardless of their insurance status, many individuals with mental illness report difficulty accessing services, particularly those with serious mental illness. In 2018, approximately half of adults with serious mental illness reported that they needed but did not receive treatment. In comparison, approximately one in five adults with mild to moderate mental illness reported that they needed but did not receive treatment during the same year (SHADAC 2020). (For discussion of access to mental health care for children and youth, see Chapter 3.)

Many state Medicaid programs do not cover the full continuum of mental health care. This continuum includes ongoing access to outpatient treatment, supportive services, such as supported employment and peer supports—supportive services delivered by a trained and certified individual who has lived experience with a mental health condition—as well as crisis services (e.g., hotline services, mobile crisis care, and crisis receiving and stabilization centers) (AACF 2020). The absence of a full continuum, including a sufficient number of psychiatric beds and real-time access to community-based care, has serious consequences for beneficiaries. It has resulted in the criminalization of mental illness, as law enforcement is often first to respond when individuals experience mental health crises (Hepburn 2020). As a result, a disproportionate share of individuals with mental illness, including

Medicaid beneficiaries, wind up in jail or prison (SHADAC 2020).

In accordance with the Americans with Disabilities Act of 1990 (ADA, P.L. 101-336), Medicaid beneficiaries with serious mental illness are entitled to receive necessary mental health treatment in the most integrated setting possible.¹ As a result of the Supreme Court’s ruling in *Olmstead v. L.C.* (119 S. Ct. 2176 (1999)), states must provide treatment for individuals with disabilities, including serious mental illness, in community-based settings if the individuals are not opposed to such services and such placement is appropriate and can be reasonably accommodated by the state.²

Although *Olmstead v. L.C.* generally requires states to provide community-based services to individuals with disabilities, it did not create an immediate right to services or to a community placement in lieu of institutional care. As such, Medicaid beneficiaries with mental illness still have difficulty accessing services in the community (MACPAC 2019a). Medicaid beneficiaries with mental illness are less likely than their privately insured peers to receive treatment from a private therapist and more likely to receive inpatient psychiatric treatment (SHADAC 2020).

While Medicaid beneficiaries with mental illness have multiple needs that could be addressed through changes in public policy, in this chapter the Commission focuses on policy to define the role of Medicaid in improving access to care for individuals in crisis. The goal of crisis services is not just to resolve behavioral health crises so that a higher level of care is not necessary, these services also triage and assess individuals and connect them with the appropriate level of care in real time. As such, crisis services can be used to address many problems faced by state behavioral health delivery systems, including inappropriate use of psychiatric hospital beds and boarding—that is, prolonged stays—in emergency departments. Such services can also help divert individuals from the criminal justice system.

National initiatives to address rising rates of suicide, specifically, implementation of 9-8-8, the three-digit dialing code for the National Suicide Prevention Lifeline (National Lifeline), is due to be completed by July 2022, and is expected to increase demand for behavioral health services (FCC 2020). States and localities are now grappling with how this will affect the ability of existing crisis hotlines to engage with individuals who are in crisis or at imminent risk of suicide and how to fund the needed changes in infrastructure (FCC 2020).

As the largest payer of behavioral health services in the United States, Medicaid plays an important role in supporting individuals in crisis. We examine the role of Medicaid (and that of the State Children's Health Insurance Program (CHIP)) in supporting 9-8-8, and how these programs can support state crisis systems more broadly. In particular, it is the Commission's view that Medicaid's critical role in supporting 9-8-8 implementation and state crisis systems needs to be more clearly defined. We therefore recommend the following actions be taken as an important first step toward improving access to mental health services for adults and youth in Medicaid and CHIP:

- The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to issue joint subregulatory guidance that addresses how Medicaid and the State Children's Health Insurance Program can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises.
- The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to provide education and technical assistance on the implementation of a behavioral health crisis continuum that coordinates and responds to people in crisis in real time. Additionally,

the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of crisis services.

To set the context for the recommendations in this chapter and future work on improving access for Medicaid beneficiaries with mental illness, this chapter begins by discussing the prevalence of mental health conditions among Medicaid beneficiaries and the rates at which they receive treatment, comparing the experience of Medicaid beneficiaries to individuals with private coverage. We also examine racial and ethnic health disparities among individuals with mental health conditions. The Commission found that Black and Hispanic beneficiaries with mental health conditions receive treatment at lower rates than their white counterparts. Moreover, they are less likely to receive treatment in a private therapist's office and take a prescription medication for their mental health condition (SHADAC 2021). We also discuss how rising rates of suicide and the criminalization of mental illness affect beneficiaries.

Next, the chapter addresses Medicaid's role in supporting a mental health continuum of care. We summarize state coverage policies and explore the availability of such services, including access at the state level and the rates at which providers participate in Medicaid.

Finally, we turn to current issues regarding implementation of 9-8-8 and how it will affect state and local crisis response systems. We examine national guidelines for crisis care, issued by the Substance Abuse and Mental Health Services Administration (SAMHSA), including how Medicaid can support the three components of state crisis systems: (1) crisis hotlines; (2) mobile crisis services; and (3) crisis stabilization and receiving facilities. The degree to which state Medicaid programs currently support these components, as well as current federal guidance, are also discussed. We conclude that Medicaid's role in supporting these components is critical, yet largely undefined, and that states have little guidance

to implement crisis services in accordance with SAMHSA's national guidelines. The chapter ends with a discussion of planned Commission work on improving access to mental health services.

Mental Health: Prevalence, Treatment Rates, and Disparities

Below, we describe the prevalence of mental health conditions among adults covered by Medicaid and the rates at which they receive treatment, comparing their levels of access, where possible, to access for individuals with mental illness with other sources of coverage. Where possible, we also examine prevalence and treatment rates for Medicaid beneficiaries by race and ethnicity. Estimates are reported where sample size permits. This analysis is based on the National Survey on Drug Use and Health (NSDUH), a federal survey of approximately 70,000 individuals conducted annually in all 50 states and the District of Columbia (SAMHSA 2019a). NSDUH collects information from residents of households and non-institutionalized group quarters (e.g., shelters, rooming houses, dormitories) and from civilians living on military bases, age 12 and older. The survey excludes those experiencing homelessness who are not residing in shelters, military personnel on active duty, and residents of institutional group quarters, including jails, nursing homes, mental institutions, and long-term care hospitals (SAMHSA 2019a). (Additional analysis of NSDUH and mental health conditions among adults is discussed in Chapter 4.)

For adult respondents, the NSDUH captures prevalence of mental health conditions that vary in terms of severity.³ Prevalence estimates for mental health conditions are reported in three categories:

- Any mental illness—This category includes adults age 18–64 who currently have or at any time in the past year reported having had a diagnosable mental, behavioral, or emotional disorder.⁴ Mental illnesses in this category can vary in severity.
- Mild to moderate mental illness—This category includes adults age 18–64 with any mental illness except serious mental illness who currently have or at any time in the past year reported having had a diagnosable mental, behavioral, or emotional disorder resulting in less than substantial impairment in carrying out major life activities.^{5, 6}
- Serious mental illness—This category includes adults age 18–64 who currently have or at any time in the past year reported having had a diagnosable mental, behavioral, or emotional disorder resulting in substantial impairment in carrying out major life activities.^{7, 8} Major life activities include activities of daily living, such as eating or dressing; instrumental activities of daily living, including managing money and taking prescribed medication; and functioning in social, family, and vocational or educational contexts (SAMHSA 2019a).

It is important to note that NSDUH may over- or underreport certain variables related to mental health and substance use disorder (SUD). Specifically, information obtained through this survey is self-reported; these responses are subjective and are not validated using psychiatric diagnostic information. Individual responses are likely influenced by a variety of social and cultural factors, including beliefs and perceptions of mental health issues that may vary culturally (Ward et al. 2013). Moreover, emerging evidence suggests that women are more likely to underreport a past year major depressive episode than men (Tam et al. 2020).

Prevalence

In 2018, 41.5 million adults (21 percent of U.S. civilian, non-institutionalized individuals age 18–64) had a mental health condition (SHADAC 2020). The share of adults reporting any mental illness was higher for those enrolled in Medicaid than for adults with private coverage and those without insurance (Table 2-1). In part, this may be because many individuals qualify for Medicaid based on a disability, including those with serious mental illness, such as schizophrenia. In 2019, among

those qualifying for Supplemental Security Income, 6 out of 10 were diagnosed with a mental disorder (SSA 2020). Generally, across all racial and ethnic categories, adults who are enrolled in Medicaid are more likely to report that they had any mental illness than those with private coverage. (See Appendix 2A, Table 2A-1 and Table 2A-2, for additional information on the prevalence of mild to moderate mental illness and serious mental illness among non-institutionalized adults, respectively.)

TABLE 2-1. Reported Prevalence of Mental Illness in the Past Year among Non-Institutionalized Adults Age 18–64, by Demographic Characteristics, 2018

Demographic characteristics	Percentage of adults 18–64 with any mental health condition	Percentage of adults age 18–64 in each coverage category with any mental health condition		
		Medicaid	Private coverage	Uninsured
Total	21.0%	27.6%	18.7%	21.3%
Age				
18–25	26.1	26.2	27.4	22.2*
26–34	26.3	33.6	23.9*	25.1*
35–49	19.8	28.3	17.2*	19.7*
50–64	16.0	21.4	13.1*	17.9
Sex				
Male	16.8	21.6	14.9*	17.5*
Female	25.1	31.4	22.5*	26.2*
Race and ethnicity				
White, non-Hispanic	23.6	34.0	20.7*	28.9*
Black, non-Hispanic	16.7	20.0	12.9*	17.9
Hispanic	16.7	22.8	15.6*	13.4*
Asian American, non-Hispanic	15.5	25.2	13.9*	14.6
American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, non-Hispanic	20.6	22.8	16.1	25.2
Two or more races, non-Hispanic	27.9	36.4	24.6*	38.1

TABLE 2-1. (continued)

Demographic characteristics	Percentage of adults 18–64 with any mental health condition	Percentage of adults age 18–64 in each coverage category with any mental health condition		
		Medicaid	Private coverage	Uninsured
Education				
Less than high school	17.9	24.4	13.9*	13.6*
High school graduate	20.1	24.7	16.3*	21.2
Some college or associate degree	24.6	33.2	21.8*	25.3*
College graduate	19.3	29.4	18.2*	29.6
Employment				
Working full time	18.1	23.6	17.5*	19.0*
Working part time	25.3	28.4	23.6*	27.0
Unemployed	26.5	24.7	30.8	22.9
Other	25.1	31.0	18.8*	21.7*

Notes: Estimates for any mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as primary coverage at the time of the interview.

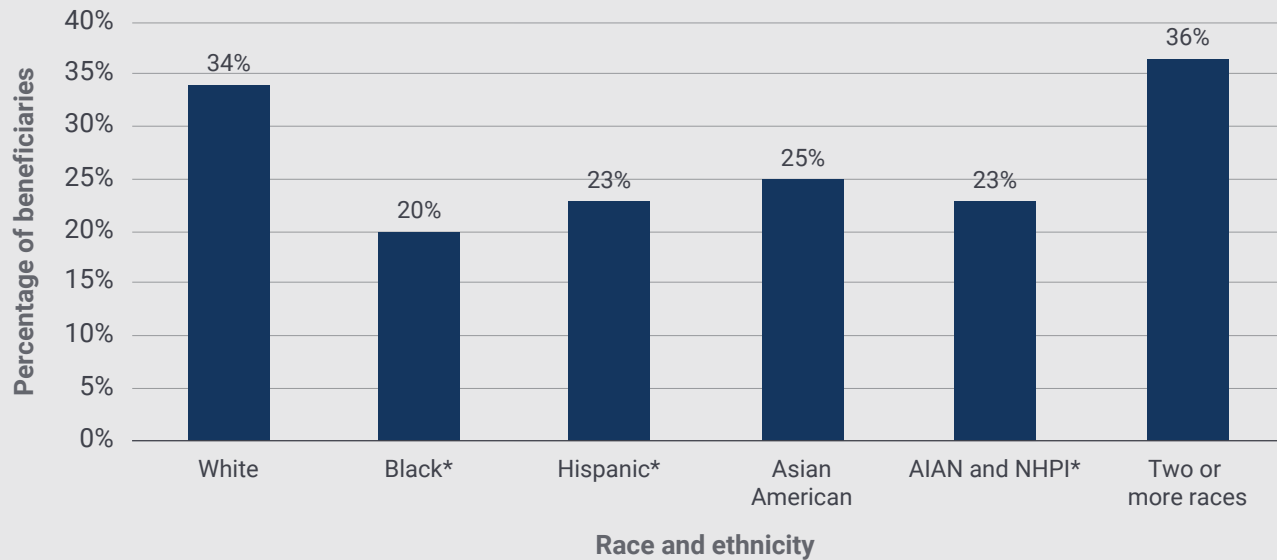
* Difference from Medicaid is statistically significant at the 0.05 level.

Source: SHADAC 2020.

Prevalence of any mental illness among beneficiaries across racial and ethnic groups.

Medicaid beneficiaries report experiencing mental health conditions at higher rates than individuals with other forms of insurance, and rates of mental illness among Medicaid beneficiaries vary across racial and ethnic groups (Figure 2-1). Reported rates of any mental illness among Medicaid beneficiaries are highest for those who identify as white, and individuals who identify as two or more races. Beneficiaries who identify as Black, Hispanic, or American Indian, Alaska Native, Native Hawaiian, or Pacific Islander report having mental health conditions at rates significantly lower than their white counterparts (SHADAC 2021).

FIGURE 2-1. Reported Prevalence of Any Mental Illness in the Past Year among Non-Institutionalized Adults Covered by Medicaid, Age 18–64, by Race and Ethnicity, 2018



Notes: Hispanic is anyone of Hispanic, Latino, or Spanish origin. AIAN and NHPI combines data for respondents who identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander and are not of Hispanic origin. White, Black, Asian American, and two or more races do not include respondents of Hispanic origin.

Estimates for any mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as primary coverage at the time of the interview.

* Difference from white beneficiaries is statistically significant at the 0.05 level.

Source: SHADAC 2021.

Effects of the COVID-19 pandemic on mental health.

The COVID-19 pandemic has created additional mental health challenges for adults (Ahmad et al. 2021, Czeisler et al. 2020). From April to June 2020, symptoms of anxiety disorder and depressive disorder increased considerably in comparison with the same period in 2019. A representative survey of adults over the age of 18 conducted in June 2020 found that 40 percent of adults were struggling with mental health or substance use conditions. These conditions disproportionately affected young adults

age 18–25, individuals identifying as Hispanic or Black and individuals with less than a high school education, and adults reporting less than \$25,000 in household income. Rates of mental health conditions and substance use were also high among unpaid adult caregivers and essential workers (Czeisler et al. 2020). Preliminary data regarding drug overdose deaths occurring in the 12-month period leading up to September 2020 indicate that overdose deaths increased by nearly 30 percent over the prior year (Ahmad et al. 2021).

Use of mental health treatment by insurance status

Medicaid beneficiaries with mental health conditions, regardless of the severity of their illness, receive treatment at similar rates as their peers with private coverage (Appendix 2A, Table 2A-3). This includes taking prescription medication for their mental illness and receiving services at outpatient medical clinics at the same rate as adults with private coverage.

Nonetheless, beneficiaries with any mental illness received treatment in different settings than those with private insurance:

- **Inpatient psychiatric treatment.** Adults with any mental illness enrolled in Medicaid were nearly four times as likely to receive inpatient treatment for their mental health condition as those with private coverage. Medicaid beneficiaries with mild to moderate mental illness were nearly five times as likely to receive inpatient treatment as their privately insured peers. Those with serious mental illness who were enrolled in Medicaid were more than twice as likely to receive treatment in an inpatient setting than those with private coverage (SHADAC 2020).⁹
- **Outpatient treatment.** Adults with any mental illness enrolled in Medicaid were nearly three times more likely to receive treatment in an outpatient mental health center or a day treatment program than those with private coverage. But they were less likely to receive treatment in a private therapist's office. Specifically, adults with any mental illness with private coverage received treatment in a private therapist's office at nearly twice the rate of their Medicaid-enrolled peers. This was consistent for individuals with mild to moderate mental health conditions and for those with serious mental illness (SHADAC 2020).

Unmet treatment needs. Adults with any mental illness enrolled in Medicaid were more likely to report that they needed but did not receive mental health treatment or counseling in the past year than those with private coverage (Table 2-2). Moreover, Medicaid beneficiaries with serious mental illness were more than twice as likely to report that they needed but did not receive treatment than Medicaid beneficiaries with mild to moderate mental illness.

TABLE 2-2. Needed but Did Not Receive Mental Health Treatment or Counseling among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Condition	Percentage of adults 18–64	Percentage of adults age 18–64 in each coverage category		
		Medicaid	Private coverage	Uninsured
Any mental illness	26.0%	30.2%	24.5%*	28.2%
Mild to moderate mental illness	18.7	22.0	18.5	17.5
Serious mental illness	47.1	49.5	44.8	55.5

Notes: Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

Source: SHADAC 2020.

Treatment rates across racial and ethnic groups.

Among Medicaid beneficiaries, treatment rates for individuals with any mental illness vary across racial and ethnic groups (Table 2-3). In 2018, beneficiaries identifying as American Indian, Alaska Native, Native Hawaiian, or Pacific Islander reported receiving mental health treatment at the same rate as white beneficiaries. In contrast, Black beneficiaries with mental illness were less likely to receive treatment than their white peers; 52 percent of white beneficiaries reported receiving mental health treatment in the past year, while 36 percent of Black beneficiaries received treatment. When compared to white beneficiaries, similar disparities are observed for receipt of treatment among Hispanic beneficiaries and beneficiaries who report two or more races.

Some beneficiaries of color were less likely to receive treatment in certain settings than their white counterparts. Specifically, Black and Hispanic beneficiaries were less likely to receive treatment in a private therapist’s office than white beneficiaries.

White beneficiaries were also more likely to take a prescription medication for their mental health condition than beneficiaries who identified as Black, Hispanic, and two or more races.

TABLE 2-3. Reported Use of Mental Health Treatment among Non-Institutionalized Adult Medicaid Beneficiaries Age 18–64 with Past Year Mental Illness, by Racial and Ethnic Group, 2018

Treatment characteristics	Percentage of Medicaid beneficiaries age 18–64 in each racial and ethnic group with any mental illness					
	White	Black	Hispanic	Asian American	AIAN and NHPI	Two or more races
Received any mental health treatment in the past year	52.3%	35.5%*	35.0%*	27.2%*	51.3%	31.9%*
Received treatment in a private therapist's office	14.8	7.0*	9.4*	–	–	–
Took any prescription medication for a mental health condition	46.2	30.6*	27.5*	–	–	24.6*

Notes: Hispanic is anyone of Hispanic, Latino, or Spanish origin. AIAN and NHPI combines data for respondents who identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander and are not of Hispanic origin. White, Black, Asian American, and two or more races do not include respondents of Hispanic origin.

Estimates for any mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as primary coverage at the time of the interview.

* Difference from white beneficiaries is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Mental Health, Mortality, and Rising Rates of Suicide

Among Medicaid beneficiaries with mental health conditions, low treatment rates, the criminalization of mental illness, and stigma associated with their disease have serious health consequences. While data specific to Medicaid are not available, individuals with mental health conditions often die prematurely (Insell 2011, Parks et al. 2006). Based on mortality data from eight states, one study concluded that on average, Americans with a major mental illness die 14 to 32 years earlier than the

general population. In these states, the average life expectancy for people with major mental illness ranged from 49 to 60 years (Insel 2011).

Comorbid medical conditions are often cited as the main factor contributing to shortened life expectancy for those with mental illness; however, other factors, including rising rates of suicide, also result in premature mortality (Roberts et al. 2017). (For additional information on comorbid conditions and mortality among beneficiaries with mental health conditions, see Chapter 4.) Suicide is one of the most widely acknowledged contributors to premature mortality among individuals with mental

illness (Roberts et al. 2017). It is the 10th leading cause of death for all ages in the United States, and the second leading cause of death for individuals age 10–34 (Hedegaard et al. 2020).

While there are no national statistics on suicide-related death in the Medicaid population, overall deaths by suicide increased nearly 35 percent from 1999 to 2017. Over this time period, the suicide rate among men was nearly four times the rate of suicide among women (Curtin et al. 2019). However, suicide rates grew significantly for women of all racial and ethnic groups over this time period, with the exception of those identifying as Asian, or Pacific Islander.¹⁰ One study from Ohio found higher rates of suicide among Medicaid beneficiaries with multiple co-occurring conditions. Overall, this study found that the suicide rate among Medicaid beneficiaries (18.9 per 100,000) was higher than that of the general U.S. population (12.6 per 100,000) and in Ohio (16.3 per 100,000) (Fontanella et al. 2017).

Suicide rates vary by geography and population characteristics. For example, suicide rates tend to be higher in rural counties than in urban counties. This is true for both males and females (Hedegaard et al. 2020). Youth who identify as lesbian, gay, bisexual, or transgender also attempt suicide at higher rates than the general population (NAMI 2020a). (See Chapter 3 for additional information on suicidal thoughts and behaviors among children and youth covered by Medicaid and CHIP.)

Mental Illness and the Criminal Justice System

In many parts of the United States, the absence of a robust mental health system has resulted in the criminalization of mental illness, given that law enforcement is often the de facto mental health crisis system. When police are first responders, persons in mental health crisis are often taken into custody, rather than taken to mental health treatment centers. Law enforcement response to

mental health crises often contributes to the anxiety and fear experienced by individuals in crisis. This can occur solely based on the presence of police vehicles and armed officers (SAMHSA 2020a). Such fears are well founded; from 2015–2020, one in four individuals shot and killed by police officers had a mental health condition (Hepburn 2020).

People with mental health conditions are overrepresented in the nation's prisons and jails. In 2018, an estimated 6.4 million individuals were under the supervision of the adult correctional system, including 4.4 million on probation or parole, and 2.1 million under the custody of state or federal prisons or local jails (BJS 2020). Approximately 40 percent of individuals in prison or jail have a history of mental illness, with higher rates for those in jail (44 percent) than for those in federal prison (37 percent) (BJS 2017). Among incarcerated individuals, rates of mental illness are higher among women than men (NAMI 2020b).

Most (63 percent) individuals with a history of mental illness do not receive treatment while incarcerated in prison, and fewer than half (45 percent) receive treatment while held in local jails. People of color are disproportionately affected.¹¹ Among those incarcerated, people of color with a mental health condition are more likely to be held in solitary confinement, to sustain injuries, and to stay in jail longer. Moreover, suicide is the leading cause of death for people held in local jails (NAMI 2020b).

Beneficiary involvement with the criminal justice system

Individuals enrolled in Medicaid are more likely to experience involvement with the criminal justice system than their privately insured peers. In 2018, one in three non-institutionalized adults with any mental illness who were enrolled in Medicaid reported that they had been arrested or booked for breaking the law at some point in their lives (Table 2-4). This is nearly double the rate of individuals with private coverage. In addition, adults with any mental illness who were enrolled in Medicaid were

more than three times as likely to report that they were on probation or parole in the past year than those with private coverage (SHADAC 2020). Due to sample size issues, we were unable to provide

estimates of involvement with the criminal justice system among beneficiaries by race and ethnicity (SHADAC 2021, 2020).

TABLE 2-4. Reported Rates of Involvement with the Criminal Justice System among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Involvement with the criminal justice system	Percentage of adults 18–64	Percentage of adults age 18–64 in each coverage category		
		Medicaid	Private coverage	Uninsured
Ever been arrested and booked for breaking the law				
Any mental illness	24.0%	33.7%	17.6%*	33.3%
Mild to moderate mental illness	22.9	31.2	17.3*	32.3
Serious mental illness	27.4	39.6	18.6*	35.7
On probation or parole, past year				
Any mental illness	3.1	5.8	1.8*	5.5
Mild to moderate mental illness	2.6	5.3	1.4*	5.3
Serious mental illness	4.7	7.1	3.2*	5.9

Notes: Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

Source: SHADAC 2020.

Forthcoming federal guidance may allow Medicaid agencies to play a larger role in community reentry. Section 5032 of the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act (SUPPORT Act, P.L. 115-271) requires the Centers for Medicare & Medicaid Services (CMS) to issue guidance for demonstration waivers under Section 1115 of the Social Security Act (the Act) targeting beneficiaries leaving jail or prison. This guidance must be based on best practices to improve care

transitions for Medicaid-eligible individuals leaving jail or prison. Under the SUPPORT Act, care transition services can be provided up to 30 days prerelease and may include providing education about and assistance with Medicaid enrollment, as well as providing health care services. This guidance was supposed to have been issued in October 2019; as of May 2021, it has yet to be released.

Components of a Mental Health Continuum

Appropriate mental health treatment varies with the severity of an individual's condition. As noted above, some individuals experience mild to moderate mental illness, while others have serious mental illness that substantially interferes with or limits their ability to perform one or more major life activity (e.g., eating, bathing, or dressing) or instrumental activities of daily living (e.g., maintaining a household or taking prescribed medications). Moreover, mental health conditions are often episodic and the severity of symptoms can vary over time. Adults with mental illness need access to a continuum of care, with

services that vary in intensity. This includes both clinical services—such as outpatient treatment, partial hospitalization, and inpatient psychiatric treatment—and supportive services, such as peer support and supported employment (CMS 2018).

Established by the American Association for Community Psychiatry (AACP), the *Level of Care Utilization System for Psychiatric and Addiction Services* (LOCUS) describes a continuum of care, characterized by the amount and scope of resources available at each of six levels of care (AACP 2020). These range from monthly treatment for clients who are living independently with minimal support in the community to around-the-clock inpatient psychiatric care (Box 2-1).

BOX 2-1. Level of Care Utilization System for Psychiatric and Addiction Services

The *Level of Care Utilization System for Psychiatric and Addiction Services* (LOCUS) identifies six levels of care that vary in intensity. Each level includes an array of services, combining crisis, supportive, clinical, and environmental interventions, based on individual need. At each level, basic services, often referred to as crisis resolution or emergency services, should be available to all individuals regardless of the severity of their disease.

Basic services. These services can prevent the onset or limit the magnitude of morbidity associated with a preestablished disease. They should include outreach to special populations, including individuals experiencing homelessness, screening of high-risk individuals, consultation with other community providers, and use of crisis hotlines to support individuals with behavioral health conditions.

Recovery maintenance and health management (Level 1). This level of care includes treatment for clients who are living independently with minimal support in the community. Clinical services should be available up to one hour per month, and usually no less than one hour every three months.

Low-intensity community-based services (Level 2). Services at this level are for individuals in need of ongoing treatment who are living independently. Services are usually offered in clinic-based programs up to two hours per week, but no less than one hour every four weeks.

High-intensity community-based services (Level 3). This level includes intensive treatment for individuals that live independently with minimal support in the community. Treatment should occur three days per week for two to three hours per day.

BOX 2-1. (continued)

Medically monitored non-residential services (Level 4). Services at this level include intensive community-based treatment provided by a multidisciplinary treatment team for most of the day, on a daily basis. This level of care includes partial hospitalization and assertive community treatment.

Medically monitored residential services (Level 5). Services are provided in a 24-hour residential treatment setting in the community. Clinical care is available at all times and psychiatric care should be available on site or by remote communication 24 hours a day, 7 days a week.

Medically managed residential services (Level 6). This level is considered 24-hour hospital-based psychiatric care. Psychiatric, nursing, and medical services must be available at all times and treatment must be provided daily (AACAP 2020).

Medicaid Coverage of Mental Health Services

State Medicaid programs are required to cover certain mental health services for adults, including medically necessary inpatient hospital services, outpatient hospital services, rural health clinic services, nursing facility services, home health services, and physician services. However, many other services important for the treatment of mental health conditions are optional, including other diagnostic, screening, preventive, and rehabilitative services; case management; and personal care services (SAMHSA 2013).

Medicaid's role in financing mental health services for adults varies considerably at the state level and many states do not offer a full complement of services (Appendix 2B, Table 2B-1).¹² Most states have gaps in mental health coverage, covering on average 12 out of 15 mental health services. There are particularly large gaps for residential services (covered by 27 states and the District of Columbia) and crisis residential services (covered by 28 states and the District of Columbia).^{13, 14} Supportive services, including supported employment (covered by 24 states and the District of Columbia), and skills training and development (covered by 33 states)

are offered less frequently. All states cover mental health screening and assessment services, some form of outpatient mental health treatment, and inpatient psychiatric care.¹⁵

Access to Mental Health Providers

In addition to gaps in coverage, there are a number of other reasons Medicaid beneficiaries with mental health conditions do not receive treatment. They may have difficulty finding mental health providers—concerns about such shortages have been well documented over the past decade (Hoge et al. 2013; SAMHSA 2013, 2007). General shortages and geographic maldistribution of behavioral health providers, coupled with the unwillingness of some providers to serve individuals enrolled in Medicaid, limit access to mental health treatment (MACPAC 2016).

In addition, lack of diversity in the workforce may affect access, given that minority health professionals are more likely than white peers to treat people of color (Hoge et al. 2013). Minorities account for only 21.3 percent of psychiatrists, 6.2 percent of psychologists, 5.6 percent of

advanced practice psychiatric nurses, and 12.6 percent of social workers (Hoge et al. 2013). There is also evidence that when physicians and patients share the same race or ethnicity, patients experience improved health outcomes, such as better medication adherence (Huerto 2020). Still, differences in beliefs about culture, health, and health care may exist even when providers and patients identify as the same race or ethnicity (Hoge et al. 2013).

Because there is no single, uniform data source providing information on the U.S. mental health workforce, we examined multiple data sources to illustrate the availability of several components of the specialty mental health treatment system including: freestanding specialty mental health facilities; office-based, solo, and small group practices, comprised of psychiatrists and other mental health providers (e.g., counselors and therapists); and other providers, including community health centers. Below we describe the availability of these components of the mental health treatment system. We also discuss provider participation in Medicaid, as well as the types of services provided by the specialty mental health treatment system. Where possible, we describe availability at the state level.

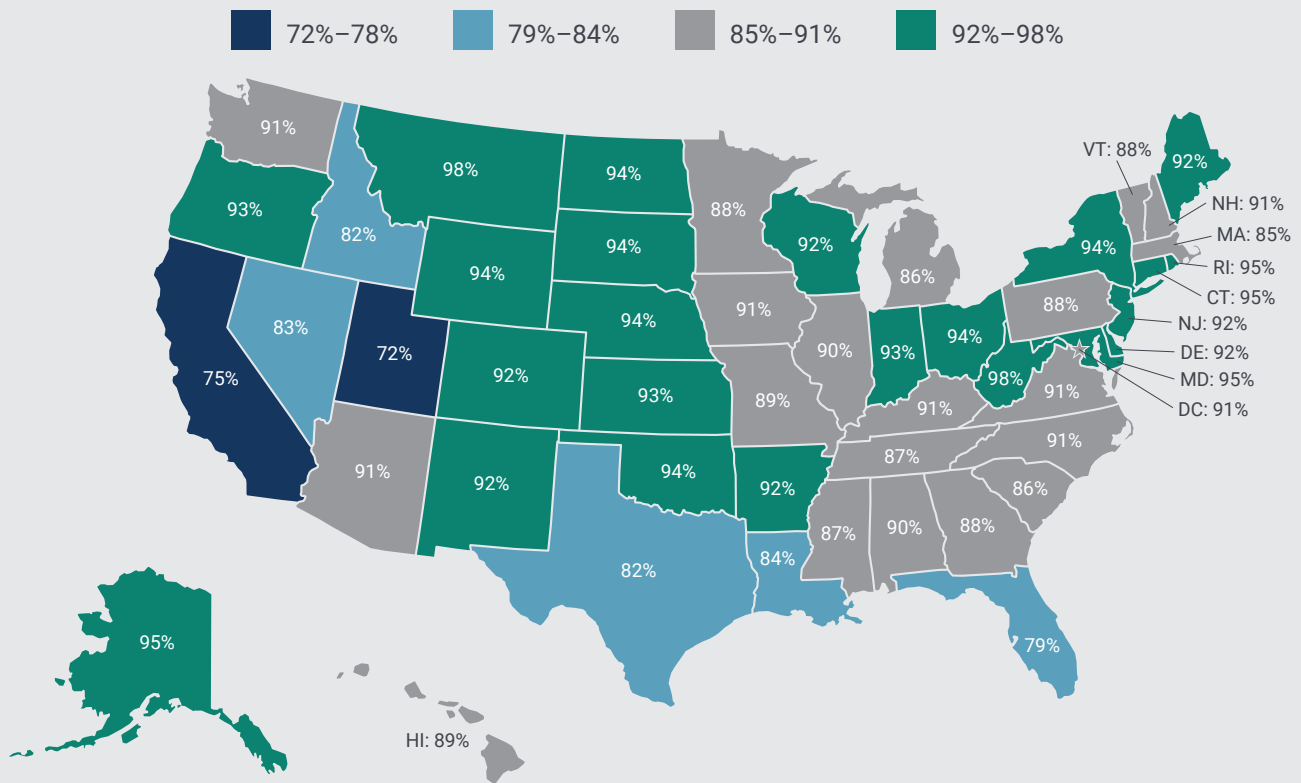
Supply of specialty mental health facilities

Using the 2018 National Mental Health Services Survey (N-MHSS), we examined the availability of specialty mental health treatment facilities and their participation in Medicaid.¹⁶ These treatment facilities provide services ranging from outpatient mental health services, to partial hospitalization, to inpatient psychiatric services. Most commonly, these facilities offer a variety of treatment approaches, including psychotherapy, cognitive behavioral therapy, group therapy, and psychotropic medication (SAMHSA 2019b).

In 2018, there were nearly 12,000 specialty mental health treatment facilities in the United States; 89 percent of these facilities reported accepting Medicaid, which was higher than the acceptance rate for private insurance (81 percent) (SAMHSA 2019b). However, Medicaid participation varies by state, ranging from 72 percent in Utah to 98 percent in Montana (Figure 2-2).

Most specialty mental health treatment facilities report offering outpatient mental health services; of these facilities, the majority report acceptance of Medicaid (Appendix 2C, Figure 2C-1). It is worth noting that the availability of the most intensive community-based mental health services varies at the state level (SAMHSA 2019b). In addition, nearly half of specialty mental health facilities report offering on- or off-site crisis services (Appendix 2C, Figure 2C-1). However, these facilities offer intensive services—such as partial hospitalization, assertive community treatment, and residential treatment—less often than traditional outpatient services.¹⁷

FIGURE 2-2. Share of Mental Health Treatment Facilities Accepting Medicaid by State, 2018



Sources: MACPAC, 2020, analysis of SAMHSA 2019b.

Recovery-oriented services. Few specialty mental health treatment facilities offer supportive services, such as peer support, supported employment, and vocational rehabilitation. In 2018, one in four specialty mental health treatment facilities reported offering peer support services and nearly all these facilities reported acceptance of Medicaid (Appendix 2C, Figure 2C-2).¹⁸ Even fewer facilities reported offering supported employment or vocational rehabilitation services.¹⁹

Telehealth. About 28 percent of specialty mental health facilities reported offering telehealth services and accepting Medicaid in 2018 (SAMHSA 2019b). The availability of such services varies widely across states, ranging from 3 percent of facilities in Connecticut to 71 percent of facilities in North Dakota (SAMHSA 2019b). While use of telehealth for

behavioral health has increased during the COVID-19 pandemic, we do not have data to document if the number of specialty mental health facilities offering telehealth services also grew. However, given their high Medicaid participation, and the fact that all states and the District of Columbia expanded use of telehealth during the pandemic, it is likely the percentage of facilities has increased.

Crisis services and emergency psychiatric services. In 2018, 44 percent of facilities reported accepting Medicaid and having a crisis intervention team to handle acute mental health issues on- or off-site (SAMHSA 2019b). Fewer facilities offered psychiatric emergency walk-in services and accepted Medicaid (28 percent). Facilities that offered psychiatric emergency walk-in services had specially trained staff to provide services such as

crisis intervention. These services enable individuals, family members, and friends to cope with an emergency while helping the individual function as a member of the community (SAMHSA 2019b).

Certified community behavioral health clinics.

The certified community behavioral health clinic demonstration (CCBHC) initially allowed eight state Medicaid programs to make enhanced, prospective payments to behavioral health clinics that meet federal standards designed to support comprehensive, high-quality, accessible care for adults with serious mental illness and children with serious emotional disturbance (SED), as well as individuals with SUD (SAMHSA 2018b). In 2020, Congress expanded the demonstration to two additional states (HHS 2020). Results from the national evaluation are pending, but initial assessments show that CCBHCs have hired additional staff, offered new services—including 24-hour mobile crisis services—and invested in health information technology to support care coordination and quality reporting (ASPE 2020, SAMHSA 2018b). Several states have taken steps to sustain this effort beyond the demonstration period, which was initially scheduled to end in 2019 and has been extended by Congress multiple times. In Missouri, the CCBHC model has led to fewer interactions with law enforcement among individuals treated by CCBHCs. Emergency department visits and hospitalizations in Missouri have also declined (Schuffman 2020).

Office-based mental health services and other providers

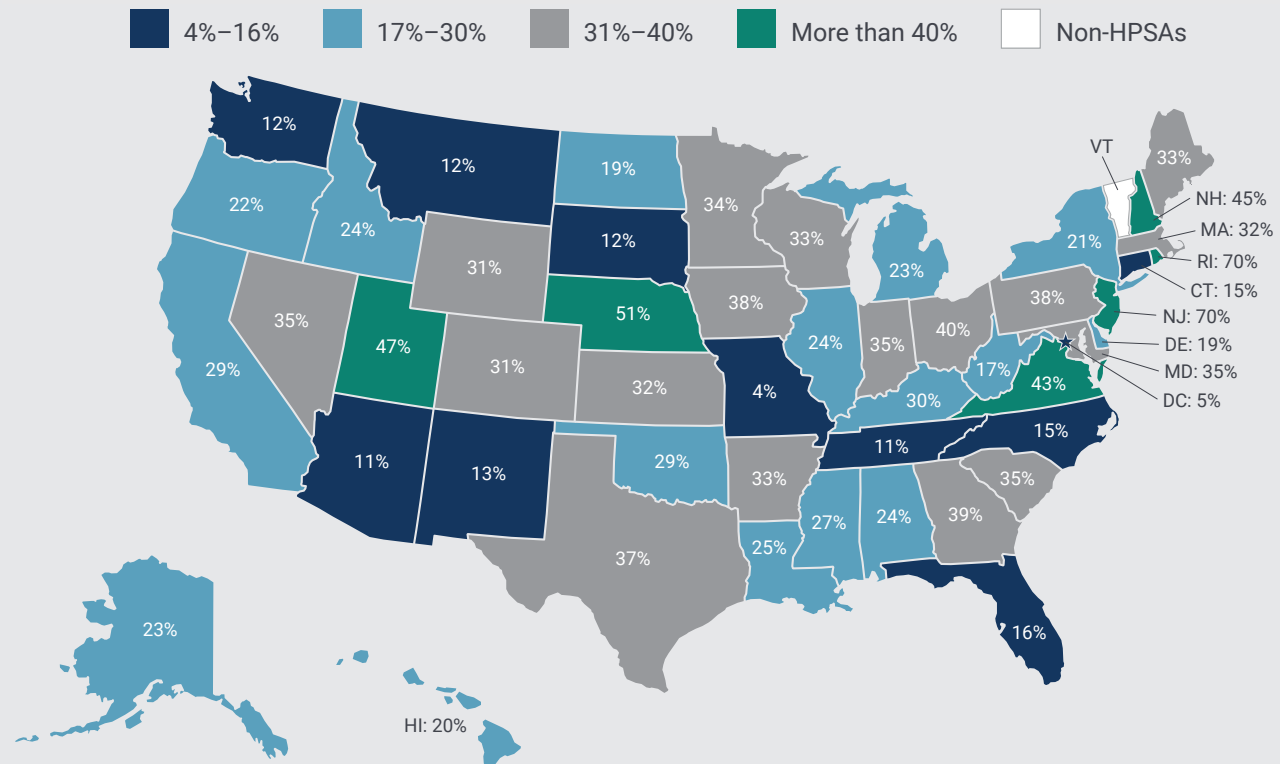
Many different types of providers, including social workers, psychologists, psychiatrists, psychiatric nurse practitioners, and professional counselors, deliver office-based mental health services. Given data limitations, we used information from other federal programs to assess the availability of mental health providers at the state level.

The Health Resources and Services Administration (HRSA) oversees Health Professional Shortage

Area (HPSA) designations, which identify geographic areas with provider shortages, including mental health provider shortage areas.²⁰ These designations are not specific to Medicaid but rather reflect the overall need of a geographic area. To be considered a provider shortage area for mental health, the population-to-provider ratio must be at least 30,000 to 1, or 20,000 to 1 for certain high-need communities.

As of September 2019, nearly 6,200 mental health practitioners were needed to remove all mental health HPSA designations (KFF 2019).²¹ Most states (47 states) fall short of meeting even 50 percent of the estimated mental health need in these HPSAs, with a range of 4 percent in Missouri to 100 percent in Vermont (Figure 2-3) (KFF 2019).²²

FIGURE 2-3. Share of Met Need in Designated Mental Health Professional Shortage Areas, 2019



Note: HPSA is Health Professional Shortage Area. Share of met need is the number of psychiatrists that would be necessary to eliminate the mental health HPSA in the state (based on a ratio of 30,000 to 1, or 20,000 to 1 in high-need areas).

Source: KFF 2019.

Access to office-based mental health services is also affected by provider participation in Medicaid. A recent MACPAC study found that providers are less likely to accept new patients with Medicaid than patients with other forms of insurance. Just 35 percent of psychiatrists accepted new patients enrolled in Medicaid in 2014–2015, in contrast with 62 percent accepting new patients covered by Medicare and private insurance (Heberlein and Holgash 2019).

Low Medicaid participation among psychiatrists may reflect low payment rates. One study using 2014 Medicaid claims data from 11 states found that in 10 of the 11 states, psychiatrists were paid less than primary care physicians (ranging from \$1–\$34) for an established patient office visit for individuals with moderate severity mental health

needs (Mark et al. 2020).²³ It should be noted that the disparity in payment rates between psychiatrists and primary care physicians documented in this study appears to be inconsistent with federal mental health parity requirements set out by the Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA, P.L. 110-343).²⁴ However, this study included data prior to the application of MHPAEA requirements for Medicaid, which occurred in October 2017.²⁵ Moreover, in many states, Medicaid physician fees are well below rates paid by Medicare and private insurance (Zuckerman et al. 2021).

Community health centers. Community health centers play an important role in the health care of Medicaid beneficiaries and a growing number are providing behavioral health services

(NACHC 2020). In 2019, community mental health centers employed nearly 13,600 full-time equivalent professionals providing mental health services. This includes a variety of mental health practitioners, such as psychiatrists, licensed clinical psychologists, licensed clinical social workers, and other licensed mental health providers. Combined, these practitioners conducted almost 12 million clinic visits in 2019 (HRSA 2020).

Federal programs to address behavioral health workforce shortages. Though not specific to the Medicaid program, several federal programs are addressing behavioral health workforce shortages. The National Health Service Corps (NHSC), overseen by HRSA, provides loan repayment or scholarships to clinicians who agree to treat patients in HPSAs. In 2020, NHSC membership included more than 16,000 clinicians who provided care to 17 million individuals. More than 60 percent of NHSC members work at community health centers. Moreover, behavioral health is a top discipline among NHSC clinicians (HRSA 2020). There is a similar loan assistance repayment program, Nurse Corps, for registered nurses, advanced practice nurses, and nurse faculty (HRSA 2021).

The American Rescue Plan Act of 2021 (ARP, P.L. 117-2) includes a number of provisions to address workforce shortages, including additional funding for training opportunities to improve the distribution and supply of the behavioral health workforce. The law includes funding increases for the NHSC (\$800 million) and Nurse Corps (\$200 million). It also allocates \$80 million to HRSA for behavioral health training for health care professionals, paraprofessionals, and public safety officers. Such funding must be used to plan, develop, operate, or participate in evidence-informed strategies to reduce and address suicide, burnout, mental health conditions, and SUD among health care professionals. Finally, ARP provides an additional \$100 million for the Behavioral Health Workforce Education Training Program, administered by HRSA, to expand access to behavioral health services through focused training.

Current Efforts to Address Behavioral Health Crises

Medicaid agencies are playing a growing role in building a coordinated continuum of behavioral health care. To ensure beneficiaries receive the right care at the right time, some states have developed crisis systems to intervene when an individual is experiencing a behavioral health crisis (Gordon 2020). Crisis systems also triage and assess individuals and connect them with the appropriate level of care (SAMHSA 2020a).

Ultimately, the goal of crisis services is to resolve behavioral health crises so more intensive services are not needed (SAMHSA 2020a). Offering such care is a key strategy to reduce inappropriate use of psychiatric hospital beds, decrease boarding in emergency departments, and reduce the need for law enforcement to respond to behavioral health crises (SAMHSA 2020a). These services help individuals, and their families and friends, cope in emergencies while helping the individual function as a member of the community (SAMHSA 2020a).

Several national and state efforts are underway to address rising rates of suicide and to ensure access to behavioral health care for individuals in crisis. The implementation of 9-8-8, a new national three-digit dialing code for a national suicide prevention and mental health crisis hotline, is scheduled for July 2022. SAMHSA has also established national guidelines for crisis care (SAMHSA 2020a). However, the role of Medicaid remains undefined in both initiatives, and CMS guidance does not address how to pay for crisis services. Below we discuss these initiatives and the degree to which state Medicaid programs currently support crisis continuums. We also discuss the need for collaboration between SAMHSA and CMS and prior congressional action to improve interagency coordination on issues related to serious mental illness.

Implementation and financing of 9-8-8

SAMHSA funds the National Lifeline, a national network of approximately 184 crisis centers linked by a toll-free number that is available 24 hours a day, 7 days a week.²⁶ In September 2020, the Federal Communications Commission (FCC) designated 9-8-8 as the national three-digit dialing code for a suicide prevention and mental health crisis hotline. This will go into effect by July 16, 2022, and link to the current network of crisis call centers. Designating a three-digit code for the National Lifeline is meant to send the message that addressing mental health crisis and suicide prevention are as important as medical emergencies, and will improve resources to respond to behavioral health crises at a local level (FCC 2020).

Many stakeholders are concerned that there will not be sufficient capacity and funding to meet increased demand when 9-8-8 goes live (FCC 2020).²⁷ In part, this is because funding for crisis hotlines is typically a state and local responsibility and the resources necessary to operationalize 9-8-8 have not been fully identified. The National Suicide Hotline Designation Act of 2020 (P.L. 116-172) requires the Assistant Secretary for Mental Health and the Assistant Secretary of Veterans Affairs to submit a joint report that details the resources. Although this report was due to Congress on April 15, 2021, as of May 2021, it had not been submitted.

There are multiple ways states may finance hotline services. The National Suicide Hotline Designation Act of 2020 allows states to assess a fee on cell phone bills to recover 9-8-8 implementation costs for state and local crisis hotlines. A similar fee supports 9-1-1 in most states (MHA and VEH 2020). As discussed below, Medicaid may play a role in supporting crisis hotlines because some states are billing Medicaid for a portion of hotline services delivered to beneficiaries.

Core crisis services

In February 2020, SAMHSA issued the *National Guidelines for Behavioral Health Crisis Care – A Best*

Practice Toolkit, establishing for the first time, the three core elements of a crisis system as outlined below (SAMHSA 2020a).²⁸

Regional or statewide crisis call centers. Crisis call centers connected to the National Lifeline are staffed by clinicians providing intervention services via telephone, text, or chat. Staff conduct risk assessments and engage with individuals who are in crisis or at imminent risk for suicide. They also coordinate crisis care in real time, communicating with mobile teams and providing so-called warm handoffs—the transfer of care between two members of a care team—to facility-based care if necessary.^{29,30} Ideally, call centers use real-time regional bed registry technology to connect individuals to residential or inpatient care, when needed, and employ caller ID and GPS-enabled technology to dispatch mobile teams (SAMHSA 2020a).

Crisis mobile response. Community-based mobile crisis teams operate 24 hours a day, 7 days a week, and can reach individuals in their homes, workplaces, and other community locations. They can evaluate and stabilize individuals and, if needed, take them to short-term stabilization facilities or acute care settings (SAMHSA 2020a).³¹ Per SAMHSA guidelines, mobile crisis teams should include peer support specialists. In addition, they should respond without law enforcement unless special circumstances warrant the inclusion. This is needed to support true diversion from the criminal justice system (SAMHSA 2020a).

Crisis receiving and stabilizing facilities. These facilities provide short-term (less than 24 hours) observation and crisis stabilization services to all individuals outside of hospitals.³² Ideally, these facilities offer trauma-informed and suicide-safer care, which is designed to monitor for suicide risk and intervene with specific, evidence-based approaches delivered by mental health professionals and peers with lived experience (SAMHSA 2020a). Among other things, receiving and stabilizing facilities should have dedicated first responder drop-off areas and crisis beds within a

real-time regional bed registry operated by the call center. Facilities should also coordinate ongoing care for individuals at discharge (SAMSHA 2020).

Medicaid's current role in the provision of crisis services

Although most states are using Medicaid to pay for some form of crisis services, most state crisis systems are not fully aligned with SAMHSA's national guidelines (SAMHSA 2020a, SAMHSA 2020b). For example, 46 states pay for emergency crisis services, but some states do not have crisis receiving and stabilizing facilities, or such facilities may serve only a particular region. Generally, crisis services are rarely available statewide because many states organize crisis services regionally or at the county level, and this means some communities have limited or no access to true crisis services. Where crisis receiving or stabilizing facilities do not exist, Medicaid may pay for individual practitioners to deliver stabilization services in office-based settings. Such providers likely lack the ability to treat all

patients, including walk-ins and first responder drop-offs, and may only offer services during business hours. Many states (35) also pay for some form of mobile crisis services, but payment is often limited to the time the crisis team is with the beneficiary. Travel time to and from the beneficiary is not a billable service (SAMHSA 2020b).

The full continuum of crisis services cannot be supported solely by Medicaid, so many states use other state revenues, county and local monies, and donations and investments by insurers and private health care organizations to support such services (Gordon 2020). However, Medicaid programs in a handful of states are playing a growing role in supporting the crisis continuum (Box 2-2). It is important to note that even in these innovator states, crisis services may not always be provided in accordance with SAMHSA's guidelines. For example, states may operate a crisis hotline, but the hotline may lack caller ID and GPS capabilities to efficiently coordinate with mobile crisis teams.

BOX 2-2. Medicaid Support of Behavioral Health Crisis Services in Selected States

Arizona. Arizona's behavioral health crisis system is operated by the state Medicaid agency and administered by three regional behavioral health authorities that contract directly with community behavioral health providers. Crisis services include three regional 24-hour hotlines, mobile crisis response teams, and facility-based crisis stabilization. In fiscal year (FY) 2020, Arizona spent \$245 million on these services. Medicaid funded the majority (\$217 million) of these services while state and local funds were used to serve individuals who were not eligible for Medicaid (\$28 million) (Gordon 2020). The state also generates funding for its crisis hotlines by billing Medicaid for crisis intervention and emergency management services rendered by mental health providers employed by the hotlines (AHCCCS 2020).

Georgia. In 2009, the U.S. Department of Justice sued the state of Georgia for violating the Americans with Disabilities Act of 1990 (ADA, P.L. 101-336) and the 1999 Supreme Court's decision in *Olmstead v. L.C.* (119 S. Ct. 2176 (1999)), noting that people with serious mental illness or intellectual and developmental disability were stuck in institutional settings due to inadequate community-based care. Among other things, the settlement agreement gave Georgia roughly five years to integrate 9,000 people with serious mental illness into the community. This group included

BOX 2-2. (continued)

people in state hospitals, those with frequent emergency room or hospital stays, and those who were homeless or released from the criminal justice system. The settlement agreement also required the state to provide certain services, including mobile crisis teams and assertive community treatment (Hepburn 2021).

The Georgia Department of Behavioral and Developmental Disabilities operates the state's behavioral health crisis system which includes mobile crisis teams, statewide crisis hotlines, and crisis stabilization centers that include walk-in care and temporary observation. The state's crisis hotline has the capability to use GPS to dispatch mobile crisis teams (Gordon 2020). The state has also incorporated a psychiatric bed registry into its crisis continuum that operates in real time. Recently, the state expanded its bed registry to include 72-hour crisis residential programs and detoxification beds (Hepburn 2021). In FY 2019, Medicaid supported roughly 20 percent of costs for the state's crisis continuum (\$12.8 million), while remaining costs were covered by state general funds (\$45.4 million) (Gordon 2020).

The costs of implementing a crisis continuum are significant, but crisis services can lead to cost savings by reducing inpatient hospital and emergency department use, diverting individuals from the criminal justice system, and fostering more appropriate use of community-based behavioral health care (SAMHSA 2020a). The crisis system in Maricopa County, Arizona, which includes all three core components, led to an estimated \$260 million reduction in inpatient spending after accounting for a \$100 million investment in the crisis continuum (Gordon 2020).

Recently, Congress has taken several actions to increase funding for crisis services:

- The Consolidated Appropriations Act of 2021 (P.L. 116-260) includes a new 5 percent set-aside in SAMHSA's Mental Health Services Block Grant for evidence-based crisis care programs to address the needs of individuals with serious mental illness and children with SED.³³
- Section 2701 of ARP appropriated \$1.5 billion under the Mental Health Services Block Grant. States have until September 30, 2025, to spend

these funds. These increases to the block grant are in addition to funding previously appropriated by Congress for FY 2021.

- Section 9814 of ARP offers an 85 percent federal matching assistance percentage (FMAP) for certain community-based mobile crisis intervention services offered under a state plan or a Medicaid waiver. The enhanced FMAP is available for five years, beginning in March 2022.³⁴ Congress also appropriated \$15 million for state planning grants to develop a state plan amendment or waiver program under Sections 1115, 1915(b), or 1915(c) to provide qualifying mobile crisis intervention services.

Medicaid guidance to support crisis care and similarly structured services

Current federal guidance does not fully address how states can use Medicaid to support a crisis continuum. Below we discuss various Medicaid and CHIP authorities and identify areas where additional guidance to states would be useful.

Crisis hotlines and bed registries. CMS guidance aimed at improving systems of care for adults with serious mental illness and children with SED outlines how states can use existing authorities to support innovative service delivery systems for these populations. CMS also offers a separate demonstration opportunity to increase the availability of community-based mental health care, including non-hospital-based and non-residential crisis stabilization services. In paying for a full continuum of care, states are eligible to receive federal matching funds for mental health services provided in institutions for mental diseases (CMS 2018).

Current CMS guidance notes that states may be able to access Medicaid administrative match for crisis call centers as long as they use an appropriate methodology to allocate costs to Medicaid. However, it does not describe what constitutes an appropriate methodology, instead referring states to guidance on tobacco quitlines issued in 2011 (CMS 2018).^{35, 36} Given that so few states currently use Medicaid to support crisis hotlines, it would be helpful for CMS to further advise states on how to properly allocate a portion of crisis hotline costs to Medicaid. Methods for cost allocation could include conducting a survey of crisis hotline callers to determine Medicaid eligibility (CMS 2018, 2011).

Current CMS guidance also indicates that states may be able to obtain an enhanced administrative match of up to 90 percent under Medicaid Information Technology Infrastructure (MITA) 3.0 to help support the crisis continuum in several ways. First, enhanced funding under MITA 3.0 may be used to establish crisis call centers to connect beneficiaries with treatment and develop technologies to link mobile crisis units to beneficiaries with serious mental illness. Such funding may also be used to develop capacity to use a bed registry to track the real-time availability of providers and to improve data sharing between the criminal justice system and specialty mental health service providers (CMS 2018).

Although CMS guidance indicates MITA funding may be used to support crisis systems, the current

MITA framework does not address these types of projects. MITA planning tools and processes specific to behavioral health activities have not been updated since 2008 when they were created by SAMHSA and CMS with the goal of facilitating coordination, cooperation, and interoperability among state Medicaid and behavioral health agencies (CMS 2008).

Additional guidance regarding Medicaid's role in supporting hotlines and bed registries is needed. In anticipation of 9-8-8 implementation in July 2022, states are beginning to consider how to fund these services. As of May 2021, bills have been introduced in 20 states to fund local crisis hotlines in the 9-8-8 network (RI International 2021). In Utah, legislation was recently enacted requiring the Medicaid agency to submit a waiver or state plan amendment to allow payment for 9-8-8 services provided to Medicaid enrollees (Utah SB0155: 988 Mental Health Crisis Assistance (enacted March 11, 2021)).

Mobile crisis services. Current CMS guidance identifies existing authorities, such as those under the state plan, that could be used to pay for crisis stabilization services, including screening, assessment, and treatment services for beneficiaries in crisis (CMS 2018). However, states continue to face challenges in developing payment methodologies for mobile crisis services, because two components of mobile crisis services—provider costs for outreach and team supervision—may not be covered under the Medicaid state plan (Wilkniss 2020, CMS 2018). Additional CMS guidance would be useful to assist states in braiding funding among state agencies to support crisis-related outreach and engagement activities for which Medicaid cannot pay for. Moreover, guidance could further clarify whether states can pay for outreach and engagement activities under a Section 1115 demonstration or other Medicaid authorities.

CHIP health services initiatives

Additional CHIP guidance to states could also address how to pay for a crisis continuum for children. For example, CHIP allows states to use a

limited amount of CHIP funding to implement health services initiatives (HSIs) focused on improving the health of eligible children (§ 2105(a)(1)(D)(ii) of the Act).³⁷ Specifically, a state may use up to 10 percent of its total CHIP spending for certain allowable administrative activities such as outreach and HSIs after it covers all other CHIP state plan administrative expenses (§ 2105(c)(2)(A) of the Act). Permissible HSI activities include public health programs or the provision of certain services, including preventive care and other interventions, to improve the health of low-income children eligible for CHIP or Medicaid as well as other low-income children. To reiterate, although HSIs should have a direct impact on the health of low-income children, they may also serve other children (MACPAC 2019c, CMS 2017).³⁸ This authority is underutilized; only 27 states have an approved HSI.³⁹

Some states use HSIs to support ongoing community needs to respond to individuals in crisis and various public health needs. For example, in 2019, 12 states used HSIs to support poison control centers (MACPAC 2019c).⁴⁰ Arkansas and California have used HSI funding for over 10 years to support such activities. Massachusetts uses HSI funding to support child abuse and neglect hotlines.

Other HSIs focus on particular populations or addressing acute public health issues, such as the opioid crisis. In 2016, Oklahoma used HSI funding to purchase naloxone rescue kits for youth at risk of opioid overdose in high-need counties, and in 2017, New York used HSI funding to train school staff to effectively administer medication used to treat an opioid overdose (MACPAC 2019c).

HSIs can also be used to fund public health initiatives to support the crisis continuum, including crisis hotlines, mobile crisis services, crisis receiving and stabilizing facilities, and other suicide prevention initiatives. To date, however, there has been relatively little guidance on the appropriate use of HSIs.⁴¹

Coordinating federal programs

Improving access to crisis services requires effective coordination between CMS and SAMHSA. However, a 2014 report issued by the U.S. Government Accountability Office (GAO) highlighted the lack of coordination among federal programs that serve individuals with serious mental illness. This was documented in several areas, including failure to call meetings of the Federal Executive Steering Committee for Mental Health, which is charged with coordination across the federal government. Moreover, GAO found that agencies relied on program-level staff for coordination, which, they argued, was important, but could not take the place of higher-level coordination. GAO noted that the absence of higher-level leadership hindered the federal government's ability to develop an "overarching perspective" of programs supporting individuals with serious mental illness. Without stronger leadership from the U.S. Department of Health and Human Services (HHS), GAO noted, it was difficult to determine whether there are gaps in services (GAO 2014).

GAO recommended that HHS establish a mechanism to facilitate interagency coordination across programs that support individuals with serious mental illness. However, HHS disagreed with this recommendation, noting that because Congress allocates specific programs to SAMHSA, that coordination should include coordination at the congressional level (GAO 2014).

These findings prompted congressional action to improve coordination among programs that serve individuals with serious mental illness. Specifically, as part of the 21st Century Cures Act of 2016 (Cures Act, P.L. 114-255) Congress established an Assistant Secretary for Mental Health and Substance Use within HHS. This law directed the Assistant Secretary, in addition to overseeing SAMHSA, to do the following: promote the dissemination of research findings and evidence-based practices; monitor and evaluate grants; collaborate with other federal departments to improve care for special populations, including

veterans and homeless individuals; and improve recruitment and retention of mental health and SUD professionals.

The Cures Act also mandated the creation of an Interdepartmental Serious Mental Illness Coordinating Committee to enhance coordination across federal agencies to improve service access and care delivery for people with serious mental illness or SED. This committee includes members from several federal agencies and departments, including CMS, as well as mental health providers and individuals with lived experience. In December 2017, the committee issued a major report to Congress with various recommendations, including defining and implementing a national standard for crisis care. SAMHSA's national guidelines discussed earlier in this section were largely informed by this report, as were the agency's 15 years of experience in funding the National Lifeline (ISMICC 2017). Since the publication of the 2017 report, the committee has continued to meet, most recently in September 2020.

Recommendations

In this report, the Commission makes two recommendations to address the needs of Medicaid and CHIP beneficiaries experiencing a behavioral health crisis. These recommendations serve as an important first step in providing states with the appropriate guidance and technical assistance to leverage Medicaid and CHIP to support state crisis systems.

Recommendation 2.1

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to issue joint subregulatory guidance that addresses how Medicaid and the State Children's Health Insurance Program can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises.

Rationale

The role Medicaid and CHIP can play in supporting state and local crisis continuums needs to be further defined. Subregulatory guidance could further clarify how Medicaid and CHIP can be used to pay for the three core components of a behavioral health crisis continuum: (1) regional or statewide crisis call centers that coordinate in real time; (2) mobile crisis response; and (3) crisis receiving and stabilizing facilities. At a minimum, guidance should:

- address how Medicaid and CHIP can support the implementation of 9-8-8, the national three-digit dialing code for a national suicide prevention and mental health crisis hotline;
- address how states can design a crisis continuum to support the needs of children, youth, and families, including how to use the Medicaid state plan and CHIP HSIs to support the crisis continuum;
- explain how Medicaid administrative funding and the MITA 3.0 framework can be used to establish or enhance regional or statewide crisis call centers that coordinate in real time;
- include preprint templates to simplify state access to Medicaid and CHIP funding for crisis services, including administrative funding under MITA 3.0 and funding under the state plan;
- identify policies and practices to promote evidence-based suicide risk screenings and assessments and the provision of trauma-informed and culturally competent care;
- discuss the need for a multipayer approach to fund crisis services, including Medicaid, Medicare, and commercial insurers, as well as the role of federal block grants, state general funds, and local funding;
- identify how states can pay for outreach and engagement activities associated with crisis services, including combining funding streams

from various agencies, or using Medicaid authorities outside of the state plan;

- discuss how to meet the unique needs of urban, rural, and frontier communities, including how telehealth can be used to ensure access to crisis care; and
- include recent examples from innovator states.

In developing new guidance, the Secretary should invite the participation of other relevant HHS agencies, including but not limited to the Administration for Children and Families (ACF). Given its role in 9-8-8 implementation, the Secretary should also consult with FCC.

The Commission recognizes that significant improvements to state and local behavioral health systems are needed to address high rates of unmet mental health need among adult beneficiaries as well as children and adolescents covered by Medicaid and CHIP. Providing states with the appropriate guidance to leverage Medicaid and CHIP to support state crisis systems is an important first step to address unmet mental health need and enable real-time access to behavioral health care for beneficiaries of all ages. Moreover, such guidance could play a critical role in advancing state efforts to address disparities in mental health treatment access among communities of color.

Implications

Federal spending. This recommendation would not have a direct effect on federal Medicaid and CHIP spending. Depending upon how states respond to guidance by providing additional or different services, costs to the federal government could be affected. The extent to which spending will increase (due to more services being provided) or decrease (by diverting care from more expensive settings) is difficult to predict.

States. This recommendation would improve state capacity to address the needs of Medicaid and CHIP beneficiaries with behavioral health conditions, reducing a barrier to the expansion of a real-time crisis continuum. Providing guidance to

state Medicaid and CHIP officials and other relevant agencies could help them overcome barriers to designing and implementing a crisis continuum that responds to behavioral health crises in real time.

Beneficiaries. To the degree that additional federal guidance supports states' ability to implement new or improved crisis services, it could enhance access to community-based behavioral health services and divert beneficiaries experiencing a behavioral health crisis from inpatient and emergency department settings as well as from the criminal justice system. These gains could be particularly important for beneficiaries of color who are generally less likely to receive mental health treatment than their white counterparts (SHADAC 2021).

Plans and providers. There would be no direct effect on plans and providers; however, additional guidance could assist states in setting clear expectations for plans and providers to ensure access to crisis services.

Recommendation 2.2

The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to provide education and technical assistance on the implementation of a behavioral health crisis continuum that coordinates and responds to people in crisis in real time. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of crisis services.

Rationale

Additional subregulatory guidance is necessary but not sufficient to help states use Medicaid and CHIP to expand access to the full behavioral health crisis continuum. Support for the planning and implementation or enhancement of crisis hotlines, mobile crisis services, and crisis stabilization centers is needed, particularly in light of 9-8-8 implementation.

Dedicated planning efforts are needed to coordinate multiple state agencies and delivery systems involved in behavioral health care and to support collaboration with law enforcement and criminal justice agencies. Technical assistance and planning opportunities could assist states in streamlining systems and identifying the appropriate Medicaid authorities to support the crisis continuum. Technical assistance should be structured to facilitate both state-to-state learning opportunities, as well as individual technical assistance tailored to state-specific needs. State-to-state learning opportunities could be modeled after the Medicaid Innovation Accelerator Program, which used a variety of approaches to advance state efforts in selected program areas. These learning opportunities could disseminate best practices and lessons learned and serve as a forum for cross-state learning.

In addition, states would benefit from individualized technical assistance to support the design and implementation, or enhancement, of the crisis continuum. This should include technical support on how to use relevant Medicaid and other authorities, including the state plan, administrative funding, Section 1915(b) waivers, and the MITA 3.0 framework. CMS and other federal partners should encourage the involvement of state officials representing Medicaid, behavioral health, child welfare, and public safety and criminal justice agencies as needed to ensure the engagement and buy-in of key decision makers. Moreover, such assistance could help states consider how to combine funding streams from various agencies to achieve broader objectives, such as:

- reducing avoidable emergency department and inpatient hospital use for behavioral health conditions;
- eliminating barriers or mechanisms (e.g., state law, Medicaid state plan, or state budget restrictions) that prevent or restrict a state from investing in an appropriate and necessary crisis continuum;

- increasing use of non-hospital-based behavioral health services; and
- addressing provider capacity to offer evidence-based behavioral health care that is trauma-informed and culturally competent.

The Secretary should consider the use of existing federal grant programs, such as the Mental Health Services Block Grant, to support state planning efforts. Planning support is needed to help state behavioral health agencies dedicate staff time to engage relevant partners, including state Medicaid agencies, and develop a coordinated plan to address the behavioral health needs of beneficiaries and their families. Under current Mental Health Services Block Grant requirements, states must submit a plan to SAMHSA every two years explaining how they will use block grant funds to provide comprehensive community mental health services to adults with serious mental illness and children with SED (42 U.S. Code § 300x-1). This plan must be approved by the Secretary, who should consider whether such a plan is comprehensive if it does not include the active participation and input of the state Medicaid agency.

As with the first recommendation, the Secretary should work with other relevant agencies as needed, including but not limited to ACF and FCC, when providing technical assistance.

Implications

Federal spending. This recommendation would not have a direct effect on federal Medicaid and CHIP spending.

States. This recommendation would improve state capacity to address the needs of Medicaid and CHIP beneficiaries with behavioral health conditions, reducing a barrier to the expansion of a real-time crisis continuum. Providing technical assistance to state Medicaid and CHIP officials and other relevant agencies could help them overcome barriers to designing and implementing a crisis continuum that responds to behavioral health crises in real time.

Beneficiaries. To the degree that planning and technical assistance support states' ability to implement new or improved crisis services, this assistance could improve access to community-based behavioral health services and divert beneficiaries in crisis from inpatient and emergency department settings as well as from the criminal justice system. These gains could be particularly important for beneficiaries of color who are generally less likely to receive treatment than their white counterparts (SHADAC 2021).

Plans and providers. This has no direct effect on plans and providers; however, technical assistance and planning opportunities could help more states set clear expectations for plans and providers to ensure access to crisis services.

Next Steps

In the course of the Commission's work, several areas for further inquiry have emerged. First, the Commission is concerned about the high rates of involvement with the criminal justice system among Medicaid beneficiaries with mental health conditions. We expect future work to examine the health care needs of beneficiaries who have come into contact with the criminal justice system, the behavioral health services accessible to those leaving correctional settings, and strategies to ensure Medicaid or CHIP enrollment upon release for eligible individuals. This work will also examine linkages between behavioral health outcomes for children and youth and beneficiary involvement with the juvenile justice system.

The Commission is also interested in gaining insight into the availability of home- and community-based services (HCBS) for beneficiaries with behavioral health conditions. Future work will examine the behavioral health care needs of beneficiaries who would benefit from such services and barriers that states encounter when designing HCBS for beneficiaries with significant behavioral health conditions. Moreover, the Commission plans on examining whether existing federal authorities

are suited to serving beneficiaries with significant impairment resulting from their behavioral health condition.

The Commission is also concerned about high rates of suicide and attempted suicide among individuals that identify as lesbian, gay, bisexual, or transgender. The Commission will examine the health care needs of these beneficiaries, the challenges they experience in accessing services, and state strategies to ensure access to care.

Finally, the Commission will continue to monitor states' ability to offer a continuum of mental health care that is aligned with SAMHSA guidelines. The recommendations offered in this report serve as a first step in improving access to care for beneficiaries with mental health needs. In accordance with ARP, the availability of enhanced FMAP for mobile crisis services offers states an opportunity to improve the availability of mobile crisis services. As states increase their activity in this area, the Commission will continue to monitor their successes and challenges.

Endnotes

- ¹ The ADA extends protections to individuals with a mental health condition that “substantially limits” one or more major life activities (e.g., bipolar disorder, schizophrenia, major depression) (42 USC § 12102).
- ² The *Olmstead v. L.C.* ruling was based on two conclusions. First, that institutionalization of individuals with disabilities able to live in community settings perpetuates the unwarranted assumption that such persons are unable to live in a community. Second, that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment” (119 S. Ct. 2176 (1999)).
- ³ The NSDUH estimates of any mental illness and serious mental illness are generated from a prediction model created by clinical interview data collected for a subset of adult NSDUH respondents who completed an adapted version of the Structured Clinical Interview for DSM-IV-TR Axis I Disorders and was differentiated by level of functional impairment based on the Global Assessment of Functioning Scale. This assessment includes diagnostic modules that assess mood, anxiety, eating, impulse control, substance use, and adjustment disorders, as well as psychotic symptoms screening. The assessment does not include modules assessing adult attention deficit hyperactivity disorder, autism spectrum disorders, schizophrenia, or other psychotic disorders; however, the assessment does include a psychotic symptom screen (SAMHSA 2019a).
- ⁴ Estimates for any mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main NSDUH interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age (SAMHSA 2019a).
- ⁵ Estimates for mild or moderate mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main NSDUH interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age (SAMHSA 2019a).
- ⁶ Less than substantial impairment is defined based on clinical interview Global Assessment of Functioning scores of 50 or less (SAMHSA 2019a).
- ⁷ Estimates for serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main NSDUH interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).
- ⁸ Substantial impairment is defined based on clinical interview Global Assessment of Functioning scores of 50 or less (SAMHSA 2019a).
- ⁹ The institutions for mental diseases (IMD) designation, which is unique to Medicaid, is defined in the Social Security Act (the Act) 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. These include a variety of residential and inpatient facilities providing mental health and SUD services. Even though federal statute largely prohibits payments to these facilities, in 2018, nearly all states made payments for services provided in IMD settings via one or more of the following statutory exemptions: exemptions related to older adults and children and youth; demonstration waivers under Section 1115 of the Act; a state plan option; and in managed care arrangements under certain conditions (MACPAC 2019b).
- ¹⁰ The largest increase in suicide rates occurred for American Indian or Alaska Native females (139 percent increase). Suicide rates among American Indian and Alaska Native males grew by 71 percent over the same time period. It is likely that suicide rates for individuals identifying as American Indian, Alaska Native, and Pacific Islander are undercounted because they are sometimes misclassified to other race and ethnicity groups. This underestimation is also common among Hispanic persons (Curtin et al. 2019).

¹¹ In 2016, the incarceration rate of Black men was more than six times greater than that of white men. The incarceration rate of Black women was nearly double that of white women (MHA 2021).

¹² To determine what services are covered by states, staff reviewed Medicaid state plans, provider manuals, enrollee handbooks, fee schedules, Section 1115 and 1915(b) waivers, Section 1915(c) waivers, and other publicly available documents. We used this documentation to align state service descriptions with 15 clinical and supportive mental health services. State definitions of mental health services are not standardized and vary widely; as such, MACPAC's categorization of state-level coverage approximates the closest service description, which does not fully align with SAMHSA's definitions of crisis services. In part, this reflects the lack of an official Medicaid definition for crisis services (SAMHSA 2020b).

¹³ For other populations, such as individuals with developmental disabilities, employment supports are typically covered under Section 1915(c) waivers. However, according to our analysis, few states use this authority to provide services to adults with mental illness.

¹⁴ Gaps in coverage of residential services may reflect the IMD exclusion, especially in states where most mental health treatment facilities are considered IMDs.

¹⁵ In order to determine state coverage policies for all 50 states and the District of Columbia, MACPAC analyzed Medicaid state plans, provider manuals, enrollee handbooks, fee schedules, Section 1115 and 1915(b) waivers, Section 1915(c) waivers, and other publicly available documents (Appendix 2, Table 2B-1).

¹⁶ The N-MHSS, administered by SAMHSA, is an annual survey that collects data on the location, characteristics, and utilization of mental health treatment services for all known specialty mental health treatment facilities in all 50 states and the District of Columbia.

¹⁷ Facilities may offer multiple and different services; therefore, the percentage of facilities accepting Medicaid is not necessarily indicative of the share of facilities that accept Medicaid payment for a specific service. For example, a provider offering two services, partial hospitalization and psychosocial rehabilitation, may report accepting Medicaid,

but the state Medicaid program may only cover one of these services.

¹⁸ Mental health peer support services are delivered by consumers of mental health services and include mental health treatment or support services (e.g., social clubs, peer support groups) and other organized activities such as peer-driven consumer satisfaction evaluations of mental health services (SAMHSA 2018a).

¹⁹ Supported employment includes services such as assisting individuals with finding work; assessing individuals' skills, interest, and attitude relevant to work; providing training; and providing work opportunities. Vocational rehabilitation includes assistance with job seeking and assessment and enhancement of work-related skills, attitudes, and behavior (e.g., writing a resume, taking part in an interview). It also includes providing patients with on-the-job experience and transitional employment (MACPAC 2019b).

²⁰ There are three categories of HPSA designations: primary medical, dental, and mental health. These designations are determined based on the number of providers in a geographic area relative to the population (HRSA 2020). They may be specific to any of the following:

- a geographic area, where it is determined a shortage of providers exists for an entire population within a defined geographic area;
- a population group, where it is determined there is a shortage of providers for a specific population group within a defined geographic area; or a facility, including correctional facilities or state psychiatric hospitals with a shortage of psychiatric professionals. Certain facilities are automatically designated as HPSAs by HRSA, including federally qualified health centers (FQHC) and FQHC look-a-likes, Indian Health Service facilities and tribal hospitals, dual-funded community health centers or tribal clinics, and CMS-certified rural health clinics that meet the National Health Service Corps site requirements (HRSA 2020).

²¹ The majority of these designations are specific to a facility, while fewer HPSAs are designated for entire geographic areas or specific population groups within a defined area (HRSA 2020).

²² The percentage of met need was calculated by dividing the number of psychiatrists available to serve the population of area, group, or facility, by the number of psychiatrists that would be necessary to eliminate the mental health HPSA (based on a ratio of 30,000 to 1, or 20,000 to 1 in high-need areas) (KFF 2019).

²³ This analysis only reflects non-facility claims.

²⁴ MHPAEA requires that provider payment rates for the treatment of behavioral health conditions be based on criteria that are comparable to the criteria for setting payment rates for medical providers and applied more stringently. CMS guidance further notes that disparities in provider payment can lead to parity violations (CMS 2016).

²⁵ Mandatory compliance with such requirements did not take effect until October 2017.

²⁶ Using the caller's area code, calls to the National Lifeline are routed to the closest certified local crisis center. If the call center is overwhelmed, the system automatically routes callers to a backup center. The National Lifeline network is staffed with trained counselors who assess callers for suicide risk, provide crisis counseling and crisis intervention, engage emergency services as needed, and offer referrals to behavioral health care (FCC 2020).

²⁷ In the final rule, the FCC indicated that these issues fall outside of the agency's jurisdiction, and that other federal partners are aware of the effects of 9-8-8 on community-based crisis capacity (FCC 2020).

²⁸ Other elements of a system of crisis care include short-term residential treatment facilities and peer-operated respite programs (SAMHSA 2020a).

²⁹ Tracking the status and disposition of referrals to treatment is also needed, including requirements for service approval and transportation. Best practices for operating crisis call centers include use of real-time bed registry technology that includes the number of beds in crisis stabilization programs and private psychiatric hospitals (SAMHSA 2020a).

³⁰ SAMHSA does not define what a warm handoff entails, but the Agency for Healthcare Research and Quality (AHRQ) notes that a warm handoff is a transfer of care between two members of a health care team. Such handoffs occur

in front of the patient, and if applicable, their family. This transparency gives patients and their families an opportunity to ask questions about their care as they are transitioning from one service to another (AHRQ 2017).

³¹ Essential functions of mobile crisis services including screening, assessment, de-escalation and resolution, peer support, coordination with medical and behavioral health services, and crisis planning and follow-up. Services are delivered in a timely manner by teams that include a licensed clinician capable of assessing the needs of individuals in crisis. These teams are equipped to transition individuals to facility-based care if warranted. Best practices also indicate peers should be incorporated into crisis teams and schedule outpatient follow-up to support ongoing care. Finally, teams should respond without law enforcement in order to support true diversion from the criminal justice system (SAMHSA 2020a).

³² These facilities must accept all referrals and not require medical clearance prior to admission. Assessment and support for medical stability occurs while the individual is at the facility, along with services to address mental health and substance use crisis, as well as the capacity to assess physical health needs and deliver care for minor physical health concerns with the ability to transfer the individual to another facility if needed. Facilities should be staffed with a multidisciplinary team including psychiatrists or psychiatric nurse practitioners, nurses, licensed clinicians, and peers. Facilities must offer walk-ins and first responder drop-offs. Facilities must be able to screen for suicide risk, complete comprehensive suicide assessments and planning when clinically indicated, and screen for violence risk. Facilities should also offer some form of intensive support beds with a partner program and coordinate connection to ongoing care (SAMHSA 2020a).

³³ The set-aside will be funded by \$35 million of the \$96 million increase in SAMHSA funding over FY 2020, \$83 million of which is designated for mental health programs. The Mental Health Services Block Grant is a non-competitive formula grant awarded to all 50 states, the District of Columbia, the territories, and 1 tribal entity to provide community mental health services. Among other requirements, states must use this grant to target certain populations, including children with emotional disorders and adults with serious mental illness.

³⁴ Enhanced FMAP must be used to supplement, and not supplant, the level of state funds expended for such services. To qualify for enhanced FMAP, mobile crisis services must be offered outside of a hospital or facility and be available 24 hours a day, 365 days a year, and must respond to crises in a timely manner. Mobile crisis services must be delivered by a multidisciplinary team that includes at least one behavioral health professional capable of conducting an assessment of an individual in crisis in accordance with state law. Other individuals, including peer support specialists, nurses, and social workers, may also provide services via a mobile crisis team. Where appropriate, mobile crisis providers must also provide screening and assessment, stabilization, and de-escalation services, and offer coordination with and referrals to health, social, and other services as needed. Team members must be trained in trauma-informed care, de-escalation strategies, and harm reduction.

³⁵ Tobacco quitlines follow evidence-based protocols and are considered an allowable Medicaid administrative activity for the “proper and efficient” administration of the state plan, to the extent that they provide support to beneficiaries. In order for states to claim such expenditures as an administrative cost at the 50 percent federal Medicaid matching rate, such claims may not duplicate costs that have been, or should have been, paid through another source. States can only claim Medicaid matching funds to the degree that the quitline serves Medicaid beneficiaries as documented using several permissible methods (CMS 2020b).

³⁶ As of 2015, 16 states (Alabama, Arizona, California, Colorado, Connecticut, Georgia, Iowa, Indiana, Kansas, Louisiana, Maryland, Massachusetts, Montana, North Carolina, Oklahoma, and Texas) received Medicaid funding to support their tobacco quitlines (NAQC 2015).

³⁷ Federal rules define HSIs as activities that protect the public health, protect the health of individuals, improve or promote a state’s capacity to deliver public health services, or strengthen the human and material resources necessary to accomplish public health goals relating to improving the health of children, including targeted low-income children and other low-income children (42 CFR 457.10).

³⁸ CHIP HSIs may be used for a number of activities. Permissible activities include public health programs or the provision of certain services, including preventive care and other interventions, to improve the health of low-income

children eligible for CHIP or Medicaid, and other low-income children. Although HSIs should have a direct impact on the health of low-income children, they may also serve other children (CMS 2017). Under the CHIP HSI option, states may use part of their annual allotments and receive the federal CHIP matching rate for expenditures associated with HSIs. Funding for HSIs is subject to the CHIP 10 percent administrative cap.

³⁹ In 2020, 24 states had not adopted an approved HSI; 25 states had approved HSIs; 15 states had multiple initiatives. In some cases, states may choose not to claim CHIP funds for an approved HSI.

⁴⁰ Arkansas, California, Indiana, Iowa, Maryland, Michigan, Nebraska, New Jersey, New York, Oregon, Washington, and Wisconsin use CHIP HSIs to support poison control centers (MACPAC 2019c).

⁴¹ In 1997, the Health Care Financing Administration (the prior name of CMS) issued guidance on implementing CHIP, including guidance on HSIs (HCFA 1997). This guidance focused on what activities could be included in the 10 percent administrative cap and how the cap would be calculated (HCFA 1997). In 2017, CMS issued subregulatory guidance on HSIs that addressed general questions about what activities or populations could be included and highlighted steps states would need to take to implement HSIs focused on lead poisoning prevention (MACPAC 2019c).

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Commission Vote on Recommendations

In MACPAC’s authorizing language in Section 1900 of the Social Security Act, Congress requires the Commission to review Medicaid and CHIP 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 on access to behavioral health services for adults. 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 Recommendations 2.1 and 2.2 on April 9, 2021.

Behavioral Health Services for Adults

2.1 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to issue joint subregulatory guidance that addresses how Medicaid and the State Children’s Health Insurance Program can be used to fund a crisis continuum for beneficiaries experiencing behavioral health crises.

Yes: Bella, Barker, Brooks, Burwell, Carter, Cerise, Davis,
Douglas, George, Gordon, Gorton, Lampkin, Milligan,
Retchin, Scanlon, Szilagyi, Weno

17 Yes

2.2 The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, and the Substance Abuse and Mental Health Services Administration, to provide education and technical assistance on the implementation of a behavioral health crisis continuum that coordinates and responds to people in crisis in real time. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of crisis services.

Yes: Bella, Barker, Brooks, Burwell, Carter, Cerise, Davis,
Douglas, George, Gordon, Gorton, Lampkin, Milligan,
Retchin, Scanlon, Szilagyi, Weno

17 Yes

APPENDIX 2A: Prevalence and Treatment Rates Among Non-Institutionalized Adults with Mental Health Conditions

TABLE 2A-1. Reported Prevalence of Mild or Moderate Mental Illness in the Past Year among Non-Institutionalized Adults Age 18–64, by Demographic Characteristics, 2018

Demographic characteristics	Percentage of adults 18–64 with mild or moderate mental illness	Percentage of adults age 18–64 in each coverage category with mild or moderate mental illness		
		Medicaid	Private coverage	Uninsured
Total	15.6%	19.4%	14.5%	15.3%
Age				
18–25	18.4	18.7	19.0	16.5
26–34	19.1	22.0	18.6*	17.7*
35–49	14.9	20.3	13.9*	13.1*
50–64	12.4	16.1	10.5*	14.3
Sex				
Male	12.9	16.4	11.7*	13.7
Female	18.2	21.3	17.2*	17.3*
Race and ethnicity				
White, non-Hispanic	17.1	22.9	15.8*	19.6*
Black, non-Hispanic	12.9	14.5	10.2*	18.6
Hispanic	12.9	16.8	12.5*	12.7*
Asian American, non-Hispanic	13.3	21.1	12.0	18.1
American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, non-Hispanic	14.9	17.5	11.1	–
Two or more races, non-Hispanic	19.5	22.5	17.1	17.4
Education				
Less than high school	13.2	17.2	10.7*	10.6*
High school graduate	14.4	17.0	12.4*	14.6
Some college or associate degree	17.5	23.0	15.9*	18.1*
College graduate	15.4	23.2	14.8*	21.7

TABLE 2A-1. (continued)

Demographic characteristics	Percentage of adults 18–64 with mild or moderate mental illness	Percentage of adults age 18–64 in each coverage category with mild or moderate mental illness		
		Medicaid	Private coverage	Uninsured
Employment				
Working full time	14.0	18.2	13.7*	14.3*
Working part time	18.5	20.0	17.9	18.0
Unemployed	18.7	16.7	22.9*	16.3
Other	17.4	20.8	13.9*	15.2*

Notes: Estimates for mild or moderate mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

TABLE 2A-2. Reported Prevalence of Serious Mental Illness in the Past Year among Non-Institutionalized Adults Age 18–64, by Demographic Characteristics, 2018

Demographic characteristics	Percentage of adults 18–64 with serious mental illness	Percentage of adults age 18–64 in each coverage category with serious mental illness		
		Medicaid	Private coverage	Uninsured
Total	5.4%	8.2%	4.3%	6.0%
Age				
18–25	7.6	7.4	8.4	5.7
26–34	7.2	11.6	5.3*	7.4*
35–49	4.9	8.0	3.3*	6.6
50–64	3.6	5.3	2.6*	3.6
Sex				
Male	3.9	5.2	3.2*	3.9
Female	6.9	10.1	5.3*	8.8

TABLE 2A-2. (continued)

Demographic characteristics	Percentage of adults 18–64 with serious mental illness	Percentage of adults age 18–64 in each coverage category with serious mental illness		
		Medicaid	Private coverage	Uninsured
Race and ethnicity				
White, non-Hispanic	6.5	11.1	4.9*	9.6
Black, non-Hispanic	3.8	5.5	2.7*	3.9
Hispanic	3.8	6.0	3.1*	2.9*
Asian American, non-Hispanic	2.3	–	1.9	–
American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, non-Hispanic	5.7	–	–	–
Two or more races, non-Hispanic	8.4	13.9	7.5	–
Education				
Less than high school	4.7	7.2	3.3*	3.0*
High school graduate	5.7	7.7	3.9*	6.7
Some college or associate degree	7.0	10.2	5.8*	7.3*
College graduate	3.9	6.2	3.4*	7.9
Employment				
Working full time	4.1	5.4	3.8*	4.7
Working part time	6.8	8.5	5.7*	9.0
Unemployed	7.7	8.1	7.9	6.6
Other	7.7	10.2	4.9*	6.5*

Notes: Estimates for serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

TABLE 2A-3. Treatment for Mental Health Conditions among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Treatment characteristics	Percentage of adults 18–64 with past year any mental illness	Percentage of adults age 18–64 in each coverage category with any mental illness		
		Medicaid	Private coverage	Uninsured
Received any mental health treatment				
Any mental illness	44.3%	44.2%	44.9%	28.4%*
Mild to moderate mental illness	37.8	36.2	39.6	20.1*
Serious mental illness	63.2	63.1	62.7	49.5*
Received inpatient treatment for mental health				
Any mental illness	3.6	7.1	1.9*	4.4*
Mild to moderate mental illness	2.3	5.3	1.1*	2.8*
Serious mental illness	7.5	11.3	4.7*	8.5
Received treatment in an outpatient mental health center or a day treatment program				
Any mental illness	8.1	13.7	4.9*	6.9*
Mild to moderate mental illness	4.9	8.8	3.1*	3.1*
Serious mental illness	17.5	25.3	11.2*	16.6*
Received treatment in a private therapist's office				
Any mental illness	16.4	11.9	20.3*	6.3*
Mild to moderate mental illness	13.4	9.3	16.9*	3.8*
Serious mental illness	25.1	17.9	32.1*	12.6
Received treatment in a non-clinic doctor's office				
Any mental illness	4.3	3.2	5.2*	2.0
Mild to moderate mental illness	3.1	1.9	3.8*	1.7
Serious mental illness	7.8	6.2	9.8	–
Received treatment in an outpatient medical clinic				
Any mental illness	1.9	2.4	1.5	0.7*
Mild to moderate mental illness	1.5	2.3	1.1	0.6*
Serious mental illness	3.1	2.7	3.0	–

TABLE 2A-3. (continued)

Treatment characteristics	Percentage of adults 18–64 with past year any mental illness	Percentage of adults age 18–64 in each coverage category with any mental illness		
		Medicaid	Private coverage	Uninsured
Received treatment in some other place				
Any mental illness	1.7	1.4	1.4	1.6
Mild to moderate mental illness	1.1	0.9	1.0	0.8
Serious mental illness	3.3	–	2.7	–
Took any prescription medication for a mental health condition				
Any mental illness	37.1	37.6	36.8	23.4*
Mild to moderate mental illness	30.8	30.1	31.7	15.7*
Serious mental illness	55.2	55.5	54.2	42.9*

Notes: Inpatient treatment settings for mental health include a public or private psychiatric hospital, a psychiatric unit or medical unit of an acute care hospital, a residential treatment facility, or some other inpatient setting. A private therapist’s office includes a psychologist, psychiatrist, social worker, or counselor that was not part of a clinic. Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

APPENDIX 2B: Medicaid Coverage of Mental Health Benefits for Adults

TABLE 2B-1. Medicaid Coverage of Clinical and Supportive Services for Adult Beneficiaries with Mental Illness, 2020

Mental health service	Medicaid coverage
Case management or care coordination	
Includes targeted case management, transitional case management, and care coordination.	45 states and the District of Columbia cover some form of case management or care coordination.
Mental health screening and assessment services	
Concise testing, which evaluates the existence of a mental health condition, and assessment services, which are more in depth and include diagnosing a mental health condition and identifying appropriate treatment.	50 states and the District of Columbia cover some type of mental health screening and assessment services.
Outpatient mental health services	
Include individual and group therapy, psychotherapy, and family counseling.	50 states and the District of Columbia cover some form of outpatient mental health services.
Partial hospitalization or day treatment services	
Intensive mental health treatment provided during the day. They allow the beneficiary to live in the community while commuting to a hospital or outpatient mental health center a certain number of times each week.	43 states and the District of Columbia cover partial hospitalization or day treatment services.
Assertive community treatment	
An evidence-based multidisciplinary team approach that provides intensive services where and when consumers need them (at home, work, or other community settings), 24 hours a day, 7 days a week.	40 states and the District of Columbia cover assertive community treatment.
Psychosocial rehabilitation services	
Sometimes referred to as the clubhouse model, these services include, but are not limited to, reducing symptoms through appropriate pharmacotherapy, psychological treatment, and psychological intervention. The approach provides a restorative environment as well as therapeutic intervention services to support daily and community-living skills.	42 states and the District of Columbia cover psychosocial rehabilitation services.
Residential services	
Mental health services, such as counseling, medication management, and psychiatric services are provided to a beneficiary in a residential setting. Such settings may include clinically managed 24-hour non-hospital-based care or less intensive treatment.	27 states and the District of Columbia cover residential services.

TABLE 2B-1. (continued)

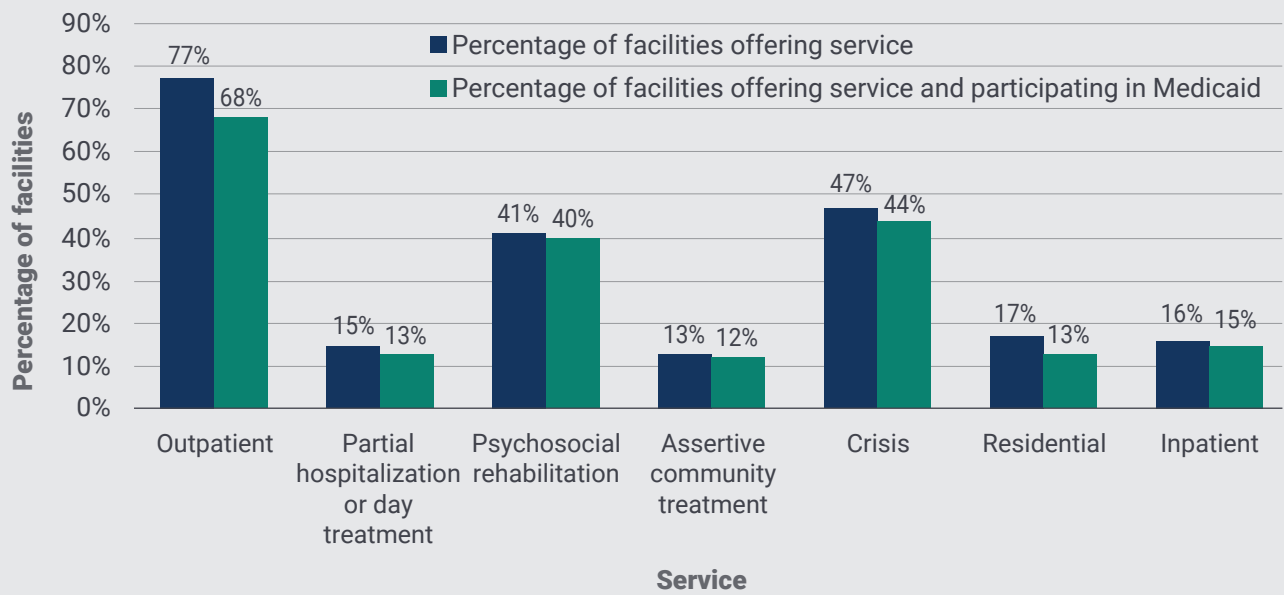
Mental health service	Medicaid coverage
Inpatient psychiatric treatment	
Psychiatric treatment, including close monitoring by staff, psychiatric evaluation, and other services are provided in an inpatient hospital setting. Hospital settings may include acute care hospitals as well as institutions for mental diseases (under certain authorities).	50 states and the District of Columbia cover inpatient psychiatric treatment.
Peer support	
Supportive services delivered by a trained and certified peer (someone with lived experience with a mental health condition). Peer support can be delivered to an individual or a group of beneficiaries.	42 states cover some form of peer support.
Supported employment	
Helps individuals achieve competitive employment in a community setting. This can include job development, career planning, and ongoing supportive services.	24 states and the District of Columbia cover supported employment.
Skills training and development	
Services that help a beneficiary with mental illness acquire new skills, ranging from basic living skills to restoration in the community.	33 states cover some form of skills training and development.
Emergency crisis services	
Includes crisis intervention or stabilization services as well as crisis management services. Services may be delivered in a freestanding facility or by an individually licensed provider.	45 states and the District of Columbia cover some form of emergency crisis services.
Mobile crisis services	
Psychiatric and supportive services meant to stabilize a beneficiary having a psychiatric crisis. Services are delivered in a community setting, which may include a beneficiary's natural environment, such as their home, a shelter, or work. It is often provided to individuals for whom more traditional forms of outpatient treatment have been ineffective.	34 states and the District of Columbia cover mobile crisis services.
Residential crisis services	
Short-term, intensive mental health support in a community-based setting. Services are provided to prevent psychiatric inpatient admission, to provide an alternative to inpatient admission, or to shorten an inpatient length of stay.	28 states and the District of Columbia cover some form residential crisis services.

Notes: Analysis includes all 50 states and the District of Columbia. State definitions of mental health services are not standardized and vary widely; as such, MACPAC's categorization of state-level coverage approximates the closest service description. In instances where publicly available information was insufficient to determine coverage, staff contacted states for clarification. Services provided only to health home beneficiaries or as an in-lieu-of service were excluded for the purposes of this analysis.

Sources: MACPAC, 2020, analysis of Medicaid state plans, provider manuals, enrollee handbooks, fee schedules, Section 1115 and 1915(b) waivers, Section 1915(c) waivers, and other publicly available documents. MACPAC 2016, SAMHSA 2015, NAMI 2013, and WHO 1997.

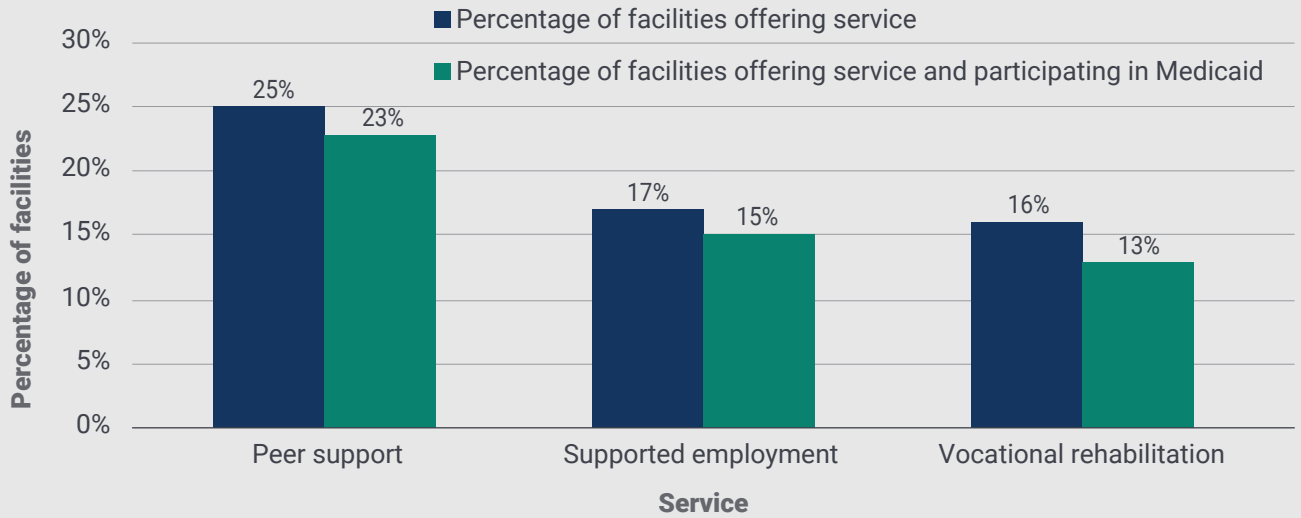
APPENDIX 2C: Specialty Mental Health Treatment Facilities Offering Certain Services

FIGURE 2C-1. Percentage of Specialty Mental Health Treatment Facilities Offering Certain Services and Accepting Medicaid, 2018



Sources: MACPAC, 2020, analysis of, SAMHSA 2019b.

FIGURE 2C-2. Percentage of Facilities Offering Certain Recovery-Oriented Services and Accepting Medicaid, 2018



Sources: MACPAC, 2020, analysis of SAMHSA 2019b.

Chapter 3:

Access to Behavioral Health Services for Children and Adolescents Covered by Medicaid and CHIP

Access to Behavioral Health Services for Children and Adolescents Covered by Medicaid and CHIP

Recommendations

- 3.1** The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program.
- 3.2** The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to provide education and technical assistance to states on improving access to home- and community-based behavioral health services for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of these services.

Key Points

- Behavioral health disorders usually begin in childhood or adolescence and can have long-term implications for health and well-being.
- For children and youth covered by Medicaid and the State Children's Health Insurance Program (CHIP), federal requirements, including Medicaid's early and periodic screening, diagnostic, and treatment (EPSDT) benefit, are intended to ensure access to behavioral health services.
- Yet, the behavioral health needs of many children and adolescents go unmet. In 2018, only 54.1 percent of non-institutionalized youth enrolled in Medicaid or CHIP who experienced a major depressive episode received mental health treatment. These adolescents were more likely than those with private coverage to receive treatment in institutional settings, as opposed to outpatient care.
- While home- and community-based services for children and adolescents with significant mental health conditions can prevent institutional placement, these services are often unavailable or difficult to access.
- States generally have the legal authorities needed to design such benefits, but often lack the awareness and capacity to use them.
- Looking forward, the Commission will explore additional opportunities to improve access to behavioral health services for children and adolescents, including those in foster care and the juvenile justice system.

CHAPTER 3: Access to Behavioral Health Services for Children and Adolescents Covered by Medicaid and CHIP

Behavioral health disorders usually begin in childhood or adolescence and can have long-term implications for an individual's physical and mental health (WHO 2020, CMS 2018, Kessler et al. 2005). In 2018, approximately one in five non-institutionalized youth age 12–17 had experienced a major depressive episode (MDE) in their lifetime and roughly 4 percent had a substance use disorder (SUD) in the past year (SHADAC 2020). Having SUD increases one's risk of mental health disorders and vice versa, and the majority of youth with SUD have a co-occurring mental health disorder (CMS and SAMHSA 2015).

Because many mental disorders begin in childhood or adolescence, interventions aimed at early detection and treatment can mitigate problems before these conditions become disabling (Kessler et al. 2007, NIHCM 2009). Children and youth with behavioral health conditions benefit from treatment that may involve a combination of medications, therapies, and inpatient and outpatient visits (MACPAC 2015). Services may be delivered in a variety of settings, including schools, office-based settings, specialty treatment facilities, foster care settings, or a child's home.¹

For children and youth covered by Medicaid and the State Children's Health Insurance Program (CHIP), federal laws are intended to ensure access to appropriate behavioral health services. In accordance with the Americans with Disabilities Act of 1990 (ADA, P.L. 101-336), Medicaid beneficiaries with serious mental illness are entitled to receive necessary mental health treatment in the most

integrated setting possible.² As a result of the Supreme Court's ruling in *Olmstead v. L.C.* (119 S. Ct. 2176 (1999)), states must provide treatment for individuals with disabilities, including serious mental illness, in community-based settings, if the individuals are not opposed to such services, and such placement is appropriate and can be reasonably accommodated by the state.³

Although *Olmstead v. L.C.* generally requires states to provide community-based services to individuals with disabilities, it did not create an immediate right to a community placement in lieu of institutional care. As such, Medicaid beneficiaries with mental illness still have difficulty accessing services in the community (MACPAC 2019a).

The Social Security Act (the Act) also requires state Medicaid programs and CHIP to meet certain obligations that are unique to children and adolescents. Under Medicaid's mandatory early and periodic screening, diagnostic, and treatment (EPSDT) benefit, Medicaid-eligible individuals under age 21 are entitled to all medically necessary services, including behavioral health services. In separate CHIP, behavioral health services are now a required benefit.

Despite these requirements, the behavioral health needs of many children and adolescents often go unmet (SAMHSA 2019a, MACPAC 2018a). Experts have noted that although access to behavioral health services is a challenge across the lifespan, young people often face additional barriers to care, including a shortage of behavioral health providers offering tailored programming for youth willing to provide services to Medicaid and CHIP beneficiaries (Tsai 2020). In 2018, only about half of non-institutionalized youth enrolled in Medicaid or CHIP who experienced an MDE in the past year received some form of mental health treatment, and only 6 percent of adolescent beneficiaries with SUD received treatment. Moreover, beneficiaries were more likely than their privately insured peers to receive mental health treatment in a hospital or a residential facility (SHADAC 2020).

Unmet need for behavioral health services among children and adolescents has been exacerbated by COVID-19. Families have been under increased stress due to the health and economic effects of the pandemic (Brown et al. 2020). Moreover, school closings and social distancing measures have contributed to social isolation and limited access to services (Hoffman and Miller 2020). Preliminary data show a 44 percent drop in outpatient mental health visits among children covered by Medicaid and CHIP, even after accounting for an uptick in telehealth visits (CMS 2020a). Meanwhile, the proportion of mental health-related emergency department visits among children has increased (Leeb et al. 2020). The mental health consequences of COVID-19 are likely to persist, given the increased risk of depression and anxiety among children and adolescents during and after periods of isolation (Loades et al. 2020).

As the Commission examined access to behavioral health services for children and adolescents covered by Medicaid and CHIP over the past year, experts and state officials highlighted the lack of home- and community-based behavioral health services available to this population (Herman 2020, O'Brien 2020). These services have been shown to improve clinical and function outcomes, prevent out-of-home placements, and reduce involvement with child welfare and the juvenile justice system (McEnany et al. 2020, O'Brien 2020, MHA 2015, Lee et al. 2014).

While many factors affect access to services, the Commission heard from experts who highlighted state capacity as an immediate concern. States generally have the legal authorities needed to design home- and community-based behavioral health benefits for children and adolescents with significant mental health conditions; however, they often lack the awareness and ability to use them effectively (O'Brien 2020). Moreover, states often face obstacles bringing together the various agencies—behavioral health, child welfare, juvenile justice, and others—that play a role in addressing the needs of this population (Herman 2020).

The Commission, therefore, recommends that the following actions be taken by the Secretary of the

U.S. Department of Health and Human Services (the Secretary) as an important initial step toward improving access to behavioral health services for children and adolescents covered by Medicaid and CHIP.

- The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program.
- The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to provide education and technical assistance to states on improving access to home- and community-based behavioral health services for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of these services.

This chapter begins by describing the prevalence of behavioral health conditions among adolescents and the rates at which they receive treatment. Next, we discuss the availability of behavioral health providers serving children and adolescents in Medicaid and CHIP, including state-by-state estimates of service availability. The chapter then focuses on the needs of children and adolescents with significant mental health conditions, who are often at risk of being placed in restrictive settings when appropriate home- and community-based alternatives are unavailable. We conclude by

discussing factors affecting access to care for this population, including the role of various state and federal agencies, Medicaid and CHIP coverage policies, and barriers that states encounter when trying to improve access to home- and community-based behavioral health services.

Prevalence, Disparities, and Treatment Rates

Mental health disorders usually emerge in childhood or adolescence, and the consequences of such disorders can extend into adulthood (WHO 2020, CMS 2018). About half of all lifetime cases of mental illness begin by age 14 and three-fourths by age 24 (Kessler et al. 2005). Adolescence is also the period when most individuals with SUD begin using drugs or alcohol (NIDA 2014). More than 90 percent of adults with SUD started using substances before the age of 18 (CMS and SAMHSA 2015). The majority of youth with SUD have a co-occurring mental health disorder (Chan et al. 2008). (For discussion of mental health conditions in adulthood, see Chapter 2.)

Behavioral health disorders can negatively affect physical, emotional, and social development. For example, adolescents with depression have a higher risk of attempting suicide, engaging in drug use and high-risk sexual behavior, and having problems in school or in relationships with family and peers (Murphey et al. 2013, CBHSQ 2016). SUDs can also interfere with normal brain maturation (NIDA 2014).

Below, we describe the prevalence of behavioral health conditions and treatment rates among non-institutionalized adolescents age 12–17, comparing the experience of adolescents enrolled in Medicaid or CHIP to those with other forms of coverage. Where possible, we also examine prevalence and treatment rates for Medicaid beneficiaries by race and ethnicity. Estimates are reported where sample size permits. This analysis is based on self-reported data from the National Survey on Drug Use and Health (NSDUH), a federal survey of non-institutionalized individuals age 12 and older conducted annually in all 50 states

and the District of Columbia.⁴ (Additional analysis of NSDUH and mental health conditions in adults is discussed in Chapters 2 and 4.)

It is important to note that because NSDUH data are self-reported, the survey may over- or underrepresent prevalence and need for treatment—individual responses are subjective and not validated using psychiatric diagnostic information (SAMHSA 2019a). They may be influenced by a variety of social and cultural factors, including beliefs and perceptions regarding mental health and SUD (Ward et al. 2013). Stigma and fear of reporting drug use that involves criminalized behavior, for example, may lead to underreporting (Wogan and Restrepo 2020). Furthermore, NSDUH does not include residents of institutional group quarters, such as juvenile detention centers. Youth in these facilities tend to have high rates of mental health conditions and disproportionate numbers of underserved racial and ethnic minority youth (Alegria et al. 2010).

Prevalence of mental health conditions

For adolescent respondents, the NSDUH captures prevalence of mental illness in two categories:

- Major depressive episode—This category includes adolescents who reported experiencing certain symptoms nearly every day in the same two-week period at any point in their life. Adolescents were defined as having an MDE in the past year if they had a lifetime MDE, felt depressed or lost interest or pleasure in daily activities for two weeks or longer in the past 12 months, and experienced during that time some of the symptoms they reported for a lifetime MDE.⁵
- MDE with severe role impairment—This category includes adolescents who reported impairment caused by an MDE in the past 12 months. Severe impairment was 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.^{6,7}

Prevalence of mental health conditions was similar across coverage groups. In 2018, approximately 5 million (one in five) non-institutionalized youth age 12–17 experienced a lifetime MDE (Table 3-1). Nearly 2.5 million (1 in 10) youth experienced an MDE with severe role impairment within the past year. Rates of lifetime MDE and MDE within the past year were similar when comparing adolescents covered by Medicaid or CHIP to those with private

coverage and those who were uninsured (SHADAC 2020). However, when compared to their privately insured peers, Black and Hispanic youth covered by Medicaid were less likely to report a past year MDE. Females were generally more likely to report an MDE than their male peers, regardless of their coverage status (Table 3A-1) (SHADAC 2020).

TABLE 3-1. Major Depressive Episodes and Suicidal Thoughts and Behaviors among Non-Institutionalized Adolescents Age 12–17, by Insurance Status, 2018

Type of condition	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Major depressive episode (MDE)				
Lifetime MDE	20.7%	19.6%	21.2%	20.4%
MDE in past year	14.5	13.5	15.0	13.0
MDE with severe role impairment in past year	10.0	9.1	10.3	10.0
Suicide				
Thoughts of suicide in past year	11.9	11.5	12.2	8.3*
Plans of suicide in past year	5.6	5.7	5.6	4.2
Attempted suicide in past year	3.9	4.4	3.8	–

Notes: The 2018 National Survey on Drug Use and Health (NSDUH) used criteria from the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* to identify major depressive episodes. The NSDUH did not exclude depressive symptoms that occurred exclusively in the context of bereavement. Questions from the Sheehan Disability Scale determined if a major depressive episode caused severe role impairment by creating major problems with the ability to do chores at home, do well at work or school, get along with family, or have a social life.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Rates of suicidal thoughts and behaviors were similar across coverage groups. Suicidal thoughts and behaviors among adolescents have increased over time, with suicide now the second leading cause of death among those age 12–17 (KFF 2020). In 2018, roughly 12 percent of youth reported thoughts of suicide and nearly 4 percent reported

attempting suicide in the past year (Table 3-1). Reported rates of past year suicidal ideation and suicide attempts were generally similar across coverage groups, with the exception of adolescents covered by Medicaid or CHIP being more likely than those without insurance to report thoughts of suicide (SHADAC 2020).

Mental health conditions were common among white beneficiaries and youth of two or more races.

Among youth enrolled in Medicaid or CHIP, the reported rate of MDE for certain racial and ethnic groups differed from that of white beneficiaries. In 2018, Black and Hispanic youth covered by Medicaid or CHIP were less likely to report a lifetime MDE, MDE within the past year, or MDE with severe role impairment when compared to their white counterparts (Table 3-2). In contrast, youth of two

or more races reported rates similar to those of white beneficiaries. Prevalence estimates for Asian American, American Indian or Alaska Native, and Native Hawaiian or other Pacific Islander youth covered by Medicaid or CHIP are limited due to the small sample size. However, where data are available, they show that these youth reported rates of lifetime MDE similar to those of their white counterparts (SHADAC 2021).

TABLE 3-2. Major Depressive Episodes and Suicidal Thoughts and Behaviors among Non-Institutionalized Adolescents Age 12–17 Enrolled in Medicaid or CHIP, by Race and Ethnicity, 2018

Type of condition	Percentage of youth age 12–17					
	White	Black	Hispanic	Asian American	AIAN and NHPI	Two or more races
Major depressive episode (MDE)						
Lifetime MDE	24.2%	12.3%*	18.9%*	22.6%	19.2%	24.5%
MDE in past year	17.1	7.6*	12.9*	16.0	–	18.5
MDE with severe role impairment	11.8	5.6*	7.8*	–	–	12.5
Suicide						
Thoughts of suicide	15.6	7.4*	9.8*	–	–	13.8
Plans of suicide	8.1	3.5*	4.4*	–	–	8.1
Attempted suicide	6.1	3.1*	3.8*	–	–	6.0

Notes: Hispanic is anyone of Hispanic, Latino, or Spanish origin. AIAN and NHPI combines data for respondents who identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander and are not of Hispanic origin. White, Black, Asian American, and two or more races do not include respondents of Hispanic origin.

The 2018 National Survey on Drug Use and Health (NSDUH) used criteria from the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* to identify major depressive episodes. The NSDUH did not exclude depressive symptoms that occurred exclusively in the context of bereavement. Questions from the Sheehan Disability Scale determine if a major depressive episode caused severe role impairment by creating major problems in the ability to do chores at home, do well at work or school, get along with family, or have a social life.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2021.

Black and Hispanic youth covered by Medicaid or CHIP were also less likely to report thoughts of suicide, plans of suicide, and attempted suicide compared to their white counterparts (Table 3-2). In contrast, rates of suicidal thoughts and behaviors reported by those of two or more races were similar to their white peers.

Prevalence of substance use disorders

Although the prevalence of past year illicit drug or alcohol misuse, abuse, and dependence was similar across coverage groups, rates at which adolescents reported using alcohol and certain

drugs varied when comparing adolescents covered by Medicaid or CHIP to those with private insurance (Table 3-3).⁸ In 2018, Medicaid beneficiaries were less likely than those with private insurance to have ever used alcohol or to have used alcohol in the past year. Conversely, adolescents with Medicaid or CHIP coverage reported higher rates of marijuana use and were more likely to have used a pain reliever not directed by a doctor. The prevalence of past year illicit drug or alcohol dependence or abuse did not vary significantly by coverage status when examining rates by sex or race and ethnicity (Table 3A-2) (SHADAC 2020).

TABLE 3-3. Substance Misuse, Abuse, and Dependence among Non-Institutionalized Adolescents Age 12–17, by Insurance Status, 2018

Type of use	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Ever used alcohol	26.6%	24.3%	27.8%*	30.0%
Alcohol use in past year	20.1	16.3	22.5*	19.8
Ever used marijuana	15.3	17.1	14.0*	17.0
Marijuana use in past year	11.8	12.2	11.7	11.8
Ever used a pain reliever not directed by a doctor	4.5	5.5	3.8*	6.3
Ever misused psychotherapeutics	6.3	6.9	5.8	8.2
Psychotherapeutic misuse in past year	4.7	5.0	4.4	7.2
Nicotine dependent in past year	0.5	0.5	0.4	–
Illicit drug dependence or abuse in past year	2.8	3.0	2.6	3.4
Illicit drug or alcohol dependence or abuse in past year	3.8	3.8	3.8	4.0

Notes: The 2018 National Survey on Drug Use and Health (NSDUH) defined illicit drugs as including any of the following substances: marijuana, cocaine, heroin, hallucinogens, inhalants, methamphetamine, and the misuse of prescription psychotherapeutic drugs (i.e., pain relievers, tranquilizers, stimulants, and sedatives). Nicotine dependence was defined by meeting dependence criteria derived from the Nicotine Dependence Syndrome Scale or the Fagerstrom Test of Nicotine Dependence

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Substance misuse, abuse, and dependence among Medicaid beneficiaries varied by race and ethnicity.

In general, non-white youth enrolled in Medicaid or CHIP were less likely than their white counterparts to report using drugs and alcohol. In 2018, Black and Hispanic youth covered by Medicaid or CHIP were less likely to report experiencing drug or alcohol abuse or dependence within the past year when compared to white beneficiaries (Table 3-4). Alcohol and marijuana use were less commonly

reported among Black and Hispanic youth enrolled in Medicaid or CHIP when compared to their white counterparts. Asian American beneficiaries were also less likely to report having ever used alcohol. Reported rates of alcohol and marijuana use were generally similar for American Indian, Alaska Native, Native Hawaiian, and other Pacific Islander beneficiaries and multiracial youth compared to white adolescents (SHADAC 2021).

TABLE 3-4. Substance Misuse, Abuse, and Dependence among Non-Institutionalized Adolescents Age 12–17 Enrolled in Medicaid or CHIP, by Race and Ethnicity, 2018

Type of use	Percentage of youth age 12–17					
	White	Black	Hispanic	Asian American	AIAN and NHPI	Two or more races
Ever used alcohol	30.7%	18.0%*	22.5%*	16.3%*	26.2%	29.4%
Alcohol use in past year	22.4	10.8*	14.9*	–	11.2*	16.1
Ever used marijuana	20.3	15.7*	15.6*	–	19.5	22.3
Marijuana use in past year	15.1	11.0*	10.4*	–	15.3	15.7
Ever used a pain reliever not directed by a doctor	6.0	5.2	5.1	–	–	–
Illicit drug dependence or abuse in past year	4.4	2.4*	1.9*	–	–	–
Illicit drug or alcohol dependence or abuse in past year	5.0	2.9*	3.1*	–	–	–

Notes: Hispanic is anyone of Hispanic, Latino, or Spanish origin. AIAN and NHPI combines data for respondents who identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander and are not of Hispanic origin. White, Black, Asian American, and two or more races do not include respondents of Hispanic origin.

The 2018 National Survey on Drug Use and Health (NSDUH) defined illicit drugs as including any of the following substances: marijuana, cocaine, heroin, hallucinogens, inhalants, methamphetamine, and the misuse of prescription psychotherapeutic drugs (i.e., pain relievers, tranquilizers, stimulants, and sedatives). Nicotine dependence was defined by meeting dependence criteria derived from the Nicotine Dependence Syndrome Scale or the Fagerstrom Test of Nicotine Dependence.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from white Medicaid or CHIP beneficiaries is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2021.

Use of behavioral health services

In 2018, nearly one in four (24.3 percent) non-institutionalized youth age 12–17 received any form of mental health services (specialty or non-specialty) (Table 3-5). This includes a wide variety of mental health services, ranging from non-specialty services provided by a pediatrician or school counselor to specialty services provided in a psychiatrist’s office or residential treatment setting. For adolescents with mental health conditions, there were a substantial number who needed but did not receive services: among Medicaid and CHIP beneficiaries, only 54.1 percent of youth with MDE and 60.4 percent of youth with MDE with severe role impairment received some form of mental health treatment in the past year (SHADAC 2020).

Adolescents covered by Medicaid or CHIP received treatment at similar rates as their peers with private coverage. However, there were differences across the types of services and settings in which adolescents accessed care (Table 3-5). Among all youth, Medicaid and CHIP beneficiaries were more likely to receive non-specialty mental health services (e.g., from a pediatrician or school counselor) than their privately insured peers, who more often received services from a private therapist, psychologist, psychiatrist, or social worker. Medicaid and CHIP beneficiaries were also more likely to have stayed overnight in a hospital or a residential facility. There was less variation across coverage groups for adolescents with MDE and MDE with severe role impairment, although youth with MDE enrolled in Medicaid or CHIP were more likely than their privately insured peers to receive specialty treatment from an in-home therapist, counselor, or family preservation worker (SHADAC 2020).

TABLE 3-5. Mental Health Treatment among Non-Institutionalized Adolescents Age 12–17 in the Past Year, by Insurance Status, 2018

Treatment characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Received specialty or non-specialty mental health services				
All youth	24.3%	25.7%	24.4%	14.1%*
Youth with MDE	50.0	54.1	49.5	30.4*
Youth with MDE with severe role impairment	56.3	60.4	57.3	33.1*
Received specialty mental health services				
All youth	16.1	16.0	17.0	8.1*
Youth with MDE	38.4	38.6	39.9	22.1*
Youth with MDE with severe role impairment	44.7	44.6	47.5	25.2*
Received non-specialty mental health services				
All youth	15.9	18.5	14.8*	9.5*
Youth with MDE	32.0	38.1	29.7*	20.8*
Youth with MDE with severe role impairment	35.0	40.5	33.5	24.1*
Stayed overnight in a hospital				
All youth	2.5	3.5	1.8*	–
Youth with MDE	5.3	5.8	4.6	–
Youth with MDE with severe role impairment	6.8	7.4	6.0	–
Stayed overnight in a residential center for emotional treatment				
All youth	1.2	2.0	0.7*	–
Youth with MDE	2.9	4.1	2.2	–
Youth with MDE with severe role impairment	3.6	4.7	2.9	–
Spent time in a day treatment program				
All youth	1.9	2.3	1.8	–
Youth with MDE	6.5	8.4	5.9	–
Youth with MDE with severe role impairment	7.3	8.5	7.3	–
Received specialty treatment in a mental health clinic				
All youth	3.9	4.4	3.8	–
Youth with MDE	15.1	17.7	14.4	–
Youth with MDE with severe role impairment	17.9	21.8	17.1	–

TABLE 3-5. (continued)

Treatment characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Received specialty treatment from a private therapist, psychologist, psychiatrist, social worker, or counselor				
All youth	12.4%	11.0%	13.9%*	5.1%*
Youth with MDE	34.0	33.7	35.4	18.1*
Youth with MDE with severe role impairment	39.4	39.2	42.0	–
Received specialty treatment from an in-home therapist, counselor, or family preservation worker				
All youth	3.9	4.5	3.8	–
Youth with MDE	9.8	13.6	8.3*	–
Youth with MDE with severe role impairment	11.3	14.2	10.4	–
Received mental health treatment from a family doctor or pediatrician				
All youth	3.1	3.6	3.1	–
Youth with MDE	8.8	10.6	8.6	–
Youth with MDE with severe role impairment	10.4	12.3	10.6	–

Notes: MDE is major depressive episode. The 2018 National Survey on Drug Use and Health (NSDUH) defined specialty mental health services as treatment or counseling for emotional or behavioral problems provided in outpatient, inpatient, or residential mental health settings. Outpatient settings include: (1) private therapists, psychologists, psychiatrists, social workers, or counselors; (2) mental health clinics or centers; (3) partial day hospitals or day treatment programs; and (4) in-home therapists, counselors, or family preservation workers. Inpatient settings include hospitals and residential treatment centers. Non-specialty mental health services are defined as treatment from a pediatrician or other family doctor; from a school social worker, psychologist, or counselor; in a juvenile detention center, prison, or jail; through participation in a school program inside a regular school or attendance at a special school for students with emotional or behavioral problems; or staying overnight or longer in foster care or in a therapeutic foster care home because of emotional or behavioral problems.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Beneficiaries of color received treatment at lower rates than their white counterparts. In 2018, among all youth covered by Medicaid or CHIP, Black, Hispanic, American Indian or Alaska Native, and Native Hawaiian or other Pacific Islander youth were less likely to receive any form of mental health services (specialty or non-specialty) than their white counterparts (Table 3-6). Generally,

among Medicaid and CHIP beneficiaries with MDE, treatment rates were similar across racial and ethnic groups.

When compared to their white counterparts, access to mental health treatment is more limited for beneficiaries of color with MDE with severe role impairment (Table 3-6). Specifically, less than half

(48 percent) of Black beneficiaries with MDE with severe role impairment reported receiving some form of specialty or non-specialty mental health treatment compared to 68 percent of their white peers.

Moreover, Black and Hispanic beneficiaries with MDE with severe role impairment were less likely to report receiving specialty mental health treatment than their white counterparts (SHADAC 2021).

TABLE 3-6. Mental Health Treatment among Non-Institutionalized Adolescents Age 12–17 Enrolled in Medicaid or CHIP in the Past Year, by Race and Ethnicity, 2018

Treatment characteristics	Percentage of youth age 12–17					
	White	Black	Hispanic	Asian American	AIAN and NHPI	Two or more races
Received specialty or non-specialty mental health services						
All youth	31.1%	24.9%*	23.1%*	–	19.8%*	30.4%
MDE	59.0	50.1	54.0	–	–	60.1
MDE with severe role impairment	68.1	48.0*	62.3	–	–	57.8
Received specialty mental health services						
All youth	20.9	13.6*	14.1*	–	–	17.6
MDE	45.5	34.9	34.3	–	–	40.3
MDE with severe role impairment	55.3	36.2*	37.7*	–	–	44.4
Received non-specialty mental health services						
All youth	20.9	19.0	16.9*	–	13.8*	24.5
MDE	41.4	34.2	38.6	–	–	49.4
MDE with severe role impairment	46.1	29.6*	41.3	–	–	51.2

Notes: Hispanic is anyone of Hispanic, Latino, or Spanish origin. AIAN and NHPI combines data for respondents who identified as American Indian or Alaska Native or Native Hawaiian or other Pacific Islander and are not of Hispanic origin. White, Black, Asian American, and two or more races do not include respondents of Hispanic origin.

MDE is major depressive episode. The 2018 National Survey on Drug Use and Health (NSDUH) defined specialty mental health services are defined as treatment or counseling for emotional or behavioral problems provided in outpatient, inpatient, or residential mental health settings. Outpatient settings include: (1) private therapists, psychologists, psychiatrists, social workers, or counselors; (2) mental health clinics or centers; (3) partial day hospitals or day treatment programs; and (4) in-home therapists, counselors, or family preservation workers. Inpatient settings include hospitals and residential treatment centers. Non-specialty mental health services are defined as treatment from a pediatrician or other family doctor; from a school social worker, psychologist, or counselor; in a juvenile detention center, prison, or jail; through participation in a school program inside a regular school or attendance at a special school for students with emotional or behavioral problems; or staying overnight or longer in foster care or in a therapeutic foster care home because of emotional or behavioral problems.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from white Medicaid or CHIP beneficiaries is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2021.

Youth often received specialty mental health treatment because they felt depressed. In 2018, among all adolescents age 12–17 covered by Medicaid or CHIP, the majority (62 percent) reported receiving specialty mental health treatment because they felt depressed (Figure 3B-1). Other common reasons for receiving treatment were having thought about or attempted suicide (37 percent), feeling afraid or tense (26 percent), and having problems at home or with family (23 percent). These reasons were generally reported more often among beneficiaries with MDE and MDE with severe role impairment (SHADAC 2020).

Access to school-based services

Schools fill a critical role in identifying children and adolescents with behavioral health needs and connecting them with mental health and SUD treatment as well as other needed services. They offer a point of access for care because children are in school for many hours a day, for approximately half the days of the year (CMS 1997). In addition, under the Individuals with Disabilities Education Act (IDEA, P.L. 101-476), public schools must provide all children with disabilities (generally those age 3–21) with a free and appropriate public education. This includes both education and related services, such as speech or physical therapy and behavioral health services, which support a child’s ability to learn.⁹ Services may be provided by school-based personnel or community providers offering outpatient services in a school setting, regardless of whether there is a school-based health center on-site. Most of the services that must be provided to children in schools are covered by Medicaid under the mandatory EPSDT benefit (MACPAC 2018b). A joint informational bulletin issued by CMS and SAMHSA in 2019 outlines how certain Medicaid authorities can help support school-based mental health and SUD services for children and adolescents (CMS and SAMHSA 2019).

In 2018, all youth and youth with MDE covered by Medicaid or CHIP were more likely to report receiving mental health services from education sources than youth with private coverage and uninsured youth (Table 3-7). All youth with Medicaid or CHIP coverage were also more likely to receive specialty treatment in a school or attend a school program for emotional problems than their privately insured and uninsured peers. Unsurprisingly, youth with MDE and MDE with severe role impairment were generally more likely than others to receive school-based services. This was observed across all coverage groups. Those with Medicaid or CHIP, regardless of diagnosis, were three times more likely than uninsured youth to speak with a school social worker, psychologist, or counselor for emotional problems (SHADAC 2020). Compared to their white counterparts, American Indian or Alaska Native and Native Hawaiian or other Pacific Islander youth enrolled in Medicaid or CHIP were less likely to report receiving mental health services from education sources, and Black beneficiaries were less likely to report talking to a school social worker, psychologist, or counselor (SHADAC 2021).

TABLE 3-7. School-Based Mental Health Services among Non-Institutionalized Adolescents Age 12–17 in the Past Year, by Insurance Status, 2018

Treatment characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Received mental health services from education sources				
All youth	13.8%	15.9%	12.8%*	8.6%*
MDE	27.8	32.7	25.9*	18.5*
MDE with severe role impairment	30.6	35.4	29.0	24.1
Received specialty treatment in a school or school program for emotional problems				
All youth	5.8	7.6	4.8*	3.3*
MDE	9.8	13.7	7.8*	–
MDE with severe role impairment	10.8	14.3	9.5	–
Talked to a school social worker, psychologist, or counselor for emotional problems				
All youth	9.6	10.5	9.4	1.3*
MDE	22.7	25.5	22.0	–
MDE with severe role impairment	25.6	29.1	24.5	–

Notes: MDE is major depressive episode. The 2018 National Survey on Drug Use and Health (NSDUH) defined mental health services from education resources as having talked to a school social worker, school psychologists, or school counselors and/or having attended a special school or participated in a special program at a regular school for problems with behavioral or emotions that were not caused by alcohol or drugs.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Youth often received school-based mental health services because they felt depressed. Nearly half (46 percent) of all youth enrolled in Medicaid or CHIP who received school-based mental health services reported receiving such services because they felt depressed (Figure 3B-2). Other common reasons for receiving school-based services included feeling afraid or tense (22 percent), having problems at school (22 percent), and having thought about or attempted suicide (18 percent). These reasons were generally reported more often among beneficiaries with MDE and MDE with severe role impairment (SHADAC 2020).

Access to substance use treatment

Across all coverage categories, adolescents with past year drug or alcohol dependence reported high rates of unmet need (Table 3-8). In 2018, nearly all (93.9 percent) non-institutionalized Medicaid and CHIP beneficiaries age 12–17 with SUD reported that they needed but did not receive alcohol or drug treatment in the past year. Only 14.6 percent of youth enrolled in Medicaid or CHIP with SUD ever received alcohol or drug treatment, and just 9.2 percent received treatment for alcohol or drug use in the past 12 months.

TABLE 3-8. Substance Use Treatment for Non-Institutionalized Adolescents Age 12–17 with Past Year Drug or Alcohol Dependence or Abuse, by Insurance Status, 2018

Treatment characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Needed but did not receive alcohol or drug treatment in the past year	94.3%	93.9%	94.6%	96.3%
Received treatment for alcohol or drug use in the past 12 months	9.2	9.0	9.5	–
Ever received alcohol or drug treatment	11.5	14.6	10.2	–

Notes: We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The National Survey on Drug Use and Health classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

Availability of Behavioral Health Providers in Medicaid

Children with behavioral health conditions need access to a range of treatment services that vary in intensity. These services can be provided in a variety of settings, predominantly the following:

- Office-based settings—primary care physicians, child and adolescent psychiatrists, counselors, and other behavioral health professionals play an important role in diagnosing and treating youth and adolescents with behavioral health conditions.
- School-based health centers—often, children and adolescents with behavioral health conditions are first identified as needing treatment in schools (CMS 2018). Access to school-based health centers (SBHCs) has increased substantially in recent years, in part due to new partnerships with federally qualified health centers (FQHCs).
- Behavioral health treatment facilities—facility-based specialty care includes mental health treatment facilities that typically treat children

with greater functional impairment and specialty substance use treatment facilities for youth with SUD. These facilities provide services ranging from outpatient behavioral health services, to partial hospitalization, to inpatient behavioral health care.

Below we describe the availability of behavioral health screening and treatment in these settings. We also discuss provider participation in Medicaid and the types of services offered by these providers. Where possible, we describe availability at the state level. We do not have data at the substate level.

Several data limitations prevent us from analyzing access to behavioral health care in certain settings that play an important role in treating children and adolescents enrolled in Medicaid and CHIP. First, although schools may bill Medicaid for services delivered by school-based personnel and community providers offering services outside of SBHCs, data on the availability of such services is limited. Foster care settings and juvenile detention centers also provide behavioral health services; however, the Commission does not have access to data on care delivery in these settings. Finally, home- and community-based behavioral health services play an important role for children and

adolescents with behavioral health needs, but those services are not addressed in this section due to data limitations.

Office-based settings

Many different types of providers, including social workers, psychologists, psychiatric nurse practitioners, psychiatrists, and professional counselors deliver office-based behavioral health services to children and adolescents. Because there is no data source that captures the availability of all of these providers or their willingness to participate in Medicaid, below we summarize select findings related to the availability of child and adolescent psychiatrists and pediatricians authorized to prescribe medications used to treat opioid use disorder (MOUD). Chapter 2 provides additional information on the availability of office-based behavioral health services based on an analysis of federal Health Professional Shortage

Area designations, community health center data, and rates of psychiatrist participation in Medicaid. We also discuss recent federal efforts to address the capacity of the behavioral health workforce in Chapter 2.

Practicing child and adolescent psychiatrists.

There is a substantial shortage of child and adolescent psychiatrists in the United States, with shortages in all 50 states, the District of Columbia, and Puerto Rico, and severe shortages in 41 states, the District of Columbia, and Puerto Rico (AACAP 2020). Shortages are particularly acute in rural areas, which face unique challenges in recruiting and retaining health professionals (Beck et al. 2018). To help address these challenges, many states have established specialty consultation models that extend the behavioral health workforce by helping pediatric primary care providers manage the behavioral health needs of their patients (Box 3-1).

BOX 3-1. Child Psychiatry Access Programs

In 2004, Massachusetts established the nation's first statewide child psychiatry access consultative program. The Massachusetts Child Psychiatry Access Program (MCPAP) is a system of regional children's mental health consultation teams who help primary care providers manage the mental health needs of their pediatric patients. Through consultation and education, MCPAP is designed to extend the mental health workforce by improving the ability of primary care providers to conduct behavioral health screening, identification, and assessment; use evidence-based practices to treat mild-to-moderate behavioral health disorders; and make appropriate referrals to community-based specialty behavioral health services when appropriate. Telephone, video, and in-person consultations are provided for free to primary care practices across the Commonwealth, regardless of a patient's insurance status (MCPAP 2021). Over 95 percent of pediatric primary care practices are enrolled in the program, and more than 80 percent use it each year to help manage behavioral health conditions and avoid the need for a specialty referral (Straus 2020).

In 2019, Massachusetts expanded MCPAP to improve the identification and treatment of adolescent substance use in primary care settings through a partnership with the Adolescent and Substance Use and Addiction Program (ASAP) at Boston Children's Hospital. Using the existing MCPAP structure, the ASAP-MCPAP program routes substance use-related consultation requests to an ASAP clinician. ASAP-MCPAP is also piloting a program in which primary care providers can connect adolescents to telehealth counseling services provided by an ASAP clinician (Thompson 2020).

BOX 3-1. (continued)

MCPAP began as a pilot program supported by a grant from MassHealth, the Commonwealth's Medicaid program. Today, it is financed through a state appropriation to the Department of Mental Health, which covers operational costs, and reimbursement from commercial insurers. In fiscal year 2014, 58 percent of encounters were for patients with commercial insurance and 42 percent were for those with Medicaid. Although the Commonwealth's Medicaid program, MassHealth, does not currently provide reimbursement for virtual MCPAP consultation services provided to beneficiaries, in-person visits are eligible for reimbursement (Thompson 2020, Straus and Sarvet 2014).

Variations of this model have been replicated in 38 states and the District of Columbia to build provider capacity and promote integration of behavioral health services into primary care settings (NNCPAP 2021). These programs are generally financed through state general revenue, private foundations, and Medicaid (Straus and Sarvet 2014). The Pediatric Mental Health Care Access Program, administered by the Health Resources and Services Administration (HRSA), also provides grant funding for child psychiatric programs in 21 states (HRSA 2021).¹⁰

Access to MOUD. As part of their SUD treatment, youth with opioid use disorder may receive medication by an office-based provider, such as a primary care physician, as well as through opioid treatment programs.¹¹ The U.S. Food and Drug Administration has approved buprenorphine for opioid dependent adolescents age 16 and older (FDA 2002). Methadone may also be used for youth age 16 to 18 under limited circumstances.¹² However, access to MOUD is limited, particularly in rural areas (Andrilla et al. 2018). Most pediatricians have limited training in addiction medicine and the number of these physicians currently prescribing buprenorphine to youth enrolled in Medicaid is unknown (Saloner et al. 2017). A 2017 study found that pediatricians account for only 1 percent of physicians who have received waivers needed to prescribe buprenorphine under the Drug Addiction Treatment Act of 2000 (DATA 2000, P.L. 106-310) (Olfson et al. 2020).¹³

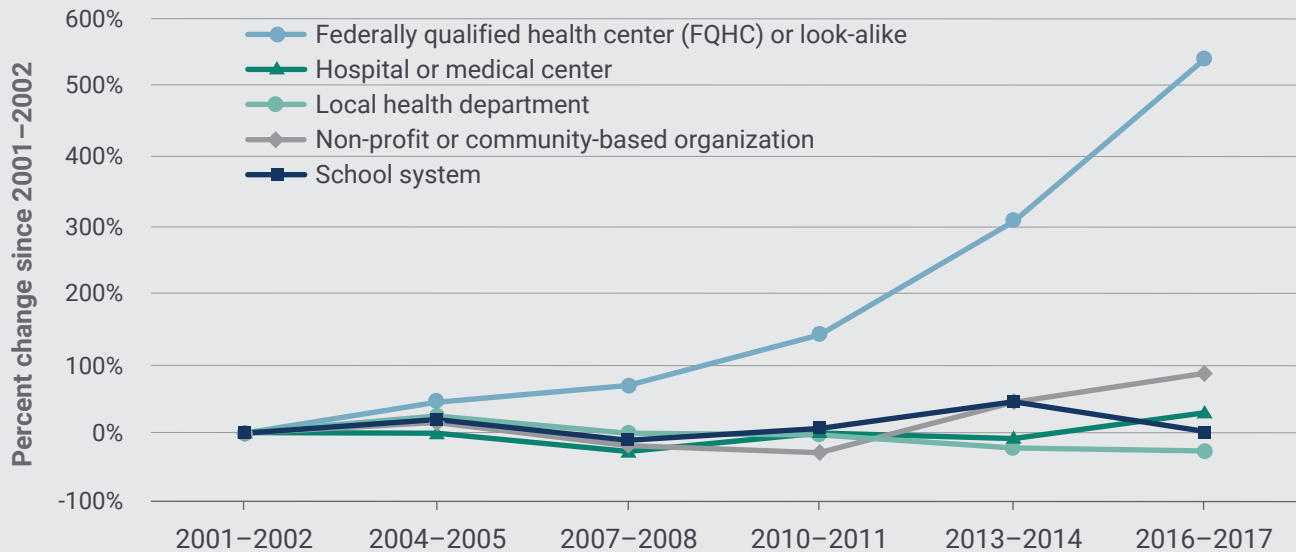
an on-site SBHC (2 percent) or access to one (10 percent).¹⁴ Even so, these providers are an important source of care for many children (MACPAC 2018b). SBHCs provide a variety of health services that go far beyond first aid treatment, including preventive care (e.g., immunizations) and routine screenings (HRSA 2017). Almost two-thirds (65 percent) of SBHCs employ a behavioral health professional, such as a psychologist, professional counselor, or social worker (Love et al. 2018a).

Over the last 10 years, there has been a substantial increase in the number of SBHCs, largely driven by an increase in FQHC sponsorship (Figure 3-1). In 2016–2017, approximately 2,500 SBHCs operated in nearly every state, providing access to 6.3 million students in over 10,600 schools.¹⁵ More than half (51 percent) of SBHCs were sponsored by FQHCs (Love et al. 2018b).¹⁶

School-based health centers

SBHCs can improve access to behavioral health care for youth, but few public schools have

FIGURE 3-1. Change in School-Based Health Center Sponsorship Type, 2001–2017



Notes: Data represents change compared to the number of school-based health centers in 2001–2002 for each sponsor type. FQHC look-alikes are community-based health care providers that meet the requirements of the Health Resources and Services Administration’s Health Center Program, but do not receive funding under that program. They provide primary care services in underserved areas on a sliding fee scale based on ability to pay and operate under a governing board that includes patients.

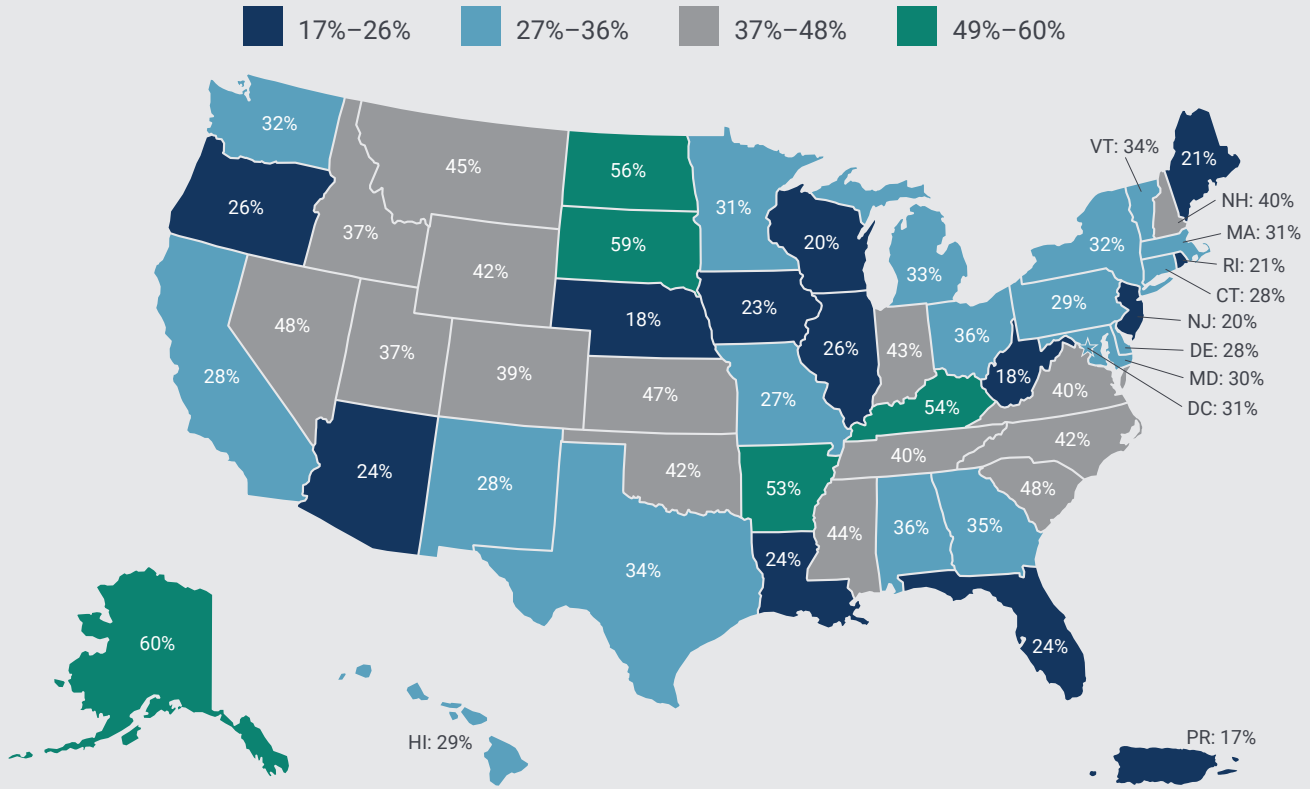
Source: Love et al. 2018b.

Supply of specialty mental health facilities

Using the 2018 National Mental Health Services Survey (N-MHSS), we examined the availability of specialty mental health treatment facilities, whether these facilities offer tailored services for youth with serious emotional disturbance (SED), and the rate at which these facilities participate in Medicaid.^{17, 18} Specialty mental health treatment facilities provide services ranging from outpatient mental health services, to partial hospitalization, to inpatient psychiatric services. Generally, these facilities offer psychotherapy, cognitive behavioral therapy, group therapy, and psychotropic medication therapy. Most facilities offer family therapy (71 percent) and psychoeducation (64 percent) (SAMHSA 2019c).

In 2018, there were nearly 12,000 specialty mental health treatment facilities in the United States, but many did not accept children or youth or offer tailored programming for adolescents with SED.¹⁹ Only one-third (32 percent) of these facilities offered such programming and participated in Medicaid. Moreover, Medicaid participation among facilities offering tailored programming for SED varied greatly by state, ranging from 17 percent in Puerto Rico to 60 percent in Alaska (Figure 3-2) (SAMHSA 2019c).

FIGURE 3-2. Share of Mental Health Treatment Facilities Offering Tailored Programming for Youth with Serious Emotional Disturbance and Accepting Medicaid by State, 2018



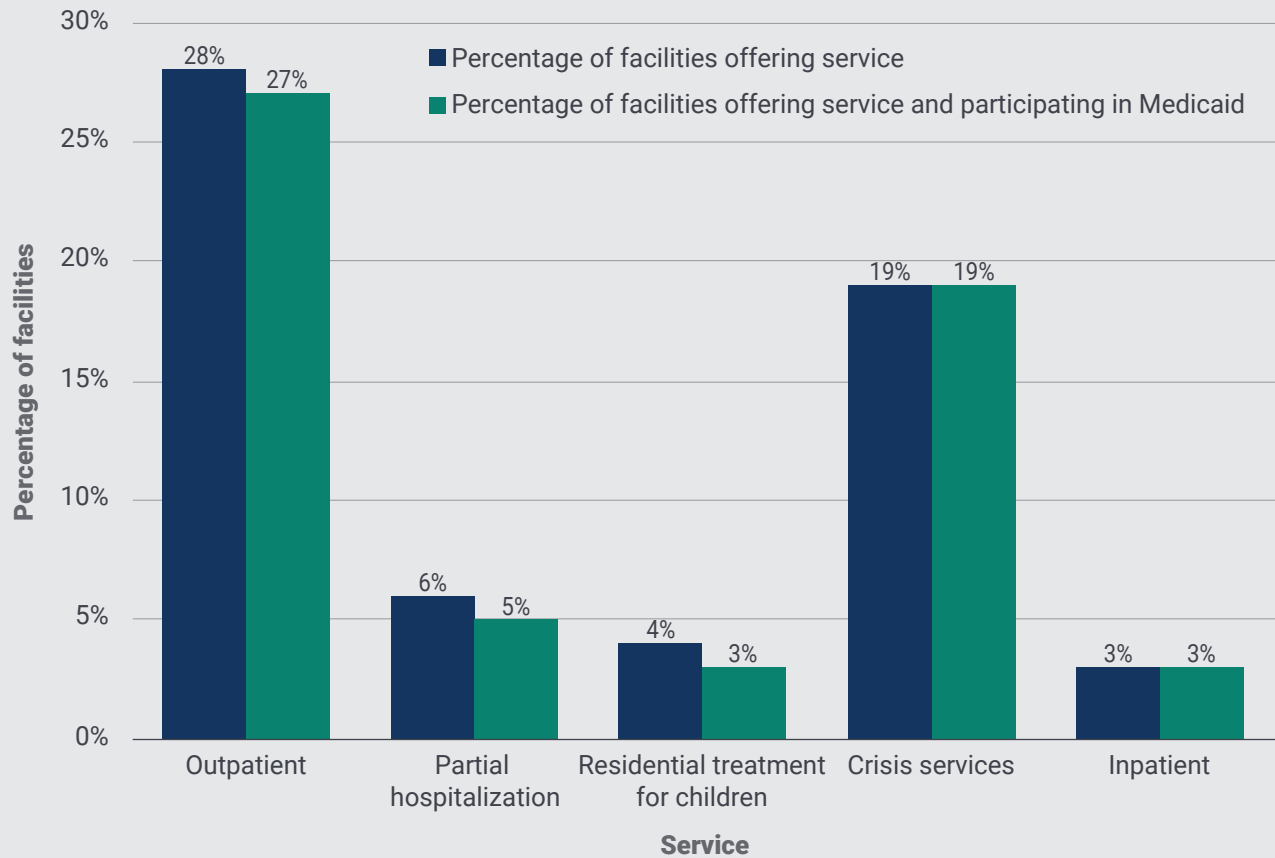
Sources: MACPAC, 2020, analysis of SAMHSA 2019c.

Adolescents with SED have limited access to specialized mental health treatment at certain levels of care. In 2018, approximately 28 percent of specialty mental health treatment facilities offered tailored programming for adolescents with SED and provided outpatient treatment services; of these facilities, the majority reported accepting Medicaid (Figure 3-3). In addition, roughly one in five facilities offered tailored programming for adolescents with SED and reported offering on- or off-site crisis services. However, more intensive services—partial hospitalization, residential treatment, and inpatient care—were much less likely to be available to Medicaid beneficiaries with SED.

Given that facilities may offer multiple services, the percentage of those accepting Medicaid is

not necessarily indicative of the share of facilities that accepted Medicaid payment for a specific service. For example, a provider offering partial hospitalization and residential treatment for children may report accepting Medicaid, but may have a Medicaid provider agreement with the state only for residential treatment and choose to limit partial hospitalization services to youth with private insurance. In this instance, a child that needs partial hospitalization services would still be entitled to such services and the state would be obligated to provide or arrange for such a child to get the services from another provider.²⁰

FIGURE 3-3. Share of Specialty Mental Health Facilities Offering Tailored Programming for Youth with Severe Emotional Disturbance and Accepting Medicaid by Service, United States, 2018



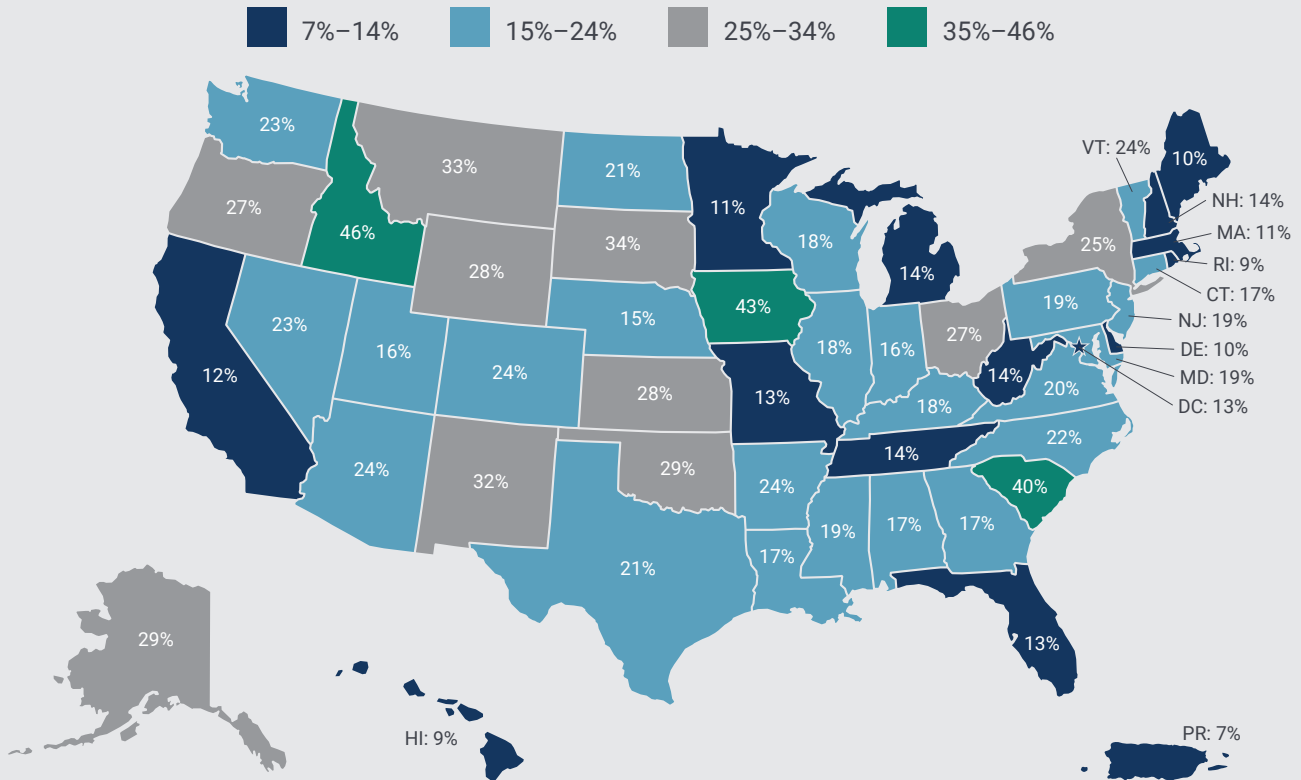
Sources: MACPAC, 2020, analysis of SAMHSA 2019c.

Supply of specialty substance use treatment facilities

Using the 2018 National Survey of Substance Abuse Treatment Services (N-SSATS), we examined the availability of specialty substance use treatment facilities, whether these facilities offer tailored services for youth with SUD, and the rate at which these facilities participate in Medicaid.²¹ Specialty substance use treatment facilities provide services ranging from outpatient SUD, to partial hospitalization, to inpatient treatment. Most offer individual counseling (95 percent), group counseling (95 percent), and family counseling (85 percent) (SAMHSA 2019d).

In 2018, one-fourth (25 percent) of specialty SUD treatment programs in the United States offered tailored programming for adolescents; fewer than one in five (19 percent) offered tailored programming for adolescents and accepted Medicaid. Medicaid participation among such facilities varied greatly by state, ranging from 7 percent in Puerto Rico to 46 percent in Idaho (Figure 3-4).

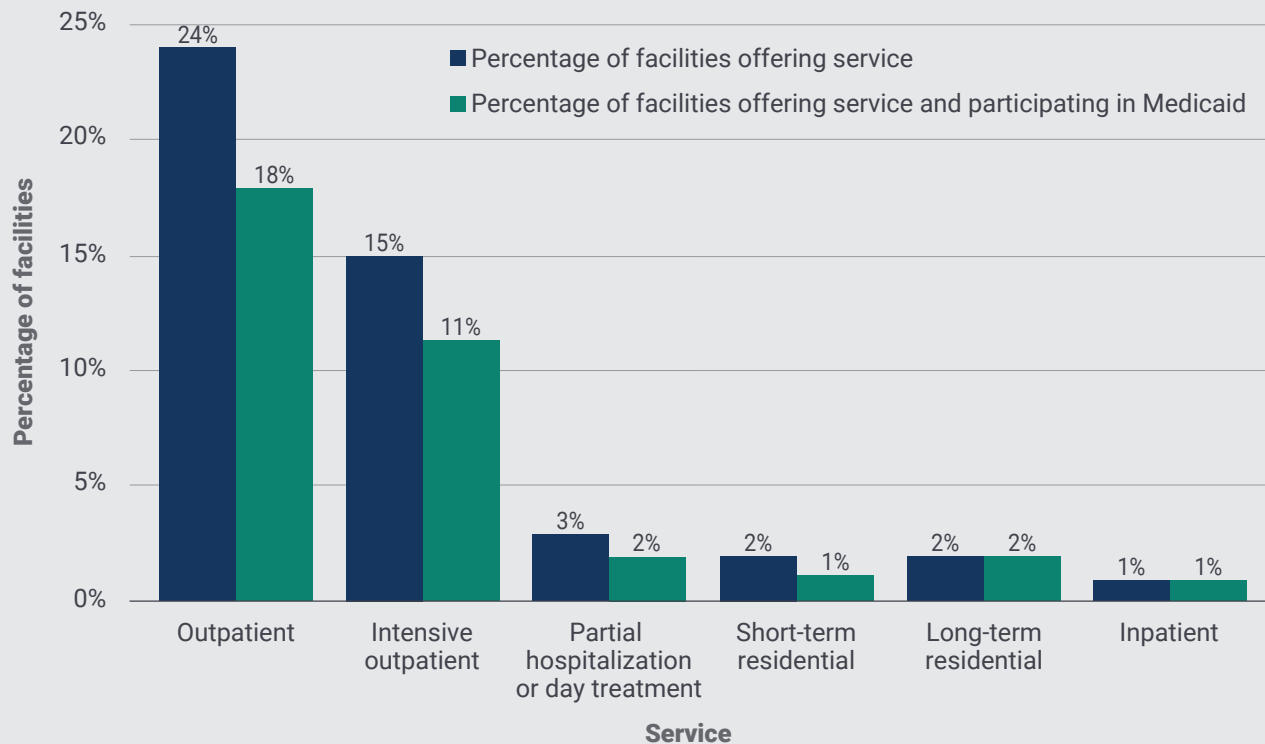
FIGURE 3-4. Percentage of Substance Use Treatment Facilities Offering Tailored Programming for Youth and Accepting Medicaid by State, 2018



Sources: MACPAC, 2020, analysis of SAMHSA 2019d.

Youth have limited access to specialty SUD treatment across all levels of care (Figure 3-5). In 2018, few facilities offered tailored programming as well as intensive outpatient treatment (15 percent), partial hospitalization (3 percent), short-term residential treatment (2 percent), long-term residential treatment (2 percent), or hospital-based inpatient treatment (1 percent). In some states, there are no facilities offering partial hospitalization, short-term residential treatment, long-term residential treatment, inpatient treatment, or tailored programming for adolescents with SUD (SAMHSA 2019d).

FIGURE 3-5. Share of Substance Use Treatment Facilities Offering Tailored Programming for Youth and Accepting Medicaid by Service, United States, 2018



Sources: MACPAC, 2020, analysis of SAMHSA 2019d.

Addressing the Needs of Children and Adolescents with Significant Mental Health Conditions

Medicaid and CHIP are a major source of coverage for adolescents with significant mental health conditions, covering one in three adolescents with a past year MDE with severe role impairment (SHADAC 2020). Such conditions can have a detrimental effect on the lives of young people as well as their families. Those with significant mental health conditions are less likely to finish high school and attain higher education (Wagner and Newman 2012, Stagman and Cooper 2010). They are also

at increased risk for institutional placements, co-occurring SUD, and suicidal thoughts and behaviors (O’Brien 2020, SAMHSA 2020, Simon et al. 2018).

Intensive home- and community-based behavioral health services can help children and adolescents with significant mental health conditions remain in their communities, but these services are often unavailable or difficult to access. Below we discuss factors affecting access to care, including the role of various state and federal agencies, Medicaid and CHIP coverage policies, and barriers to using Medicaid authorities to design benefits for children and adolescents with significant mental health conditions.

Multiple agencies involved

No single government agency is responsible for addressing the needs of children and adolescents with significant mental health conditions (Sundararaman 2009). At the federal level, multiple agencies within the U.S. Department of Health and Human Services provide policy guidance, oversight, and funding to address the health and well-being of this population. The same is true at the state level. As such, designing and implementing Medicaid benefits for children and adolescents, including those with significant mental health conditions, requires state Medicaid agencies to collaborate with multiple partners. Coordination can be complex and time consuming. Key state and federal agencies involved in this process, including the design of home- and community-based behavioral health benefits, include the following:

Centers for Medicare & Medicaid Services (CMS).

CMS and the states jointly administer Medicaid and CHIP, which together represent the largest payer of mental health services in the United States (CMS 2021). Benefits for children and adolescents with significant mental health conditions must be described in the state plan or waiver; both are subject to CMS approval. States may also use a portion of their CHIP administrative funds for health services initiatives to implement programs that provide behavioral health services to low-income children that are not otherwise covered by federal funding sources.

Substance Abuse and Mental Health Services Administration (SAMHSA). SAMHSA develops policy and regulations and administers grants to support access to behavioral health services and practice improvement. This includes formula grants to states, territories, and one tribal entity to prevent substance use and provide community mental health services. Among other requirements, states must target use of these formula grants to certain populations, including children with emotional disturbance (SAMHSA 2018).

Administration for Children and Families (ACF).

ACF promotes the economic and social well-being of families, children, individuals, and communities through a variety of programs and activities, including guidance, funding, and technical assistance to state child welfare agencies. Specifically, ACF administers funding under Title IV-E of the Act, which allows states, territories, and tribes to claim partial federal reimbursement for the cost of providing foster care, adoption assistance, and kinship guardianship assistance to children who meet federal eligibility criteria. The Family First Prevention Services Act (FFPSA, P.L. 115-123) expanded the use of Title IV-E funds to include certain behavioral health services that prevent out-of-home placements and added new restrictions on the use of Title IV-E funding for children in non-family settings (Box 3-2).

State behavioral health authorities. State behavioral health authorities are responsible for the public mental health and SUD delivery system. In some states, the behavioral health authority is a unit within the state Medicaid agency because Medicaid is a major payer of behavioral health services (Sundararaman 2009). Mental health and substance use authorities may also exist independent of one another. Behavioral health authorities oversee the use of federal grants for behavioral health services, including formula grants awarded by SAMHSA. When Medicaid does not pay for certain behavioral health services, they are typically financed by the state behavioral health authority.

State child welfare agencies. State child welfare agencies are tasked with promoting the safety, permanency planning and placement, and well-being of children. Low-income children currently or formerly served by the child welfare system are generally eligible for Medicaid and often have substantial behavioral health needs (MACPAC 2015). In some states, child welfare and children's mental health are administered by the same agency (Fields 2021a).

Juvenile justice agencies. In addition to maintaining public safety, juvenile justice agencies focus on skills development, habilitation, rehabilitation, treatment, and successful reintegration of youth into their communities (IWGYP 2021). Mental health conditions are prevalent among youth in the juvenile justice system, with as many as 70 percent of individuals having a diagnosable mental health problem (DSG 2017). Many youth served in the juvenile justice system are eligible for Medicaid or

CHIP; however, federal law prohibits use of federal Medicaid funds for most health care services for individuals incarcerated in public institutions, including juvenile detention facilities, except in cases of inpatient care lasting 24 hours or more (MACPAC 2018c). In some states, the juvenile justice agency is part of the department that oversees children's mental health and child welfare (Fields 2021a).

BOX 3-2. The Family First Prevention Services Act

Enacted as part of the Bipartisan Budget Act of 2018 (P.L. 115-123), the Family First Prevention Services Act (FFPSA) enhances federal support for services that prevent out-of-home foster care placements while limiting the use of federal funds for certain types of congregate care settings. Responding to long-standing concerns that most federal child welfare funding is available only after a child has been removed from the home, the law expands eligibility for services funded under Title IV-E of the Act, allowing child welfare agencies to provide certain evidence-based behavioral health services and parenting supports before a child is placed in foster care. As of fiscal year (FY) 2020, federal support for these services is available for any child determined to be at imminent risk of entering foster care, and to the child's parents or kin caregivers if the service enables that child to remain safely at home.

At the same time, FFPSA restricts the availability of Title IV-E room-and-board payments for children in foster care unless the child is placed in specified settings, including newly designated qualified residential treatment programs (QRTPs) that meet clinical quality requirements, involve families in treatment plans, and help children and youth return to family-based settings as quickly and safely as possible. These FFPSA provisions took effect in FY 2020 but states had the option to delay implementation until FY 2022 (October 1, 2021).

FFPSA implementation will require ongoing coordination among multiple stakeholders. At the federal level, the Administration for Children and Families is responsible for providing guidance and oversight as the agency administering Title IV-E funds to states and tribal entities. CMS has provided guidance on when a QRTP may be considered an institution for mental diseases (IMD), thereby prohibiting federal financial participation for any Medicaid services provided to eligible children residing in settings that the state determines is an IMD (CMS 2019).²²

At the state and local level, child welfare agencies are leading cross-agency efforts to enhance prevention services and implement new requirements for children in congregate foster care settings. Such efforts include coordinating with state Medicaid agencies to avoid duplication of services and to ensure Medicaid-eligible children in QRTPs can receive Medicaid-covered services as permitted by federal law.

Medicaid and CHIP coverage requirements

Medicaid, including Medicaid-expansion CHIP, must cover medically necessary behavioral and other health services for enrollees under age 21 as part of the EPSDT benefit, regardless of whether the required services are covered in the state plan (CMS 2014). EPSDT benefits are intended to discover and treat childhood health conditions before they become serious or disabling. In addition, the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities Act (SUPPORT Act, P.L. 115-271) made behavioral health coverage a required CHIP benefit, effective October 24, 2019. The statute specifically requires states with separate CHIP to cover services necessary to prevent, diagnose, and treat a broad range of behavioral health conditions. CMS guidance notes that states are now required to:

- cover all the developmental and behavioral health-related screenings and preventive services recommended by the American Academy of Pediatrics Bright Futures periodicity schedule, as well as those designated grade A or grade B by the U.S. Preventive Services Task Force;
- use age-appropriate, validated screening tools;
- demonstrate that CHIP benefits are sufficient to treat a broad range of behavioral health symptoms and disorders;
- cover MOUD and tobacco cessation benefits;
- identify a strategy for the use of validated assessment tools and specify tools in use; and
- deliver behavioral health services in a culturally and linguistically appropriate manner regardless of the delivery system (CMS 2020b).²³

Despite these requirements, many children and adolescents covered by Medicaid and CHIP do not receive needed services (SHADAC 2020, MACPAC 2018a). In 2018, only 54.1 percent of beneficiaries

with MDE and 60.4 percent of beneficiaries with MDE with severe role impairment received some form of specialty or non-specialty mental health treatment in the past year. In many instances, the reported unmet need for mental health treatment was greater among beneficiaries of color.²⁴ Adolescents enrolled in Medicaid or CHIP were also more likely than adolescents with private insurance to have stayed overnight in a hospital or residential setting (SHADAC 2021, 2020).

Although states have an obligation to provide intensive home- and community-based behavioral health services that can help these beneficiaries remain in their communities, such services are often unavailable or difficult to access. In numerous class action lawsuits, courts have ruled that states have not met their obligations under the EPSDT requirement. Settlements related to these cases identified a set of home- and community-based behavioral health services to which children and adolescents with significant mental health conditions are entitled under EPSDT benefits when determined medically necessary. One of the most far-reaching was *Rosie D. v. Romney* (410 F. Supp. 2d 18 (D. Mass. 2006)), a class action lawsuit in which a federal district court ordered Massachusetts to provide additional home- and community-based services for children with serious mental illness and ensure the use of standardized behavioral health screenings (Lav and Lewis 2018).²⁵ Joint guidance issued by CMS and SAMHSA in 2013 further clarifies the obligation of state Medicaid programs with regard to the EPSDT benefit, as well as under the ADA (Box 3-3) (CMS and SAMHSA 2013).

Home- and community-based services can prevent the use of emergency departments and other restrictive settings, such as inpatient and residential treatment facilities, that remove children and adolescents from their homes, schools, and communities (McEnany et al. 2020, O'Brien 2020, Tsai 2020, Lav and Lewis 2018). They can also prevent youth involvement in the foster care and juvenile justice systems (McEnany et al. 2020, O'Brien 2020, Zeller et al. 2014). In a survey of state officials, approximately 30 percent reported

inadequate coverage of home- and community-based behavioral health services as a somewhat or very common contributing cause of custody relinquishment, situations in which parents transfer

legal custody of their child to the state to access services that the child could not obtain otherwise (Stroul 2019).

BOX 3-3. Home- and Community-Based Behavioral Health Services for Children and Adolescents

CMS and SAMHSA guidance describes specific home- and community-based behavioral health services demonstrated to be effective in improving clinical and functional outcomes, school attendance, and other measures of well-being. These include the following:

Wrap-around approach. The wrap-around approach is a form of intensive care coordination in which teams collaborate to develop and implement individualized care plans for those with complex needs and their families. This approach focuses on all life domains and includes clinical interventions and formal and informal supports.

Peer support services. Peer support services are designed to help youth, parents, and other caregivers identify goals, develop and connect with formal and informal supports, and acquire skills to improve coping abilities. Peer support providers are family members or youth who have personally faced the challenges of coping with serious mental health conditions and who serve as advocates and mentors.

Intensive in-home services. Intensive in-home services are therapeutic interventions delivered to children and families in their homes and other community settings to improve youth and family functioning and prevent out-of-home placement in inpatient or residential settings. The services are typically developed by a team that can offer a combination of therapy from a licensed clinician and skills training and support from a paraprofessional.

Respite services. Respite services help children and adolescents remain in their homes by temporarily relieving their primary caregivers. They offer safe and supportive environments on a short-term basis for children and adolescents with mental health conditions when their families need relief. Services are provided either in the home or in approved out-of-home settings.

Mobile crisis response and stabilization services. Mobile crisis response and stabilization services are designed to de-escalate difficult mental health situations and prevent hospitalizations and other out-of-home placements. Mobile crisis services are available 24 hours a day, 7 days a week, and can be provided in the home or other non-hospital-based setting. Residential crisis stabilization provides short-term, out-of-home care for children and adolescents to address acute mental health needs and coordinate a successful return to the family at the earliest possible time with ongoing services (CMS and SAMHSA 2013).

Using Medicaid authorities to design benefits for children and adolescents with significant mental health conditions

Federal guidance and legal decisions make clear that home- and community-based behavioral health services must be made available under the EPSDT benefit, but states do not always identify such services under the state plan or a waiver, which can create barriers to access. For instance, when families and health care providers seek authorization and payment for medically necessary services that are not explicitly covered in the state plan or a waiver, access to services may be delayed. Such delays may occur because the state does not have a payment methodology for the service. Moreover, if the provider is not enrolled in Medicaid, the state may need to execute a single-service agreement with the provider (Autism Speaks 2017). Providers and families who are unfamiliar with the Medicaid program may not understand their rights or how to raise concerns about these issues (Fields 2021b).

State officials and other experts have noted that it can be extremely challenging to use Medicaid authorities to define home- and community-based behavioral health services for children and adolescents with significant mental health conditions, particularly if multiple authorities are needed to meet the state's goals (O'Brien 2020, Herman 2020). Waivers under Section 1915(c) of the Act are frequently used to provide home- and community-based services as an alternative to care in institutional settings, but rarely to serve individuals with behavioral health conditions, including children and adolescents.²⁶ This may be because such waivers must be targeted to beneficiaries who require an institutional level of care and such services must be cost neutral to the federal government (HHS 2020, MACPAC 2020). Although states have expressed interest in using Section 1915(i) state plan authority to expand home- and community-based services for behavioral health, they report difficulty doing so and there is limited federal guidance and technical

support to assist them. Challenges include defining eligibility to create highly targeted programs. In addition, states may not cap enrollment under Section 1915(i) as they can under Section 1915(c) (Herman 2020, HHS 2020, ASPE 2016).²⁷

Stakeholders have also highlighted the challenges states face when designing benefits to meet the needs of children and adolescents with significant mental health conditions. Despite growing evidence of the effectiveness of interventions to support parents and legal guardians, federal guidance concerning how Medicaid can be used to support these approaches is limited and does not sufficiently address services provided to families when the child is not present. In 2016, CMS issued an informational bulletin clarifying that state Medicaid agencies may allow maternal depression screenings conducted during a well-child visit to be claimed as a service for the child as part of the EPSDT benefit, because the maternal screening is for the direct benefit of the child. Diagnostic and treatment services delivered to the child and mother together, when directly related to the needs of the child, may also be claimed as a direct service for the child (CMS 2016). CMS has also clarified that parents and legal guardians of Medicaid-eligible children can receive peer support services when the service is directly for the benefit of the child (CMS 2013). However, further guidance is needed to help states implement these options (Fields 2021b).

States and other stakeholders have also commented on the need for federal officials to clarify the ability of state Medicaid programs and CHIP to pay for early intervention services for children who do not have a formal mental health diagnosis, but who have experienced certain traumatic events (e.g., death of a parent or exposure to domestic violence) that put them at risk for a mental health condition. Early intervention is critical to preventing and addressing mental health conditions before they become serious or disabling. Providing services to children with certain risk factors, in the absence of a mental health diagnosis, can also ensure access to critical services even when a child's symptoms are not appropriately diagnosed.

Recommendations

Recommendation 3.1

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program.

Rationale

Updated subregulatory guidance could facilitate state adoption of home- and community-based behavioral health services that permit children and adolescents with significant mental health conditions to live in their communities and avoid institutional placements. Guidance issued in 2013 has been valuable but is now outdated. In addition, states would benefit from the opportunity to learn about innovative approaches to benefit design.

At a minimum, new guidance should describe:

- home- and community-based behavioral health services shown to improve outcomes for children and adolescents with significant mental health conditions, including intensive care coordination, family and youth peer support services, intensive in-home services, respite care, therapeutic mentoring, and crisis services;
- approaches to achieve universal behavioral health screening of children and adolescents through effective engagement of providers and managed care organizations;
- opportunities to improve access to services among communities of color;
- strategies to address barriers to care for children and youth with multiple diagnoses,

such as those with significant mental health conditions and intellectual and developmental disabilities or SUD;

- policies and practices to promote trauma-informed systems of care, including early intervention services for at-risk children who do not have a formal mental health diagnosis;
- when a service can be directed toward the parent or caregiver in support of a child or adolescent with mental health needs;
- opportunities to cover telehealth and other technology-enabled services;
- the role of state Medicaid, behavioral health, child welfare, and other relevant agencies, as well as strategies for promoting interagency coordination;
- relevant Medicaid authorities and demonstration opportunities, including Section 1915(c) waivers and the Section 1915(i) state plan option; and
- recent examples from innovator states.

In developing such guidance, the Secretary should involve all relevant agencies, including but not limited to CMS, SAMHSA, and ACF. This coordination is needed to ensure the guidance adequately addresses the role of state Medicaid, behavioral health, and child welfare agencies in serving youth with significant mental health conditions, particularly as states continue implementing new requirements under FFPSA.

Implications

Federal spending. This recommendation would not have a direct effect on federal Medicaid and CHIP spending. Depending upon how states respond to guidance by providing additional or different services, costs to the federal government could be affected, although the extent to which spending will increase (due to more services being provided) or decrease (by averting care in more expensive settings) is difficult to predict.

States. Providing subregulatory guidance can raise awareness among state officials, encourage cross-agency collaboration, and expedite state efforts to expand services for children and adolescents with significant mental health conditions. States are often unaware of opportunities in Medicaid and CHIP to improve outcomes for youth with significant mental health conditions. Outlining these approaches in new guidance may draw the attention of state officials and other stakeholders and expedite efforts to expand access to effective services for this vulnerable population.

Beneficiaries. To the degree that guidance helps states implement new or improved home- and community-based services for children and youth with significant mental health conditions, this recommendation could improve access to care. These gains could be particularly important for beneficiaries of color, who are currently less likely to receive treatment for a significant mental health condition than their white counterparts (SHADAC 2021).

Plans and providers. There is no direct effect on plans and providers. However, state actions pursuant to the guidance may eventually affect these parties insofar as they are involved in the provision of services.

Recommendation 3.2

The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to provide education and technical assistance to states on improving access to home- and community-based behavioral health services for children and adolescents with significant mental health conditions covered by Medicaid and the State Children's Health Insurance Program. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of these services.

Rationale

Subregulatory guidance without technical assistance and planning opportunities may be insufficient to enhance state capacity and jump-start efforts to expand the continuum of services for children and adolescents with significant mental health conditions. States are operating with limited resources and multiple competing priorities, particularly during the COVID-19 pandemic. Moreover, they face a number of challenges when designing and implementing benefits for this population, including difficulty addressing state agency silos and identifying the appropriate Medicaid authority.

Technical assistance could be modeled after the Medicaid Innovation Accelerator Program. States would benefit from general learning opportunities that disseminate best practices and lessons learned, as well as multistate forums that enable cross-state learning. CMS, working in partnership with SAMHSA and ACF, should also provide individualized technical assistance to support benefit design and implementation. This should include technical support regarding use of Section 1915(c) waivers, the Section 1915(i) state plan option, and other relevant authorities. CMS and federal partners should encourage the participation of state leaders representing Medicaid, behavioral health, child welfare, juvenile justice, and other child-serving agencies as needed to ensure the engagement and buy-in of key decision makers.

Among other options, the Secretary could consider recent increases in behavioral health funding as one avenue for supporting state planning efforts. The American Rescue Plan Act of 2021 (P.L. 117-2), for example, provided an additional \$1.5 billion for the Mental Health Services Block Grant. Some of this funding could be used to help state behavioral health agencies engage key partners, including Medicaid agencies, and develop a coordinated plan to address the behavioral health needs of children and adolescents with significant mental health conditions. Under current grant requirements, states must submit a plan to SAMHSA every two years

explaining how they will use block grant funds to provide comprehensive, community mental health services to this population (as well as adults with serious mental illness). This plan must be approved by the Secretary, who could consider whether such a plan is comprehensive if it does not actively include the participation and input of the state Medicaid agency, the largest payer of behavioral health services.

Support for the planning process is particularly important now given the effects of COVID-19 on mental health and state budgets (Leeb et al. 2020, Loades et al. 2020, NASBO 2020). Designing a benefit package for children and adolescents with significant mental health conditions requires extensive planning, interagency coordination, and dedicated staff. State Medicaid agencies may identify a need for additional staff or consultant support and require approval from state legislatures for the added Medicaid expense.

Implications

Federal spending. This recommendation would not have a direct effect on federal Medicaid and CHIP spending.

States. This recommendation would enhance state capacity and address other common barriers to expanding home- and community-based behavioral health services for children and adolescents with significant mental health conditions.

Beneficiaries. To the degree that planning and technical assistance support states' ability to implement new or improved home- and community-based services for children and youth with significant mental health conditions, this recommendation could improve access to behavioral health services. These gains could be particularly important for beneficiaries of color, who are currently less likely to receive treatment for a significant mental health condition than their white counterparts (SHADAC 2021).

Plans and providers. There is no direct effect on plans and providers. However, new state actions may eventually affect these parties insofar as they are involved in the provision of new services.

Next Steps

Adoption of the Commission's recommendations would be an important initial step by the federal government to improve access to behavioral health services for children and adolescents covered by Medicaid and CHIP. MACPAC will continue to monitor state capacity to design home- and community-based services for children and youth with significant mental health needs. As discussed in Chapter 2, we will examine whether existing federal authorities are suited to serving beneficiaries of all ages who have a functional impairment resulting from a behavioral health diagnosis.

Going forward, the Commission is interested in exploring additional opportunities to improve access, with a particular focus on children and adolescents in foster care. Relative to their peers in the general population, these youth are more likely to experience mental illness and SUD (Turney and Wildeman 2016). Among other things, the Commission is interested in examining concerns that the IMD exclusion may preclude eligible youth from receiving Medicaid-covered services in certain residential treatment facilities established under the FFPSA.²⁸ We will also examine the experience of children and adolescents in future work on access to behavioral health services for individuals involved in the justice system and individuals who identify as lesbian, gay, bisexual, or transgender.

Endnotes

¹ Foster care settings include foster family homes and child care institutions caring for children who are under supervision of the state because they have experienced abuse or neglect (ACF 2021).

² The ADA extends protections to individuals with a mental health condition that “substantially limits” one or more major life activities (e.g., bipolar disorder, schizophrenia, major depression) (42 USC § 12102).

³ The *Olmstead v. L.C.* ruling was based on two conclusions. First, that institutionalization of individuals with disabilities able to live in community settings perpetuates the unwarranted assumption that such persons are unable to live in a community. Second, that “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”

⁴ NSDUH respondents are residents of households and individuals in non-institutional group quarters, such as shelters, rooming houses, college dorms, and halfway houses. Individuals with no fixed household address are excluded, for example, individuals who are homeless and not in shelters, active-duty military personnel, and residents of institutional group quarters, including correctional facilities, nursing homes, and mental institutions (SAMHSA 2019a).

⁵ The 2018 NSDUH defined individuals as having had a lifetime MDE if they reported at least five or more of the following symptoms in the same two-week period during their lifetime (with at least one of the symptoms being a depressed mood or loss of interest or pleasure in daily activities): (1) depressed mood most of the day, nearly every day; (2) markedly diminished interest or pleasure in all or almost all activities most of the day, nearly every day; (3) significant weight loss when not dieting or weight gain or decrease or increase in appetite nearly every day; (4) insomnia or hypersomnia nearly every day; (5) psychomotor agitation or retardation at a level that is observable by others nearly every day; (6) fatigue or loss of energy nearly every day; (7) feelings of worthlessness or excessive or inappropriate guilt nearly every day; (8) diminished ability to think or concentrate or indecisiveness nearly every day; and

(9) recurrent thoughts of death or recurrent suicidal ideation (SAMHSA 2019a).

⁶ For adolescent respondents, the NSDUH collects data on impairment caused by MDE using the Sheehan Disability Scale, a measure of impairment due to mental health issues in four major life activities or role domains. Each section consists of four questions, and each item uses an 11-point scale ranging from 0 (no problems) to 10 (very severe problems). Ratings of seven or greater for problems in one or more role domains were classified as severe impairment (SAMHSA 2019a).

⁷ As discussed, the NSDUH examines prevalence rates for MDE and MDE with severe role impairment among adolescents. It does not provide data on psychiatric diagnoses, and therefore may not reflect important trends related to the prevalence of certain mental health conditions among adolescents. Other federal data sources, using parental reports of their child’s diagnoses, find that attention-deficit/hyperactivity disorder, anxiety, and behavior disorders are most commonly diagnosed among adolescents age 12-17 (CDC 2021).

⁸ The NSDUH defines substance misuse as the use of a prescription drug in a manner other than how a drug is indicated or prescribed (SAMHSA 2019a).

NSDUH questions about criteria for abuse of alcohol or illicit drugs ask about the following symptoms, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition*: (1) problems at work, home, and school; (2) doing something physically dangerous; (3) repeated trouble with the law; and (4) problems with family or friends because of use of alcohol or illicit drugs in the past 12 months. Respondents meet criteria for abuse if they report one or more of these symptoms and if the criteria for dependence were not met for that substance (SAMHSA 2019a).

NSDUH dependence questions for alcohol or illicit drugs ask about the following symptoms, consistent with the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition*: (1) spent a lot of time engaging in activities related to substance use; (2) used the substance in greater quantities or for a longer time than intended; (3) developed tolerance (i.e., needing to use the substance more than before to get desired effects or noticing that the same

amount of substance use had less effect than before); (4) made unsuccessful attempts to cut down on substance use; (5) continued substance use despite physical health or emotional problems associated with substance use; (6) reduced or eliminated participation in other activities because of substance use; and (7) experienced withdrawal symptoms. For specific illicit drugs and alcohol that include a withdrawal criterion as one of the criteria that can be used to establish dependence, respondents were defined as meeting the criteria for dependence if they met three out of the seven criteria. For illicit drugs that do not include questions in NSDUH about a withdrawal criterion for establishing dependence, respondents were defined as meeting the criteria for dependence if they met three out of the six criteria for that substance (SAMHSA 2019a).

⁹ Under IDEA, services provided to children with disabilities in a school setting are documented in each child's individualized education plan or, for infants and toddlers (children under age three), the individualized family service plan.

¹⁰ The American Rescue Plan Act of 2021 (P.L. 117-2) provided \$80 million to expand the Pediatric Mental Health Care Access Program administered by HRSA.

¹¹ Medicaid-eligible children under age 21 are entitled to receive MOUD when medically necessary under Medicaid's EPSDT benefit. MOUD is also a required benefit for separate CHIP as of October 24, 2019 (CMS 2020).

¹² A person under age 18 must have undergone two documented unsuccessful attempts at short-term withdrawal management or drug-free treatment within a 12-month period to be eligible for maintenance treatment, and must have written consent from a parent, legal guardian, or responsible adult (42 CFR 8.12) (MACPAC 2019b).

¹³ Buprenorphine was the first MOUD authorized by the U.S. Food and Drug Administration to be prescribed or dispensed in an office-based setting. Under DATA 2000, those prescribing buprenorphine in general medical settings are subject to certain federal requirements, including mandatory training and a limit on the number of patients for whom they may prescribe. Qualifying practitioners must obtain a DATA 2000 waiver to prescribe buprenorphine in settings such as offices, community hospitals, health departments, opioid treatment programs, and correctional facilities. Waivered

prescribers are also required to certify to their capacity to provide counseling and ancillary services (MACPAC 2019b). Effective April 28, 2021, new federal guidelines allow certain prescribers to treat up to 30 patients without meeting certification requirements pertaining to training, counseling, and other ancillary services (HHS 2021).

¹⁴ Compared to schools without access to SBHCs, those with SBHC access had a higher percentage of Black and Hispanic students. They also had a higher percentage of students who received free or reduced-price lunches (Love et al. 2019).

¹⁵ In 2016–2017, Wisconsin and North Dakota did not have any SBHCs (Love et al. 2018a).

¹⁶ The growth of SBHCs over the past two decades can be attributed to two federal efforts. First, beginning in the 2000s, funding was doubled to build an additional 1,200 new primary care access points. In addition, the Patient Protection and Affordable Care Act (ACA, P.L. 111-148) included \$11 billion to support the operation, expansion, and construction of health centers, including SBHCs. The ACA provided \$200 million over four years for use by health centers for capital expenses, including construction and renovation (Love et al. 2019).

¹⁷ SED refers to a diagnosable mental, behavioral, or emotional disorder that results in functional impairment that substantially interferes with or limits the child's role or functioning in family, school, or community activities (SAMHSA 2019c).

¹⁸ Administered by the Substance Abuse and Mental Health Services Administration (SAMHSA), the N-MHSS is an annual survey that collects data on the location, characteristics, and utilization of mental health treatment services for all known specialty mental health treatment facilities in all 50 states, the District of Columbia, Puerto Rico, and other jurisdictions (SAMHSA 2019c).

¹⁹ Roughly half (55 percent) of facilities report accepting youth age 12 or younger and participating in Medicaid, and slightly more facilities (59 percent) report accepting youth age 13–17 and participating in Medicaid. However, many of these facilities do not offer tailored programming for adolescents with SED (SAMHSA 2019c).

²⁰ The percentage of mental health treatment facilities accepting Medicaid and offering multiple services, including residential treatment, to adolescents with SED may not accurately reflect the percentage of facilities accepting Medicaid for residential treatment. This is due to the institutions for mental diseases (IMD) exclusion, which generally prohibits federal financial participation for otherwise coverable Medicaid services delivered in a facility with more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases (§ 1905(i) of the Act).

²¹ Administered by SAMHSA, the N-SSATS is an annual survey that collects data on the location, characteristics, and utilization of SUD treatment services for all known specialty substance use treatment facilities in all 50 states, the District of Columbia, Puerto Rico, and other jurisdictions.

²² Since Medicaid was established in 1965, federal statute has largely prohibited payments to IMDs. See note 20.

²³ States must submit a CHIP state plan amendment to demonstrate compliance with the new behavioral health coverage provisions outlined in guidance issued by CMS on March 2, 2020.

²⁴ For example, less than half (48 percent) of Black beneficiaries with MDE with severe role impairment received some form of mental health treatment, compared to 68 percent of their white peers. Black and Hispanic beneficiaries with MDE with severe role impairment were also less likely to receive specialty mental health treatment than their white counterparts (SHADAC 2021).

²⁵ For the latest opinion, which pertains to reporting and monitoring obligations set forth in the remedial plan agreed to by the two parties, see the May 4, 2020, Federal Court of Appeals decision, *Rosie D. v. Baker*, 958 F.3d 51 (1st Cir. 2020), available at <https://www.clearinghouse.net/chDocs/public/MH-MA-0005-0028.pdf>.

²⁶ As of March 2020, there were nine states operating Section 1915(c) waivers to provide home- and community-based services to children with SED (MACPAC 2020).

²⁷ Federal guidance clarifies that states may use Section 1915(c) waivers to supplement the service otherwise available to children under Medicaid or to provide services to children who otherwise would not be eligible for Medicaid.

In both cases, states must ensure that all children, including those made eligible under the waiver, receive the EPSDT services to which they are entitled. A child's enrollment in a Section 1915(c) waiver cannot be used to deny, delay, or limit access to medically necessary EPSDT services. Although states may limit services under the waiver, they may not limit medically necessary services needed by a child who is eligible for EPSDT benefits that otherwise would be covered under Medicaid (HCFA 2001).

²⁸ In 2019, MACPAC published a report to Congress on oversight of IMDs. The report identifies and describes facilities designated as IMDs in selected states; summarizes state licensure, certification, and accreditation requirements; and outlines Medicaid clinical and quality standards for these facilities.

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Commission Vote on Recommendations

In MACPAC’s authorizing language in Section 1900 of the Social Security Act, Congress requires the Commission to review Medicaid and CHIP 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 on access to behavioral health services for children and adolescents. 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 Recommendations 3.1 and 3.2 on April 9, 2021.

Behavioral Health Services for Children and Adolescents

3.1 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to issue joint subregulatory guidance that addresses the design and implementation of benefits for children and adolescents with significant mental health conditions covered by Medicaid and the State Children’s Health Insurance Program.

Yes:	Bella, Barker, Brooks, Burwell, Carter, Cerise, Davis, Douglas, George, Gordon, Gorton, Lampkin, Milligan, Retchin, Scanlon, Szilagyi, Weno	17 Yes
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3.2 The Secretary of the U.S. Department of Health and Human Services should direct a coordinated effort by the Centers for Medicare & Medicaid Services, the Substance Abuse and Mental Health Services Administration, and the Administration for Children and Families to provide education and technical assistance to states on improving access to home- and community-based behavioral health services for children and adolescents with significant mental health conditions covered by Medicaid and the State Children’s Health Insurance Program. Additionally, the Secretary should examine options to use existing federal funding to support state-level activities to improve the availability of these services.

Yes:	Bella, Barker, Brooks, Burwell, Carter, Cerise, Davis, Douglas, George, Gordon, Gorton, Lampkin, Milligan, Retchin, Scanlon, Szilagyi, Weno	17 Yes
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APPENDIX 3A: Prevalence of Behavioral Health Conditions by Demographic Characteristics

TABLE 3A-1. Prevalence of Major Depressive Episode in the Past Year among Non-Institutionalized Adolescents Age 12–17, by Demographic Characteristics, 2018

Demographic characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Sex				
Male	7.9%	7.6%	7.9%	9.0%
Female	21.4	19.6	22.3	17.8
Race and ethnicity				
White, non-Hispanic	15.2	17.1	14.3	18.8
Black, non-Hispanic	11.0	7.6	15.7*	–
Hispanic	14.5	12.9	17.0*	10.0
Asian American, non-Hispanic	13.7	16.0	13.4	–
American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, non-Hispanic	15.0	–	–	–
Two or more races, non-Hispanic	18.6	18.5	19.9	–

Notes: The 2018 National Survey on Drug Use and Health (NSDUH) used criteria from the *Diagnostic and Statistical Manual of Mental Disorders, 5th edition* to identify major depressive episodes. The NSDUH did not exclude depressive symptoms that occurred exclusively in the context of bereavement.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

TABLE 3A-2. Prevalence of Illicit Drug or Alcohol Dependence or Abuse in the Past Year among Non-Institutionalized Adolescents Age 12–17, by Demographic Characteristics, 2018

Demographic characteristics	Percentage of youth age 12–17			
	Total	Medicaid or CHIP	Private coverage	Uninsured
Sex				
Male	3.6%	3.9%	3.5%	–
Female	4.0	3.7	4.2	–
Race and ethnicity				
White, non-Hispanic	3.9	5.0	3.5	–
Black, non-Hispanic	3.0	2.9	–	–
Hispanic	4.0	3.1	5.4	–
Asian American, non-Hispanic	–	–	–	–
American Indian, Alaska Native, Native Hawaiian, or Pacific Islander, non-Hispanic	–	–	–	–
Two or more races, non-Hispanic	5.6	–	–	–

Notes: The 2018 National Survey on Drug Use and Health (NSDUH) based estimates of illicit drug or alcohol dependence or abuse on criteria in the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition*. Included are respondents who reported either dependence on or abuse of one or more of the following illicit drugs: marijuana, cocaine, heroin, hallucinogens, inhalants, methamphetamine, or prescription psychotherapeutics drugs that were misused.

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, or uninsured. The NSDUH classified respondents who reported they were covered by CHIP as being covered by Medicaid. Coverage source is defined as primary coverage at the time of the interview.

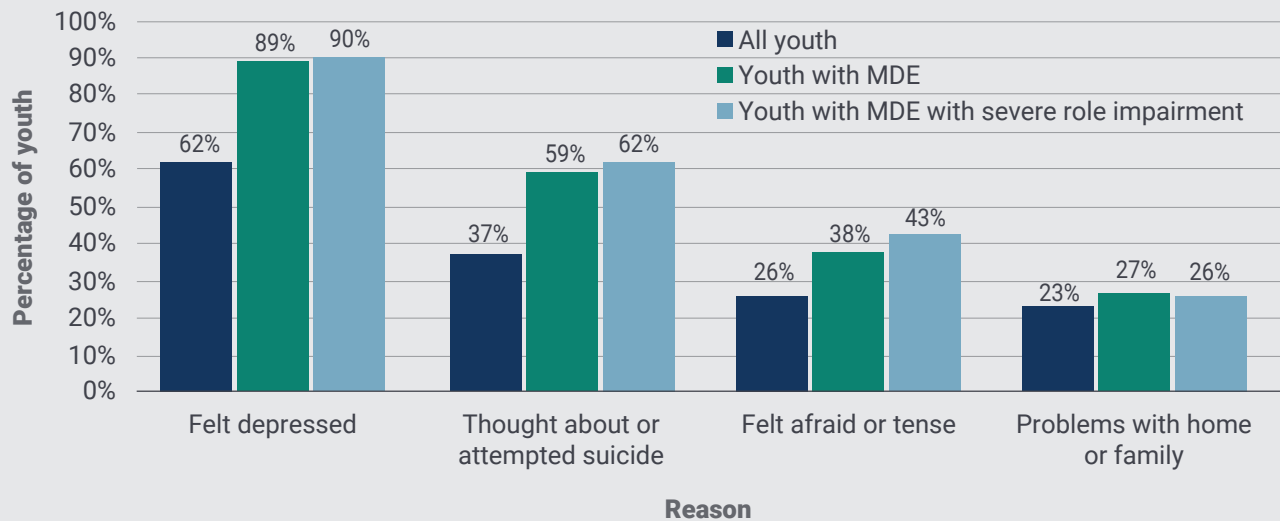
* Difference from Medicaid or CHIP is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020.

APPENDIX 3B: Reasons for Receiving Mental Health Treatment

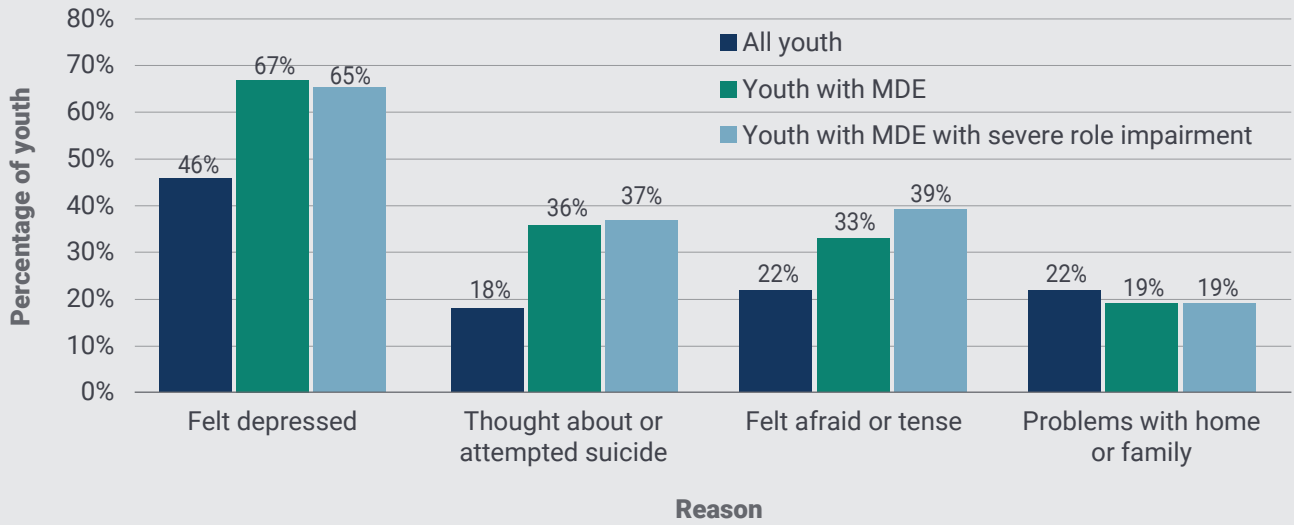
FIGURE 3B-1. Top Reasons for Receiving Specialty Mental Health Treatment among Non-Institutionalized Adolescents Age 12–17 in Medicaid or CHIP in the Past Year, 2018



Notes: MDE is major depressive episode. The 2018 National Survey on Drug Use and Health examines other reasons adolescents received specialty mental health services, including because they broke rules, had problems at school, had trouble controlling anger, had problems with friends or other people, had eating problems, got into fights, and had a self-reported mental disorder.

Source: SHADAC 2020.

FIGURE 3B-2. Top Reasons for Receiving School-Based Mental Health Services among Non-Institutionalized Adolescents Age 12–17 in Medicaid or CHIP in the Past Year, 2018



Notes: MDE is major depressive episode. The 2018 National Survey on Drug Use and Health examines other reasons adolescents received school-based mental health services, including because they broke rules or acted out, had an eating problem, had trouble controlling anger, were in physical fights, had problems at home or in their family, had problems with a friend, had problems with other people, had a diagnosed mental disorder, and other reasons.

Source: SHADAC 2020.

Chapter 4:

Integrating Clinical Care through Greater Use of Electronic Health Records for Behavioral Health

Integrating Clinical Care through Greater Use of Electronic Health Records for Behavioral Health

Key Points

- Compared to adults with private insurance, Medicaid beneficiaries suffer from higher rates of substance use disorder (SUD) and mental health conditions. They also experience other chronic conditions, such as hepatitis B or C, at higher rates than their privately insured peers.
- Specialty behavioral health providers and programs interact on a limited basis with other parts of the health care system. This represents a barrier to clinical integration and missed opportunities to provide high-quality care for beneficiaries with behavioral health conditions.
- Adopting certified electronic health record (EHR) technology (CEHRT) is one strategy that could improve communication between behavioral and physical health providers and strengthen clinical integration.
- Adoption of CEHRT among behavioral health providers supports clinical integration because it:
 - strengthens communication and data sharing among providers and allows them to make and monitor referrals to treatment across the care continuum;
 - provides easier access to state health information exchanges, which allow providers and patients to access and securely share medical information in real time; and
 - enables provider participation in value-based payment arrangements and supports federally mandated state quality reporting efforts.
- CEHRT adoption among behavioral health providers remains low because these providers were mostly left out of federal programs offering incentives to spur adoption of health information technology and EHR platforms.
- Due to low operating margins and limited working capital, behavioral health providers are often unable to invest in the expensive hardware, software, and training necessary for EHR adoption.
- When behavioral health providers can afford to adopt EHR platforms, they face additional challenges. For example, federal CEHRT requirements are not designed for federal standards regarding the confidentiality of SUD treatment information (known as 42 CFR Part 2).
- In the coming year, the Commission plans to examine potential solutions to address low rates of EHR adoption among behavioral health providers serving Medicaid beneficiaries.

CHAPTER 4: Integrating Clinical Care through Greater Use of Electronic Health Records for Behavioral Health

Compared to privately insured adults, Medicaid beneficiaries suffer from higher rates of substance use disorder (SUD) and mental health conditions. They also experience other chronic conditions at higher rates than their privately insured peers (SHADAC 2020a, MACPAC 2018). Many individuals with behavioral health conditions experience poor health outcomes (Roberts et al. 2017, Miller 2012, Druss et al. 2011). Evidence suggests that people with behavioral health conditions, especially those with serious mental illness, have a lower life expectancy than the general population. This is likely the result of a number of patient-related factors, including clinical risk and socioeconomic status, but can also be partially attributed to a lack of integration when care is required across different service settings (Druss et al. 2011, Rodgers et al. 2018). In part, poorly integrated health care stems from limited or inefficient coordination between specialists and minimal data sharing between the physical and behavioral health delivery systems. This can affect the provision of effective treatments and may even cause patient harm (Roberts et al. 2017, MACPAC 2016).

The Commission has previously commented on the siloed nature of physical and behavioral health care as well as the fragmented delivery systems for mental health and SUD (MACPAC 2020a, 2018, 2017, 2016). Generally, behavioral health providers encompass practitioners that treat SUD, mental health conditions, or both. Specialty behavioral health providers and programs interact on a limited basis with other parts of the health care system (MACPAC 2018, 2017, 2016). In addition, SUD treatment is generally not well coordinated or integrated with mental health services or the treatment of other physical health conditions (MACPAC 2018). We

have also pointed to concerns that federal SUD confidentiality regulations under 42 CFR Part 2 (referred to as Part 2) are meant to ensure patient privacy but have the unintended consequence of creating barriers to sharing SUD treatment information among providers (MACPAC 2018).¹

Adopting certified electronic health record technology (CEHRT) is one strategy to improve communication between behavioral and physical health providers and to provide better integrated care for beneficiaries.² Although electronic health records (EHRs) allow providers to retrieve and electronically transfer patient information easily, behavioral health providers were left out of large-scale federal efforts to promote clinical data sharing under the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH Act, Title XIII of P.L. 111-5) (ASPE 2013). As such, many behavioral health providers continue to rely on phone, paper, or fax, missing out on opportunities to share information with other providers (MACPAC 2018, Wolf et al. 2012).

This chapter represents the beginning of the Commission's work focused on the potential of EHRs to improve integration of physical and behavioral health and how federal policy can support EHR adoption among behavioral health providers. It first outlines the benefits of clinical integration and how fragmentation within the health care system can affect quality of care for Medicaid beneficiaries. In this discussion, the Commission largely focuses on the needs of those with mental illness, considering that we have extensively documented the needs of beneficiaries with SUD (MACPAC 2020a, 2019a, 2019b, 2018, 2017). For those unfamiliar to our prior work, we mention prior findings related to SUD as appropriate.

The chapter then discusses how use of health information technology (IT) can strengthen clinical integration through improved information sharing and communication among providers and patients. Next, the chapter analyzes low rates of EHR use among specialty behavioral health facilities and describes barriers preventing these providers from adopting EHRs.

As we look to next steps, the chapter concludes by describing several Medicaid funding authorities that could be used to strengthen clinical integration via health IT funding. Our work over the next year will focus on the merits and challenges of using these financing sources and on policy options to promote greater use of CEHRT among behavioral health providers.

Clinical Integration and Co-Occurring Conditions among Medicaid Beneficiaries

Poor health outcomes among individuals with mental illness have serious consequences. People with mental health conditions often die prematurely; those with serious mental illness die up to 32 years earlier than the general population (Roberts et al. 2017, Miller 2012). Premature death may be due to several factors, including limited insurance coverage, an insufficient mental health work force, and stigma that leads to delays in care, but comorbid conditions are a major factor (Roberts et al 2017, NASHMPD 2012). One study found that 95 percent of premature deaths among people with mental disorders are attributable to medical causes (e.g., cardiovascular diseases and adverse effects of psychotropic medications, including sudden death due to cardiac arrhythmias) as opposed to unnatural causes, such as suicide (Roberts et al. 2017). Co-occurring SUDs among individuals with mental illness also contribute to premature mortality (Roberts et al. 2017, Miller 2012). (Additional discussion of mortality among individuals with mental health conditions can be found in Chapter 2.)

The sharing of clinical information between behavioral and physical health providers, an important element of integrated models, can lead to improved health outcomes for adults with mental illness. For example, patients with serious mental illness served by highly integrated programs are more likely to self-report improvements in health status

and have higher screening rates for blood pressure, cholesterol, and glucose (Gilmer et al. 2016).

When providers are unable to share information about their patients, gaps in knowledge may lead to conflicting treatments, such as prescribing medications with potentially dangerous or even deadly interactions with other medications (MACPAC 2018, SAMHSA 2018). Given the high rates of co-occurring physical ailments and SUD among beneficiaries with mental illness, limited data sharing represents a barrier to clinical integration and leads to lower quality of care (MACPAC 2016, Gilmer et al. 2016).

In this section, we provide an overview of the benefits of clinical integration for behavioral health patients. We then present data on rates of co-occurring physical conditions that disproportionately affect Medicaid beneficiaries, underscoring the importance of integration to this specific population. We then briefly discuss how poor integration is particularly harmful for those covered by Medicaid given the large amount of care provided through specialty behavioral treatment centers.

Behavioral health and clinical integration

Clinical integration of physical and behavioral health care can help close the gap between the number of people with behavioral health disorders and the much smaller number accessing care (SHADAC 2020a, MACPAC 2016, NASHPMD 2012). The term “clinical integration” is used to describe a wide range of activities designed to provide care to the whole person, rather than focusing on specific body systems, diagnoses, or conditions (Box 4-1).³ Evidence suggests that integration efforts for certain populations and circumstances can lead to improved care and reduced costs, although evidence on efficacy for those with mental illness is mixed (MACPAC 2016). The mixed evidence may stem in part from delayed initiation of behavioral health treatment. For individuals with mental health conditions, the average delay between symptom

onset and treatment is 11 years (NAMI 2020). Similarly, the stigma associated with SUD can affect the willingness of individuals to seek help, providers

to offer care, and payers to cover treatment (MACPAC 2017).

BOX 4-1. Components of Clinical Integration

Clinical integration refers to the actions taken by clinicians and care coordinators to provide person-centered care. Models of integration can vary; some components of integration are listed below.

Care coordination or care management. Care coordinators or care managers act as single points of contact for patients and as hubs for the multiple providers treating a patient. Care coordinators can be located in behavioral health, physical health, or other settings, such as within the state or local Medicaid program office.

Co-location. Co-location refers to physically locating behavioral health and physical health providers in the same facility. It can encourage face-to-face contact between providers, it is convenient for beneficiaries, and it fosters communication about patients, improving efficiency and enhancing quality through a team-based approach to care.

Data sharing. Sharing clinical and other patient information can help care managers and providers from different disciplines communicate and coordinate care. Electronic health records can give patients and providers immediate access to clinical data and support knowledge transfer and informed decision making between providers. Data sharing allows providers and systems to exchange information on demographics, type of insurance coverage, hospital admissions, medications, lab results, diagnoses, allergies, treatment plans, clinical documentation, appointments, care team information, and activity logs. Furthermore, data sharing between the patient and provider enables patients to be active participants in their own treatment planning process, which is necessary given substance use disorder (SUD) privacy standards under 42 CFR Part 2.

Formal or informal agreements with external partners. Formal and informal arrangements between providers of behavioral health, physical health, and auxiliary community-based services (e.g., transportation, housing) can ensure beneficiary access to a full complement of services. Such arrangements allow providers to use community resources (e.g., contracting with a local non-profit organization for transportation services) without co-locating services. For example, SUD treatment facility may contract with a medical group to provide physical examinations and routine medical care for its patients.

Screening and referral to treatment. Screening and referral to treatment refers to a comprehensive and integrated approach to identifying appropriate treatments (including preventive care) and recommending the appropriate source of care for identified treatments. Screening and referrals can occur in both physical and behavioral health settings.

Provider education and training. Introducing concepts of behavioral health and interdisciplinary care teams during training can influence the future health care workforce's expertise and expectations about clinical practice. Residency training in family medicine and psychiatry is evolving to address person-centered care. For example, family medicine residents are now required to receive training in behavioral health, and psychiatric residents undergo some training in primary care settings (MACPAC 2016).

Co-occurring conditions among Medicaid beneficiaries

Services for physical and behavioral health are typically financed and delivered under separate systems. This means Medicaid enrollees with co-occurring conditions often find themselves interacting with multiple public and private agencies and receiving physical and behavioral health care from different sources (CMS 2020b, MACPAC 2020a). This fragmentation impedes access to care and may result in inappropriate or limited use of services, poor health status, and increased costs.

In 2018, non-institutionalized adults with any mental illness who were enrolled in Medicaid reported

having a co-occurring physical health condition over the course of their lifetime at higher rates than those with private coverage (Table 4-1).⁴ Medicaid beneficiaries also reported higher rates of co-occurring conditions than adults who were uninsured. Across all coverage categories, rates were higher for adults with serious mental illness than for adults with mild to moderate conditions. Furthermore, adults with serious mental illness who were enrolled in Medicaid reported higher rates of co-occurring conditions than Medicaid beneficiaries with mild to moderate mental illness for virtually all conditions. (For more detailed tables on specific co-occurring conditions, see Appendix 4A, Table 4A-1.)

TABLE 4-1. Reported Lifetime Rates of Co-Occurring Physical Health Conditions among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Condition	Percentage of adults ever having a co-occurring condition	Percentage of adults age 18–64 in each coverage category		
		Medicaid	Private coverage	Uninsured
Any mental illness	44.1%	48.2%	40.6%*	37.5%*
Mild to moderate mental illness	42.1	45.1	39.0*	35.8*
Serious mental illness	49.9	55.3	46.0*	41.8*

Notes: Co-occurring conditions include HIV or AIDS, heart conditions, diabetes, chronic bronchitis, cirrhosis of the liver, hepatitis B or C, kidney disease, asthma, cancer, high blood pressure, and sexually transmitted diseases. Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

Source: SHADAC 2020a.

Substance use disorder. Prior MACPAC work documented comorbidities among beneficiaries with SUD; in this section we will discuss rates of co-occurring SUD among those with mental illnesses.⁵ Among adults who report experiencing mental illness, co-occurring SUD is more prevalent among Medicaid beneficiaries than their privately

insured peers. In 2018, one in four (26.2 percent) non-institutionalized adults with any mental illness who were enrolled in Medicaid had a co-occurring alcohol or drug dependence or abuse in the past year (Table 4-2). The reported rate of co-occurring alcohol or drug dependence or abuse was even higher (35.7 percent) among those with serious mental illness.⁶

TABLE 4-2. Reported Rates of Co-Occurring Substance Use Disorder in the Past Year among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Condition	Percentage of adults 18–64	Percentage of adults age 18–64 in each coverage category		
		Medicaid	Private coverage	Uninsured
Any mental illness	21.0%	26.2%	19.2%*	26.2%
Mild to moderate mental illness	18.3	22.2	16.8*	22.8
Serious mental illness	28.8	35.7	27.3*	34.9

Notes: Co-occurring substance use disorder includes alcohol or drug dependence or abuse. Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on: distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

Source: SHADAC 2020a.

Use of the specialty behavioral health treatment system

Medicaid beneficiaries often receive treatment in specialty mental health facilities, which typically treat individuals with serious mental illness and are separate from other health care facilities (MACPAC 2018). These facilities provide a range of services from outpatient behavioral health services, to partial hospitalization, to residential treatment. Despite high rates of co-occurring conditions among beneficiaries with behavioral health conditions, these specialty facilities rarely offer fully integrated care (SAMHSA 2019b). Many of these facilities

participate in Medicaid and are more likely to be located in low-income communities than in higher income neighborhoods (SAMHSA 2019b, Cummings et al. 2017).

Medicaid beneficiaries with mental illness are more likely to receive care in these specialty facilities than their privately insured peers (SHADAC 2020a, Cummings et al. 2017). Moreover, beneficiaries are less likely to receive specialty behavioral health services in office-based settings than their privately insured peers (SHADAC 2020a, Cummings et al. 2017). (For additional information on access to mental health treatment, see Chapter 2.)

In 2018, specialty mental health facilities that accept Medicaid were more likely to offer SUD treatment (roughly half of facilities) than integrated primary care services (about one-quarter of facilities). The proportion of specialty mental health treatment facilities offering integrated care also varied by state, ranging from 10 percent of facilities in Nevada to 43 percent in the District of Columbia (SAMHSA 2019b). Furthermore, the frequency of operational integration and routine co-occurring treatment may fall short of these reported offerings of integrated care (LeVota 2021).

Health IT: A Tool for Clinical Integration

EHRs can foster clinical integration through data sharing, care coordination, and referral to treatment across the care continuum. EHRs alone will not fully integrate patient care, but the ability to share information among providers and between providers and patients is an important step toward this goal. In general, EHRs can promote coordinated care by allowing clinicians to update patient health information quickly and distribute it to other authorized providers in disparate care settings (Falconer et al. 2018).

To confer confidence that electronic health information can be easily shared between providers using different EHR platforms, the Office of the National Coordinator for Health Information Technology (ONC) certifies EHRs to confirm that they meet a minimum quality standard (ONC 2015). The structure of EHRs that have not received ONC certification may not conform to standards, making data transfers between providers a challenge (CMS 2020c). Because CEHRT meets basic minimum standards on core functions and data structures, it is more likely to enable and ensure interoperability and data exchange than non-certified EHR platforms (CMS 2020c).

Below we describe in more detail how CEHRT could enable greater clinical integration between behavioral and physical health services.

CEHRT provides easier access to state health information exchanges

Health information exchanges (HIEs) are entities that facilitate the transfer of health care information electronically across organizations within a geographic region, hospital system, or insurer. Virtually all states have some HIE infrastructure that allows providers and patients to access and securely share medical information, often in real time (ONC 2021). Immediate access to medical information has numerous benefits, including making available vital patient information to inform decision making at the point of care. For example, experts agree that the integration that comes with participation in an HIE may lower the probability of readmission, lower the risk of medication discrepancies, reduce redundant imaging and laboratory tests, and decrease emergency department (ED) use (Menachemi et al. 2018, Boockvar et al. 2017, Murphy et al. 2017, Vest et al. 2015, Yaraghi 2015).

Providers who have adopted CEHRT have easier access to patient data stored in the HIE. Under the 21st Century Cures Act (Cures Act, P.L. 114-255), CEHRT must store data in the same standardized structure as used by HIEs. This makes it easier for providers with CEHRT to send and receive patient records from an HIE.

As we will discuss later in this chapter, behavioral health providers have adopted CEHRT at lower rates than other providers and consequently access clinical and patient data from HIEs at lower rates than other types of providers (Barker 2020). As a result, many behavioral health providers cannot easily obtain patient information to proactively strengthen quality of care and coordination, for instance, accessing state prescription drug monitoring programs to determine whether the patient has multiple prescribers or receiving real-time notifications if a patient has been admitted to a hospital for a behavioral health treatment. Similarly, physical health providers are often unaware of a beneficiary's participation in behavioral health services (Box 4-2).

BOX 4-2. Maryland's Health Information Exchange Supports Care Coordination

The Chesapeake Regional Information System for Our Patients (CRISP) is a regional health information exchange (HIE). It receives information on emergency and inpatient admissions in real time from acute care hospitals in Maryland and the surrounding jurisdictions, including Delaware, the District of Columbia, and West Virginia.

All providers partnering with CRISP may upload patient information to the HIE. When an individual is admitted to a hospital, the hospital will ask the patient for basic information and the reason for the visit. This information is then entered in the patient's hospital medical record, which is immediately sent to CRISP. If the patient's record is matched with information on the HIE, then CRISP sends an immediate notification to any provider who has opted to receive this information and whose certified electronic health record technology or electronic health record platform has the functionality to accept real-time alerts. These encounter notification systems can help a behavioral health provider proactively engage with an individual who might be at risk of frequent emergency department visits (Martin and Chute 2017).

CEHRT enables participation in value-based payment arrangements and supports quality reporting

CEHRT is a necessary precursor to increased behavioral health provider participation in value-based payment (VBP) arrangements (LeVota 2021). State Medicaid agencies and managed care organizations (MCO)s are increasingly developing VBP arrangements that require the use of CEHRT or other EHR platforms with some of the advanced functionalities of CEHRT. The latter include EHRs that can identify high-risk and high-need patients within a provider's patient panel but may lack other CEHRT functions. Use of CEHRT enables different specialists involved in a patient's care to transmit patient information critical to the value-based models. For example, CEHRT can be used to analyze different levels of risk within a patient population and to determine provider quality scores for purposes of VBP (AmeriHealth Caritas 2021, AmeriHealth Caritas DC 2019).⁷ Providers responsible for health outcomes such as non-emergent ED visits need CEHRT capable

of generating risk profiles that predict such use (MACPAC 2020b). CEHRT can also ease the burden of reporting to state agencies or Medicaid MCOs on behalf of the provider (Box 4-3).

BOX 4-3. Certified Electronic Health Record Technology and Value-Based Payments in Medicare

One of the better-known value-based payment (VBP) programs—the Quality Payment Program (QPP)—operates under Medicare Part B and illustrates the importance of certified electronic health record technology (CEHRT). Clinician participation in QPP requires the meaningful use of CEHRT to determine provider quality scores. Examples of QPP measures include expanded use of e-visits and telehealth and sharing consultations with referring clinicians. These measures can influence the provider’s total payment. Additionally, CEHRT can enable clinicians to capture, track, and report clinical quality measures. A clinician can rely on CEHRT to automatically collect the data, incorporate any exclusion criteria, and calculate a quality score. Without CEHRT, the labor and capital costs required to calculate these scores could make participation in QPP cost prohibitive for the clinician (Gillen et al. 2018).

Increased adoption of CEHRT would support the data collection needed to calculate provider quality scores and the Medicaid core set of health care quality measures (MACPAC 2020b). Currently, few behavioral health providers use CEHRT, so even when electronic data are available, the data are in non-standardized data formats. This creates challenges for states and MCOs as they work with providers to collect data according to federal core set measure technical specifications. In addition, without CEHRT, behavioral health providers may not have the technical capacity to transmit behavioral health data electronically to the Medicaid agency (MACPAC 2020b).

The inability of many behavioral health providers to analyze and transmit the data required for Medicaid’s core set of health care quality measures is a pressing concern given that beginning in fiscal year (FY) 2024, states are required to report on behavioral health quality measures in the Adult Core Set. As of 2020, eight of the adult behavioral health measures rely exclusively on administrative data, which include data that could be collected from CEHRT (MACPAC 2020b).⁸ However, states have indicated that it is unlikely they will be able to address the challenges of CEHRT interoperability and data extraction from EHRs by the deadline (MACPAC 2020b).

Behavioral Health Providers Adopt EHRs at Low Rates

As noted above, behavioral health providers generally, and specialty behavioral health providers in particular, lag behind hospitals and physicians in adoption of EHRs. Below we discuss rates of EHR adoption among a subset of these providers: specialty mental health and SUD treatment facilities. These treatment facilities provide services ranging from outpatient behavioral health services, to partial hospitalization, to inpatient behavioral health care. We also discuss barriers to EHR adoption for the broader specialty behavioral health community, such as psychiatric hospitals and individual providers.

To quantify EHR uptake among behavioral health providers, we used the National Mental Health Services Survey (N-MHSS) and the National Survey of Substance Abuse Treatment Services (N-SSATS).⁹ The N-MHSS collects data from facilities providing specialized mental health services, while the N-SSATS collects data from facilities providing SUD treatment. Both are administered annually by the Substance Abuse and Mental Health Services Administration (SAMHSA) and are used to conduct a census of facilities that provide specialty mental health or SUD treatment services, respectively. It

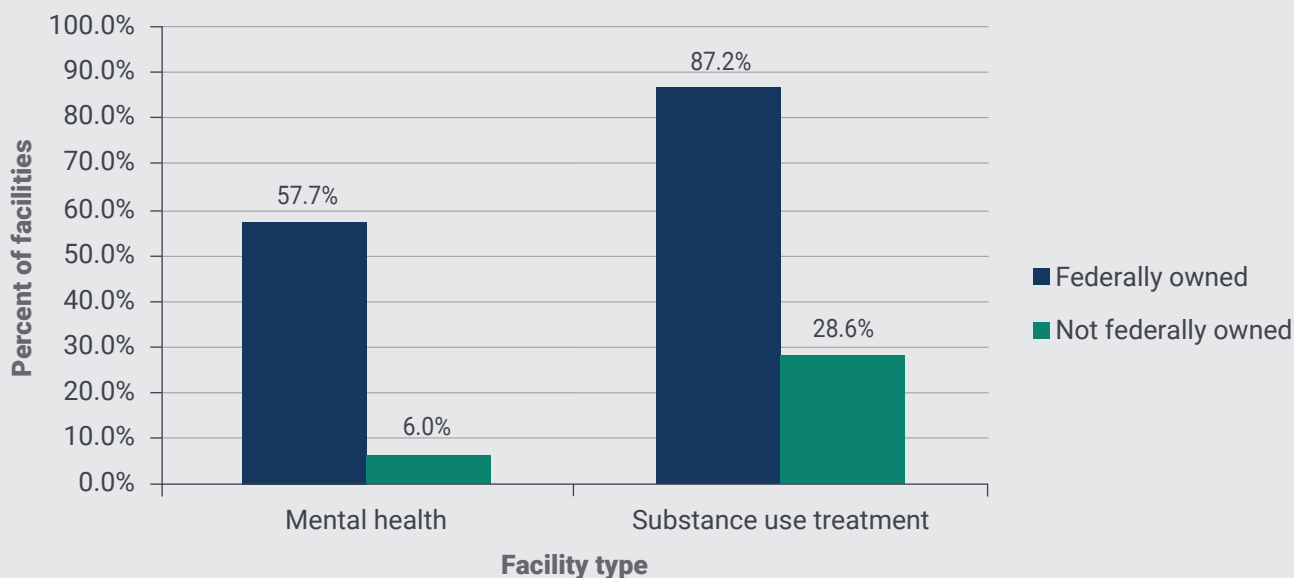
should be noted that the results presented here are an approximation of CEHRT functionality because neither survey asks specific questions about CEHRT adoption.¹⁰ More details on our methodology can be found in Appendix 4B.

EHR adoption rates vary based on facility ownership

MACPAC’s analysis of N-MHSS and N-SSATS shows that whether providers use electronic means for recordkeeping and basic clinical functions varies extensively by ownership status. Federally owned mental health and substance use treatment facilities are predominantly operated by the U.S.

Department of Veterans Affairs and the U.S. Department of Defense. Generally, federally owned behavioral health facilities have benefited from government efforts to digitize health care records, and they have adopted EHRs at higher rates than non-federally owned facilities. For mental health facilities, in 2017–2018, 58 percent of federally owned facilities used an electronic system for basic clinical functions compared to 6 percent of non-federally owned facilities. For substance use treatment facilities, 87 percent of federally owned substance use treatment facilities used an electronic system for basic clinical functions compared to 29 percent of non-federally owned facilities (Figure 4-1).¹¹

FIGURE 4-1. Percentage of Behavioral Health Facilities That Use an Electronic System for Basic Functions and Accept Medicaid, 2017–2018



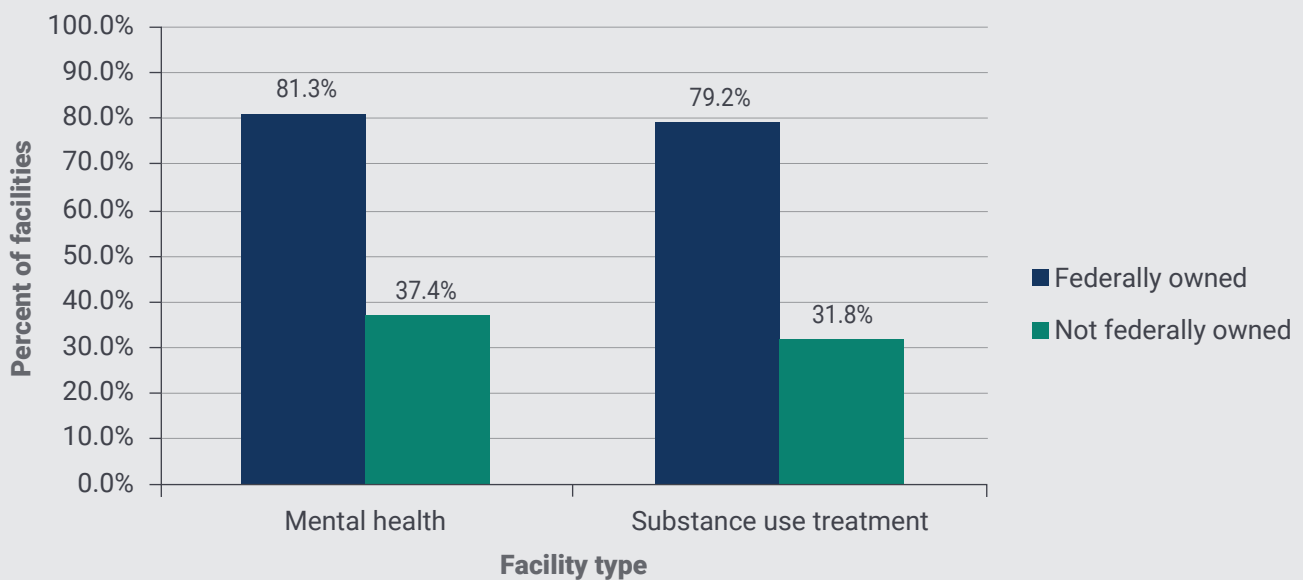
Notes: Includes only facilities that accept Medicaid-enrolled patients. The measure is a composite based on how providers answered a series of survey questions; it measures whether a facility uses only electronic means—as opposed to a combination of electronic and paper or only paper means—for basic clinical functions, such as storing and maintaining health records, assessing a client, creating a treatment plan, or checking for medication interactions. If a facility does not execute a specific clinical function, then it was dropped from the composite measure. For more on how this measure was calculated, please refer to Appendix 4B.

Source: SHADAC 2020b.

We found that facilities also use an electronic system for specific clinical functions, such as maintaining health records and sharing client information with other providers. Among substance use treatment facilities, the percentage of federally owned facilities that maintain health records on a

computer or electronically was more than double the rate among non-federally owned facilities (79 percent versus 32 percent). Between federally owned and non-federally owned mental health facilities, the difference was similar, 81 percent and 37 percent, respectively (Figure 4-2).

FIGURE 4-2. Percentage of Behavioral Health Treatment Facilities That Store and Maintain Health Records Electronically and Accept Medicaid, 2017–2018



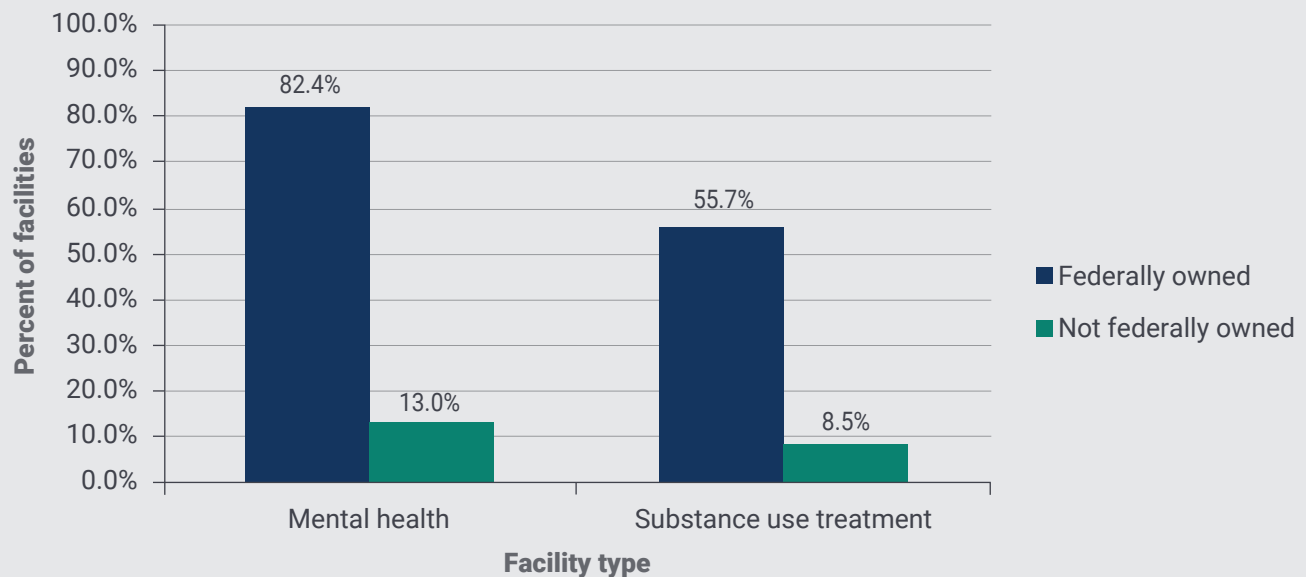
Notes: This analysis includes only facilities that report acceptance of Medicaid. The measure is based on whether the facility uses only computer and electronic means—as opposed to a combination of electronic and paper or only paper means—to store and maintain health records.

Source: SHADAC 2020b.

Differences in electronic sharing of client information were even greater.¹² A higher share of federally owned mental health facilities (82 percent) than non-federally owned mental health facilities (13 percent) reported sharing client information

electronically. Similarly, a higher share of federally owned substance use treatment facilities than non-federally owned facilities shared patient information electronically (56 percent versus 9 percent) (Figure 4-3).

FIGURE 4-3. Percentage of Behavioral Health Facilities That Electronically Share Client Data with Other Providers and Accept Medicaid, 2015–2016



Notes: This analysis includes only facilities that report acceptance of Medicaid. Question on interoperability changed in 2017 and therefore is not comparable in future years. The measure is based on whether the facility uses only computer and electronic means—as opposed to a combination of electronic and paper or only paper means—to electronically share client data with other providers.

Source: SHADAC 2020b.

Peer effects may explain low rates of electronic client information sharing. That is, when few facilities can share information electronically, the incentive for them to invest in EHR systems or other patient information-sharing mechanisms declines. EHR peer effects have been noted as a reason for lower rates of electronic data sharing throughout the health care system (Patel et al. 2019, Henry et al. 2018). For example, half of hospitals indicate that their patient data exchange partners are unable to receive data, either because their EHR systems are incompatible or because partners cannot electronically receive

the data (Pylypchuk et al. 2020). Facilities that were ineligible for incentive payments under the HITECH Act are less likely to have an operable EHR system (Adler-Milstein et al. 2017).

Barriers to CEHRT adoption among behavioral health providers

The barriers to CEHRT adoption are multifaceted. Behavioral health providers often have limited capital to invest in technology. Moreover, as noted

above and discussed more fully below, most were ineligible to receive federal incentive payments to adopt CEHRT (MACPAC 2018, MACPAC 2016).

To understand how limited CEHRT adoption and use affects behavioral and physical health care, we reviewed comments submitted in response to federal rulemaking on behavioral health EHR interoperability, including a request for information on how to assist behavioral health providers in leveraging technology to exchange health data and coordinate care in a more agile fashion. The comments, submitted by insurance carriers and Medicaid MCOs, EHR vendors, HIEs, behavioral health provider associations, state Medicaid agencies, and various health IT coalitions, provide insight on use of CEHRT among behavioral health providers as well as potential federal solutions.¹³

Costs. Behavioral health providers report that cost is the principal barrier to CEHRT uptake (NASMHPD 2018).¹⁴ Despite a strong demand for CEHRT adoption, the costs of purchasing and installing the system and training staff remain substantial for behavioral health providers—especially solo practitioners and those in small practices—as well as state behavioral health agencies with limited budgets (NASMHPD 2018).¹⁵ Although many hospitals and physicians received federal incentive payments for EHR adoption under the HITECH Act, with the exception of psychiatrists, behavioral health providers were not included in this effort. For context, previous federal incentives for CEHRT adoption could equal almost \$64,000 over a six-year period per individual eligible provider and almost \$15 million over a four-year period.¹⁶

Due to low operating margins, behavioral health providers often have little capital available to invest in the expensive hardware, software, and training needed to use EHRs (MACPAC 2016). The COVID-19 pandemic has further strained provider finances. An April 2020 survey conducted by the National Council of Behavioral Health found that nearly all (93 percent) of behavioral health providers had reduced operations and nearly half (46.7 percent) of behavioral health organizations

had laid off or furloughed employees or planned to do so (NCBH 2020).

Privacy rules. Federal CEHRT standards were designed to comply with the Health Insurance Portability and Accountability Act of 1996 (HIPAA, P.L. 104-191), which governs use and disclosure of individually identifiable health information (i.e., information related to all health conditions, health care services, and payment). HIPAA generally allows information to be shared without patient consent among providers and payers for payment, treatment, and health care operations purposes. As such, it can easily be shared among providers that are using CEHRT.

In contrast, SUD treatment information is subject to additional requirements that affect information sharing among providers. Specifically, Part 2 does not allow the disclosure or redisclosure of protected SUD treatment information for treatment purposes. As such, Part 2-covered providers must obtain patient consent to disclose, and redisclose, such information, including for care coordination and case management.¹⁷ These requirements mean that CEHRT must be able to segment Part 2-protected SUD treatment information from the rest of a patient's health record.¹⁸ In practice, CEHRT often does not have such segmentation capabilities. There are no federal requirements for CEHRT to include the functionality to comply with Part 2. There is also disagreement within the behavioral health community as to whether, and to what degree, widespread Part 2-compliant interoperability is even technically feasible.¹⁹

Recent changes in federal privacy laws may make it easier for providers to share this information. The Coronavirus Aid, Relief, and Economic Security Act (CARES Act, P.L. 116-136) aligned the statutory basis for Part 2 more closely with HIPAA. Among other things, it requires providers to obtain general consent for disclosure of SUD treatment records and allows disclosure of SUD information for treatment, payment, and health care operations. However, providers subject to Part 2 must still obtain consent to disclose information, and

information may be shared only with other Part 2-regulated providers and HIPAA-covered entities and business associates. Moreover, the CARES Act allows recipients of Part 2-protected information to make redisclosures in accordance with HIPAA. Individuals have the right to request a restriction on the use of SUD records for treatment, payment, and health care operations, and covered entities are required to make every reasonable effort to comply with a patient's request.²⁰

Regardless of the provisions of the CARES Act, CEHRT will likely still need to have segmentation capabilities, because an individual can still request restrictions on the use of their SUD treatment records. Moreover, in addition to being subject to HIPAA, certain other sensitive health data (e.g., related to HIV/AIDS, mental health, reproductive health, and domestic violence) may also be subject to state laws mandating heightened protections for disclosure or redisclosure.

Guidance on EHR suitability. Federal EHR adoption incentives spurred a large and active vendor market, especially for office-based practices (Gold 2016). This allowed providers to choose an EHR that was affordable and met their specific clinical needs. However, the large market also has drawbacks. Due to the extensive choice of products available, a provider had to be highly informed to purchase the right EHR for a specific practice. In some cases, the product met requirements at the time of purchase but later turned out to be inadequate for subsequent reporting stages (Gold 2016).²¹

For many behavioral health providers, sharing information electronically will be a major shift in how they operate, and they will need technical assistance (AmeriHealth Caritas 2021, Covered California 2021, NYeC 2021). For example, provider education and technical assistance will be needed both for buy-in and for adopting new practice workflows that integrate technology (AmeriHealth Caritas 2021). Technical assistance is also necessary for addressing the long-standing reluctance of behavioral health providers to share information due to Part 2-related privacy concerns.

Addressing privacy concerns may also have further cost implications. For example, legal counsel could be required to update privacy practice notifications and disclosure and redisclosure consent documentation (OHA 2021).

Additional voluntary standards may also be necessary to instill confidence that the EHR provides a minimum set of functionalities to meet the needs of behavioral health patients and providers. It is unclear if all behavioral health providers need access to the same type of EHR as physical health providers and if they will require additional functionality than currently available from CEHRT. Additional voluntary behavioral health EHR standards above current CEHRT standards may be needed to address Part 2-related segmentation requirements, and these may affect the collection of standardized information about plans of care, encounter notes, and patient-directed goals. Even specialized behavioral health EHRs that are currently in use primarily capture these data elements in ways that are not easily analyzed.

There is precedent for creating a federal voluntary CEHRT standard for different types of providers. For example, ONC facilitated a working group that created voluntary standards for EHR modules for pediatrics. These standards identify the need for CEHRT to compute weight-based drug dosages, synchronize immunization histories with registries, and segment access to information (ONC 2020b). ONC has also advised that the CEHRT used in pediatric settings must be able to tag certain sensitive information (e.g., pertaining to sexual health, mental health, and social history) and limit electronic access to such information (ONC 2020b).

Next Steps

There are a number of ways federal Medicaid policy could be used to support EHR adoption among behavioral health providers. In future work, the Commission will examine potential solutions to address low rates of CEHRT adoption among behavioral health providers, including the following:

Strengthening behavioral health EHR adoption through new health IT incentives. Given low rates of data sharing and CEHRT adoption among behavioral health providers, the Commission is interested in exploring whether new legislation targeting providers that were ineligible for incentive payments under the HITECH Act is necessary and how such support could be structured. The HITECH Act was instrumental in increasing the adoption of EHRs among acute care hospitals and other providers and could serve as a model for new legislation (Adler-Milstein et al. 2017, Henry et al. 2016).²² However, making CEHRT incentive payments to behavioral health providers would be costly. The Congressional Budget Office estimates that an EHR incentive program that targets behavioral health providers would cost \$5 billion to \$10 billion over a 10-year period. With this in mind, the Commission will also explore targeted and less expensive interventions to assist behavioral health providers' participation in an HIE or to offer guidance on EHR suitability.

Enhanced health IT federal financial participation (FFP). The Commission is interested in understanding whether the enhanced federal administrative match of up to 90 percent under Medicaid Information Technology Architecture 3.0 could be used to support state efforts to integrate clinical care and enable and encourage data sharing. Under current law, state agencies can access enhanced FFP to make state health IT infrastructure improvements under Sections 1903(3)(A) and (B) of the Social Security Act (the Act).²³ We plan to examine closely whether states are accessing enhanced match to promote data sharing among behavioral health providers, physical health providers, and patients. The Commission will also examine how health IT administrative funding can be used to strengthen HIEs and to target data-sharing payments to behavioral health providers, similar to what was allowed under the HITECH Act.

Testing different approaches to making behavioral health EHR incentive payments. The Commission is interested in learning more about the role that the Centers for Medicare and Medicaid Innovation

(CMMI) could play in strengthening clinical integration of behavioral health services. The Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment and Communities Act (SUPPORT Act, P.L. 115-271) authorized CMMI to test EHR incentive payments for behavioral health providers that contract with state Medicaid plans under Section 1115A of the Act. However, as of May 2021, CMMI has yet to implement such a demonstration.

Behavioral health IT and Section 1115 demonstrations. Finally, the Commission will explore how Section 1115 demonstrations are addressing clinical integration among behavioral health providers. Section 1115 demonstrations for adults with serious mental illness and children with severe emotional disturbance, as well as for individuals with SUD, require states to submit a health IT plan that describes the state's ability to leverage health IT systems, advance the exchange of health information electronically across organizations, and ensure health IT interoperability.^{24,25} State Medicaid agencies are investing substantial resources in establishing behavioral health treatment systems that are separated from physical health care providers, and the Commission plans on examining whether these demonstrations enable greater integration.²⁶ Although evaluation results are not yet available, in the future they may provide important insight into how state Medicaid agencies are addressing behavioral health IT, including interoperability.

Endnotes

¹ The confidentiality of SUD patient records regulations contained in Part 2 establish patient protections and set the conditions for disclosure of SUD treatment and prevention records for people receiving treatment from federally assisted programs. These regulations were first promulgated in 1975 and implement statutory requirements intended to encourage individuals to seek treatment for SUDs by addressing stigma and concerns that individuals receiving treatment could be subject to negative consequences. Among other things, the statute (42 USC 290dd-2) requires the patient to consent in writing to the disclosure or redisclosure of any identifiable information in connection to their SUD treatment.

² CMS and the Office of the National Coordinator for Health Information Technology (ONC) have established standards and other criteria for structured data that electronic health records (EHRs) must meet in order to qualify for use in the Promoting Interoperability program, formerly known as Meaningful Use or the Medicare and Medicaid EHR Incentive Program. Structured data allow health care providers to retrieve and transfer patient information easily and use the EHR in ways that can aid patient care. EHR technology that meets these requirements is known as certified EHR technology (CEHRT). CEHRT is a specific classification of EHR that has been certified to support certain security and clinical functions such as prescribing, ordering, and receiving laboratory and diagnostic imaging results, and making transition plans for care (ONC 2020a, 2015, 2013). CEHRT gives assurances to purchasers and others that an EHR system or module offers the necessary technological capability, functionality, and security to help meet the meaningful-use criteria outlined within the Promoting Interoperability program. Certification can also give providers and patients confidence that the electronic health information technology (IT) is secure, can maintain data confidentially, and can work with other systems to share information (CMS 2020a, ONC 2020a).

³ This description of the components of clinical integration is not meant to be an all-encompassing clinical integration framework. For example, frameworks codeveloped by the Health Resources and Services Administration (HRSA) and the Substance Abuse and Mental Health Services Administration (SAMHSA) provide a more in-depth and

comprehensive model for how to advance integration within a medical setting (SAMHSA and CIHS 2017).

⁴ Co-occurring physical conditions can include HIV or AIDS, heart conditions, diabetes, chronic bronchitis, cirrhosis of the liver, hepatitis B or C, kidney disease, asthma, cancer, high blood pressure, and sexually transmitted diseases. We should note that “sexually transmitted diseases” is the term used by the National Survey on Drug Use and Health (NSDUH). The clinically appropriate term is “sexually transmitted infections”.

⁵ Prior MACPAC work on individuals with SUD includes the degree to which individuals with SUD experience other behavioral health disorders as well as physical health conditions (MACPAC 2018, 2017). For example, heroin use in particular is associated with other serious health conditions such as HIV, hepatitis C, and hepatitis B. Intravenous drug use can cause bacterial infections of the skin, bloodstream, and heart (MACPAC 2017). Some physical health conditions, including liver disease, pancreatitis, and hypertension, may also be attributable to an individual’s SUD (MACPAC 2018).

⁶ The term “alcohol or drug dependence or abuse” no longer aligns with current practice. However, we use this terminology because it is the language used by the NSDUH.

⁷ Behavioral health providers may be evaluated on a number of Health Care Effectiveness Data and Information Set measures, such as follow-ups after a mental illness hospitalization or emergency department (ED) visit and antidepressant medication management. However, they may also be evaluated on other quality measures, such as non-emergent ED visits or avoidable hospital admissions, reflecting a need for these providers to be involved in care provided by multiple providers.

⁸ The often fragmented delivery of behavioral health services can make it difficult to obtain data needed for core set reporting. For example, to report on the measure of screening for depression and follow-up plan for children age 12–17, data for a single individual may be needed from multiple care settings.

⁹ These surveys do not capture behavioral health services delivered by office-based solo practices.

¹⁰ For example, facilities could report that they use an electronic record system if they track information in a spreadsheet rather than certified EHR technology. However, these results can be interpreted as the upper bound estimate of the rate of basic EHR adoption and interoperability among behavioral health facilities, and may overstate the use of EHRs among surveyed facilities.

¹¹ “Using an electronic system for basic functions” is a composite measure based on how providers answered a series of questions; it looks at whether a facility uses only electronic means—as opposed to a combination or only paper means—for basic clinical functions, such as storing and maintaining health records, assessing a client, creating a treatment plan, or checking for medication interactions. If a facility does not execute a specific clinical function, then it was dropped from the composite measure. For more on how this measure was calculated, please refer to Appendix 4B.

¹² Client information is the term used by SAMHSA in both surveys. The information can include basic patient information, such as type of insurance and demographic information.

¹³ In December 2020, CMS and ONC issued a proposed rule on prior authorization, which included a request for information on how to assist behavioral health providers in leveraging technology to exchange health data and care coordination in a more agile fashion. Most comment letters gathered were in response to this proposed rule, though other comment letters have been used as well.

¹⁴ Additionally, designing and maintaining systems that comply with Part 2 requirements (including incorporating updates such as those made by the 2017 and 2018 Part 2 regulatory changes) can be costly (MACPAC 2018).

¹⁵ Even if a provider adopts CEHRT, there are additional costs associated with sharing data with other providers. These may include getting set up or into an information exchange, fees charged by a state HIE, and legal counsel for interpreting HIE legal agreements.

¹⁶ For context, each HITECH-eligible provider could receive an initial payment of \$21,250 in the first year of adoption, and \$8,500 for each subsequent year for a total of \$63,750 over six years (CMS 2013). Hospitals could be eligible for up to \$6.4 million in their first year, \$4.8 million in their second, \$3.2 million in their third, and \$1.6 million in their fourth year.

¹⁷ When patients are unable or unwilling to authorize Part 2 providers to disclose SUD treatment information, inadequate or even dangerous care, such as prescribing medications with dangerous or deadly interactions, may be the result (SAMHSA 2018, Wakeman and Friedman 2017, APA 2016, MHA 2016).

¹⁸ CEHRT segmentation capabilities enable appropriate controls to share information in accordance with state and federal law (ONC 2015). Data segmentation includes capabilities to tag health care data and allow certain documents, messages, or individual data elements to be marked as sensitive, without restricting access to the entire EHR. This is typically not automated, but it serves as an important technological step to protect patient privacy.

¹⁹ For example, ONC and SAMHSA have developed the Data Segmentation for Privacy (DS4P) standard and the Consent2Share software application to manage patient consent preferences and share Part 2-protected information electronically through EHRs and HIEs. The Health Information Technology Standards Committee advising ONC called into question the maturity of the DS4P standard, suggesting that additional testing and refinements are needed (MACPAC 2018).

²⁰ The CARES Act also requires the Secretary of the U.S. Department of Health and Human Services (HHS) to update federal regulations to align with statutory changes to SUD confidentiality standards. However, there is no timeline associated with this provision. As of April 2021, HHS is still in the rulemaking process, and this provision has yet to be implemented.

²¹ This program is called Promoting Interoperability, though it has gone through many name changes since its inception. Promoting Interoperability is now the umbrella term for most of the EHR incentive payment programs. The Medicaid component of Promoting Interoperability is administered by the states. This name change went into effect in April 2018.

²² Between 2008 and 2015, the share of non-federally owned hospitals that used an EHR system with basic functionalities (e.g., constructing medication lists, keeping physician notes, and viewing lab results) grew from less than 10 percent to over 80 percent (Henry et al. 2016). Almost all eligible hospitals (96 percent) adopted CEHRT by 2015. Certain HITECH-eligible providers lag behind these numbers. These

include office-based physicians, small and rural hospitals, and children's hospitals. However, even among these groups, EHR adoption has significantly increased since the passage of the HITECH Act (ONC 2019). As noted previously, HITECH funding was meant to target funding only to physicians that drive most decisions on care and to hospitals where the largest share of health care dollars is spent, which led to behavioral health providers being ineligible for incentive payments (Stark 2010).

²³ The rules governing this enhanced FFP are outlined under the Medicaid Information Technology Architecture (MITA) framework. States are interested in understanding how the MITA framework can be used to bolster HIE data-sharing capabilities, especially as the enhanced administrative HITECH Act funding comes to a close in October 2021 (WAHCA 2021, CMS 2016).

²⁴ The plan must address electronic care plan sharing, care coordination, and behavioral health and physical health integration. Terms and conditions for Section 1115 SUD demonstrations also require states to describe how the state will centralize information exchange with its prescription drug monitoring program.

²⁵ Interoperable health IT is electronic health information that can be securely exchanged between providers, patients, and insurance companies without any special effort on the part of the user. Any effort to intentionally or unintentionally block the sharing of health data to those authorized for access constitutes information blocking and is subject to financial penalties starting in FY 2021 (CMS 2020c).

²⁶ As of April 2020, 30 states and the District of Columbia have an approved Section 1115 SUD demonstration waiver to provide inpatient and residential SUD treatment in institutions for mental diseases; these also require states to offer a full continuum of facility-based SUD treatment (MACPAC 2020c). A similar demonstration opportunity is available to states to offer a full continuum of mental health care for adults with serious mental illness and children with serious emotional disturbance. However, fewer states have sought this demonstration opportunity. See Chapter 2 for additional information on Section 1115 demonstrations for serious mental illness.

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APPENDIX 4A: Methodology for Quantifying Co-Occurring Conditions

To quantify the rates of co-occurring disorders within the Medicaid population, MACPAC analyzed the 2018 National Survey on Drug Use and Health (NSDUH) to estimate the prevalence of mental illness among non-institutionalized adults age 18–64 and the rates at which they receive treatment, comparing the experience of adults enrolled in Medicaid to those with other sources of coverage. For this analysis, prevalence estimates for mental health conditions are reported in three categories that range in severity: any mental illness, mild to moderate mental illness, and serious mental illness. (See Chapter 2 for more information on the prevalence of mental illness among adult Medicaid beneficiaries.)

TABLE 4A-1. Reported Lifetime Rates of Co-Occurring Conditions among Non-Institutionalized Adults Age 18–64 with Past Year Mental Illness, by Insurance Status, 2018

Condition	Percentage of adults ever having co-occurring condition	Percentage of adults age 18–64 by coverage category		
		Medicaid	Private coverage	Uninsured
Ever had a heart condition				
Any mental illness	8.9%	10.6%	6.7%*	7.2%*
Mild to moderate mental illness	8.3	9.8	6.6*	6.8
Serious mental illness	10.7	12.5	7.3*	8.0
Ever had diabetes				
Any mental illness	8.8	11.5	6.2*	7.8*
Mild to moderate mental illness	9.1	11.9	6.1*	8.0
Serious mental illness	8.2	10.7	6.4	7.3
Ever had chronic bronchitis				
Any mental illness	6.2	9.1	3.8*	5.0*
Mild to moderate mental illness	5.2	7.5	3.5*	4.8
Serious mental illness	9.0	13.0	5.2*	5.6*
Ever had hepatitis B or C				
Any mental illness	1.6	2.2	0.7*	–
Mild to moderate mental illness	1.3	2.4	–	–
Serious mental illness	–	–	–	–
Ever had kidney disease				
Any mental illness	2.0	3.5	1.1*	–
Mild to moderate mental illness	1.8	–	1.0	–
Serious mental illness	2.5	2.8	–	–

TABLE 4A-1. (continued)

Condition	Percentage of adults ever having co-occurring condition	Percentage of adults age 18–64 by coverage category		
		Medicaid	Private coverage	Uninsured
Ever had asthma				
Any mental illness	15.5%	18.6%	15.8%	12.1%*
Mild to moderate mental illness	14.0	15.5	14.6	10.3*
Serious mental illness	19.9	25.9	19.8*	16.7*
Ever had cancer				
Any mental illness	4.4	4.9	3.8	3.3
Mild to moderate mental illness	4.2	4.5	3.9	–
Serious mental illness	5.0	5.9	3.6	–
Ever had high blood pressure				
Any mental illness	17.3	17.5	15.7	11.2*
Mild to moderate mental illness	16.3	15.4	15.0	10.6*
Serious mental illness	20.5	22.4	18.0	12.8*

Notes: Estimates for any mental illness, mild to moderate mental illness, and serious mental illness are based on a statistical model of a clinical diagnosis and responses to questions in the main National Survey on Drug Use and Health (NSDUH) interview on distress, using the Kessler-6 scale; impairment, which is assessed through an abbreviated version of the World Health Organization Disability Assessment Schedule; past year major depressive episode; past year suicidal thoughts; and age. Mental illnesses in this category can vary in severity, ranging from no impairment, to mild or moderate, to severe impairment. Within the 2018 NSDUH survey, a diagnosable mental, behavioral, or emotional disorder is defined based on the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition* and excludes developmental and substance use disorders. Respondents were asked whether they had any of the chronic conditions listed in this table over their lifetime (SAMHSA 2019a).

We used the following hierarchy to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid, other, or uninsured. Coverage source is defined as of the time of the most recent survey interview.

* Difference from Medicaid is statistically significant at the 0.05 level.

– Dash indicates that estimate is based on too small of a sample or is too unstable to present.

Source: SHADAC 2020a.

APPENDIX 4B: Methodology for Quantifying EHR Use among Specialty Behavioral Health Facilities

This appendix provides supplementary information to help readers interpret figures in this chapter.

Data Sources

Using the National Mental Health Services Survey (N-MHSS) and the National Survey of Substance Abuse Treatment Services (N-SSATS), we estimated the extent to which certain behavioral health facilities have adopted electronic health records (EHRs). The N-MHSS collects data from facilities providing specialized mental health services, and the N-SSATS collects data from facilities providing substance use disorder (SUD) treatment. Both surveys are administered annually by the Substance Abuse and Mental Health Services Administration (SAMHSA). Neither captures behavioral health services delivered by office-based solo practices. Because different sets of questions are asked in different years, we used the 2016 and 2018 N-MHSS data years and the 2015 and 2017 N-SSATS data years.

Electronic Record Use

Neither survey asks facilities to answer questions regarding EHRs or certified EHR technology (CEHRT), both of which store patient records in a structured format that allows providers to easily retrieve and transfer patient data. Both surveys include similar questions on whether different clinical functions are accomplished using only electronic or computer means, both electronic and

paper means, or only paper means. We defined electronic record use as use of only electronic or computer means to accomplish clinical functions. Both surveys categorize tools such as EHRs, web portals, and spreadsheet software as electronic records, while e-fax, pdf, or scanned documents are considered paper records. Because using computer or electronic means can also include non-EHR software, we consider the answer to these questions to represent an upper bound on EHR use. Therefore, our analysis of the surveys may overstate use of EHRs among surveyed facilities.

Defining basic use of electronic records

We sought to quantify whether substance use treatment facilities and mental health facilities meaningfully use electronic records for clinical protocols by creating a composite measure to capture routine use of electronic or computer mechanisms for various functions. This composite measure is based on questions about creating treatment plans, monitoring client progress, and receiving lab results. Table 4B-1 displays all the questions related to staff use of electronic resources included in the 2017 N-SSATS and the 2018 N-MHSS, and the questions that were included in our composite measure evaluating electronic resources for basic clinical functions. This is similar to the approach used in other studies assessing meaningful use of EHRs (Jha et al. 2009).

TABLE 4B-1. Questions Used to Define Basic Use of Clinical Records

Do staff members routinely use computer or electronic resources for:	2017 N-SSATS	2018 N-MHSS
Intake	Not used for basic composite	Not used for basic composite
Scheduling appointments	Not used for basic composite	Not used for basic composite
Assessment/evaluation	Basic composite	Basic composite
Treatment plan	Basic composite	Basic composite
Client progress monitoring	Basic composite	Basic composite
Discharge	Basic composite	Basic composite
Referrals	Basic composite	Basic composite
Issue/receive lab results	Basic composite	Basic composite
Outcomes management	Basic composite	NA
Medication prescribing/dispensing	Basic composite	Basic composite
Checking medication interactions	NA	Basic composite
Store and maintain client health and/or treatment records	Basic composite	Basic composite
Send client health and/or treatment records to providers or sources outside your organization ¹	Not used for basic composite	Not used for basic composite
Receive client health and/or treatment records from providers or sources outside your organization ¹	Not used for basic composite	Not used for basic composite
Billing	Not used for basic composite	Not used for basic composite
Client or family satisfaction surveys	NA	Not used for basic composite

Notes: NA means questions were not asked in this survey. Basic composite means we used these questions in our composite measure for evaluating whether a facility only used electronic or computer resources for basic clinical functions, as opposed to both paper and electronic, or paper only. Because questions are slightly different on the N-SSATS and N-MHSS, the basic composite measure is not identical for each survey.

¹ “Sending and receiving client health and/or treatment records” was a new question in the 2017 N-SSATS and 2018 N-MHSS. Previous years used a single question that asked about sharing patient information. Because 2017 and 2018 were the first years where these questions were split, we used the 2015 and 2016 version of the question for possible trending purposes.

Source: SHADAC 2020b.

Chapter 5:

Mandated Report on Non- Emergency Medical Transportation

Mandated Report on Non-Emergency Medical Transportation

Key Points

- Non-emergency medical transportation (NEMT) is a mandatory Medicaid benefit created to help beneficiaries access medically necessary services. NEMT was initially described in regulation as an administrative requirement. Congress clarified that NEMT is a statutorily required benefit in the Consolidated Appropriations Act of 2021 (P.L. 116-260).
- This chapter responds to a U.S. Senate Appropriations Committee request to study the benefits of NEMT for beneficiaries and the benefits of improving coordination of NEMT with other federally assisted transportation services. Our analysis is based on an environmental scan of state policies and stakeholder interviews, beneficiary focus groups, and analysis of administrative data on NEMT use and spending.
- The NEMT benefit includes a broad range of transportation services and is available to all full-benefit beneficiaries. States may manage the benefit directly, contract with a third-party broker, or provide services under Medicaid managed care contracts.
- Federal policy encourages coordination across federally assisted transportation programs. However, in most states, NEMT is not well coordinated with other programs.
- In fiscal year (FY) 2018, there were over 60 million NEMT ride-days (i.e., days in which a beneficiary had at least one NEMT ride). State and federal spending on NEMT was \$2.6 billion (excluding managed care payments to providers).
- Less than 5 percent of beneficiaries used NEMT in FY 2018. For beneficiaries who do use NEMT, it plays a vital role in facilitating access to care. Focus group participants said it is essential to maintaining their health, and in some cases, has been lifesaving.
- The most frequent users of NEMT include beneficiaries who are eligible for Medicaid on the basis of disability or age and those with certain conditions, including end-stage renal disease, intellectual or developmental disabilities, and behavioral health conditions.
- NEMT program performance varies across and within states. For example, beneficiaries report concerns such as late pickups, ill-equipped vehicles, and long call center wait times.
- States and other entities that administer NEMT benefits are working to improve program administration, program integrity, and beneficiary experience. For example, they have introduced new technologies and new NEMT provider types such as Uber and Lyft.
- Changes in health care delivery during the COVID-19 pandemic may reduce the need for NEMT services in certain circumstances. However, the extent to which beneficiary need for NEMT is changing remains unclear.
- As states consider how to address policy goals, such as reducing racial disparities and increasing COVID-19 vaccination rates, they may want to consider the role of NEMT in promoting access to care.

CHAPTER 5: Mandated Report on Non-Emergency Medical Transportation

Federal law requires that state Medicaid programs ensure transportation to and from providers, a benefit known as non-emergency medical transportation (NEMT). The scope of the benefit varies by state, but NEMT generally covers a broad range of transportation services, including trips in taxis, buses, vans, ambulances, public transportation, and personal vehicles belonging to beneficiaries and their families or friends. States differ in how they deliver NEMT services and in how they administer the benefit. Medicaid differs from other payers in its broad coverage of transportation, although the U.S. Department of Veterans Affairs provides such services to certain veterans. Medicare Advantage plans are also increasingly offering transportation to enrollees.

The requirement to provide NEMT, referred to as the assurance of transportation, was established as an enabling service to help beneficiaries access medically necessary services. Unlike other mandatory Medicaid benefits, the NEMT benefit was initially described only in regulation as an administrative requirement. It was not specified in statute until December 2020, when Congress added a requirement for states to provide NEMT to the Social Security Act (the Act) through the Consolidated Appropriations Act of 2021 (P.L. 116-260).

In the years leading up to this action, some federal and state policymakers were reexamining whether the NEMT benefit was necessary for all Medicaid beneficiaries. Some states received approval from the Centers for Medicare & Medicaid Services (CMS) to waive the benefit, through a demonstration authorized under Section 1115 of the Social Security Act (the Act), for the new adult group made eligible under the Patient Protection and Affordable

Care Act (ACA, P.L. 111-148, as amended).¹ Moreover, the Trump Administration considered issuing new regulations that would make the NEMT benefit an optional, rather than mandatory, benefit (OIRA 2019a, 2018).

Congress was largely skeptical of or opposed to these efforts, and on several occasions, considered bipartisan legislation to codify existing NEMT regulations into statute before ultimately doing so with the Consolidated Appropriations Act of 2021 (P.L. 116-260).² In its fiscal year (FY) 2020 report language, the Senate Appropriations Committee directed MACPAC to do the following:

Examine, to the extent data are available, the benefits of NEMT from State Medicaid programs on Medicaid beneficiaries, including beneficiaries with chronic diseases including ESRD, substance abuse disorders, pregnant mothers, and patients living in remote, rural areas, and to examine the benefits of improving local coordination of NEMT with public transportation and other federally assisted transportation services (Committee on Appropriations 2019).

In anticipation of the Trump Administration making regulatory changes to NEMT, Congress also directed the U.S. Department of Health and Human Services (HHS) to take no regulatory action on availability of NEMT until completion of the MACPAC study. Congress's subsequent decision to include the NEMT benefit in statute precluded further administrative action to alter the NEMT benefit through regulation alone, and also changed the context for this required study.

In this report, we examine a number of different analytic questions focused on the populations who use NEMT and which services they access with it; state approaches to administering NEMT

and ensuring adequate quality and oversight; and beneficiaries' experiences using NEMT and the extent to which it helps them overcome barriers to access. In addition to our review of the literature, statutory and regulatory requirements, and state policies, the information presented here comes from three activities: semistructured interviews with state and federal officials and other stakeholders, focus groups with Medicaid beneficiaries who use NEMT, and analyses of administrative data.

Consistent with prior research, we find that although the portion of Medicaid beneficiaries who use NEMT is relatively small, NEMT plays a vital role in enabling access to care for beneficiaries who rely on the benefit. This is particularly true for beneficiaries with chronic conditions such as end-stage renal disease (ESRD), intellectual or developmental disabilities (ID/DD), and behavioral health conditions such as opioid use disorder (OUD) and serious mental illness (SMI), but beneficiaries who do not have chronic or complex medical conditions also rely on NEMT services to receive care.

The extent to which NEMT programs meet the needs of beneficiaries appears to vary widely across and within states. States and other entities that administer NEMT benefits, including Medicaid managed care plans and third-party transportation brokers, are engaged in a number of efforts to improve NEMT program administration, program integrity, and beneficiary experience. These involve introducing new provider types including transportation network companies (TNCs) such as Uber and Lyft, sophisticated processes to ensure beneficiaries are matched with appropriate transportation, more substantive or specialized driver training programs, and integration of new technologies such as global positioning system (GPS) tracking.

These changes in NEMT administration are occurring at the same time that the delivery of health care is changing due to the COVID-19 pandemic. States have dramatically expanded availability of telehealth services, possibly

supplanting the need for NEMT services in certain circumstances (Libersky et al. 2020). The extent to which beneficiary need for NEMT is changing, and for which beneficiaries and medical appointments, remains unclear, and will require additional data than are currently available. NEMT use appears to have rebounded after an initial decline in the first half of 2020, albeit unevenly across states and service destinations. In focus groups, beneficiaries reported returning to many of their regular medical appointments and health services after experiencing gaps in care or replacing in-person care with telehealth earlier in the pandemic. Many states are also promoting NEMT as part of a strategy to encourage and enable beneficiaries to be vaccinated against COVID-19 (AHCCCS 2021, HCA 2021, Hinton et al. 2021, MDH 2021, OHA 2021). These experiences suggest that NEMT is likely to continue to play a central role in helping beneficiaries access care, especially medical care that must be provided in person.

This chapter begins with background information on the origin and evolution of NEMT requirements and an overview of MACPAC's study approach. It goes on to discuss the extent to which Medicaid beneficiaries experience transportation barriers, the characteristics of beneficiaries that use NEMT, and the types of services they are accessing when they do so. The chapter then turns to matters of NEMT administration, including state approaches to delivering NEMT and the challenges they face. It then discusses the extent to which state NEMT programs are meeting the needs of beneficiaries, highlighting various performance issues and quality concerns. The chapter concludes with a discussion of the role of NEMT in Medicaid, including in promoting beneficiary health, and looks ahead to how this might change in the future, particularly as the COVID-19 pandemic comes to an end.

Background

The NEMT benefit provides transportation to and from medical appointments and visits to the pharmacy for Medicaid beneficiaries with no other means of accessing services. MACPAC analysis of data from the Transformed Medicaid Statistical Information System (T-MSIS) revealed that in FY 2018, approximately 3.2 million Medicaid beneficiaries used NEMT. There were over 60 million NEMT ride-days (i.e., days in which a beneficiary had an NEMT ride).^{3,4} State and federal spending on NEMT was \$2.6 billion, or an average of about \$40 per full-year-equivalent (FYE) enrollee.⁵ (Spending figures do not reflect payments to providers for services delivered through Medicaid managed care plans.⁶) See Appendix 5A for an explanation of how these numbers were calculated.

Medicaid programs have provided transportation services since early in the program's history. The provision of transportation is rooted in the notion that to achieve Medicaid's objectives, states must not only provide coverage, but also ensure access to medical appointments and covered services (Rosenbaum et al. 2009).⁷ The obligation to provide transportation is referenced in federal interpretive guidance as early as the 1966 Handbook of Public Assistance (Supplement D).⁸ It was among the administrative requirements established in regulation by the Secretary of HHS in the late 1960s.⁹ Although the requirement was not specifically outlined in statute until December 2020, numerous statutory provisions formed the legal basis for HHS policy and regulations requiring states to provide NEMT. These provisions include requirements for statewideness and comparability, efficient program administration, administration in the best interest of beneficiaries, free choice of provider, and others (Rosenbaum 2009).¹⁰

States must comply with several federal requirements related to NEMT: They must ensure necessary transportation to and from providers, cover transportation and related travel expenses necessary to secure medical examinations or treatment, and describe the methods they use

to meet this requirement in their state plan (42 CFR 431.53, 42 CFR 440.170, CMS 2016a). They must also provide children and their families with transportation assistance as part of Medicaid's early and periodic screening, diagnostic, and treatment (EPSDT) benefit, and provide written and oral methods of effectively informing children and their families that transportation assistance is available (42 CFR 441.62).¹¹

NEMT benefit design and administration

The federal government's role in NEMT administration is fairly limited. CMS's primary role is to review state plan amendments and other materials to ensure that they meet the federal regulatory requirements, respond to state queries, and provide technical assistance.¹² CMS and HHS also conduct oversight of state NEMT programs through routine program integrity mechanisms.

Benefit design varies from state to state but typically includes transportation by taxi, van, ambulance, private vehicle, public transportation, and in some cases, TNCs. As with other mandatory benefits, states retain flexibility to define other coverage parameters, including the breadth of coverage (i.e., amount, duration, and scope), and the tools they use to manage utilization.

Medicaid beneficiaries may use NEMT for any medical appointment or service that is coverable by Medicaid, including trips to the pharmacy.¹³ For individuals dually enrolled in Medicaid and Medicare and in full-benefit Medicaid, NEMT services are generally also covered by Medicaid, even if Medicare serves as the primary payer for the medical service being accessed (MMCO 2021, Engelhardt 2020).¹⁴

In general, beneficiaries are eligible for NEMT services as long as transportation is necessary and they do not have another means of transportation. States vary in how they define who has no other means of transportation. For example, beneficiaries with no other means of transportation may not have

a car or driver's license, or may have physical or intellectual limitations or disabilities that limit their ability to provide or arrange their own transportation (CMS 2016a, 2016b).¹⁵ Most states require that beneficiaries attest that they need the ride for covered medical services and have no other way to get to their appointment. Others require a health care provider to document that the beneficiary needs NEMT, although this approach is less common.¹⁶

States may limit services based on medical necessity or utilization control (42 CFR 440.230(d)). They commonly require prior authorization either for all rides or under certain conditions (e.g., trips over a certain mileage threshold). Some states limit trip mileage or number of trips. States may also impose nominal copayments (MACPAC 2017).

States can also choose how to deliver NEMT. They may manage the benefit directly and pay for rides on a fee-for-service (FFS) basis (i.e., an in-house approach), contract with a transportation broker to manage and deliver benefits (i.e., a brokerage model), or use Medicaid managed care plans to manage and deliver NEMT along with other Medicaid benefits (i.e., a managed care carve-in model). These delivery models are discussed in detail later in the chapter.

States can claim federal Medicaid matching payments for NEMT as either an administrative or medical assistance expense, and must specify their choice in the Medicaid state plan (42 CFR 440.170). States reporting NEMT spending as an administrative expense receive payment at the federal medical assistance percentage (FMAP) for administrative expenses, which is 50 percent.¹⁷ States claiming NEMT as a medical assistance expense receive payment at their regular FMAP, which ranges from 50 percent to 77.76 percent for FY 2021, depending on the state, or the appropriate FMAP for certain populations or circumstances (MACPAC 2020a).¹⁸ If states choose to report NEMT spending as medical assistance, they are subject to additional statutory requirements, including the requirements for comparability, statewideness, and giving Medicaid beneficiaries free choice among

any qualified Medicaid provider willing to provide the service (CMS 2008).

States contracting with a broker to provide NEMT are not subject to the statutory requirements related to claiming NEMT as a medical assistance expense (CMS 2008).¹⁹ However, brokerage arrangements must meet certain requirements, including that the state must use a competitive procurement process to select each broker and perform regular auditing and oversight, and that the contract must ensure drivers are licensed, qualified, and competent (CMS 2006).²⁰

Past efforts to exclude NEMT from benefit packages

State and federal policymakers have sought to limit or exclude NEMT services in some circumstances. They have argued, for example, that other payers do not provide NEMT, and that limiting or excluding NEMT would better align Medicaid benefit packages with those offered by commercial health plans.

The Trump Administration proposed making NEMT an optional benefit in its annual budgets beginning in FY 2019 (HHS 2020, 2019, 2018). In fall 2018, CMS announced plans to issue a proposed rule by May 2019 that would provide states with greater flexibility in NEMT benefits, although it later delayed this plan until 2021 (OIRA 2019b, 2018). However, in December 2019, CMS shifted these plans, and noted its intention to issue a request for information (RFI) seeking input on “whether the Assurance of Transportation in the Medicaid program remains administratively necessary given the delivery of healthcare both in terms of technological advances and the commercial market design” (OIRA 2019a). CMS also indicated that it would “request stakeholder comment regarding the merits of the transportation assurance on selected populations and services.” For example, CMS noted that commenters might suggest maintaining the assurance for certain groups, including individuals who are pregnant, medically frail, or eligible for EPSDT (OIRA 2019a). However, the administration

ultimately did not issue the RFI or publicly share any input submitted informally.

States have at times been permitted to exclude NEMT for certain enrollees. For example, several states received Section 1115 demonstration authority to exclude NEMT for certain low-income adults eligible for Medicaid on a basis other than disability.^{21, 22} These include:

- Indiana’s Healthy Indiana Plan 2.0 demonstration excludes NEMT for the new adult group, except for those determined to be medically frail (CMS 2020a).²³ Even so, all four of the state’s Medicaid managed care plans are currently providing transportation to members as a value-added service (Long et al. 2020).
- Originally approved in 2013, and now authorized through 2024, the Iowa Wellness Plan demonstration excludes NEMT for the new adult group, except for those who have been determined medically frail or are eligible for EPSDT services (i.e., beneficiaries age 19 and 20) (CMS 2019a).
- The Georgia Pathways to Coverage demonstration, approved in October 2020 and scheduled for implementation as early as July 2021, will extend coverage to individuals with income up to 95 percent of the federal poverty level (FPL) who are not otherwise eligible for Medicaid. These individuals will not receive NEMT unless eligible for EPSDT services (CMS 2020b).
- The Kentucky Helping to Engage and Achieve Long-Term Health demonstration, originally approved in 2018 and currently authorized through 2023, allows the state to exclude NEMT for transportation to methadone treatment services for all beneficiaries except pregnant women, former foster care youth, and beneficiaries eligible for EPSDT services (CMS 2020c). A previous iteration of the demonstration also allowed the state to exclude NEMT for all services for members

of the new adult group, but this waiver was withdrawn by the state.²⁴

- Under its Primary Care Network demonstration, Utah excludes NEMT for parent and caretaker relatives unless they are eligible for EPSDT services (CMS 2019b).

Because the special terms and conditions for these demonstrations specifically waive Section 1902(a)(4) of the Act (insofar as it incorporates 42 CFR 431.53), the statutory change requiring NEMT will not automatically affect states with approved waivers (CMS 2020a, 2020b, 2020c, 2019a, 2019b). However, CMS recently notified Indiana, Georgia, and Utah (along with other states) that certain elements of their demonstrations (i.e., work and community engagement requirements) are being withdrawn, and that other elements of their demonstrations (which include waivers of NEMT) are under review.²⁵ As such, it is unclear which elements of these waivers will continue, or whether the Biden Administration will approve renewals or grant new waivers of NEMT.

In 2008, the Bush Administration changed federal rules to allow states to exclude NEMT for certain beneficiaries enrolled in benchmark or benchmark-equivalent benefit packages.²⁶ At least three states received state plan approval for benchmark plans that excluded NEMT. However, this rule was rescinded by the Obama Administration and replaced with a new policy requiring NEMT in benchmark plans (CMS 2010, Rosenbaum et al. 2009).

The effects of policies that exclude NEMT for certain Medicaid enrollees have not been systematically studied.²⁷ However, that may change as more states conduct evaluations of their Section 1115 demonstrations under new CMS evaluation guidance and practices implemented in 2017.²⁸

Study Approach

The information in this chapter primarily derives from three study components, which are described below.

Environmental scan of state NEMT policies and semistructured stakeholder interviews. Together with our contractor, Health Management Associates (HMA), MACPAC conducted an environmental scan of NEMT policies for all 50 states and the District of Columbia.²⁹ We selected six states for further study: Arizona, Connecticut, Georgia, Indiana, Massachusetts, and Texas.³⁰ We conducted 21 interviews with 51 individuals, including Medicaid officials, federal officials from CMS and the Federal Transit Administration (FTA), NEMT providers, transportation brokers, health plans, beneficiary advocates, public transportation representatives, and other subject matter experts.

Beneficiary focus groups. MACPAC contracted with PerryUndem to hold eight virtual beneficiary focus groups across the six study states to hear from beneficiaries about how they use NEMT, transportation barriers, and their experiences using the benefit. The sessions were held in October and November 2020.³¹

Analysis of administrative data on NEMT use and spending. To examine NEMT use and spending, MACPAC analyzed FY 2018 T-MSIS data to provide a national picture of NEMT use. Due to state-level variation in billing policies, we counted the number of days when a beneficiary used the NEMT benefit to quantify utilization (referred to as ride-days). The true number of NEMT door-to-door trips is likely higher than our estimate, which should therefore be interpreted as a floor. For example, beneficiaries might require a round trip to a physician office, or trips to multiple specialists in a day. Some states may report a round trip or multileg trip as one ride, with others reporting the same type of trip as two or more rides.³² Moreover, although utilization data reflect utilization by all beneficiaries, spending figures exclude managed care payments to

providers. For a more complete explanation of our methods and limitations, please refer to Appendix 5A.

Transportation as an Access Enabler

Medicaid beneficiaries face many barriers to access, including difficulty arranging transportation to medical appointments. Transportation-related barriers may occur because beneficiaries face a variety of obstacles, for example:

- lack of a car or a driver's license;
- inability to drive or use public transportation because of their medical conditions (e.g., impaired vision, a weakened immune system, or mobility issues);
- need for a specialty vehicle, such as a wheelchair van;
- inability to afford the cost of transportation;
- residence in areas where public transportation is either unavailable or difficult to access; or
- difficulty finding rides to appointments (especially if asking friends or family members would cause them to miss work or school or require them to arrange child care).

Without transportation services, focus group participants said they would have no other way to get to their medical appointments. Many reported that they often missed or could not schedule appointments before they began using NEMT. This is consistent with the findings of other studies.³³

Among the Medicaid population more broadly, 2.5 million beneficiaries (5.2 percent) reported delaying care due to transportation in 2018 (Table 5-1).³⁴ Of those, 60 percent were adults age 19–64, and 39 percent were children age 0–18.³⁵ Almost all (98 percent) adults who delayed care had either basic action difficulty or complex activity limitations.³⁶

Moreover, about three-quarters had been diagnosed with conditions such as hypertension, diabetes, and weak or failing kidneys.³⁷ Among children who delayed care due to transportation barriers, just over half had been diagnosed with selected conditions such as asthma, autism, or intellectual disability.³⁸ Nearly all had a special health care need requiring ongoing care.³⁹

The share of Medicaid beneficiaries reporting that they delayed care due to transportation varies by race and ethnicity, as well as income and health status (Table 5-1). Specifically:

- Black, non-Hispanic Medicaid beneficiaries were significantly more likely to report delaying care due to transportation than white, non-Hispanic beneficiaries. Hispanic beneficiaries were significantly less likely to report delaying care due to transportation than white, non-Hispanic beneficiaries.
- Beneficiaries with incomes less than 138 percent FPL were significantly more likely to report delaying care due to transportation than those with higher incomes.
- Adults receiving Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) were significantly more likely to report delaying care due to transportation than those not receiving these benefits.
- Adults diagnosed with one or more specific conditions (e.g., hypertension, coronary heart disease, cancer, weak or failing kidneys) were significantly more likely to report delaying care due to transportation than beneficiaries who do not have such conditions.⁴⁰
- Children diagnosed with one or more specific conditions (e.g., asthma, autism, intellectual disability) were significantly more likely to report delaying care due to transportation than other children.⁴¹
- Children with special health care needs were significantly more likely to report delaying care due to transportation than those without a special health care need.

TABLE 5-1. Rates of Reported Transportation Barriers among Medicaid Beneficiaries, 2018

Beneficiary characteristic	Number of beneficiaries	Beneficiaries who delayed care	Share of beneficiaries who delayed care
Total	47,182,736	2,468,600	5.2%
Gender			
Male	21,334,525	1,141,444	5.4
Female	25,848,211	1,327,156	5.1
Age			
0–18	26,586,509	956,511	3.6
19–64	20,146,091	1,491,327	7.4
65 and older	*	*	*
Race and ethnicity			
Hispanic	15,735,267	464,435	3.0
White, non-Hispanic	17,749,513	862,869	4.9
Black, non-Hispanic	10,082,599	917,045	9.1
Other non-white, non-Hispanic	3,615,357	224,251	6.2
Income			
Has income less than or equal to 138 percent FPL	27,941,796	1,913,654	6.8%
Has income greater than 138 percent FPL	19,240,940	554,946	2.9
Limitations			
Children			
Special needs, impairments, or health conditions ¹			
Yes	7,176,289	443,391	6.2
No	19,410,220	513,120	2.6
Ever been told they have selected conditions ²			
Yes	6,969,393	495,311	7.1
No	19,617,116	461,200	2.4
Adults			
Has either basic action difficulty or complex activity limitation ³			
Yes	19,957,553	1,484,051	7.4
No	*	*	*
Currently pregnant ⁴			
Yes	*	*	*
No	8,173,801	531,340	6.5

TABLE 5-1. (continued)

Beneficiary characteristic	Number of beneficiaries	Beneficiaries who delayed care	Share of beneficiaries who delayed care
Ever been told they have selected conditions ⁵			
Yes	10,389,672	371,052	3.6
No	10,206,555	1,141,037	11.2
Has SSI or SSDI			
Children			
Yes	*	*	*
No	25,712,346	893,809	3.5
Adults			
Yes	2,922,442	485,526	16.6
No	17,617,164	1,026,563	5.8

Notes: FPL is federal poverty level. SSI is Supplemental Security Income. SSDI is Social Security Disability Insurance. The following hierarchy was used to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or CHIP, other, uninsured. As a result, individuals dually enrolled in Medicaid and Medicare and those who are covered by private insurance and Medicaid or CHIP are not captured in these figures.

* Estimate is unreliable because it is based on a small sample or has a relative standard error greater than or equal to 30 percent.

¹ To be considered to have a special health care need, a child must have at least one diagnosed or parent-reported condition expected to be an ongoing health condition and also must meet at least one of five criteria related to elevated service use or elevated need, including reported unmet need for care. For more information on the methods used to identify children with special health care needs, see the Technical Guide to MACStats, in *MACStats: Medicaid and CHIP Data Book* (MACPAC 2020b).

² The list of conditions includes: attention deficit hyperactivity disorder or attention deficit disorder, asthma, autism, cerebral palsy, congenital heart disease, diabetes, down syndrome, intellectual disability, and other developmental delay.

³ The definition of basic action difficulty includes limitations in movement and sensory, emotional, or mental functioning that are associated with some health problem. Adults are defined as having a complex activity limitation if they have one or more of the following types of limitations: self-care limitation, social limitation, or work limitation.

⁴ Information is limited to individuals age 19–44.

⁵ The list of conditions includes: hypertension, coronary heart disease, heart attack, stroke, cancer, diabetes, arthritis, asthma, chronic bronchitis in the past 12 months, liver condition in the past 12 months, and weak or failing kidneys in the past 12 months.

Source: MACPAC, 2021, analysis of 2018 National Health Interview Survey.

Characteristics of Beneficiaries Using NEMT

As noted above, Medicaid beneficiaries are generally eligible for NEMT as long as the transportation is necessary and the beneficiary does not have another means of transportation. We examined national administrative data and interviewed stakeholders to try to learn more about

the characteristics of beneficiaries who frequently use NEMT. Generally, we found that Medicaid beneficiaries eligible on the basis of disability and age and those who have conditions that require frequent medical appointments use NEMT most often, although no particular condition or service drove use. Information on utilization by eligibility group, geographic location, and diagnoses are presented below.

Use by eligibility group and geographic location

As noted above, 3.2 million beneficiaries (4.8 percent) used NEMT in FY 2018, averaging 19 ride-days

during the year. This concentration of rides among a small percentage of users was present across various eligibility groups and people living in urban and rural areas (Table 5-2).

TABLE 5-2. NEMT Use by Selected Beneficiary Characteristics, FY 2018

Characteristic	Total number of ride-days	Total number of NEMT users	NEMT users as a percentage of FYE	Ride-days per FYE	Ride-days per NEMT user
Overall	61,500,628	3,233,313	4.8%	0.9	19.0
Basis of eligibility					
Children	3,426,029	473,419	1.6	0.1	7.2
Aged	14,642,824	713,242	13.5	2.8	20.5
Disabled	31,889,094	1,308,047	15.3	3.7	24.4
Pregnant women ¹	234,774	25,732	3.0	0.3	9.1
New adult group ²	7,213,327	433,446	3.0	0.5	16.6
Other adults ³	4,094,580	279,428	3.1	0.5	14.7
Dually eligible status					
Dually eligible ⁴	29,887,916	1,240,528	14.9	3.6	24.1
Medicaid only	31,612,712	1,992,785	3.4	0.5	15.9
Urban or rural					
Urban	51,143,758	2,577,265	4.7	0.9	19.8
Rural	10,252,554	649,847	5.6	0.9	15.8

Notes: NEMT is non-emergency medical transportation. FY is fiscal year. FYE is full-year equivalent. NEMT users are displayed as FYEs. Ride-days are defined as days with an NEMT procedure code (i.e., when any full-benefit Medicaid beneficiary had an NEMT ride). Ambulances are not included in our Transformed Medicaid Statistical Information System (T-MSIS) definition of NEMT. Some rides could not be classified as urban or rural based on the beneficiary's ZIP code, and therefore urban and rural ride-days do not sum to the overall ride-days total. Children and adults under age 65 who qualify for Medicaid on the basis of disability are included in the disabled category. Individuals age 65 and older eligible through an aged, blind, or disabled pathway are included in the aged category.

¹ MACPAC uses the term pregnant women because this is the term used in the statute and regulations. However, the term birthing people is being used increasingly, because it is more inclusive and recognizes that not all individuals who become pregnant and give birth identify as women.

² Includes both newly eligible and not newly eligible adults who are eligible under Section 1902(a)(10)(A)(i)(VIII) of the Social Security Act (the Act). Newly eligible adults include those who were not eligible for Medicaid under the rules that a state had in place on December 1, 2009. Not newly eligible adults include those who would have previously been eligible for Medicaid under the rules that a state had in place on December 1, 2009; this includes states that had already expanded to adults with incomes greater than 100 percent of the federal poverty level as of March 23, 2010, and receive the expansion state transitional matching rate.

³ Includes adults under age 65 who qualify through a pathway other than disability or Section 1902(a)(10)(A)(i)(VIII) of the Act (e.g., parents and caretakers).

⁴ Dually eligible individuals are defined as individuals who are dually eligible for Medicaid and Medicare. Includes only individuals eligible for full Medicaid benefits.

Source: MACPAC, 2021, analysis of T-MSIS.

NEMT use by eligibility group. Of the 3.2 million NEMT users in FY 2018, approximately two-thirds were eligible on the basis of age or disability. Those eligible on the basis of disability used NEMT services most frequently, averaging 3.7 ride-days per FYE in FY 2018, followed by beneficiaries age 65 or older, who averaged 2.8 ride-days. Children and pregnant women used NEMT services the least frequently, averaging 0.1 and 0.3 ride-days per FYE, respectively.⁴² Members of the new adult group used NEMT with similar frequency as other adults.

NEMT service use was concentrated among a subset of beneficiaries within each eligibility group. For example, members of the new adult group had an average of 0.5 ride-days per FYE; however, the average number of ride-days rose to 16.6 among those who actually used NEMT.

NEMT use by dually eligible status. Beneficiaries dually eligible for Medicare and Medicaid used NEMT with greater frequency than those only enrolled in Medicaid. Of the 3.2 million NEMT users in FY 2018, over one-third were dually eligible.⁴³ Dually eligible beneficiaries averaged 3.6 ride-days per FYE, compared to 0.5 for beneficiaries for the Medicaid-only population. This gap narrowed among beneficiaries who actually used NEMT in FY 2018: dually eligible beneficiaries averaged 24.1 ride-days, compared to 15.9 for Medicaid-only beneficiaries.

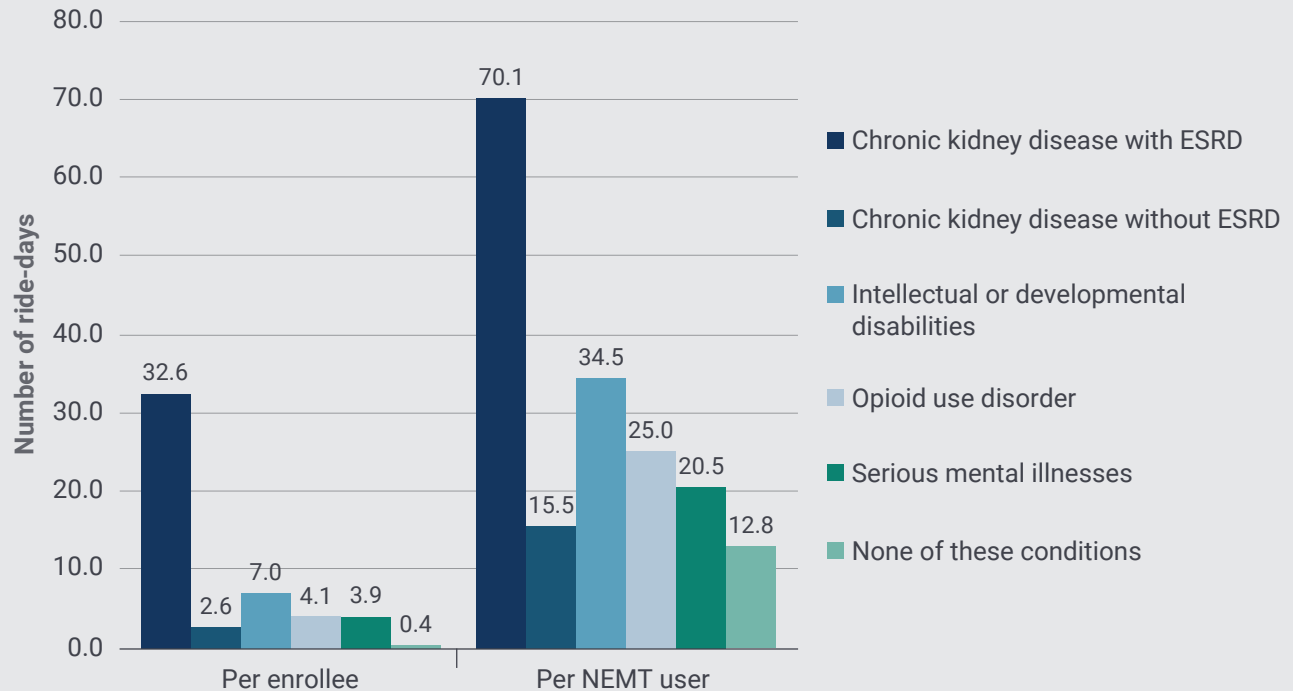
NEMT use by geographic area. Beneficiaries living in urban areas used NEMT at a similar rate to those living in rural areas, both averaging approximately 0.9 ride-days per FYE. Among beneficiaries who used NEMT, however, those living in urban areas did so with greater frequency than those living in rural areas, averaging 19.8 ride-days compared to 15.8. This may be due in part to more limited NEMT access in rural areas. For example, stakeholder interviews revealed that the NEMT provider network is usually more robust in urban areas than rural ones, and that it can be challenging to address provider shortages in rural areas (discussed further below).

Health conditions of NEMT users

Many focus group participants reported using NEMT due to health conditions that require many medical appointments, or because a major injury resulted in physical limitations or disability that requires frequent specialty care and physical therapy. Others need to travel long distances to see a specific doctor or specialist. Others lack alternative sources of transportation.

To describe the health conditions of beneficiaries using NEMT, we examined NEMT use among beneficiaries with specific diagnoses, including some mentioned in the Senate Appropriations Committee request. We were able to do so for beneficiaries with the following recorded diagnoses: chronic kidney disease (both with and without ESRD), OUD, SMI, and ID/DD (Figure 5-1).⁴⁴ We also examined NEMT use by transportation destination to get a sense of the types of appointments for which beneficiaries were using NEMT.

FIGURE 5-1. NEMT Ride-Days per Enrollee and by Selected Diagnoses, FY 2018



Notes: NEMT is non-emergency medical transportation. FY is fiscal year. ESRD is end-stage renal disease. Ride-days are defined as days with an NEMT procedure code (i.e., when any full-benefit Medicaid beneficiary had an NEMT ride). Diagnoses are defined based on a combination of billing codes, such as International Classification of Diseases versions 9 and 10, National Drug Codes, and the Healthcare Common Procedure Coding System (HCPCS). The algorithm for opioid use disorder (OUD) does not include methadone treatment, affecting MACPAC’s ability to identify rides to opioid treatment programs among beneficiaries with OUD. As a result, our estimates for NEMT utilization by diagnoses are likely undercounting beneficiaries with OUD.

Source: MACPAC, 2021, analysis of Transformed Medicaid Statistical Information System (T-MSIS).

NEMT use among beneficiaries with specific diagnoses. Of the diagnostic categories listed above, beneficiaries with chronic kidney disease with ESRD used NEMT with the greatest frequency, averaging 32.6 ride-days in FY 2018, compared to an average of 0.4 days among beneficiaries without any of the selected conditions. Among those who used NEMT, beneficiaries with ESRD averaged 70.1 ride-days, compared to 12.8 days for beneficiaries with none of the selected conditions. The frequency with which beneficiaries with ESRD use NEMT likely reflects their frequent need for dialysis treatment, which may be as often as six days per week. However, the fact that the average number of rides

per user translates to just over 1.3 rides per week indicates that many beneficiaries with ESRD may have access to other sources of transportation, or may be using home dialysis while using NEMT for other appointments.

Beneficiaries with ID/DD, OUD, and SMI also used NEMT more frequently than those without any of the conditions. This is consistent not only with findings from stakeholder interviews, but also other studies. For example, one 2016 study using data from the largest NEMT broker found that the greatest proportion of NEMT trips are for behavioral health services (Musumeci and Rudowitz 2016).

NEMT use by beneficiaries without chronic conditions or other serious health issues. Although beneficiaries with certain diagnoses used NEMT with greater frequency than others, NEMT is still an important service for beneficiaries without those or other chronic health conditions. NEMT users with none of the selected diagnoses had an average of 12.8 ride-days in FY 2018, or more than once per month. Some of these individuals likely have other conditions not analyzed as part of this study (e.g., diabetes, cancer, or hypertension). Even so, focus group participants without serious conditions stressed the importance of their NEMT benefits, typically because they lacked another form of transportation to necessary medical appointments.

NEMT use by race and ethnicity. T-MSIS data currently cannot be used to study NEMT use by race and ethnicity and we could not identify any studies that examine NEMT's role in access to care for beneficiaries of different races and ethnicities. However, racial and ethnic disparities in the conditions present among frequent NEMT users are well documented, including disparities in disease prevalence, access to care, quality of care, and outcomes (Golestaneh et al. 2020, Stein et al. 2018, Norton et al. 2016, SAMHSA 2015, Cummings et al. 2014, Scott and Havercamp 2014, Hall 2012, McGuire and Miranda 2008). More data and research are needed to understand whether there are racial and ethnic disparities in access to and use of NEMT.

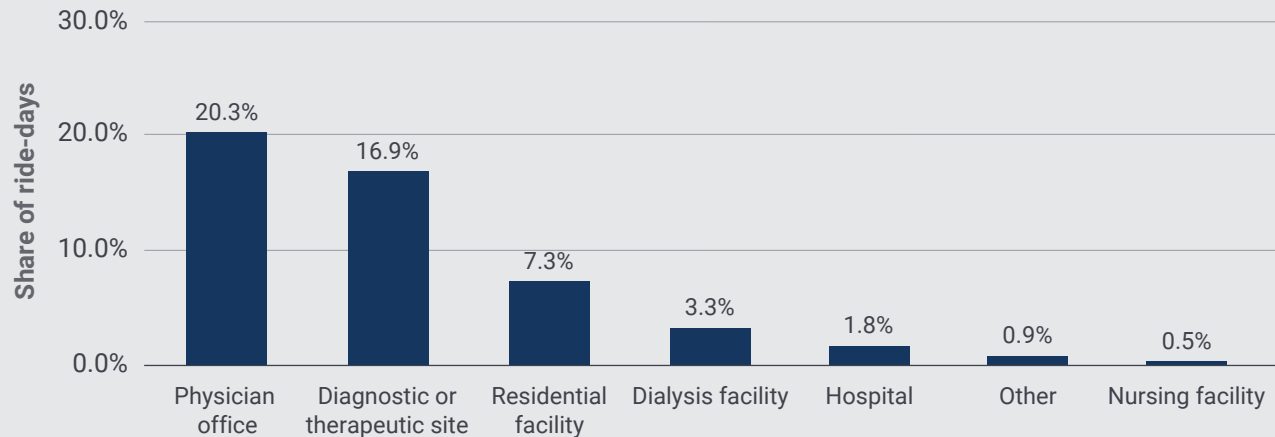
Beneficiaries who do not use NEMT

The relatively small number of NEMT users within the larger Medicaid population, combined with the relatively small proportion of Medicaid beneficiaries reporting that they delayed care due to transportation, indicates that most Medicaid beneficiaries have access to transportation and do not experience transportation barriers. However, limited use may also reflect low awareness of the benefit, especially among beneficiaries who do not have a health condition that requires frequent medical care.

Medical Services Accessed Using NEMT

Beneficiaries may use NEMT to travel to almost any medical appointment or service, including the pharmacy. To describe the types of services accessed using NEMT, we examined use by service destination for the six states where at least 95 percent of the NEMT ride-days had known or non-missing destinations.⁴⁵ We classified destinations into eight categories: the beneficiary's residence, physician office, diagnostic or therapeutic site, residential facility (defined as a non-skilled nursing facility, domiciliary, or custodial facility), dialysis facility, hospital, nursing facility, or other.⁴⁶

For these states in FY 2018, physician office and diagnosis or therapeutic site were the most common destinations, accounting for 20.3 and 16.9 percent of all ride-days, respectively (Figure 5-2). The beneficiary's residence (i.e., a return trip home) was identified as a destination in 41 percent of ride-days.

FIGURE 5-2. Share of NEMT Ride-Days by Service Destination in Selected States, FY 2018


Notes: NEMT is non-emergency medical transportation. FY is fiscal year. Ride-days are defined as days with an NEMT procedure code (i.e., when any full-benefit Medicaid beneficiary had an NEMT ride). Destinations were defined using Healthcare Common Procedure Coding System (HCPCS) modifiers. Percentages show the share of ride-days on which each destination type was specified. Multiple destinations may be specified for the same ride-day, and therefore percentages do not sum to one hundred. Only the six states with over 95 percent of identifiable destinations are included in the sample. The destination category of other may include sites of an NEMT transfer, the scene of an accident or other acute event, or an intermediate stop at a physician office on the way to a hospital. NEMT can be used as a trip to the pharmacy, but HCPCS origin and destination codes do not separately identify pharmacy as a destination. As a result, pharmacy trips are likely included in one of these other categories.

Source: MACPAC, 2021, analysis of Transformed Medicaid Statistical Information System (T-MSIS).

Focus group participants shared more specific information about why they use NEMT and the services they access through NEMT. Examples include the following:

- A Georgia woman with quadriplegia uses NEMT to go to a spinal care center three days a week.
- A Massachusetts man with substance use disorder (SUD) uses NEMT to go to a methadone clinic seven days a week.
- A Connecticut woman relies on NEMT to participate in a sleep study that requires transportation outside of usual business or public transportation hours.
- An Arizona mother of a child with autism uses NEMT regularly to take her daughter to

see developmental specialists. Her daughter also participates in a respite and living skills program that arranges transportation funded by Medicaid.

NEMT Delivery Models

States typically deliver NEMT using one or more of the following delivery models:

- In-house management—states manage NEMT directly and pay for rides on a FFS basis.
- Broker model—states contract with a third-party transportation broker to manage all or some aspects of NEMT, paying on a capitated or FFS (e.g., trip cost plus administrative fee) basis.⁴⁷

- Medicaid managed care—NEMT is frequently covered under managed care contracts. Managed care plans deliver NEMT along with other Medicaid benefits. Plans may administer the benefit directly or contract with a broker.⁴⁸

Of the 61.5 million ride-days in FY 2018, approximately one-third (23 million) were paid for on an FFS basis, and the remaining two-thirds were paid for under capitated arrangements (i.e., a capitated third-party broker arrangement or managed care plan).⁴⁹

States may use different models for different populations or geographic areas. For example, in Indiana, managed care enrollees receive NEMT through their regular managed care plan; the state contracts with a broker to deliver NEMT to the remaining Medicaid beneficiaries in FFS.

Based on our environmental scan, 35 states use a broker for certain populations or geographic areas and 26 use managed care for some populations and areas. At least a dozen states, including Arizona and Texas, manage the NEMT benefit directly for some beneficiaries, but just five states do so for all beneficiaries. Use of managed care for NEMT is growing; in 2015, just four states used this approach (either alone or in combination with another approach) (Ganuza and Davis 2017).

Interviewees described several advantages and drawbacks of each model:

- In-house management—managing NEMT directly allows states more control over policies and operations, and may enable greater coordination with other state and local transportation programs. However, it generally presents a greater administrative burden for the state and may be more vulnerable to program integrity concerns than other models. This approach also offers less flexibility to innovate, for example, implementing pay-for-performance incentives.
- Broker model—using a broker provides more budget predictability and typically decreases

state administrative burden, particularly under a capitated arrangement.⁵⁰ According to interviewees, brokers typically have more expertise and capacity than state agency staff to monitor fraud or misuse, communicate regularly with beneficiaries, and explore and implement innovations such as driver performance incentives or new technologies.⁵¹ On the other hand, some interviewees said that brokers may have a financial disincentive to authorize trips or override limits on rides under a capitated contract, even when beneficial for beneficiary health.

- Managed care carve-in model—carving NEMT into managed care is typically less administratively burdensome and provides more budget predictability than an in-house approach. It also allows integration of NEMT with other services managed by the plan, potentially enhancing care coordination. Plans have an incentive to ensure enrollees get preventive and other necessary care to avoid more expensive care later. As a result, they may override state limits or provide transportation for additional services (i.e., as value-added services) when trips are determined to add value and promote beneficiary health. They may also be more likely to solicit and respond to beneficiary input. However, some interviewees noted that managed care carve-in models can result in administrative inefficiencies and fragmentation, because different managed care plans in a state may individually subcontract with multiple brokers.

State officials reported that choices about which delivery model to adopt or whether to change approaches are influenced by a variety of factors, including the state's available financial and staff resources, its broader Medicaid delivery system, and other state-specific factors. For example:

- In Arizona, NEMT has been carved into the managed care contracts since the state adopted managed care in the early 1980s.

- Connecticut reported switching from an FFS approach to a capitated broker arrangement to provide more flexibility for the broker to implement pay-for-performance initiatives.
- Georgia adopted a broker model in part to reduce state administrative burden.
- Indiana reported moving from an in-house model to a statewide broker model for its Medicaid FFS population in 2018, in part to ensure proper oversight and reduce fraud, waste, and abuse.
- Massachusetts plans to reduce the number of regional NEMT brokers from six to no more than three in 2021. State officials observed that many beneficiaries travel to Boston for medical visits, passing through regions managed by different brokers on the way. They determined that it would be more efficient to reduce the number of brokers and increase the geographic area for each broker.
- Texas will transition from a regional broker model to a managed care carve-in model in 2021 to integrate the delivery of NEMT into the managed care delivery system used for other services.

There was no consensus among interviewees as to which NEMT delivery model is best or most likely to lead to improved beneficiary satisfaction, efficiency, or value. Some interviewees noted that the quality of a state's NEMT program depends on factors other than the model, including the strength of the broker or managed care contracts, the quality of oversight, and the extent to which the entity responsible for managing the NEMT program solicits and incorporates stakeholder feedback (see below).

NEMT Services and Providers

States are required to use the most appropriate form of transportation for the beneficiary, and this can include trips in taxis, buses, vans, and personal vehicles belonging to beneficiaries and their

families or friends (42 CFR 431.53, 42 CFR 440.170, CMS 2016b). In recent years, states have also begun to use TNCs such as Uber and Lyft. Public transportation is also used for NEMT, although its role varies considerably across, and even within, states when public transportation is not available in all areas. Air travel is used for NEMT only in limited circumstances (e.g., for people living in areas not accessible by road or for people in need of specialty treatments that are not available in their geographic area).

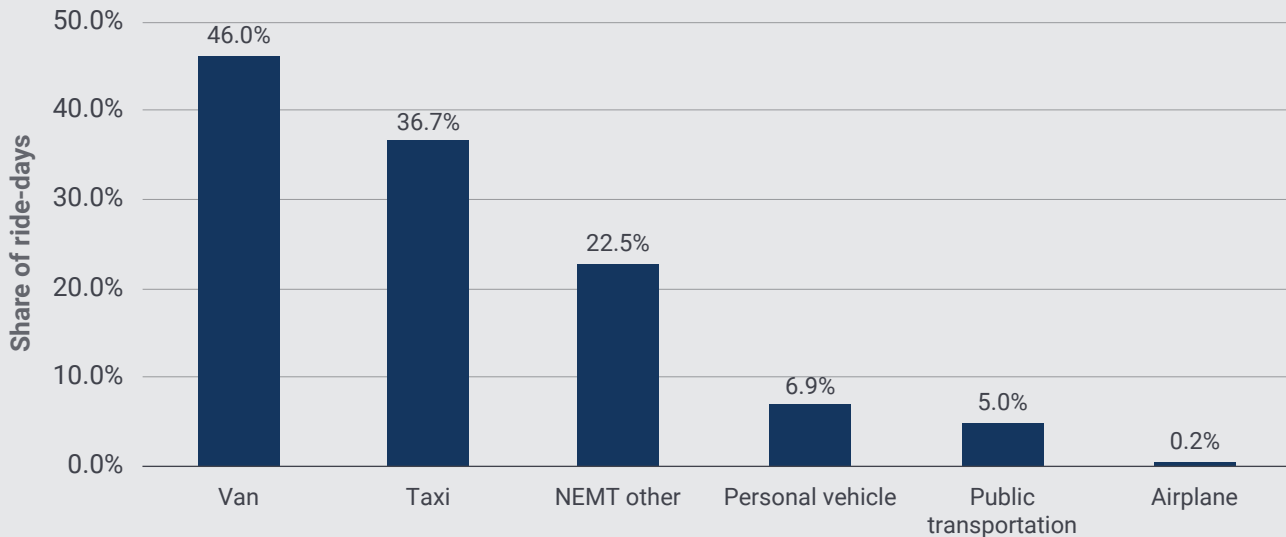
Use by mode of transportation

To examine NEMT use by mode of transportation, we classified rides into six different categories: airplanes, personal vehicles, vans, taxis, public transportation, and other or unknown.⁵² TNC rides are not distinguished in T-MSIS and, according to states we interviewed, are likely coded as taxi rides.⁵³

In FY 2018, the most prevalent forms of transportation were van, a category that includes shared vans and specialized vans such as wheelchair or stretcher vans (46 percent of all ride-days), and taxi (36.7 percent).⁵⁴ The least prevalent form of transportation was air travel (0.2 percent). Public transportation was also used infrequently (5 percent), perhaps reflecting its limited reach beyond urban areas (Figure 5-3). However, because public transportation is provided through a variety of different transportation modalities, it is possible that some public transportation ride-days are misclassified, and thus are being undercounted. For example, in rural areas, public transportation is often provided in vans, as opposed to trains or buses.

Focus group participants reported that they are usually assigned to shared or individual cars (including taxis) or vans, although few had been assigned to share rides since the onset of the COVID-19 pandemic. Few had used TNCs or public transportation.

FIGURE 5-3. Share of NEMT Ride-Days by Mode of Transportation, FY 2018



Notes: NEMT is non-emergency medical transportation. FY is fiscal year. Ride-days are defined as days with an NEMT procedure code (i.e., when any full-benefit Medicaid beneficiary had an NEMT ride). NEMT other includes a variety of procedure codes where the type of transportation is undefined; this can include a per diem or mileage reimbursement of undefined vehicle type, patient attendant or case worker escort, or wait times. Results are presented as the share of total ride-days for which each type of transportation was used. Multiple types of transportation may be used on the same ride-day and therefore percentages do not sum to one hundred. According to states we interviewed, transportation network company rides (such as Uber or Lyft rides) are likely billed as taxis. Because public transportation is provided through a variety of different transportation modalities, it is possible that some public transportation ride-days are misclassified, and are being undercounted as a result. For example, in rural areas, public transportation is at times provided in vans, unlike the trains, buses, or other public transit vehicles typically used in urban areas. Ambulances can also be used for NEMT; however, we excluded ambulances from our analysis of administrative data due to challenges in differentiating an emergency versus a non-emergency ride.

Source: MACPAC, 2021, analysis of Transformed Medicaid Statistical Information System (T-MSIS).

Factors related to mode of transportation

The modes of transportation used for NEMT are influenced by various factors including geographic location and beneficiary need.

Geographic location. Geographic characteristics affect the availability and use of different modes of transportation. In urban areas, beneficiaries tend to rely more heavily on public transportation. For instance, buses are the most common form of transportation used in Connecticut, where nearly 90 percent of the population lives in urban areas. Those living in urban areas can often request other

medically appropriate types of transportation (e.g., vans, TNC rides) with little advance notice, and in some cases, can access transportation on demand. Regions with limited public transit options tend to rely more heavily upon taxis or mileage reimbursement for personal vehicles. For example, in Arizona, a state with large remote and rural areas, taxis are the most common mode of transportation.⁵⁵ Beneficiaries living in rural areas may have to request transportation with more advance notice than their counterparts in urban areas.

State policies also affect the mode of transit. For example, Indiana offers mileage reimbursement as an option. However, according to Indiana Medicaid

officials, mileage reimbursement accounts for as little as 2 percent of NEMT, perhaps because of burdensome application requirements.⁵⁶

Beneficiary need. States and brokers also seek to match the transportation modality to the beneficiary's needs or preferences. One broker noted that the company generally matches a beneficiary with the lowest-cost transportation option available that can meet their needs, but offers some flexibility. For example, although public transportation may be the default when available, the broker might assign pregnant beneficiaries or beneficiaries with mental health needs to some form of door-to-door transportation. Another broker reported gathering notes for each member (e.g., if the member cannot ride with male drivers, if the member needs to ride in the front seat because of a physical limitation) and checking these when reviewing transportation requests so they can be factored into driver assignments.

Some interviewees reported tailoring models to ensure beneficiaries with specific needs are well matched with transportation. For example, Massachusetts implemented a model designed to deploy a subset of transportation providers that are specifically trained in and familiar with transporting members who are receiving life-sustaining services such as dialysis or cancer treatment.

Despite such efforts, inappropriate or ill-equipped vehicles are a common reason for beneficiary complaints (see below). Moreover, focus group participants reported challenges with shared rides, which, although more efficient and cost-effective than individual rides, may not be appropriate in all cases. For example, a participant from Indiana shared that she once had to travel an extra 100 miles to pick up another rider, resulting in an unnecessarily long round trip: she was picked up at 10:45 AM and dropped off at 6:30 PM. Another participant, who had physical limitations, discussed multiple times where she had to ride in the back of a sedan with three other people, making these rides cramped and uncomfortable.

Transportation network companies

In recent years, states have been allowing use of TNCs in Medicaid, a trend that is expected to continue. Nearly all stakeholders interviewed welcomed the addition of TNCs in NEMT, however, there are a number of considerations for states and the federal government as TNCs become a larger part of NEMT networks.

State approaches to using TNCs. The extent to which TNCs are involved in NEMT varies by state. Some states allow only limited use, such as a backup option in case of a driver no-show. For example, Georgia allows TNCs only when no transportation provider is available to transport the beneficiary, or if requested by the beneficiary and approved by the broker. Other states, including Arizona, have policies that allow broad use of TNCs as first-choice NEMT providers (i.e., beneficiaries can request or be assigned to a TNC ride at their initial ride request and not only as a backup option). As of February 2021, at least 14 states and the District of Columbia have incorporated TNC providers into NEMT as first-choice providers. Others are planning to start using TNCs over the next year (Cooper 2021).

There are few federal guidelines governing the use of TNCs, and states have taken different approaches. Many states require TNCs to enroll as Medicaid providers and meet similar requirements as other NEMT providers. Other states, including Arizona and Texas, have exempted TNC providers from such requirements to encourage them to join the market, citing the need to expand the NEMT provider network and the fact that TNCs have their own requirements for drivers. In these states, TNCs and their drivers are exempt from requirements such as background checks, training, credentialing, incident reporting, and insurance. This raises concerns about safety and quality for some beneficiary advocates. Although most focus group participants liked the idea of being able to use TNCs for NEMT, many had experienced problems and thought drivers should be subject to more training requirements and more strict background checks.

Several interviewees noted that guidance from CMS on minimum standards would be helpful.

Considerations in using TNCs. Because TNCs are a relatively new NEMT provider type, their effects have not been studied in a systematic way. Nevertheless, a number of studies of TNCs in pilot programs documented improvements in health outcomes and patient experience; decreases in unfulfilled trips, missed appointments, and emergency room utilization; and in some cases, cost savings (DMAS 2021, FierceHealthcare 2020, Hackensack Meridian Health 2020, Powers et al. 2018). Interviewees and focus group participants also pointed to some advantages and opportunities, largely consistent with the results of available studies. These include:

- Augmenting provider networks and alleviating other challenges. TNCs can provide on-demand transportation during surge or peak periods, are often willing to take on longer trips than traditional NEMT providers, have more flexibility to respond to urgent same-day or next-day requests and requests that come in at certain times of the day (e.g., a late-night hospital discharge), and can be used as rescue providers when traditional NEMT providers are unavailable, late, or do not arrive for pickups.
- Enhancing consumer satisfaction. Interviewees anticipate that improvements in flexibility, reliability, and timeliness may lead to higher beneficiary satisfaction. Moreover, they noted that TNCs may better reflect beneficiary preferences, and help normalize the use of NEMT by removing the stigma associated with some traditional NEMT vehicles. Focus group participants also supported the introduction of TNCs; they expressed the desire to use TNCs more regularly.
- Producing cost savings. There is little systematic data on the costs of TNCs relative to other modes, but one broker reported that TNCs have a lower cost per mile than other fleets in the network. And although TNC rides had a lower cost per trip than traditional

providers for rides under 10 miles in a pilot program in Virginia, there were little to no cost savings overall (DMAS 2021). Officials in Massachusetts are not expecting to see cost savings from the state's upcoming TNC pilot program.⁵⁷

Despite these advantages, interviewees generally agreed that TNCs are not appropriate for all Medicaid populations. They stressed that states, brokers, and managed care organizations (MCOs) must define rules around which beneficiaries can appropriately be assigned to TNCs, noting several considerations:

- TNC drivers and vehicles are not trained or equipped to meet the needs of Medicaid beneficiaries, especially those with high physical or behavioral health needs. Even ambulatory, independent beneficiaries may require additional assistance or awareness beyond what a TNC driver would typically provide.^{58, 59}
- Depending on their functional and cognitive abilities, beneficiaries may not be able to identify drivers, walk to pickup locations, or instruct drivers in the event of a wrong address.
- Because different TNC drivers are assigned to each ride, TNCs provide little continuity of care for beneficiaries who are using NEMT services daily or multiple times a week. This is an issue of particular concern for beneficiaries whose condition could change or deteriorate rapidly.⁶⁰

Provider network challenges

Interviewees agreed that one of the greatest challenges in administering NEMT is maintaining an adequate provider network. This is a bigger challenge in rural areas, which have fewer providers and longer distances to travel, but it is also present in large cities and urban areas, in part due to a declining supply of taxis. Common problems include late pickups or beneficiaries not being able to access a ride at all due to overscheduling,

lack of availability, and other performance issues (discussed further below).

Several interviewees also noted that the supply of wheelchair vans and other vehicles appropriate for high-need beneficiaries (e.g., stretcher vans or vehicles suitable for bariatric patients) is sometimes limited. Interviewees attributed strain on provider networks to a variety of factors, including high vehicle insurance costs, low Medicaid payment rates, and increased competition for drivers from companies like UPS and Amazon. The COVID-19 pandemic also caused a temporary decline in the supply of NEMT providers.⁶¹

Interviewees representing brokers and MCOs described several strategies to address NEMT provider network issues, including:

- promoting mileage reimbursement for beneficiaries and volunteer drivers (i.e., family and friends) especially in rural areas;
- leveraging public transportation and county transit programs where possible;⁶²
- using broker-owned vehicles when there is a surge in demand;⁶³
- negotiating with NEMT companies for service expansions into shortage areas; and
- incorporating TNCs into the provider network.

Coordination with Federally Funded Transportation Services

As of October 2019, there are 130 federal programs funding human services transportation for people who have difficulties providing their own transportation due to age, disability, or income (FTA 2019). These are collectively referred to as federally assisted transportation services; of these, Medicaid NEMT is the largest federal financing source (FTA 2019, Edrington et al. 2018). There are also other

state and local funding sources for these services with rules and restrictions that differ from Medicaid (FTA 2020, Edrington et al. 2018).⁶⁴

Federal policy encourages coordination across federally assisted transportation services. The FTA, the U.S. Government Accountability Office (GAO), and others have noted that coordination of transportation services can help reduce costs (e.g., by clustering passengers to reduce the number of trips and sharing equipment, personnel, and other resources) and improve services (e.g., by reducing wait times). However, delivery of transportation services has historically been fragmented among human services programs, which can result in overlap and duplication (FTA 2020, Edrington et al. 2018, GAO 2014).

States vary in the extent to which they coordinate NEMT with other programs, although Medicaid officials in three of the six study states reported coordination as a policy priority. In Massachusetts, the state's Human Service Transportation (HST) office manages transportation for six state agencies, including MassHealth.⁶⁵ Coordination by the HST office has reduced costs by allowing shared rides among individuals served by different agencies. It also creates some administrative efficiencies, because the HST office performs provider background checks and helps agencies implement universal provider standards.

Interviewees representing the federal Coordinating Council on Access and Mobility (CCAM), a federal interagency partnership tasked with improving coordination and reducing duplication across federal programs that fund transportation services, cited Pennsylvania and Vermont as examples of state Medicaid NEMT programs that promote coordination across programs.^{66, 67}

Other interviewees, however, reported limited or no coordination across federally assisted transportation programs and cited a range of barriers and challenges that are consistent with findings from past studies by other federal agencies. For example:

- Beneficiary needs differ across federally assisted programs, making it challenging to arrange shared rides. For example, although ambulatory Medicaid beneficiaries may be able to use a range of transportation options, those with greater physical or behavioral health needs may need special vehicles or drivers with specific training.
- Other federally assisted programs often have greater constraints, such as limited geographic footprints, limited operating hours, longer wait times, and greater lead time required to schedule a ride.
- The requirement that Medicaid can pay for transportation only for Medicaid beneficiaries traveling to medically necessary services can make it difficult and administratively burdensome to calculate the Medicaid-eligible portion of any shared ride. Some interviewees reported that Medicaid entities are often reluctant to have Medicaid beneficiaries share rides with beneficiaries of other programs because of these challenges. As a result, brokers, MCOs, and Medicaid agencies may be incentivized to pay more for a single-passenger on-demand trip instead of authorizing cheaper public transit or other shared-ride options.⁶⁸
- Some interviewees noted that the administrators of different federally assisted transportation programs are often not engaged in coordination efforts.

It is important to note that even in cases where NEMT programs are not actively coordinating with other federal human services transportation programs, NEMT and community transportation services are often provided by the same local transportation agencies, and are thus intertwined. This is particularly the case in rural and small communities. For example, for some rural transit providers, revenue from Medicaid NEMT rides may comprise as much as 59 percent of revenue (Adelberg et al. 2020).

NEMT Program Quality

Interviewees varied in their views on the extent to which NEMT policies meet the needs of beneficiaries and on program performance generally. Most state officials described their NEMT programs as functioning well or improving, but acknowledged problems that have led to beneficiary complaints. Advocates interviewed as part of this study noted that some states have strong programs while others have serious issues, including unsafe conditions for beneficiaries, missed appointments, and distrust of the program.

Focus group participants also reported variation in quality and satisfaction. For example, one participant who had moved from Arizona to a rural area of Indiana noted that in Arizona, she was able to use Lyft or taxis and that the transportation services were reliable and comfortable. However, since moving, she has had to use van services that are unreliable. Participants also described vast differences in quality between different transportation companies. For example, one participant had previously been assigned to a consistently reliable provider, but was then transferred to a new provider that missed multiple appointments in the first month, causing concern for the beneficiary about maintaining his SUD treatment.

Performance issues

Interviewees reported that late pickups and driver no-shows are the primary reasons for complaints from beneficiaries, providers, and care managers. Most focus group participants had experienced such issues on at least one occasion. For example, several participants reported missing appointments as a result of drivers arriving late. One Indiana woman said she had missed multiple dialysis appointments. Additionally, some participants reported waiting as long as three hours to be picked up for their return trip.

Though less common than late pickups or drop-offs, several focus group participants had also

experienced driver no-shows or late cancellations. For example, a participant from Arizona reported missing over 10 appointments in a one-year period as a result of driver no-shows. A participant from Connecticut described her father, who uses a wheelchair, being left at a doctor's appointment without a ride home. Participants also shared experiences of brokers failing to assign a driver to a scheduled ride because systems allow drivers to accept or refuse rides they view as undesirable (e.g., too short or too long).

Other common complaints include vehicles that are not appropriately equipped, safe, or accessible; behavior of other passengers in the vehicle; language barriers; customer service issues such as rude or unprofessional dispatchers or drivers; drivers who are untrained or insensitive in dealing with beneficiaries with behavioral health conditions or ID/DD; and lack of responsiveness by call centers. Participants also described examples of dangerous driver behavior including talking on their phones or texting while driving, making comments that made them feel unsafe, speeding or driving unsafely, or not wearing masks in accordance with COVID-19-related guidelines.

Interviewees discussed several factors that cause delays and other performance issues. Long distances in rural areas and in large states commonly impede on-time performance. In major metropolitan areas, traffic and construction-related detours present barriers to timely pickups. Other factors include strained NEMT provider networks, bad weather in winter months, insufficient information about correct entrances and exits in large medical complexes, or the wrong vehicle being dispatched due to incorrect or insufficient information about the beneficiary's medical needs.

Policies that create difficulties for beneficiaries

Interviewees and focus group participants cited several policies around scheduling and ride protocols put in place by states, brokers, or MCOs

that present issues for beneficiaries with specific needs or are otherwise burdensome. For example:

- Participants from several different states commented that rules require that they book rides two to three days in advance. These rules have been troublesome in certain situations; for example, when beneficiaries were told to come into the doctor right away, an appointment was changed, they got off a waitlist, or they were leaving the hospital. Participants said that their broker or health plan sometimes made exceptions to these rules, but not consistently.
- For parents, rules about not being able to bring children along for rides are problematic. In most cases, parents are not permitted to bring children along for their own appointments. Moreover, while a parent is typically permitted to ride with their child to medical appointments for that child, they are usually not allowed to bring their other children.⁶⁹ Although exceptions may be made on a case-by-case basis, these rules may create access barriers for families without child care. For example, focus group participants described asking drivers to make exceptions; others said these rules sometimes make it impossible to go to their appointments.
- Participants also felt that certain policies were too stringent, for example, rules requiring that they be outside within five minutes of the driver's arrival (or drivers may leave) even if the driver arrives early. A few participants cited physical limitations that make it difficult to get to the street within five minutes.
- Participants in some states were subject to rules requiring them to submit a specific number of complaints about a driver or NEMT provider before they would be assigned to a different one. Some participants felt this was unfair, and possibly dangerous.

Focus group participants, along with stakeholders representing beneficiary advocacy organizations,

felt that beneficiaries have little recourse when they experience problems. Interviewees noted that complaints frequently go unanswered or unresolved even when submitted through formal channels. Focus group participants felt that drivers and brokers lack accountability. For example, several had submitted complaints about drivers, late pickups, or other issues, but were never offered a resolution and never received a response. Others had little confidence that their complaints would be addressed, and therefore had never submitted complaints or feedback.

Strategies to improve performance and meet beneficiary needs

Interviewees representing states, health plans, and brokers shared strategies used to identify performance issues and improve member safety and experience, including building in extra time when scheduling rides, using technology to track driver locations, providing additional training to drivers, and removing drivers with repeated performance issues. For example, brokers in Connecticut and Georgia conducted trainings for drivers on the proper techniques for wheelchair tiedowns following a series of safety incidents.

Other interviewees noted the importance of strong contracts and oversight mechanisms. Advocates expressed that contracts should have consumer protections and oversight provisions that allow the state to take action if needed. State contracts with transportation brokers and MCOs administering NEMT often contain requirements regarding reporting, call center wait times, on-time performance, vehicle standards, driver training and criteria, and penalties for non-compliance. However, advocates and other interviewees pointed out that state agency staff often lack capacity to exercise strong and effective oversight over brokers; in other cases, they are reluctant to do so because there are few brokers in the market.⁷⁰

Some states use performance incentives. For example, Connecticut's statewide broker can earn

up to 5 percent of the contract price if it meets quality metrics related to call center performance, on-time pickups, complaint rates, and satisfaction survey results. Some brokers are also using performance-based incentives with transportation providers and drivers. For example, an interviewee representing a multistate broker noted that in many states, the broker assesses liquidated damages on providers who have performance problems, which they use to create a bonus pool to reward high-performing providers.

Advocates noted that states with formal and sustained consumer engagement mechanisms (such as advisory councils or committees), and that are diligent in integrating consumer feedback into policies and procedures, tend to have better-performing NEMT programs. For example, advocates in Georgia reported that productive conversations with the state Medicaid agency led to stronger enforcement of a policy that requires drivers to ensure the beneficiary enters their home or medical facility before departing.

Focus group participants, along with several interviewees, said that NEMT should be more widely promoted and that states and health plans should strengthen their outreach to eligible beneficiaries. They reported that NEMT is rarely well publicized, and that awareness of the benefit is low. For example, most focus group participants learned about NEMT from case workers or social workers, health care providers such as nurses and therapists, and other patients they met at their treatments. Some also found out about the service through friends and family. Only a small number learned of the benefit through their health plan or the state Medicaid program. Enhanced efforts to connect Medicaid beneficiaries with NEMT services may help improve access to care and outcomes.

Stakeholders interviewed for this study suggested a number of opportunities for federal government action that could help improve NEMT quality and performance. For example, CMS or Congress could do the following:

- more visibly and proactively promote sharing of best practices and strategies to address common issues in NEMT administration (beyond what CMS already does on an ad hoc basis);⁷¹
- issue additional guidance or implement requirements on how states should publicize the availability of NEMT and encourage use of NEMT services, and work with states to develop strategies to identify beneficiaries who have transportation barriers but are not using NEMT;
- issue guidance on use of TNCs in NEMT, including minimum standards and requirements that states could augment;
- issue guidance on how states can promote the use of NEMT to increase access to COVID-19 vaccines (Brown 2021, Beckman 2021);⁷² and
- create incentives to address provider shortages in rural areas.

Expanding Use of Technology

New technologies, such as GPS tracking and electronic scheduling software, are increasingly being used in NEMT by states, brokers, MCOs, providers, drivers, and beneficiaries. They are viewed as important tools for strengthening program integrity and improving on-time performance and customer satisfaction. For example:

- GPS data, usually collected through a smartphone or tablet in the vehicle, can document the date, time, and location for each pickup and drop-off to ensure that trips took place as authorized. They can also be used to track on-time performance.
- Advanced GPS technology (e.g., real-time location monitoring) can allow brokers to divert drivers who are going to arrive late and assign new ones before an appointment is missed. When coupled with a beneficiary-facing application, GPS capability can also provide

real-time information to riders about estimated pickup times.

- Mobile or web applications for scheduling and customer service can allow beneficiaries to schedule NEMT trips with one call or click, and in some cases, request a particular provider. They can also help reduce call volumes and wait times.
- Tablets (or similar technologies) can allow drivers to input trip information and beneficiaries to digitally sign at completion of the trip (an additional program integrity tool).

These technologies are being used to some extent in all six study states. Adoption of GPS appears to be the greatest priority, although interviewees reported uneven GPS capability across NEMT providers within the same state or provider network. Brokers reported ongoing efforts to increase GPS capability among providers with varying levels of engagement. Some states require brokers to ensure that providers have GPS capability; others do not, in part due to opposition from providers.⁷³ One interviewee representing a multistate broker noted that it is easier to require providers to adopt these technologies when it is required by the state.

Interviewees discussed some barriers to increased adoption of new technologies. These include added costs to drivers, internet and data bandwidth challenges that affect real-time location monitoring, and varying access to and literacy regarding smartphone use among drivers and beneficiaries.

Program Integrity

Federal oversight authorities have identified NEMT as high risk for fraud, waste, and abuse, noting concerns related to enrolling providers, program inefficiencies, and verifying eligibility (GAO 2016b). Additionally, studies by the HHS Office of the Inspector General have found inadequate oversight and improper payments for trips that did not meet federal and state requirements (OIG 2021, 2020).

Medicaid officials in most study states and other interviewees suggested that although there are occasional instances of fraud or misuse by beneficiaries and providers, they are not widespread and are appropriately addressed through routine channels. Consistent with findings of other studies, some interviewees noted that program integrity in NEMT has been stronger in recent years (Trent and Frizzera 2019). This may be due to the shift in administration from Medicaid agencies to brokers and managed care, which typically have greater oversight capacity and closer connections with the provider network. Interviewees also cited the growing role of new technologies in ensuring program integrity.

Federal policymakers continue to be concerned about fraud, waste, and abuse in NEMT. Under the Consolidated Appropriations Act of 2021 (the same law that added the requirement for states to provide NEMT to the Social Security Act), Congress enacted additional program integrity requirements related to NEMT including:

- Within two years of enactment, GAO must conduct and submit to Congress a report on program integrity measures.
- Within 18 months of enactment, the Secretary of HHS shall convene a series of stakeholder meetings to obtain input and facilitate discussion and shared learning for improving program integrity.
- Within two years of enactment, the Secretary of HHS must assess existing guidance and update such guidance as necessary.
- States must include in their state plans mechanisms to ensure that providers, including TNCs and individual drivers, meet minimum standards.⁷⁴
- Within one year of enactment, CMS must analyze T-MSIS data and submit to Congress a report identifying recommendations relating to coverage of NEMT.⁷⁵

The Role of NEMT in Medicaid

State and federal officials, representatives of NEMT brokers, providers, and health plans, as well as beneficiary advocates, agreed that NEMT is an important tool in promoting access to care, managing health conditions, and ultimately improving health outcomes.

Role in beneficiary health

Nearly all focus group participants commented on NEMT's critical importance for managing their mental and physical health or the health of someone in their care, noting that their health would deteriorate without it. Many of the participants, particularly those with serious conditions like ESRD, feel that their continued and regular access to health services is saving their lives, calling the transportation services the difference between "life or death." These sentiments are consistent with those identified in other studies. For example, in one survey, when asked an open-ended question about the effects of losing their NEMT benefits, 10 percent of respondents said they would die, or would probably die (Adelberg et al. 2018).

For those with behavioral health conditions, NEMT is viewed as helpful in ensuring access to regular mental health or SUD services. Other participants talked about the emotional toll of being confined to their homes because of their physical health conditions, and noted NEMT enables them to travel to day health programs, physical and occupational therapy, and other appointments that provide opportunities for human interaction and enrich their lives.

Additionally, participants pointed out that NEMT services reduce their dependence on friends and family members. Many had to request rides from others before learning about NEMT. One participant said that she is unable to drive, and without access to NEMT, her mother would have to quit her job in order to take her to dialysis six days a week.

Value of NEMT

Researchers, advocates, and others in the policy community have long argued that NEMT is valuable both in terms of improved health outcomes and in cost savings to states and the federal government. They argue that NEMT helps improve access to preventive care and regular medical treatments that can help beneficiaries manage their health conditions, thus increasing use of comparatively low-cost care and avoiding more costly emergency care. Most stakeholders interviewed for this study, including many state officials, commented that based on their own observations or internal data, NEMT also yields savings for states and the federal government in the long run.

Several studies have examined the effect of NEMT on health outcomes and cost savings. For example, a 2001 study conducted by the University of Florida estimated that if at least 1 percent of NEMT trips resulted in avoidance of an emergency room visit, the state would save \$11.08 for each dollar it invested in the program (Cronin et al. 2008). Additionally, a 2018 study of actual NEMT users found that when used as part of a care management strategy for people with certain chronic diseases (i.e., dialysis for kidney diseases and wound care for diabetic wounds), NEMT produces substantial return on investment (Adelberg et al. 2018).

The fact that Medicaid managed care plans and other payers voluntarily provide additional transportation services further reinforces the notion that NEMT adds value. Managed care plans frequently include transportation services they are not otherwise required to cover, such as trips to the grocery store or gym, or authorize trips beyond state benefit limits. Medicare Advantage plans, Medicare accountable care organizations, and even some commercial payers are also increasingly offering these services. For example, as of 2020, over one-third (35 percent) of Medicare Advantage plans and 85 percent of Medicare special needs plans offered supplemental transportation benefits, compared to 19 percent in 2018 (Kornfield et al. 2021).⁷⁶

Implications of the COVID-19 pandemic

The COVID-19 pandemic reduced NEMT use and may affect its role over the long term. Increased access to telehealth services helped address gaps in care for beneficiaries who could not, or chose not to, access regular medical services during the pandemic, and may permanently reduce the need for NEMT services. However, the extent to which this occurs will depend on the design of Medicaid telehealth policies postpandemic and acceptance of telehealth by beneficiaries and providers.

Effects on NEMT volume. Following the onset of the COVID-19 pandemic, NEMT declined sharply, as demand decreased due to stay-at-home orders, medical facility closures, risks of contagion via public transportation and shared rides, cancellation or postponement of non-emergency appointments, and increased use of telehealth. Some NEMT brokers experienced declines in trip volume of as much as 60 percent in the first half of 2020 (MTAC 2021b). Many focus group participants reported missing regular appointments, particularly those involving adult day health or physical therapy and rehabilitation services. Others found it difficult to secure an NEMT ride, either because providers were not available or because the beneficiary had COVID-19 and was prohibited from riding.

NEMT use began rebounding in the second half of 2020, although the extent of these increases has varied by state and service. Similarly, many focus group participants reported having resumed their normal appointment schedules as of October or November 2020. Others had resumed appointments but with reduced frequency, either because their providers or facilities were closed or only taking limited appointments, or because they were still afraid of exposure to the virus. Some projections indicate that in 2021, NEMT volume may actually exceed prepandemic levels for certain services, including trips for adult day health services and behavioral health appointments (MTAC 2021b).

Increased access to telehealth. States rapidly expanded the availability of telehealth services during the pandemic.⁷⁷ Increased availability of telehealth could supplant the need for NEMT for some beneficiaries. However, the extent to which this is occurring is unclear. Many policies expanding telehealth services are tied to the public health emergency (Libersky et al. 2020). Several states have moved to continue or make permanent expanded telehealth policies, which could affect demand for NEMT.

Telehealth may not be appropriate for all beneficiaries and may not be welcomed in all circumstances. Although some focus group participants had used telehealth services at the beginning of the pandemic and found them helpful, most had returned to in-person services by the time the focus groups were conducted in October and November 2020. Most said they prefer in-person visits over telehealth with some expressing discomfort with the idea of receiving health services remotely.⁷⁸ Other interviewees generally predicted that beneficiaries will continue to seek in-person treatment for the types of medical appointments that NEMT is most commonly used for, including dialysis and SUD treatment.

Focus group participants also reported technical barriers to telehealth such as not having reliable access to telehealth services or sufficient internet bandwidth and, as a result, were continuing to access in-person care.

Looking Ahead

Now that NEMT has been added to the Act as a mandatory benefit, states and other NEMT stakeholders have greater certainty that the benefit will continue. States and other entities that administer NEMT will likely continue to focus on improving NEMT program administration, promoting program integrity, and addressing beneficiary concerns by shoring up provider networks, adopting new technologies, and strengthening stakeholder engagement mechanisms. Despite the expanded

availability of telehealth services, additional research is needed to determine which beneficiaries can use telehealth in place of NEMT, and the extent to which they do so. Additional research is also needed to better understand how to address any racial and ethnic disparities in NEMT access and use.

NEMT remains a vital benefit for beneficiaries and is likely to continue to play an important role in ensuring access to care. Moreover, as states consider how to address high-priority Medicaid goals such as reducing racial disparities and increasing access to COVID-19 vaccines, they may wish to leverage NEMT by more widely promoting and connecting beneficiaries with these services.

Endnotes

¹ Under Section 1115 of the Act, the Secretary of the U.S. Department of Health and Human Services can waive almost any Medicaid state plan requirement under Section 1902 of the Act to the extent necessary to carry out a demonstration or experimental project furthering the goals of the program. States use these waivers for a wide variety of purposes. Indiana and Iowa received approval to exclude NEMT from the benefits offered to low-income adults eligible for Medicaid on a basis other than disability (except medically frail individuals and pregnant women).

² For example, two bills codifying NEMT as a mandatory benefit passed the U.S. House of Representatives in the 116th Congress, including one with bipartisan cosponsorship and support: the Protecting Patients Transportation to Care Act (H.R. 3935) and the Health and Economic Recovery Omnibus Emergency Solutions Act (HEROES Act, H.R. 6800).

³ Multiple NEMT trips can occur on the same ride-day. For example, a beneficiary's trips to and from a medical appointment would count as one ride-day.

⁴ States can use ambulances as a form of NEMT. However, we excluded ambulances from our analysis of administrative data due to challenges in differentiating an emergency versus a non-emergency ride.

⁵ Spending per FYE does not necessarily align with the per member per month (PMPM) rates that states pay to brokers

or health plans to deliver NEMT. For example, the Medical Transportation Access Coalition noted that PMPM rates range from \$4 to \$10 (MTAC 2021a).

⁶ We do not report spending on NEMT delivered through managed care plans because payments for NEMT services are not separately reported from other services.

⁷ Section 1901 of the Act specifies that states shall “furnish (1) medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services, and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care.”

⁸ Supplement D lists the provision of transportation to and from medical services as a criterion for assuring high-quality care and services in Medicaid (Rosenbaum et al. 2009).

⁹ This assurance of transportation in Medicaid has been upheld in federal courts. *Smith v. Vowell* 379 F. Supp. 139 (W.D. Tex. 1974) was the first case to test whether the transportation assurance requirement could be enforced (Rosenbaum et al. 2009).

¹⁰ The administrative efficiency statute has been cited as a particularly important legal basis for the assurance of transportation (Rosenbaum et al. 2009). It requires that Medicaid state plans provide methods of administration that are “found by the Secretary of HHS to be necessary for proper and efficient administration of the plan” (§1902(a)(4) of the Act). Successive administrations interpreted this as the basis for both the requirement that states provide NEMT and the federal government’s obligation to assist in covering the cost of doing so (Rosenbaum et al. 2009).

¹¹ The EPSDT benefit and its associated requirements have been interpreted as establishing an obligation to provide transportation, independent of the general Medicaid assurance of transportation.

¹² Other divisions of CMS also weigh in on NEMT policy. For example, the State Demonstrations Group makes decisions about state requests to remove or alter the NEMT benefit through Section 1115 demonstration authority, and is currently developing monitoring and evaluation requirements for such demonstrations.

¹³ In general, beneficiaries may use NEMT only for medical appointments. However, some managed care plans allow beneficiaries to use transportation services for additional purposes, such as transportation to the grocery store (Kornfeld et al. 2021, LogistiCare 2020, CMS 2019c). One focus group participant, who is enrolled in a Medicare Advantage plan specifically for dually eligible beneficiaries, reported that she can use the plan’s transportation service for a variety of purposes in addition to medical appointments.

¹⁴ Some dually eligible individuals (i.e., partial dually eligible individuals) do not receive NEMT benefits, although they may receive transportation benefits through a Medicare Advantage plan.

¹⁵ For example, Georgia requires its brokers to determine if beneficiaries have other means of transportation. A broker may deny transportation requests if it determines that a beneficiary has a vehicle and is capable of driving. But it cannot deny requests solely based on the beneficiary owning a vehicle or there being a vehicle in the beneficiary’s household (GDCH 2021). Arizona specifies that NEMT is covered for beneficiaries if they are not able to provide, secure, or pay for their own transportation, and free transportation is not available (AHCCCS 2019).

¹⁶ States and other entities administering NEMT (i.e., third-party brokers and managed care plans) have different requirements and processes for how beneficiaries attest to their need for NEMT and request rides.

¹⁷ Few states report NEMT spending as administrative spending. In FY 2018, 16 states reported administrative NEMT spending on the CMS-64; of those, all but 5 also reported medical assistance spending.

¹⁸ States are currently receiving enhanced FMAPs during the COVID-19 public health emergency (PHE). Specifically, the Families First Coronavirus Response Act of 2020 (P.L. 116-127) provides a temporary 6.2 percentage point FMAP increase for each calendar quarter occurring during the period beginning on the first day of the PHE period, as defined in Section 1135(g)(1)(B) of the Act, ending on the last day of the calendar quarter in which the emergency period ends. There are also multiple other exceptions to the regular FMAP (MACPAC 2021a).

¹⁹ The Deficit Reduction Act of 2005 (DRA, P.L. 109-171) created a state plan option to use a broker model for NEMT, allowing states to do so without a Section 1915(b) waiver. This action made it easier for states to adopt this approach and many states did so. Today, the majority of states use a third-party broker model for at least a portion of their NEMT program.

²⁰ These requirements were included in guidance implementing the DRA state plan option to use a broker model. States using Section 1915(b) waiver authority to use a broker model may not be subject to all of these requirements; for example, they may use a sole-source contracting process to choose their broker.

²¹ CMS has also approved Section 1115 demonstrations excluding NEMT when the state is providing limited benefits to people who are not otherwise eligible for Medicaid (e.g., certain family planning demonstrations) (Simon and Fishman 2018).

²² CMS has not approved Section 1115 demonstrations excluding mandatory benefits other than NEMT, with the exception of Section 1115 demonstrations that provide limited benefits to people who are not otherwise eligible for Medicaid (e.g., certain family planning demonstrations).

²³ States have different definitions of medical frailty; these must include at minimum the presence of serious and complex medical conditions, physical, intellectual, or developmental disabilities that impair ability to perform activities of daily living, chronic substance use disorder (SUD), disabling mental disorders including SMI, or a disability determination based on Social Security Administration criteria. States also have different methods of designating beneficiaries as medically frail. For example, most states allow beneficiaries to initiate the process by self-reporting that they are potentially medically frail, and some allow providers or managed care plans to designate patients as medically frail. In most states, a medically frail designation can be made at any time during the eligibility period (Musumeci et al. 2019).

²⁴ The decision to terminate this waiver, along with other elements of the demonstration including work and community engagement requirements as a condition of eligibility, was made following a June 2018 ruling in *Stewart v. Azar* (313 F. Supp. 3d 237 (D.D.C. 2018)) vacating the

demonstration's approval, and later, a decision by newly elected Governor Andy Beshear soon after taking office in December 2019 (MACPAC 2020c).

²⁵ Specifically, CMS sent letters to states with Section 1115 demonstration approval for work and community engagement requirements that the authority for those requirements would be withdrawn. CMS also indicated that other elements of the demonstrations are being reviewed (CMS 2021a, 2021b, 2021c). Indiana, Georgia, and Utah demonstrations include both work and community engagement requirements and waivers of NEMT requirements. In comparison, Iowa and Kentucky demonstrations contain waivers of NEMT requirements but do not include work and community engagement requirements, and CMS did not send similar letters to Iowa or Kentucky.

²⁶ As an alternative to traditional Medicaid benefits, states were given authority under the DRA to enroll state-specified groups (excluding individuals with special medical needs and certain others) in benchmark and benchmark-equivalent benefit packages. States that elect to do so can provide coverage that is equal to one of the following: the Blue Cross and Blue Shield standard provider plan under the Federal Employees Health Benefits Program; a plan offered to state employees; the largest commercial health maintenance organization in the state; or other coverage approved by the Secretary of HHS. The Bush Administration interpreted this flexibility to include state authority to eliminate the transportation assurance for affected populations because transportation was not covered for state employees (MACPAC 2021b).

²⁷ Of the six states with active Section 1115 demonstrations that exclude NEMT, evaluation results are currently available for only Indiana and Iowa. A federal evaluation of the Healthy Indiana Plan was unable to assess the effects of the NEMT waiver on beneficiaries, because managed care plans continued to provide transportation as a value-added service. Older state-led evaluations in Indiana and Iowa were conducted using beneficiary surveys. Results for both states were mixed, but indicated largely comparable access to transportation between beneficiaries with and without NEMT benefits, although those with lower incomes may be more likely to face transportation-related barriers to access regardless of NEMT eligibility (Bentler et al. 2016,

GAO 2016a, Lewin Group 2016). Additionally, the results suggest that unmet needs for transportation may result in delayed or skipped care. It is important to note certain limitations to these evaluations. For example, Indiana's evaluation focused only on missed appointments among beneficiaries who had scheduled an appointment, and was unable to assess unmet need among beneficiaries who did not schedule an appointment. Iowa's evaluation compared experiences between two groups that are not necessarily comparable: beneficiaries enrolled in the Medicaid state plan and beneficiaries included in the demonstration who were part of the new adult group.

²⁸ Since 2017, CMS has been working to improve the quality and timeliness of Section 1115 demonstration evaluations. The agency has released guidance outlining expectations for the content and research methods in evaluation design and reports, and a variety of other technical assistance resources (CMS 2021d). It also began including requirements for evaluation content and timing in the special terms and conditions of each demonstration (MACPAC 2020d). If their NEMT waivers are permitted to continue, these five states (Indiana, Iowa, Georgia, Kentucky, and Utah) will need to conduct evaluations of their demonstrations under the new guidance; however, it is not yet clear what specific hypotheses they will be asked to examine or what measures they will use in evaluating their NEMT policies.

²⁹ HMA conducted a scan of NEMT policies for all 50 states and the District of Columbia and collected state-level data about the percentage of rural population, managed care penetration rate, and Medicaid expansion status for each state. We also gathered information on the NEMT administrative model used, use of TNC providers, cost-sharing requirements, benefit limits and exclusions, geographic variation, coordination of NEMT with other transportation programs, program integrity and quality strategies, substantial programmatic changes, and notable innovations.

³⁰ We selected these six states for further study based on a set of criteria including variation in NEMT models, variation in Medicaid expansion status, geographic diversity, delivery system innovations or changes, and notable quality requirements.

³¹ Focus group participants varied in terms of gender, age, geographic area, and race and ethnicity. They have or are caring for someone who has one or more of the

following conditions: ESRD, cancer, high blood pressure, back problems, hip and knee problems, neuropathy, cirrhosis of the liver, vision issues, asthma and other breathing issues, autoimmune disorders, heart disease, post-traumatic stress disorder, bipolar disorder, anxiety, depression, and SUD. Some participants also use wheelchairs, including two participants with quadriplegia and paraplegia due to spinal injuries. A handful of participants are dually enrolled in Medicare and Medicaid. More detail on focus group participants is included in PerryUndem's as-yet unpublished report, *Understanding the Value of the Medicaid Non-Emergency Medical Transportation Benefit* (PerryUndem 2021).

³² Some states allow patient attendants or case worker escorts to also be billed under the NEMT benefit. Moreover, states are allowed to bill for certain ancillary services under the NEMT benefit such as meal deliveries, lodging, and parking reimbursement. We excluded these services from utilization estimates, but included them in spending estimates for consistency with how NEMT spending is reported within the Medicaid Budget Expenditure System.

³³ For example, a Medical Transportation Access Coalition survey of NEMT users found that over half (58 percent) reported that they would make none of their treatments without NEMT. Twenty percent reported that they would make fewer of their treatments without NEMT (Adelberg et al. 2018).

³⁴ Based on a MACPAC analysis of 2018 National Health Interview Survey data. Other surveys and studies have found a much higher share of Medicare and Medicaid beneficiaries reporting transportation barriers. For example, a 2020 survey of 9,000 Medicare and Medicaid beneficiaries found that nearly one-third had missed appointments or run out of medication due to a lack of transportation (Evidation 2021).

³⁵ We do not provide estimates for adults age 65 and over due to small sample size. The following hierarchy was used to assign individuals with multiple coverage sources to a primary source: Medicare, private, Medicaid or State Children's Health Insurance Program (CHIP), other, uninsured.

³⁶ The definition of basic action difficulty includes limitations in movement and sensory, emotional, or mental functioning that are associated with some health problem. Adults are defined as having a complex activity limitation if they have one or more of the following types of limitations: self-care limitation, social limitation, or work limitation.

³⁷ Conditions include: hypertension, coronary heart disease, heart attack, stroke, cancer, diabetes, arthritis, asthma, chronic bronchitis in the past 12 months, liver condition in the past 12 months, and weak or failing kidneys in the past 12 months.

³⁸ The list of conditions includes: attention deficit hyperactivity disorder or attention deficit disorder, asthma, autism, cerebral palsy, congenital heart disease, diabetes, Down syndrome, intellectual disability, and other developmental delay.

³⁹ To be considered as having a special health care need, a child must have at least one diagnosed or parent-reported condition expected to be ongoing and also must meet at least one of five criteria related to elevated service use or elevated need, including reported unmet need for care. For more information on the methods used to identify children with special health care needs, see the Technical Guide to MACStats, in *MACStats: Medicaid and CHIP Data Book* (MACPAC 2020b).

⁴⁰ See endnote 37.

⁴¹ See endnote 38.

⁴² MACPAC uses the term pregnant women because this is the term used in the statute and regulations. However, other terms are being used increasingly because they are more inclusive and recognize that not all individuals who become pregnant and give birth identify as women.

⁴³ Figures for dually eligible individuals include only full-benefit Medicaid beneficiaries who are also eligible for Medicare.

⁴⁴ MACPAC used diagnosis and procedure codes in the CMS chronic conditions warehouse algorithms to define these conditions. The algorithm for OUD does not include methadone treatment, perhaps because Medicare did not start paying for methadone treatment in opioid treatment programs until 2020. Therefore, we may not be fully capturing such rides.

⁴⁵ Due to data limitations, we are unable to provide nationwide data on use by service destination.

⁴⁶ Although NEMT can be used for pharmacy trips, HCPCS origin and destination codes do not separately identify pharmacy as a destination. Pharmacy trips are likely included in another category (e.g., physician office). The

“other” category includes destinations such as transfer sites (e.g., airport or helicopter pad) between modes of ambulance transport, scene of accident or other acute event, and intermediate stop at physician’s office en route to the hospital.

⁴⁷ Capitated broker arrangements are often referred to as transportation prepaid ambulatory health plans.

⁴⁸ Both managed care organizations (MCOs) interviewed by MACPAC for this study indicated that they always use a broker for NEMT, citing broker expertise and the challenges involved with having to build their own NEMT provider networks.

⁴⁹ Of the \$2.6 billion in federal and state Medicaid funds spent on NEMT in FY 2018, two-thirds (\$1.7 billion) were for NEMT paid for directly by the state or through an FFS broker arrangement; one-third (\$0.9 billion) were payments made to prepaid ambulatory health plans (i.e., third-party transportation brokers). It is important to note that spending figures do not reflect managed care payments to NEMT providers, and as a result, FFS spending makes up a higher share of total reported spending than it does of reported ride-days (which include all ride-days regardless of payment or delivery model).

⁵⁰ The general consensus among interviewees was that a broker model reduces state administrative burden, but interviewees in Connecticut reported that there was no substantial reduction in administrative burden following their shift to a broker model because of the amount of oversight required.

⁵¹ For example, Indiana Medicaid officials reported a large increase in NEMT use among their FFS Medicaid population following the shift from an in-house system to a broker, which they credit to better and more frequent member education and increased awareness of the benefit as well as an easier process for requesting rides.

⁵² States can use ambulances as a form of non-emergency transportation. However, due to challenges in differentiating an emergency versus a non-emergency ambulance ride, ambulances are excluded from MACPAC’s NEMT T-MSIS algorithm. The category of other includes a variety of procedure codes where the type of transportation is undefined; these can include per diem or mileage

reimbursements of undefined vehicle types, patient attendant or case worker escorts, or wait times.

⁵³ Use of TNCs in Medicaid is growing; the share of rides using TNCs is likely higher in 2021 than it was in FY 2018.

⁵⁴ Stretcher vans are sometimes referred to as ambulettes.

⁵⁵ State geography also plays a role in the types of transportation offered to beneficiaries. For instance, the Cape Cod Regional Transit Authority contracts with the public steamship authority to ensure that individuals can be transported from the area's islands to the mainland of Massachusetts. Similarly, Arizona offers allowances for non-ambulance air NEMT in the Grand Canyon. Texas, a large state with vast rural areas, also permits the use of commercial air transportation.

⁵⁶ This is the case for Indiana's FFS Medicaid population. NEMT for Indiana's managed care population is managed by MCOs, which may have different processes for mileage reimbursement.

⁵⁷ Massachusetts's 2020 broker procurement creates a ride hail pilot (beginning in FY 2021) that will allow certain MassHealth beneficiaries to opt-in to on-demand ride hail services using TNCs. The pilot is focused on increasing capacity to meet last-minute urgent transportation needs, but state officials do not expect to see meaningful cost savings from the pilot.

⁵⁸ Interviewees disagreed about the extent to which Medicaid beneficiaries can be well served by TNCs. Beneficiary advocates commented that a relatively narrow group are well served. A broker representative noted that although up to 80 percent of NEMT rides are for people considered ambulatory, at least half of those rides required additional awareness, training, or assistance beyond what a TNC driver would typically provide. However, a TNC representative estimated that up to 70 percent of NEMT rides are appropriate for TNC services.

⁵⁹ Some states, including Georgia, restrict the types of beneficiaries who can be assigned to TNCs; however, states do not have a uniform approach to dealing with this issue.

⁶⁰ TNCs have made efforts to better meet the needs of the Medicaid program. For example, Lyft provides automated voice calls to notify riders of their trip details; an application

programming interface (API) solution that integrates Lyft's ride management tools, communication platforms, and reporting capabilities into brokers' existing systems; and custom pickup and drop-off locations for large hospital campuses or medical buildings.

⁶¹ Some NEMT brokers and providers were able to adapt; for example, in Connecticut, large livery providers outfitted cars with Plexiglas and provided personal protective equipment (PPE) to drivers, and they were contracted to provide safe transportation including rides for COVID-19-positive individuals. The state broker for NEMT, Veyo, reported using NEMT providers to deliver meals and PPE to Medicaid beneficiaries, which also helped to maintain their network.

⁶² County transit programs include those established under FTA's Formula Grants for Rural Areas program (referred to as the Section 5311 program).

⁶³ MotivCare is allowed to use its own vehicles in rural northern Maine to ensure coverage. However, brokers noted that there are limits on this approach due to restrictions on self-referrals (§ 1902(a)(70)(B)(iv) of the Social Security Act).

⁶⁴ Spending data are not available for most other programs funding human services transportation (DOT 2019, GAO 2014).

⁶⁵ The other five state agencies are the Department of Developmental Services, Department of Public Health's Early Intervention Program, Massachusetts Rehabilitation Commission, Massachusetts Commission for the Blind, and Department of Mental Health.

⁶⁶ Executive Order 13330 established CCAM in 2004. Section 3006(c) of the Fixing America's Surface Transportation Act (P.L. 114-94), enacted in 2015, specifically requires CCAM to improve federal coordination of transportation services for people with disabilities, older adults, and individuals of low income. Federal transportation reauthorization bills since then have also required coordination.

⁶⁷ In most of Pennsylvania, the Medicaid NEMT program operates, at least partially, through an in-house or county-based model. In Vermont, the Department of Vermont Health Access contracts with the Vermont Public Transportation Association (VPTA) that serves as the statewide NEMT broker. VPTA then subcontracts with local public transit operators who are able to coordinate NEMT with other public transit in the area.

⁶⁸ According to FTA officials, CCAM is currently developing a cost allocation tool that will allow the user (e.g., the NEMT provider or transit agency) to identify and bill Medicaid for the specific costs of a Medicaid eligible beneficiary taking a specific trip or trip segment, even if the Medicaid beneficiary shared the ride with an individual from another program.

⁶⁹ This issue is most common in shared NEMT rides, such as shared vans, when every seat in the vehicle is filled by a beneficiary attending an appointment (i.e., there are no additional seats for children or siblings). There is more flexibility to allow children and siblings in rides that are not shared, such as taxi or TNC rides.

⁷⁰ These interviewees noted that brokers often refuse to share complete data on complaints or on-time performance with states, making oversight difficult.

⁷¹ For example, CMS sometimes connects states interested in adopting certain NEMT policies or approaches with other states who have already done so.

⁷² For example, advocates requested that CMS extend the 100 percent FMAP provided by Section 9811 of the American Rescue Plan Act (P.L. 117-2) for administration of vaccines to NEMT (Brown 2021). As of April 2021, CMS has not issued guidance on the parameters for the 100 percent FMAP.

⁷³ For example, New Jersey and South Carolina require real-time GPS tracking. Massachusetts will require GPS capability in its next procurement. On the other hand, Connecticut's state legislature opposed the state Medicaid agency and its broker's efforts to require providers to use a GPS-enabled application.

⁷⁴ This requirement is effective on the date of enactment with an exception for states that need legislative approval to make changes to their state plan. These states will not be considered out of compliance until the first day of the first calendar quarter beginning after the close of the first regular session of the state legislature that begins after the date of enactment.

⁷⁵ The law also notes that states that take up the state plan option to use a third-party broker to administer NEMT may consult with stakeholders. It is important to note, however, that states were not previously prohibited from consulting with stakeholders.

⁷⁶ Medicare special needs plans are Medicare Advantage plans designed specifically to serve enrollees who have chronic conditions, are dually eligible for Medicare and Medicaid, or are institutionalized.

⁷⁷ Specifically, most states have expanded coverage of telehealth, including the types of providers eligible to deliver such services and modalities (i.e., allowing telephone and text-based platforms, which had generally not been previously permitted) (Libersky et al. 2020).

⁷⁸ Available research suggests high rates of patient and provider satisfaction with telehealth, although few studies have focused specifically on Medicaid enrollees or on specific populations or settings (MACPAC 2018). Additionally, there are some anecdotal reports of beneficiary satisfaction with telehealth services during the COVID-19 pandemic (Salek 2021).

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APPENDIX 5A: Methodology and Data Limitations for T-MSIS Analysis

This technical guide is intended to help readers interpret the exhibits within this document as well as understand the data source and methods used.

Measuring NEMT utilization

Utilization estimates are based on data from the Transformed Medicaid Statistical Information System (T-MSIS) for fiscal year (FY) 2018 for services in the other services (OT) File. The OT file captures services that cannot be categorized as inpatient, prescription drugs, or long-term services and supports delivered in inpatient settings and can therefore be considered a good proxy for all outpatient services. Our utilization estimates are calculated for all full-benefit enrollees. They are calculated using both fee-for-service NEMT claims and encounters for NEMT services administered by a managed care plan.

Full-benefit enrollment was determined using characteristics from the beneficiaries' most recent month available for enrollment. For each full-benefit enrollee, we determined the number of days in which each of the following Healthcare Common Procedural Coding System (HCPCS) codes related to non-emergency transportation were used (Table 5A-1).

We have presented estimates as ride-days instead of rides because multiple procedure codes are often used for the same trip, depending on the ride's characteristic. For example, both a parking reimbursement code and a transport taxi code might be used for the same trip, because a driver would be reimbursed while the patient is attending a physician visit. Moreover, in some states, multileg trips (e.g., a round trip) are coded as multiple rides, while in others, they may be coded as one ride. To avoid potential duplications of rides and adjust for variation in state billing practices, we counted the number of days where a ride appears to have occurred, as opposed to counting individual rides.

Certain services, such as meals, lodging, and parking fees, can be considered NEMT services. These non-transportation ancillary services have not been included in estimates of NEMT use, but are included in estimates of NEMT spending.

TABLE 5A-1. NEMT Procedure Codes

Code	Code description	Code type	MACPAC description
A0080	Volunteer vehicle mileage	HCPCS	Individual
A0090	Individual vehicle mileage	HCPCS	Individual
A0100	Non-emergency transport taxi	HCPCS	Taxi
A0110	Public or mass transportation	HCPCS	Public transportation
A0120	Non-emergency transport mini-bus	HCPCS	Van
A0130	Non-emergency transport wheelchair van	HCPCS	Van
A0140	Non-emergency transport air	HCPCS	Airplane
A0160	Case worker NEMT	HCPCS	NEMT other
A0170	Transport parking fees or tolls	HCPCS	Non-transport ancillary services
A0180	NEMT: lodging recipient	HCPCS	Non-transport ancillary services

TABLE 5A-1. (continued)

Code	Code description	Code type	MACPAC description
A0190	NEMT: meals recipient	HCPCS	Non-transport ancillary services
A0200	NEMT: lodging escort	HCPCS	Non-transport ancillary services
A0210	NEMT: meals escort	HCPCS	Non-transport ancillary services
S0209	Wheelchair van mileage	HCPCS	Van
S0215	Non-emergency transportation mileage	HCPCS	Van
T2001	Non-emergency transportation: patient attendant or escort	HCPCS	NEMT other
T2002	Non-emergency transportation: per diem	HCPCS	NEMT other
T2003	Non-emergency transportation: encounter or trip	HCPCS	NEMT other
T2004	Non-emergency transportation: commercial carrier pass	HCPCS	NEMT other
T2005	Non-emergency transportation: stretcher van	HCPCS	Van
T2007	Non-emergency transport wait time	HCPCS	NEMT other
Z2713	Non-emergency transportation	Arkansas	NEMT other
W7274	Transportation (non-emergency trip): 0–20 miles	Pennsylvania	NEMT other
W7275	Transportation (non-emergency trip): 20–40 miles	Pennsylvania	NEMT other
W7276	Transportation (non-emergency trip): 40–60 miles	Pennsylvania	NEMT other
M0372	Transportation: level of care 1 (medication management)	Texas	NEMT other
M0419	Transportation: community support	Texas	NEMT other
M0373	Transportation: consumer directed services (CDS), level of care 1	Texas	NEMT other
M0374	Transportation: level of care 8	Texas	NEMT other
M0418	Transportation: CDS, level of care 8	Texas	NEMT other
M0420	Transportation: CDS, community support	Texas	NEMT other

Notes: NEMT is non-emergency medical transportation. HCPCS is Healthcare Common Procedure Code System. In our construction of our NEMT algorithm we found three states (Arkansas, Pennsylvania, and Texas) with a large number of claims and encounters with state-specific NEMT codes.

Source: MACPAC, 2021, analysis of Transformed Medicaid Statistical Information System (T-MSIS).

We also quantified NEMT destinations using HCPCS procedure code modifiers that some states use to determine the NEMT ride's destination (Table 5A-2). The results presented in this document count the number of days in which the NEMT procedure code

has a modifier that enables categorization of a ride's destination. For this specific analysis we limited the sample to the six states where more than 95 percent of NEMT claims were filled in with a known non-missing procedure code modifier.

TABLE 5A-2. NEMT Destination Procedure Code Modifiers

HCPSC modifier	HCPSC description	MACPAC description
D	Diagnostic or therapeutic site	Diagnostic or therapeutic site
E	Residential, domiciliary, custodial facility, other than a skilled nursing facility	Residential facility
G	Hospital-based end-stage renal disease facility	Dialysis facility
H	Hospital	Hospital
J	Dialysis facility	Dialysis facility
N	Nursing facility	Nursing facility
P	Physician office	Physician office
R	Residence	Residence
I	Site of transfer	Other
S	Scene of accident or acute event	Other
X	Intermediate stop at physician office on way to hospital	Other

Notes: NEMT is non-emergency medical transportation. HCPSC is Healthcare Common Procedure Code System.

Source: MACPAC, 2021, analysis of Transformed Medicaid Statistical Information System (T-MSIS) data.

Limitations

It is important to note that the NEMT project is MACPAC’s first attempt to leverage T-MSIS to review service-level utilization, and among the first attempts among T-MSIS users to review service-level utilization. Limitations in our analysis of T-MSIS data include the following:

Methods of accounting for variation in billing practices may result in undercount. As noted above, MACPAC uses ride-days to quantify utilization. This method allows us to adjust for state-level variation in how NEMT rides are reported, but it may result in an underestimate of the total number of NEMT rides.

States may differ in how they define NEMT within their medical claims. MACPAC’s method of identifying NEMT rides is unable to capture rides that are not billed under typical NEMT procedure codes (Table 5A-1). This limitation may also result in an undercount of NEMT ride-days.

Limitations in identifying non-emergency ambulance rides. Even though ambulances may be used for NEMT rides, we do not include ambulance rides in our definition of NEMT because of challenges differentiating between emergency and non-emergency ambulance claims and encounters. This limitation likely results in an undercount of NEMT ride-days.

Undercounts of ride-days for individuals accessing methadone treatment. CMS’s chronic conditions warehouse algorithm for opioid use disorder (OUD) does not include methadone treatment, affecting MACPAC’s ability to identify rides to opioid treatment programs among beneficiaries with OUD. As a result, our estimates for NEMT utilization by diagnoses are likely undercounting beneficiaries with OUD (Figure 5-1).

Limitations in identifying NEMT service destinations. Most states do not require NEMT providers to provide a destination for an NEMT claim within T-MSIS (Figure 5-2). Only the six states with over 95 percent of identifiable destinations are

included in the sample for this report. We do not have enough information to determine whether the distribution of NEMT service destinations is similar in other states or on a national level.

Inability to report managed care payments to NEMT providers. We do not report spending on NEMT delivered through managed care plans because these plans deliver many other Medicaid benefits. For example, a capitation payment for comprehensive managed care includes reasonable, appropriate, and attainable costs within the managed care plan's benefit package as specified in its contract with the state. Because of these limitations, we do not include a breakdown of NEMT spending by eligibility group, dually eligible status, urban versus rural, diagnosis, mode of transportation, or transportation destination, because such a breakdown would leave out a large segment of beneficiaries who receive their NEMT benefit through a managed care plan. This approach is consistent with other MACPAC work—MACPAC historically has not reported managed care payments to providers for services.

State-level data. Because this is one of the first efforts to estimate NEMT utilization using medical claims, there are few external benchmarks that can be used to assess results. For this reason, we decided not to report state-level estimates and are instead reporting national estimates.

Age of data. FY 2018 data, the most recent available data when MACPAC's work began, does not allow us to capture changes in NEMT utilization during the COVID-19 pandemic, or changes resulting from more states expanding Medicaid under the Patient Protection and Affordable Care Act (P.L. 111-148, as amended) in 2019 and 2020. As of March 2021, FY 2019 T-MSIS data are still preliminary.

Chapter 6:

Improving Integration for Dually Eligible Beneficiaries: Strategies for State Contracts with Dual Eligible Special Needs Plans

Improving Integration for Dually Eligible Beneficiaries: Strategies for State Contracts with Dual Eligible Special Needs Plans

Key Points

- The 12.3 million individuals dually eligible for Medicaid and Medicare may experience fragmented care and poor health outcomes when their benefits are not coordinated. Integrated care models can improve the beneficiary experience and may reduce federal and state spending. However, only about 10 percent of dually eligible beneficiaries were enrolled in integrated care models in 2019.
- In this chapter, we focus on ways state Medicaid programs can use their contracts with Medicare Advantage dual eligible special needs plans (D-SNPs) to promote greater integration and increase enrollment in integrated plans. D-SNPs currently enroll over 3 million dually eligible beneficiaries and are available in 43 states and the District of Columbia.
- The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) requires D-SNPs to have contracts with the states in which they operate, sets minimum integration standards, and gives states the authority to add requirements for D-SNPs.
- MACPAC identified strategies states can use to exercise their MIPPA authority to better integrate Medicaid and Medicare and factors affecting states' ability to implement these strategies.
- Some MIPPA strategies can be deployed by any state. For example, states can contract directly with D-SNPs to cover Medicaid benefits, so that the plan covers both Medicaid and Medicare benefits. This strategy may be particularly useful for states that do not enroll dually eligible beneficiaries in Medicaid managed care.
- Other strategies are easiest to implement in states with experience using Medicaid managed care. For example, certain states can approve D-SNPs to automatically enroll a Medicaid member becoming eligible for Medicare if the D-SNP is of the same parent company as the beneficiary's current Medicaid plan. This strategy, known as default enrollment, can ensure a smooth transition from Medicaid-only coverage to integrated coverage for those dually eligible.
- States are at different stages of integrating care for their dually eligible populations. For example, a few states, such as Arizona, Idaho, and Tennessee, have maximized their MIPPA authority and are providing fully integrated care. Other states, such as North Dakota and Wyoming, do not have D-SNPs, and no other integrated options are available. Variation in how states exercise MIPPA authorities may also reflect variations in state capacity and competing priorities.
- Over the next year, the Commission will explore how federal policy could be used to raise the bar on integration.

CHAPTER 6: Improving Integration for Dually Eligible Beneficiaries: Strategies for State Contracts with Dual Eligible Special Needs Plans

Over the past several years, the Commission has focused on integrating care for the 12.3 million Americans who are covered by both Medicaid and Medicare, known as dually eligible beneficiaries (CMS 2020a; MACPAC 2020a, 2020b).¹ As noted in our prior work, dually eligible beneficiaries often experience fragmented care and poor health outcomes due to poor coordination of services across the two programs. Beneficiaries of color, who accounted for nearly half (48 percent) of all dually eligible beneficiaries in 2019, are particularly affected, experiencing additional barriers to access, such as language barriers, when navigating both Medicaid and Medicare (CMS 2020a, Sharma 2014). Moreover, dually eligible beneficiaries account for about one-third of total costs to the federal government and the states in each program, although they represent about 15 percent of Medicaid beneficiaries and 20 percent of Medicare beneficiaries (CMS 2020a, 2020b).

While integrating care for this high-cost, high-need population has the potential to improve beneficiaries' health and reduce federal and state spending, the number of beneficiaries enrolled in integrated models remains low, at just over 1 million (10 percent) full-benefit dually eligible beneficiaries in 2019 (CMS 2020b).² Moreover, while states and the federal government have been working together to develop and implement a variety of integrated models under managed care arrangements, often the focus has been on the Financial Alignment

Initiative (FAI) or the Program of All-Inclusive Care for the Elderly (PACE).

In this chapter, we take a deeper look at the potential of dual eligible special needs plans (D-SNPs) to promote greater integration. D-SNPs, a type of Medicare Advantage (MA) plan designed to meet the specific needs of dually eligible beneficiaries, serve more beneficiaries than other integrated models with enrollment of over 3 million beneficiaries as of January 2021. In comparison, Medicare-Medicaid plans (MMPs) offered under the FAI and PACE enrolled 395,000 and 55,000 beneficiaries, respectively (CMS 2021a, ICRC 2021, NPA 2021). D-SNPs are currently available in 43 states and the District of Columbia (CMS 2021a).

Importantly, although D-SNPs are meant to address the unique needs of dually eligible beneficiaries, they do not always provide highly integrated coverage. States have authority under current law to improve integration under the D-SNP model. The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) requires all D-SNPs to have contracts with Medicaid programs in the states in which they operate. These contracts define how D-SNPs will coordinate Medicaid and Medicare benefits. MIPPA requires that state contracts with D-SNPs meet a minimum set of requirements, described in 42 CFR 422.107(c) (Box 6-1) (CMS 2019a). Although the regulations include some minimal coordination between the D-SNP and the state, they do not result in fully integrated coverage (MedPAC 2019).

BOX 6-1. Regulatory Requirements for Dual Eligible Special Needs Plan Contracts with States

42 CFR 422.107 Special needs plans and dual eligibles: Contract with State Medicaid Agency.

- (a) *Definition.* For the purpose of this section, a contract with a State Medicaid agency means a formal written agreement between an MA [Medicare Advantage] organization and the State Medicaid agency documenting each entity's roles and responsibilities with regard to dual eligible individuals.
- (b) *General rule.* MA organizations seeking to offer a dual eligible special needs plan must have a contract consistent with this section with the State Medicaid agency.
- (c) *Minimum contract requirements.* At a minimum, the contract must document—
- (1) The MA organization's responsibility to—
 - (i) Coordinate the delivery of Medicaid benefits for individuals who are eligible for such services; and
 - (ii) If applicable, provide coverage of Medicaid services, including long-term services and supports and behavioral health services, for individuals eligible for such services.
 - (2) The category(ies) and criteria for eligibility for dual eligible individuals to be enrolled under the SNP [Special Needs Plan], including as described in sections 1902(a), 1902(f), 1902(p), and 1905 of the Act.
 - (3) The Medicaid benefits covered under a capitated contract between the State Medicaid agency and the MA organization offering the SNP, the SNP's parent organization, or another entity that is owned and controlled by the SNP's parent organization.
 - (4) The cost-sharing protections covered under the SNP.
 - (5) The identification and sharing of information on Medicaid provider participation.
 - (6) The verification of enrollee's eligibility for both Medicare and Medicaid.
 - (7) The service area covered by the SNP.
 - (8) The contract period for the SNP.
 - (9) For each dual eligible special needs plan that is an applicable integrated plan as defined in § 422.561, a requirement for the use of the unified appeals and grievance procedures under §§ 422.629 through 422.634, 438.210, 438.400, and 438.402.
- (d) *Additional minimum contract requirement.* For any dual eligible special needs plan that is not a fully integrated or highly integrated dual eligible special needs plan, the contract must also stipulate that, for the purpose of coordinating Medicare and Medicaid-covered services between settings of care, the SNP notifies, or arranges for another entity or entities to notify, the State Medicaid agency, individuals or entities designated by the State Medicaid agency, or both, of

BOX 6-1. (continued)

hospital and skilled nursing facility admissions for at least one group of high-risk full-benefit dual eligible individuals, identified by the State Medicaid agency. The State Medicaid agency must establish the timeframe(s) and method(s) by which notice is provided. In the event that a SNP authorizes another entity or entities to perform this notification, the SNP must retain responsibility for complying with this requirement.

(e) Date of Compliance.

(1) Effective January 1, 2010—

(i) MA organizations offering a new dual eligible SNP must have a State Medicaid agency contract.

(ii) Existing dual eligible SNPs that do not have a State Medicaid agency contract—

(A) May continue to operate through the 2012 contract year provided they meet all other statutory and regulatory requirements.

(B) May not expand their service areas during contract years 2010 through 2012.

(2) MA organizations offering a dual eligible SNP must comply with paragraphs (c)(9) and (d) of this section beginning January 1, 2021 (42 CFR 422.107).

MIPPA authority can be a powerful tool, but few states have exercised it fully. This may be due to limited state experience using managed care to provide Medicaid coverage to dually eligible beneficiaries, a lack of Medicare expertise, and competing priorities. As a result, many D-SNPs do not provide much integration beyond the minimum requirements. However, a few states have used MIPPA contracts to require plans to cover certain Medicaid benefits and meet other standards for higher levels of integration.³ Centers for Medicare & Medicaid Services (CMS) regulations classify this subset of D-SNPs as highly integrated dual eligible special needs plans (HIDE SNPs) or fully integrated dual eligible special needs plans (FIDE SNPs), depending on the Medicaid benefits they cover (42 CFR 422.107, CMS 2020c). HIDE SNPs must cover either behavioral health or long-term services and supports (LTSS). FIDE SNPs must cover both unless the state carves behavioral health services out of the capitation rate (MACPAC 2020a).

Although the D-SNP model has its limitations as an approach to integrating care, strengthening states' ability to leverage it can be an important step in increasing the extent to which care is integrated for beneficiaries. Over the past year, with the help of a contractor, MACPAC reviewed state contracts with D-SNPs and conducted interviews with a variety of stakeholders to identify contracting strategies authorized through MIPPA that states can deploy to better integrate Medicaid and Medicare services. We share the most promising approaches in this chapter, based on state ability to implement the strategies.

Building on the Commission's work thus far, over the coming year, we will explore incentives for states to improve integration for their dually eligible populations and how federal policy could be used to raise the bar on integration, keeping in mind that state efforts to integrate care are at different stages. State progress on integration reflects past

policy choices, features of health care markets, and current state capabilities and priorities. As such, we plan to engage with stakeholders, including states, plans, providers, and beneficiaries, to consider the merits and trade-offs associated with different approaches. Our goal is to expand the discussion of integrated care that we started several years ago to identify opportunities for which incentives for states could advance integrated care efforts and lead to more enrollment in integrated models.

Why Focus on D-SNPs?

Although a number of integrated models are authorized in law, we focus on D-SNPs in this chapter because of their wide availability across geographic areas, the growing number of dually eligible beneficiaries enrolled in them, and the availability of existing tools that states can use to integrate care for beneficiaries. Maximizing the use of existing D-SNP contracting authority could further integrate coverage for a large share of dually eligible beneficiaries, without federal legislative changes or rulemaking, particularly when combined with other state policies. Although other integrated care models, such as MMPs and PACE, offer higher levels of integration than some D-SNPs because all Medicaid and Medicare services are covered and coordinated by a single health plan or organization, expanding those models could require statutory changes (Box 6-2).

The terms used to describe integrated models can be confusing and can sometimes overlap. To be clear, throughout this chapter, we will use the following terms to describe relationships among plans serving dually eligible beneficiaries:

- Aligned plans are D-SNPs and Medicaid managed care plans that are owned by the same parent company.

- Aligned enrollment refers to beneficiaries receiving Medicaid and Medicare benefits through the same entity. This occurs when a beneficiary receives all benefits from a D-SNP or is enrolled in a D-SNP and a Medicaid managed care plan that are owned by the same parent company.
- Exclusively aligned enrollment occurs when the state's contract with the D-SNP limits enrollment to full-benefit dually eligible beneficiaries who receive Medicaid benefits from the D-SNP or an aligned Medicaid managed care plan owned by the D-SNP's parent company.

D-SNPs are widely available, and enrollment is increasing. As of January 2021, D-SNPs are available in 43 states and the District of Columbia, and 93 percent of dually eligible beneficiaries live in a county in which at least one D-SNP is available (Figure 6-1) (CMS 2021a, 2021b, 2020d).⁴ The share of the dually eligible population that lives where D-SNPs are available is high because most dually eligible beneficiaries live in urban areas, where D-SNPs are more likely to be available (MACPAC and MedPAC 2018). Enrollment in D-SNPs has increased steadily since they first began operating in 2006 (Archibald et al. 2019). As of February 2021, about 3 million dually eligible beneficiaries were enrolled in D-SNPs, representing about 26 percent of the dually eligible population (CMS 2021a, CMS 2020a).⁵ The majority, 1.7 million, were enrolled in minimally integrated D-SNPs, and the remainder were enrolled in HIDE SNPs or FIDE SNPs. Enrollment in HIDE SNPs represents about 34 percent of all D-SNP enrollment, and enrollment in FIDE SNPs represents about 9 percent (CMS 2021a).

BOX 6-2. Integrated Models on a Continuum

Low level of integration

- Dual eligible special needs plan (D-SNP). The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) contract with the state meets minimum requirements for coordination of Medicaid benefits (42 CFR 422.107(c) and (d)).

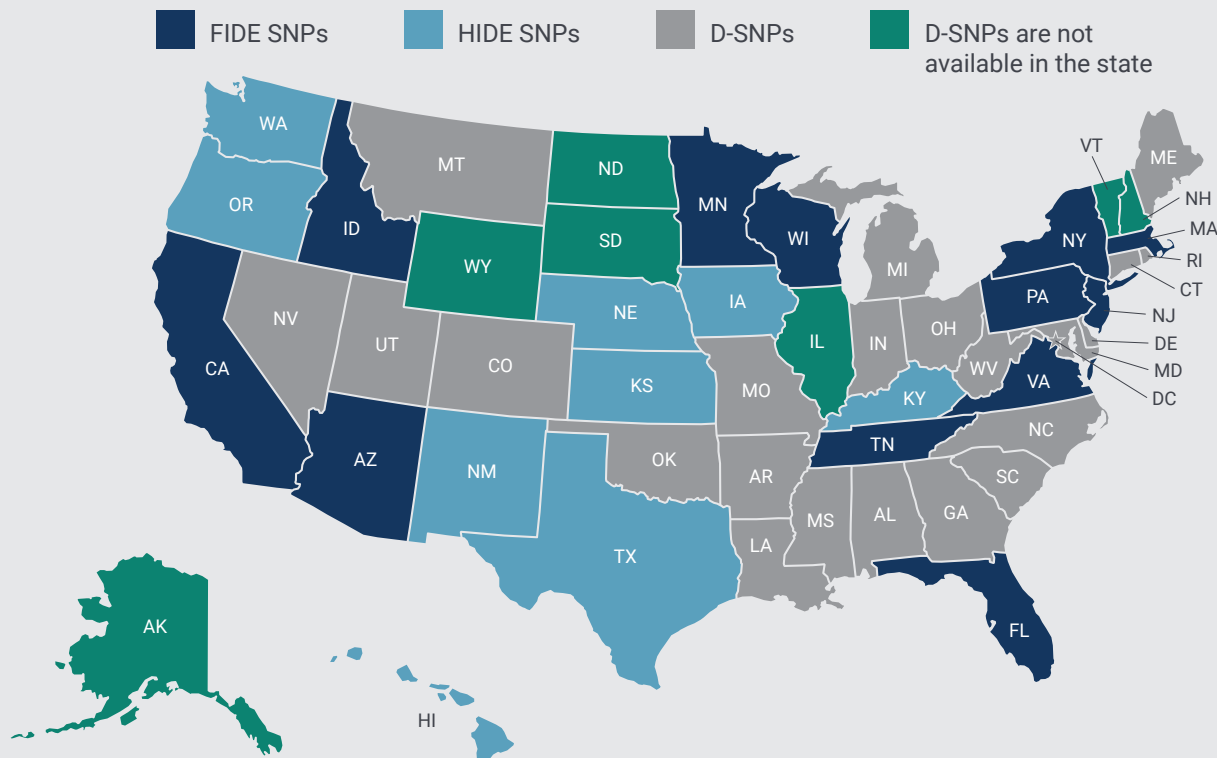
Moderate level of integration

- D-SNP plus Medicaid managed care. MIPPA contract reflects provision of some Medicaid benefits, like coverage of Medicare cost sharing, by the aligned Medicaid managed care plan, but LTSS is not covered.
- D-SNP plus managed long-term services and supports (MLTSS). MIPPA contract reflects provision of some Medicaid benefits, including LTSS, by the aligned MLTSS plan that is owned by the same parent company as the D-SNP.
- Highly integrated dual eligible special needs plan (HIDE SNP). Moderate level of coordination with Medicaid. MIPPA contract includes requirement to provide MLTSS or behavioral health or both.

High level of integration

- Fully integrated dual eligible special needs plan (FIDE SNP). Higher level of coordination with Medicaid. MIPPA contract includes requirement to provide MLTSS and behavioral health, unless the state carves behavioral health out of the capitation rate.
- Medicare-Medicaid plan (MMP). Under the Financial Alignment Initiative (FAI), MMPs enter into three-way contracts with CMS and the state to provide all Medicaid and Medicare benefits.
- Program of All-Inclusive Care for the Elderly (PACE). PACE organization contracts with CMS and the state to provide all Medicaid and Medicare benefits.

FIGURE 6-1. Most Highly Integrated Type of Dual Eligible Special Needs Plan Available by State, 2021



Notes: D-SNP is dual eligible special needs plan. FIDE SNP is fully integrated dual eligible special needs plan. HIDE SNP is highly integrated dual eligible special needs plan. This figure shows the most integrated type of D-SNP available in the state or District of Columbia as of January 2021. States may have more than one type of D-SNP available, and plans are not always available statewide. HIDE SNPs were first available starting in 2021.

In 2017, Illinois chose not to continue contracts with D-SNPs to focus on Medicare-Medicaid plans as a platform for integrating care (MedPAC 2019). Washington does not have comprehensive Medicaid managed care for dually eligible beneficiaries, but it does have HIDE SNPs formed by aligning D-SNPs with behavioral health organizations.

Source: MACPAC, 2021, analysis of Medicare Advantage special needs plan landscape file as of January 2021.

D-SNPs provide coverage to a diverse group of dually eligible beneficiaries, including individuals age 65 and older and younger people with disabilities, and the health needs of the population vary (MACPAC 2020a). They also serve both individuals eligible for full Medicaid benefits, known as full-benefit dually eligible beneficiaries, and individuals eligible for partial Medicaid benefits, known as partial-benefit dually eligible beneficiaries. Partial-benefit dually eligible beneficiaries are eligible for Medicaid assistance only with Medicare premiums and sometimes cost sharing. As discussed later in this chapter, states can use

contract requirements to limit D-SNP enrollment to full-benefit dually eligible beneficiaries.

Implementation of Bipartisan Budget Act of 2018 Requirements

In 2019, CMS finalized new regulations for D-SNPs that updated classifications of plans depending on their level of integration (CMS 2019a). Those that offer higher levels of integration by covering

some Medicaid services can be designated as HIDE SNPs or FIDE SNPs. Beginning in 2021, D-SNPs are designated as HIDE SNPs if they have a contract with the state Medicaid agency to cover either LTSS or behavioral health services.⁶ D-SNPs are designated as FIDE SNPs if they cover both LTSS and behavioral health services, in addition to other Medicaid benefits under their MIPPA contracts (MACPAC 2020a).⁷

The HIDE-SNP and FIDE-SNP designations affect plans' ability to participate in some states and the amount of Medicare payment received by the plan. States may require some or all plans applying to operate a D-SNP in the state to meet the criteria for designation as a HIDE SNP or FIDE SNP. For example, Idaho requires D-SNPs in the state to meet the FIDE SNP designation (Spencer et al. 2018). FIDE SNPs may also receive additional Medicare payments through a frailty adjustment if CMS determines beneficiaries enrolled in a FIDE SNP have an average level of frailty similar to those enrolled in PACE (MACPAC 2020a).

The Bipartisan Budget Act of 2018 (BBA 2018, P.L. 115-123), which permanently authorized D-SNPs, requires D-SNPs to take additional steps to promote integration, beyond what was required in MIPPA (42 CFR 422.107(d)) (Box 6-1). Specifically, it required D-SNPs to meet one of three criteria to improve integration or coordination of care: (1) meet the requirements to be designated as a FIDE SNP, (2) meet the requirements to be designated as a HIDE SNP, or (3) notify the state of hospital or skilled nursing facility admissions for at least one group of high-risk enrollees (CMS 2019b). For D-SNPs to comply with the third requirement, the state must specify, within its MIPPA contract, the group of high-risk individuals for whom a notification must be sent and the time frame and process for sending notifications to either the state or a designee of the state's choosing.⁸ The BBA 2018 also unified the grievance and appeals process for some D-SNPs (42 CFR 422.107(d)) (Box 6-1).

MIPPA Strategies for State Contracts with D-SNPs

States can use their MIPPA contracts with D-SNPs to require these plans to take additional steps to better integrate coverage and care (Table 6-1). Some strategies can be implemented by all states, while others can be implemented only by states with Medicaid managed care for dually eligible beneficiaries.

TABLE 6-1. Strategies for State Contracts with Dual Eligible Special Needs Plans, 2021

Strategy
All states can use these strategies:
Limit D-SNP enrollment to full-benefit dually eligible beneficiaries
Contract directly with D-SNPs to cover Medicaid benefits
Require D-SNPs to use specific or enhanced care coordination methods
Require D-SNPs to send data or reports to the state for oversight purposes
Require state review of D-SNP materials related to delivery of Medicaid benefits
Partner with D-SNPs to develop supplemental benefit packages that complement Medicaid benefits
States with Medicaid managed care can use these strategies:
Selectively contract with D-SNPs or Medicaid managed care plans that offer aligned plans
Require complete service area alignment
Require D-SNPs to operate with exclusively aligned enrollment
Allow or require D-SNPs to use default enrollment
Automatically assign D-SNP enrollees to Medicaid plans under the same parent organization
Incorporate Medicaid quality improvement priorities into the D-SNP contract
Automate Medicaid crossover claims payment processes for payment of Medicare cost sharing

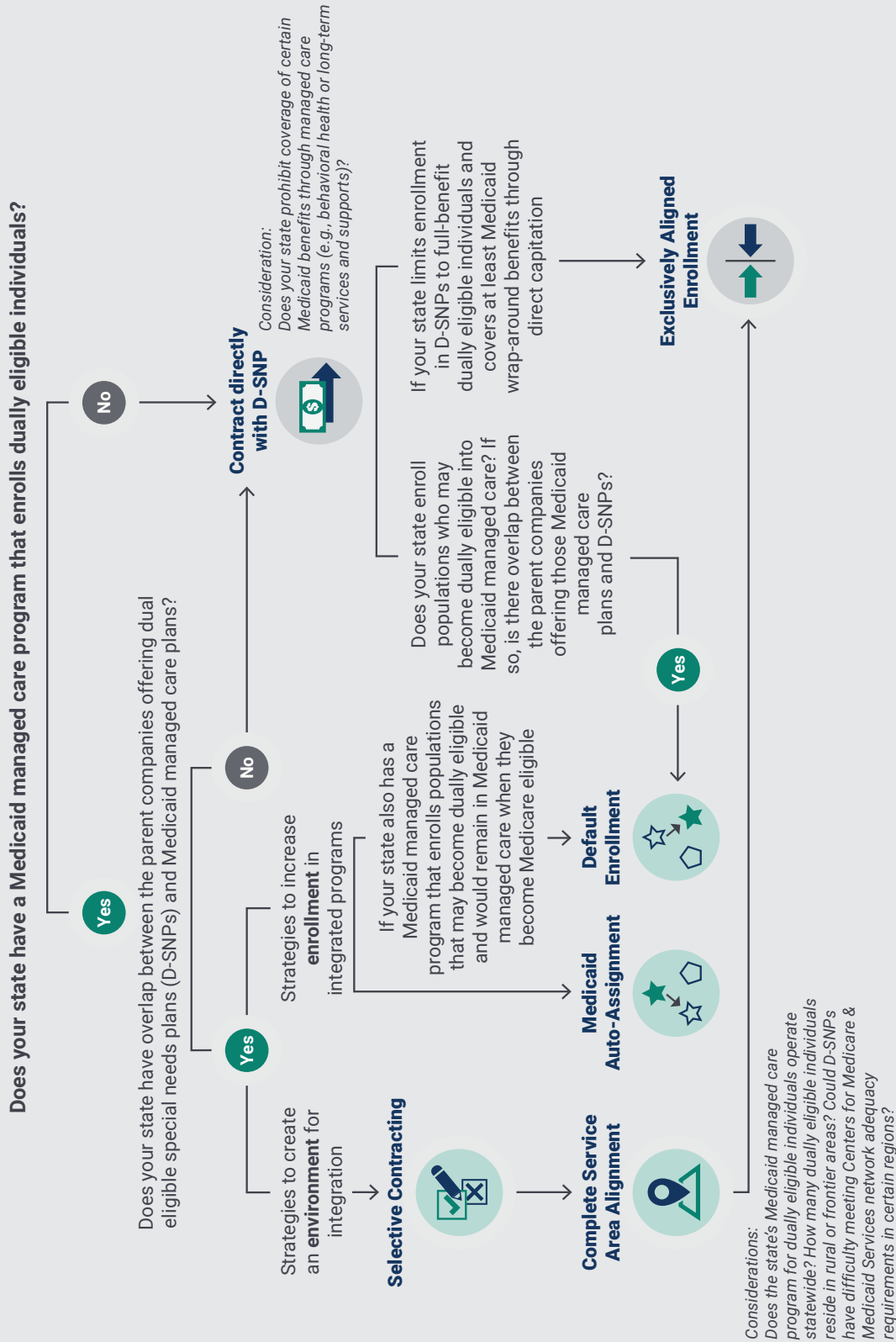
Notes: D-SNP is dual eligible special needs plan. These strategies are available to states under authority established in the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275). This list is not exhaustive. We chose these strategies based on state use of the strategies to advance integration and on interviews with stakeholders.

Source: Mathematica, 2021, analysis for MACPAC of MIPPA strategies for contract years 2020 and 2021 and interviews with stakeholders.

To explore opportunities for states to maximize their MIPPA contracting authority, we contracted with Mathematica to review state contracts with D-SNPs and conduct 16 semistructured interviews with representatives from four states (California, Idaho, Indiana, and Virginia) and the District of Columbia, five health plans, and two beneficiary advocacy organizations. The Mathematica team also spoke with officials at CMS. Specifically, we were interested in learning about the advantages and disadvantages of various contracting strategies, the factors affecting their use, and examples of states currently using them.

We briefly describe each of the MIPPA strategies available to states, including examples of states that are using them (Figure 6-2). These are described in more detail in Appendix 6A.

FIGURE 6-2. Determining Which Strategies States Can Use in Contracts with Dual Eligible Special Needs Plans, 2021



Source: Mathematica, 2021, analysis for MACPAC of MIPPA strategies states can use to improve integration in D-SNPs.

Strategies all states can use

The following are MIPPA strategies that all states can use:

Limit D-SNP enrollment to full-benefit dually eligible beneficiaries. States can require that D-SNPs limit enrollment to full-benefit dually eligible beneficiaries, as is now the case for MMPs. This strategy allows uniformity for plan enrollees, including a single set of benefits and rules around care coordination. However, requiring that partial-benefit dually eligible beneficiaries disenroll from D-SNPs and enroll in a regular MA plan potentially disrupts their coverage. Another potential drawback of requiring disenrollment is that partial-benefit dually eligible beneficiaries can still benefit from the supplemental benefits and care coordination offered by a D-SNP (that would not be available in a regular MA plan) even though they receive no Medicaid benefits. Examples of states using this strategy include Arizona, Hawaii, and Idaho.

As an alternative to limiting enrollment in D-SNPs to the full-benefit population, states could consider requiring D-SNPs to establish separate plan benefit packages for full- and partial-benefit dually eligible beneficiaries through their MIPPA contracts.⁹ Some states, including Pennsylvania and Virginia, already do this. Establishing separate plan benefit packages may address concerns about diluting integration. It could also alleviate concerns around disruptions in coverage.

Although states can require D-SNPs to use separate plan benefit packages, the Commission would need to do additional research to better understand who would be affected and the implications for beneficiaries, states, and plans. We plan to explore the benefits and challenges of using separate plan benefit packages and the advantages of cross-walking or transitioning beneficiaries between plan benefit packages. This approach avoids an enrollment transaction and beneficiaries are not required to make an enrollment election in order to remain enrolled, something that CMS recently approved for D-SNPs, starting in 2022 (CMS 2021c).

Contract directly with D-SNPs to cover Medicaid benefits under a capitation payment. States can contract directly with D-SNPs for coverage of Medicaid benefits. This strategy can be useful for states that do not otherwise enroll dually eligible beneficiaries in Medicaid managed care or states in which there is no overlap between the parent companies of the D-SNP and Medicaid managed care plans. Examples of states using this strategy to cover some or all Medicaid benefits include Alabama, Florida, and Idaho.

States that contract directly with FIDE SNPs to cover all Medicaid benefits may also be able to use other strategies that are typically available only to states with Medicaid managed care, discussed in more detail later in this chapter. For example, states may be able to require that FIDE SNPs operate with exclusively aligned enrollment, meaning that beneficiaries would receive all their benefits from the FIDE SNP. Idaho is an example of a state using this strategy. States that have Medicaid managed care and directly contract with FIDE SNPs to cover Medicaid benefits may also be able to default enroll Medicaid beneficiaries into FIDE SNPs aligned with their Medicaid managed care plan when they become eligible for Medicare.

Require D-SNPs to use specific or enhanced coordination methods. States can add requirements to their MIPPA contracts to enhance care coordination. For example, they can require that D-SNPs train their care coordinators to be familiar with Medicaid benefits to help beneficiaries access these services. Examples of states using this strategy include Idaho, Massachusetts, and Minnesota.

Require D-SNPs to send data or reports to the state for oversight purposes. States can require that D-SNPs submit data or reports to states for oversight of operations and quality of care. For example, requiring D-SNPs to submit encounter data or data on Part D prescription drugs can help the state obtain a comprehensive picture of which Medicaid and Medicare services enrollees are using and identify areas for improvement, such

as added care coordination. Examples of states using this strategy include Arizona, Massachusetts, Minnesota, and Oregon.

Require state review of D-SNP materials related to delivery of Medicaid benefits. States can require that D-SNPs submit enrollee communication materials for state review, prior to use. D-SNP materials can be complicated for dually eligible beneficiaries because they may receive two sets of materials, one for their Medicaid benefits and one for their Medicare benefits. This strategy could ensure consistency in Medicaid benefit descriptions across D-SNPs in the state, reducing confusion among both beneficiaries and providers. It could also make enrolling easier for beneficiaries who may find the number of coverage options available to them confusing, especially on the Medicare side. Examples of states using this strategy include Idaho, Massachusetts, Minnesota, New Jersey, and Tennessee.

As an alternative to requiring state review, Congress could establish a joint CMS and state review process such as the one used for the MMPs.¹⁰ The Medicare-Medicaid Coordination Office has recommended a joint review process for D-SNPs, most recently in its fiscal year 2019 report to Congress, building on the experience with the MMPs (CMS 2019c). We spoke with a health plan representative who suggested the same policy change.

More research will be needed to flesh out the advantages of state review of D-SNP materials and the process for implementing that review. We will also explore issues related to establishing a joint CMS and state review process for approving D-SNP materials, like the one used for the MMPs.

Partner with D-SNPs to develop supplemental benefit packages. States can partner with D-SNPs to develop supplemental benefit packages that complement the Medicaid benefits already available to full-benefit dually eligible beneficiaries, preventing duplication in what Medicaid and Medicare cover.¹¹ Like other MA plans, D-SNPs can use rebate dollars

to provide supplemental benefits that are not covered by traditional Medicare (e.g., dental, vision, and hearing services) and to cover Medicare cost sharing. Compared with regular MA plans, D-SNPs may allocate more rebate dollars to benefits because Medicaid already covers Medicare cost sharing for dually eligible beneficiaries. D-SNPs may also be more likely to offer supplemental benefits targeted to the needs of dually eligible beneficiaries, such as adult day care services, home-based palliative care, in-home support services, caregiver supports, medically approved non-opioid pain management, home and bath safety devices and modifications, transportation, and coverage for over-the-counter medications and items. As of 2020, D-SNPs may also offer benefits such as home-delivered meals, pest control services, non-medical transportation, indoor air quality equipment, and structural home modifications (CMS 2019d). States partnering with D-SNPs to coordinate and expand the package of benefits available to dually eligible beneficiaries include Arizona, Hawaii, and New Jersey.

Strategies for states with Medicaid managed care

The following MIPPA strategies can be used in states that enroll dually eligible beneficiaries in Medicaid managed care. They can also be used by states that are planning to launch Medicaid managed care for the dually eligible population.

Selectively contract with D-SNPs or Medicaid managed care plans that offer aligned plans.

Selective contracting refers to the practice of states contracting only with D-SNPs that offer Medicaid managed care plans under the same parent company.¹² Selective contracting allows states to improve integration and increase enrollment in D-SNPs—for example, by requiring D-SNPs to operate with exclusively aligned enrollment and default enrollment (discussed in more detail later in this chapter). This strategy assures that only D-SNPs offering a higher level of integration can enroll beneficiaries, preventing a situation in which

a minimally integrated D-SNP would compete for enrollment. Examples of states using this strategy include Arizona, Tennessee, and Virginia.

Selective contracting can be challenging to implement for several reasons. Medicaid procurement cycles and Medicare contracting with D-SNPs often occur on different timelines, which could create a gap for plans between winning a Medicaid managed care contract and obtaining state approval to operate a D-SNP. While states theoretically could align state Medicaid procurement cycles with Medicare timelines, interviewees told us that doing so would be challenging due to the state investment required and the unpredictability of Medicaid procurement decisions and health plan protests.

Another challenge is that many states periodically rebid Medicaid managed care contracts through a competitive process that permits a limited number of plans to operate. This may result in beneficiaries having to change plans if they are enrolled in a D-SNP offered by a parent company that loses its Medicaid contract. If the plan networks differ, beneficiaries will also have to change providers. This is especially true if either D-SNP uses a narrow network.

States considering this approach may also need to consider the existing role of small, local Medicaid managed care plans in serving the dually eligible population. It might be difficult for small, local health plans with no Medicare experience to implement a D-SNP contract, given the steep learning curve and challenges in developing Medicare provider networks.

Require complete service area alignment. States with Medicaid managed care and selective contracting could require complete service area alignment between D-SNPs and Medicaid managed care plans under the same parent company. However, interviewees told us this could be difficult to implement in certain cases. For example, differences between CMS requirements and state network adequacy requirements make it challenging

to require complete service area alignment, especially in rural areas. Arizona and New Jersey are examples of states using this strategy.

Require D-SNPs to operate with exclusively aligned enrollment. Exclusively aligned enrollment occurs when a state limits enrollment in a D-SNP to full-benefit dually eligible beneficiaries who receive their Medicaid benefits through the D-SNP or aligned Medicaid plan. In short, under this strategy, one organization is responsible for both Medicaid and Medicare benefits for all its members. For example, plans operating with exclusively aligned enrollment can issue streamlined and fully integrated member materials, use unified plan-level appeal and grievance processes, provide more effective care coordination, and simplify provider billing. Examples of states using this strategy include Idaho, Massachusetts, Minnesota, and New Jersey.

Allow or require D-SNPs to use default enrollment. Default enrollment refers to the process by which Medicaid beneficiaries are enrolled in a D-SNP that is aligned with their current Medicaid managed care plan when they become eligible for Medicare.¹³ Typically, D-SNPs allowed to use default enrollment have higher levels of integration because they operate under the same parent organization as the Medicaid managed care plan.¹⁴ Default enrollment can ensure an uninterrupted transition from Medicaid-only coverage to an integrated arrangement with care coordination and supplemental benefits that are not available in Medicare fee for service (FFS). It is also important to note that default enrollment is the only MIPPA contracting strategy that directly increases enrollment in D-SNPs. To ensure freedom of choice, beneficiaries receive a notice 60 days prior to the default enrollment effective date, during which they have the right to opt out and choose to enroll in Medicare FFS or another MA plan.¹⁵

One state we interviewed reported low (less than 5 percent) opt-out rates. The state also reported few complaints, grievances, and appeals due to default enrollment. Even so, the state noted

that some stakeholders may perceive default enrollment as limiting beneficiary choice, and as a result gathering and incorporating input from beneficiaries and beneficiary advocates throughout the implementation process is crucial. States may also require additional enrollee protections during default enrollment, such as continuity of care protections, including allowing beneficiaries to continue seeing existing providers outside the D-SNP's network for a certain time period. Continuity of care is especially important because many newly dually eligible beneficiaries default enrolled in a D-SNP may have existing provider relationships.¹⁶

To implement default enrollment, states must have either Medicaid managed care arrangements in place or a plan to launch Medicaid managed care for the dually eligible population. Default enrollment may also require that states have information technology systems capable of identifying Medicaid managed care plan members who will soon become eligible for Medicare and share that information with the aligned D-SNP. States reported that the up-front investments to set up default enrollment are considerable. In addition, it is essential that state staff have Medicare expertise, especially experience with the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (P.L. 108-173) file that state Medicaid agencies exchange with CMS at least monthly to identify all individuals who are dually eligible in the state. We heard from one state that implementation took about a year, but once default enrollment was operational, the state did not need to hire additional staff to manage it. Of the 23 states in which default enrollment could be implemented, 9 are implementing it (Appendix 6B).¹⁷ Among these, Arizona and Tennessee require default enrollment in their MIPPA contracts. Several other states have recently moved to encourage or require their contracted D-SNPs to use default enrollment, including Pennsylvania, New York, and Virginia. Colorado, Kentucky, Oregon, and Utah have one or two plans approved for default enrollment (CMS 2021d).¹⁸

States that would like D-SNPs to implement default enrollment may include a provision in their MIPPA contracts that either allows or requires the D-SNP to use default enrollment. States must also establish in their contracts a process to obtain prospective Medicare eligibility data and share the data with D-SNPs, so that plans can identify current Medicaid members who are about to become eligible for Medicare. States may do this by identifying the CMS data they will use, reviewing data at least monthly to monitor future eligibility for Medicare, and determining both the mechanism and the frequency with which the state will share data with D-SNPs (Stringer and Kruse 2019).

States that have elected not to use default enrollment may not have the appropriate infrastructure or may lack the Medicare expertise, resources, or staff capacity needed for implementation. Use of default enrollment may require states and D-SNPs to change their information technology systems to identify D-SNP members who are about to become eligible for Medicare. This is the kind of challenge noted in the Commission's June 2020 recommendation that Congress provide additional federal support for states to enhance their Medicare expertise and capacity to implement integrated care (MACPAC 2020b).

Automatically assign D-SNP enrollees to aligned Medicaid plans. States can use Medicaid auto-assignment algorithms to direct beneficiary enrollment into integrated models. For example, if a dually eligible beneficiary has enrolled in a D-SNP, states can automatically enroll the individual into an aligned Medicaid managed care plan offered by the same parent company. New Jersey and Minnesota are among the few states that currently incorporate D-SNP enrollment in their Medicaid auto-assignment algorithms, perhaps because it can require changes in information systems.

Medicaid auto-assignment may be viewed by beneficiary advocates as more limiting than default enrollment because beneficiaries may have fewer opportunities to change their Medicaid plans after

Medicaid auto-assignment compared with default enrollment. For example, beneficiaries often have the choice to opt out of the Medicaid managed care plan to which they were automatically assigned during the first three months, but after that period, they may be locked into that plan for the remaining nine months of the year. In contrast, dually eligible beneficiaries default enrolled in a D-SNP may opt out during the first 60 days and may also change their plans during the MA annual open enrollment period or during special enrollment periods that they may qualify for throughout the year.¹⁹

Dually eligible beneficiaries receiving Medicaid LTSS and behavioral health services through Medicaid managed care may have their provider relationships disrupted if auto-assignment switches them from one Medicaid managed care plan to another. On the other hand, many dually eligible beneficiaries, especially those without LTSS or behavioral health needs, often choose their D-SNPs based on their provider networks or supplemental benefits packages; Medicaid auto-assignment allows beneficiaries to stay in their D-SNPs of choice while moving to a more integrated arrangement.

Incorporate Medicaid quality improvement priorities into the D-SNP contract. States that contract directly with D-SNPs for Medicaid coverage can incorporate quality strategies used for their Medicaid managed care programs into their D-SNP contracts. This could advance state priorities for quality of care provided to dually eligible beneficiaries in D-SNPs. Minnesota is an example of a state using this strategy.

Automate Medicaid crossover claims payment processes for Medicaid payment of Medicare cost sharing. States with Medicaid managed care can work with D-SNPs and Medicaid managed care plans to automate the crossover claims payment process for providers who serve dually eligible beneficiaries. This would apply to cases in which a dually eligible beneficiary receives Medicaid and Medicare benefits through unaligned plans operated by different parent companies. An automated process could make it easier for providers to bill

appropriately and get paid in a timely manner. However, we are not aware of any states using this strategy, which may indicate challenges associated with setting up this process.

State Ability to Use MIPPA Strategies

The ability of states to use strategies to promote integration depends on several factors. These include whether dually eligible beneficiaries are enrolled in Medicaid managed care, the availability of D-SNPs, whether D-SNPs are operated by the same parent company as those operating Medicaid plans in the service area, state priorities, and administrative capacity. Some strategies can be implemented easily, while others would require more effort, particularly if they require changes to Medicaid procurement processes and considerable staff resources and technical capacity for implementation. States are at different stages of integrating care for the dually eligible population, with some states providing fully integrated care by maximizing their contracting authority and other states not yet offering integrated options for reasons such as a lack of available D-SNPs. In the following sections, we characterize states based on their approach to integrating care.

The availability of Medicaid managed care for dually eligible beneficiaries varies widely by state. As of 2021, 27 states enrolled full-benefit dually eligible beneficiaries in comprehensive Medicaid managed care. Twenty-two used managed care arrangements for LTSS.²⁰ States in which D-SNPs and Medicaid managed care plans are offered by the same parent company are best positioned to use their MIPPA authority to improve integration.

Limited state capacity to set up contracts with D-SNPs remains a challenge for states. As the Commission previously noted, state resources and staffing are limited and stretched across competing priorities, more so with the demands created by the COVID-19 pandemic (MACPAC 2020a, 2020b).

States without Medicaid managed care may have difficulty implementing these strategies if they lack experience with contracting and procurement. Additionally, many states lack the Medicare expertise necessary to implement new MIPPA strategies. Because implementing an integrated model can take a number of years, staff turnover can impede progress.

States that are maximizing current authority

Some states, including Arizona, Idaho, and Tennessee, have been able to maximize use of MIPPA contracting authority and enroll a large share of dually eligible beneficiaries. Over 20 percent of dually eligible beneficiaries in these states are enrolled in integrated care (CMS 2019e).

These states have taken different paths. Arizona and Tennessee both have a long history of using Medicaid managed care and also use MLTSS. They use default enrollment to enroll Medicaid beneficiaries into D-SNPs when they first become eligible for Medicare. By contrast, Idaho launched its integrated care model in 2014, the same year it began enrolling beneficiaries in managed care. It was able to leverage MIPPA contracting authority to build an integrated care model based on a single FIDE SNP that provides all Medicare services and most Medicaid services, including LTSS (Spencer et al. 2018).²¹

States with D-SNPs aligned with Medicaid managed care

States that have D-SNPs aligned with Medicaid managed care plans can more easily leverage their existing contracts to promote integration and increase enrollment. In 2021, there are 24 states in which at least one D-SNP is aligned with a Medicaid managed care plan; in 13 states all the D-SNPs operating in the state are aligned with a Medicaid managed care plan (Appendix 6C) (CMS 2021b, HMA 2020). The latter can require the D-SNP to exclusively enroll full-benefit dually eligible

beneficiaries who receive their Medicaid benefits from the aligned Medicaid managed care plan. At least four have done so.

States with D-SNPs aligned with MLTSS plans are best positioned to maximize integration because their Medicaid managed care plans cover LTSS. Of the 22 states with MLTSS programs, 15 states have D-SNPs that are aligned with MLTSS plans (CMS 2021b, MACPAC 2021, HMA 2020). While MLTSS plans are not always available statewide, in 2019, 1.6 million full-benefit dually eligible beneficiaries lived in areas in which the same parent company operated a D-SNP and an MLTSS plan. In these areas, 44 percent, or 690,000 beneficiaries, were enrolled in a D-SNP, and a smaller number was enrolled in both a D-SNP and an MLTSS plan (MedPAC 2019).

States without Medicaid managed care for dually eligible beneficiaries

States that do not enroll dually eligible beneficiaries in Medicaid managed care (23 states as of January 2021) have fewer alternatives to exercise their MIPPA authorities (Appendix 6D). These states can promote integration by contracting directly with D-SNPs to cover Medicaid benefits, but this requires substantial state resources and investment because this responsibility cannot be delegated to managed care plans. Contracting directly with D-SNPs to cover Medicaid benefits allows states to cover a range of Medicaid benefits in the D-SNP contract, and a number of states do so. For example, Mathematica found that Alabama includes Medicaid coverage of Medicare cost sharing in its D-SNP contracts, and Florida covers Medicaid wrap-around benefits. Because this strategy is resource intensive to implement, states could start by providing capitated payments directly to D-SNPs to cover just Medicare cost sharing or some basic Medicaid benefits as a stepping-stone to integrating more complex benefits, such as LTSS and behavioral health.

For states that cover at least Medicaid wrap-around benefits through direct capitation, this approach opens up the potential to use other MIPPA strategies that are otherwise available only to states with Medicaid managed care. For example, states that cover at least Medicaid wrap-around benefits through direct capitation and limit D-SNP enrollment to full-benefit dually eligible beneficiaries can also require exclusively aligned enrollment (Figure 6-2). Idaho uses this combination of strategies, which maximizes integration.

In addition, states that contract directly with FIDE SNPs may be able to use default enrollment. This strategy is relevant to states that enroll populations that are likely to become dually eligible (e.g., individuals with disabilities) in comprehensive Medicaid managed care.²² Currently, 10 states and the District of Columbia enroll individuals with disabilities in comprehensive Medicaid managed care but do not enroll dually eligible beneficiaries, possibly due to legal or political barriers to mandatory enrollment (Appendix 6D). In these states, Medicaid beneficiaries who become eligible for Medicare would be disenrolled from their managed care plans. However, if the state contracted directly with FIDE SNPs to cover Medicaid benefits for their members and Medicaid managed care plans were aligned with the FIDE SNPs, the plans could default enroll their Medicaid managed care members into the FIDE SNP when they became dually eligible (Figure 6-2).²³

Finally, contracting directly with D-SNPs may serve as an on-ramp to mandatory Medicaid managed care for dually eligible beneficiaries by creating an opportunity to demonstrate the benefits of integrated care to beneficiaries without requiring them to enroll. For example, one state reported that rolling out an integrated model in which beneficiaries voluntarily enrolled in FIDE SNPs allowed the state to build support for the program with stakeholders. This eased the state transition to an integrated care model based on mandatory Medicaid managed care.

States without D-SNPs

States that have no D-SNP experience have one advantage that others do not: they may be able to achieve higher levels of integration in their initial D-SNP contracts, as they do not have to worry about disrupting current enrollee coverage. Seven states do not contract with D-SNPs in 2021 (CMS 2021a).

Limitations of State MIPPA Authority

It is important to note that several additional factors beyond those discussed earlier in this chapter may limit states' ability to use D-SNPs as a vehicle for integration. These include whether the state carves out certain populations or benefits from Medicaid managed care, the presence of other integrated models, and whether a large proportion of dually eligible beneficiaries lives in rural areas.

Medicaid carve outs

Many states carve certain services, such as behavioral health, out of Medicaid managed care capitation payments, but this affects the level of integration that can be achieved by contracting with a D-SNP. Behavioral health services tend to be those most commonly carved out of comprehensive contracts. Other common carve outs include dental services, prescription drugs, and non-emergency medical transportation. When a benefit is carved out, the plan is not responsible for providing the benefit and does not receive payment for it. States may also prohibit certain dually eligible beneficiaries, such as LTSS users, from enrolling in managed care programs.

States carve out benefits for a number of reasons, including plans' ability to provide access to specialized providers (Inkelas 2005). Michigan carved out behavioral health services from its FAI demonstration, relying on prepaid inpatient health plans to provide those services (Holladay et al. 2019). One study noted that integrating

previously carved-out benefits can create substantial operational challenges for states (Holladay et al. 2019). Also, states have concerns such as continuity of care in the transition to new providers for populations with complex care needs (Soper 2016).

Presence of other integrated models

States may be hesitant to use MIPPA contracting authority if D-SNPs would compete for enrollment with other integrated models in the state. For example, the nine states that already operate demonstrations under the FAI may be less likely to leverage MIPPA strategies in geographic areas covered by MMPs because D-SNPs would compete with MMPs for dually eligible enrollees.²⁴

Challenges in rural areas

States with fewer dually eligible beneficiaries or states where many dually eligible beneficiaries live in rural areas may find it difficult to contract with D-SNPs, as it may be hard to attract D-SNPs if there are too few covered individuals to make plans financially viable. D-SNPs may also find it challenging to build a provider network in such areas for several reasons. First, it may be difficult to meet Medicare network adequacy requirements in rural areas because of the absence of certain provider types and difficulty contracting with a small pool of providers. Second, rural providers may expect higher payment rates from plans because they are the only providers in the geographic area. Third, some providers may also have misgivings about managed care that make them less likely to contract with D-SNPs.

Dually eligible beneficiaries in rural areas may be reluctant to enroll in a D-SNP if their providers are not in the plan's network. One study that reviewed results from the Medicare Current Beneficiary Survey found that among MA enrollees in rural areas, switching from an MA plan to Medicare FFS was more common than among non-rural enrollees (Park et al. 2021). Among high-cost, high-need MA enrollees in rural areas, switching

to FFS was even more common. Of the variables studied, dissatisfaction with access to care had the strongest association with plan switching, which could indicate issues with limited benefits or restrictive provider networks (Park et al. 2021).

States with no MA plans or only limited MA availability may find it particularly difficult to contract with D-SNPs. About 70,000 dually eligible beneficiaries live in rural counties where they can receive Medicare coverage only through FFS (CMS 2021b, 2020d). For example, Alaska currently has no MA plans. In North Dakota, South Dakota, and Wyoming, over 20 percent of dually eligible beneficiaries reside in rural counties where no MA plans are available.

Trade-offs between increasing levels of integration and increasing enrollment

States may face a trade-off between promoting integration and increasing enrollment in D-SNPs, at least in the short term. For example, selective contracting and requiring exclusively aligned enrollment can achieve a higher level of integration but may limit the number of D-SNPs in the state and may also limit the number of beneficiaries enrolled in the short run.

By definition, selective contracting makes fewer contracts available, which results in fewer D-SNPs available in the state and potentially lower D-SNP enrollment. For example, if a state offers five Medicaid managed care plan contracts, five aligned D-SNPs would be available. There is also a risk that companies that do not win D-SNP and Medicaid managed care contracts may also continue to operate D-SNP look-alike plans—that is until new CMS rules take effect in 2024. They also could operate regular MA plans rather than lose their members to a competitor D-SNP.²⁵ Therefore, selective contracting could result in an MA market with fewer integrated D-SNPs and more regular MA plans.

In addition, states with a large number of D-SNP enrollees may be hesitant to use strategies that could disrupt their coverage, even though these strategies would lead to more integration. For example, many existing D-SNPs enroll partial-benefit dually eligible beneficiaries as well as individuals enrolled in an unaligned Medicaid plan offered by a different parent company or through Medicaid FFS. These individuals would have to switch their coverage if a state required D-SNPs to move to exclusively aligned enrollment, and the plan would lose members. This dynamic may make it politically difficult for states with a large number of individuals currently enrolled in D-SNPs to move toward exclusively aligned enrollment.

Looking Ahead

As the Commission continues to explore ways to increase enrollment in integrated products, make integrated products more widely available, and promote greater integration in existing products, our focus over the next year will be on how federal policy could be used to help states move more rapidly in these directions. We recognize that some states are further along a path towards integration than others, and thus we will need to consider how the federal government can structure incentives to meet the needs of states just getting started as well as those that have already made long-standing commitments to integrated care.

We will also continue to monitor the FAI and other efforts to integrate care, including those focused on creating a wholly new approach to serving dually eligible beneficiaries by unifying Medicaid and Medicare benefits, financing, and administration under one umbrella. In addition, we plan to take advantage of the availability of new data from the Transformed Medicaid Statistical Information System (T-MSIS) to release updated information on the characteristics and health care use of dually eligible beneficiaries.

Endnotes

- ¹ See chapter 1 of MACPAC's June 2020 report to Congress for a description of the dually eligible population, including demographic characteristics, eligibility, and use of services and spending (MACPAC 2020a).
- ² Full-benefit dually eligible beneficiaries are eligible for all Medicaid benefits. They differ from partial-benefit dually eligible beneficiaries who are only eligible for Medicaid assistance with Medicare premiums and sometimes cost sharing.
- ³ These contracts are also referred to as state Medicaid agency contracts.
- ⁴ The states in which D-SNPs are not available tend to be rural states with smaller populations, including Alaska, New Hampshire, North Dakota, South Dakota, Wyoming, and Vermont. Illinois ended contracts with D-SNPs in 2017, choosing to focus instead on expanding MMPs statewide. D-SNPs are not available in rural counties in several states, including California, Colorado, Idaho, Maryland, Massachusetts, Michigan, Mississippi, Montana, Nebraska, Nevada, Oklahoma, South Dakota, Utah, Washington, and Wisconsin (CMS 2021b).
- ⁵ This figure does not include 278,000 dually eligible beneficiaries in Puerto Rico who are enrolled in D-SNPs (CMS 2021a).
- ⁶ D-SNPs are designated as HIDE SNPs if their parent organizations have a contract with the state to cover either LTSS or behavioral services or both. In the case in which Medicaid benefits are covered by an aligned Medicaid managed care plan, this would be a managed care contract. In the case in which D-SNPs directly contract to cover Medicaid benefits, this would be a MIPPA contract between the D-SNP and the state.
- ⁷ D-SNPs are designated as FIDE SNPs when LTSS and behavioral health services are covered by the same legal entity as the D-SNP. FIDE SNPs must also use aligned care management and specialty care network methods to meet the needs of high-risk enrollees and "coordinate or integrate beneficiary communication materials, enrollment, communications, grievance[s] and appeals, and quality improvement" (42 CFR 422.2). FIDE SNPs are not required

to cover behavioral health services if the state carves them out of the capitation rate. More details on these models can be found in chapter 1 of MACPAC's June 2020 report to Congress (MACPAC 2020a).

⁸ For example, Pennsylvania developed its own D-SNP data-sharing requirements in advance of the Bipartisan Budget Act of 2018 requirements that became effective in 2021. D-SNPs must send a notification of hospital and skilled nursing facility admissions for all D-SNP enrollees. The D-SNP shares information directly with the beneficiary's MLTSS plan within 48 hours of admission (ICRC 2019b). Other states have different approaches to information sharing.

⁹ MA plans submit benefit packages to CMS for approval when they apply to operate a D-SNP. Each plan benefit package has a specific set of proposed benefits, cost sharing, premiums, and supplemental benefits (MedPAC 2004).

¹⁰ During the public health emergency related to COVID-19, CMS suspended joint Medicare-Medicaid Coordination Office and state review of MMP marketing materials to reduce the burden on states and plans. States are using contract year 2020 marketing guidance for contract year 2021 (CMS 2020e).

¹¹ For example, if a D-SNP covers two dental cleanings per year and Medicaid covers four dental cleanings per year, the state could specify in its contract that the D-SNP would cover the beneficiary's first two cleanings under the Medicare supplemental benefit, and then the remaining cleanings would be covered under Medicaid. This arrangement would prevent a situation in which Medicaid and Medicare both calculate their capitation payment to the D-SNP expecting to pay for the beneficiary's first two dental cleanings, duplicating the payment the plan receives for the same service.

¹² This strategy is easier to implement if some alignment exists between organizations offering D-SNPs and Medicaid managed care plans in the state.

¹³ It is important to note that beneficiaries in limited benefit Medicaid plans—such as prepaid inpatient health plans and prepaid ambulatory health plans or those from managed fee-for-service models, including primary case management, health homes, or accountable care organizations—are not eligible for default enrollment.

¹⁴ If D-SNPs satisfy a range of other requirements, they may request approval to use default enrollment from both the state and CMS. Those requirements include the following: (1) have a minimum overall quality rating of at least three stars (although D-SNPs that are too new or have insufficient enrollment to receive a star rating are exempt from this requirement), (2) not be prohibited by CMS from enrolling new beneficiaries, (3) operate in a service area that is covered by the Medicaid managed care plan responsible for covering Medicaid benefits for members, (4) demonstrate state approval, and (5) document the state's agreement to provide the information necessary for D-SNPs to identify individuals in its Medicaid managed care plan who may become Medicare eligible.

¹⁵ Beneficiaries may also use the MA annual open enrollment period to change health plans for three months following default enrollment and may qualify for other special enrollment periods throughout the year.

¹⁶ In an analysis of pathways to dually eligible status using 2014 data, about two-thirds of dually eligible beneficiaries were initially Medicaid beneficiaries who became eligible for Medicare due to disability, and one-third of beneficiaries became eligible for Medicare when they turned age 65 (Feng et al. 2019). Slightly more than half (55 percent) who were initially Medicaid beneficiaries later qualified for Medicare based on receipt of Supplemental Security Income (Feng et al. 2019).

¹⁷ Twenty-three states have the basic infrastructure for default enrollment, including D-SNPs aligned with Medicaid managed care plans for dually eligible beneficiaries and populations likely to become dually eligible. D-SNPs in these states must also operate in the same service areas as their aligned Medicaid managed care plans and meet a range of other requirements described in 42 CFR 422.66(c)(2). Some states may not approve D-SNPs for default enrollment if these plans would compete with other integrated models in the state, like MMPs.

¹⁸ Puerto Rico has also approved five D-SNPs for default enrollment (CMS 2021d).

¹⁹ Federal regulations in 42 CFR 423.38 permit dually eligible beneficiaries to qualify for a special enrollment period for MA plans that allows them to enroll, switch plans, or disenroll outside the annual open enrollment period. Beneficiaries can use the special enrollment period once per quarter for the first nine months of the year (i.e., three times per year) (CMS 2018, MACPAC 2020b).

²⁰ Massachusetts, Rhode Island, and South Carolina have MLTSS only through their FAI demonstrations, so their MLTSS plans cannot align with D-SNPs. These states are not included in our count of states with MLTSS.

²¹ Idaho launched its integrated model with one FIDE SNP and, as of 2021, contracts with two FIDE SNPs.

²² D-SNPs may default enroll beneficiaries only from comprehensive Medicaid managed care plans. That is, they may not enroll beneficiaries from limited-benefit Medicaid plans, such as prepaid inpatient health plans and prepaid ambulatory health plans, or from managed FFS models, including primary case management, health homes, or accountable care organizations (ICRC 2019a).

²³ FIDE SNPs must also meet the requirements described in 42 CFR 422.66(c)(2) to be approved for default enrollment.

²⁴ MMPs are present in nine states: California, Illinois, Massachusetts, Michigan, New York, Ohio, Rhode Island, South Carolina, and Texas (ICRC 2021).

²⁵ D-SNP look-alike plans are MA plans with enrollment that is largely composed of dually eligible beneficiaries. In 2020, CMS finalized regulations intended to curb the growth of these plans. Beginning in 2022, CMS will not enter into an MA plan contract if 80 percent or more of projected enrollees in the plan bid are dually eligible beneficiaries. Beginning in 2023, CMS will not renew an MA plan contract if the plan has actual enrollment at this threshold as of January of the current year, unless the plan has been active for less than one year and has 200 or fewer enrollees. This requirement will apply only in states in which D-SNPs or another product (e.g., MMPs) are authorized to exclusively enroll dually eligible beneficiaries (CMS 2021c).

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APPENDIX 6A: Examples of Strategies for State Contracts with Dual Eligible Special Needs Plans

States can use a number of strategies to improve integration in their contracts with dual eligible special needs plans (D-SNPs) (Table 6A-1). Some strategies may be used in all states, while other

strategies are easiest to use in states that enroll full-benefit dually eligible beneficiaries in Medicaid managed care. Some states are already using these strategies.

TABLE 6A-1. Examples of Strategies for State Contracts with Dual Eligible Special Needs Plans, 2021

Strategy	Description	Possible in	Examples of states using this strategy
Limit D-SNP enrollment to full-benefit dually eligible beneficiaries	Limiting enrollment to individuals eligible for full Medicaid benefits is a strategy used in the Medicare-Medicaid plans. It allows plans to establish a uniform set of benefits and uniform cost sharing and care coordination requirements as well as simpler enrollee materials tailored to the full-benefit dually eligible population. Alternatively, states can require D-SNPs to use separate plan benefit packages to enroll full- and partial-benefit dually eligible beneficiaries.	All states	Arizona, Hawaii, Idaho, Massachusetts, Minnesota, New Jersey, Pennsylvania, ¹ and Virginia ¹
Contract directly with D-SNPs to cover Medicaid benefits	States can contract directly with D-SNPs to cover a range of Medicaid benefits. Making capitation payments to D-SNPs to cover Medicaid benefits ensures that the D-SNP is responsible for coverage of both Medicaid and Medicare benefits. States may contract directly with D-SNPs to cover the full range of Medicaid benefits, thereby creating a fully integrated dual eligible special needs plan (FIDE SNP). Other states may contract directly with D-SNPs to cover specific benefits such as Medicare cost sharing.	All states	Alabama, Florida, Idaho, and Massachusetts
Require D-SNPs to use specific or enhanced care coordination methods	States can incorporate requirements to enhance the amount or degree of care coordination, such as incorporating coordination of Medicaid services into the individualized care plans for members. This strategy could improve quality and beneficiary experience of care. States can also require D-SNPs to integrate Medicaid care coordination requirements into the D-SNP's model of care. Medicare Advantage plans, including D-SNPs, are required to establish models of care and submit them for approval to the Centers for Medicare & Medicaid Services (42 CFR 422.101). Models of care typically include a plan for care management and care coordination for the beneficiary.	All states	Idaho, Massachusetts, Minnesota, New Jersey, Tennessee, and Virginia

TABLE 6A-1. (continued)

Strategy	Description	Possible in	Examples of states using this strategy
Require D-SNPs to send data or reports to the state for oversight purposes	States can require D-SNPs to submit data or reports that enable state oversight of plan operations and quality of care. Encounter data, quality measures, and financial reports can help states monitor overall D-SNP performance and advance goals such as health equity.	All states	Arizona, Idaho, Massachusetts, Minnesota, New Jersey, New Mexico, Oregon, Tennessee, and Virginia
Require state review of D-SNP materials related to delivery of Medicaid benefits	States can require D-SNPs to submit marketing materials for state review prior to use. This strategy could ensure consistency in Medicaid benefit descriptions and instructions across different D-SNPs, making them less confusing for beneficiaries and providers.	All states	Idaho, Massachusetts, Minnesota, New Jersey, Tennessee, and Wisconsin
Partner with D-SNPs to develop supplemental benefit packages that complement Medicaid benefits	States can partner with D-SNPs to develop supplemental benefit packages that complement the Medicaid benefits already available to full-benefit dually eligible beneficiaries. This can reduce duplication across Medicaid and Medicare payments.	All states	Arizona, Minnesota, New Jersey, and Pennsylvania
Selectively contracting with D-SNPs that also offer Medicaid managed care plans (or vice versa)	States with Medicaid managed care programs that enroll dually eligible beneficiaries can choose to contract only with D-SNPs that offer a Medicaid managed care plan through the same parent company as the D-SNP, or they can contract only with Medicaid managed care plans that offer a D-SNP through the same organization. This ensures that no unaligned D-SNP or Medicaid managed care organizations could enroll beneficiaries into non-integrated options.	States with Medicaid managed care for dually eligible beneficiaries	Arizona, Hawaii, Minnesota, New Jersey, Tennessee, ² and Virginia
Require complete service area alignment between D-SNPs and aligned Medicaid managed care plans	States that use selective contracting can require D-SNPs and Medicaid managed care plans operated by the same parent companies to operate in the same service areas so that all eligible individuals will have the option to enroll in aligned plans for coverage, regardless of their geographic location in the state. This strategy makes exclusively aligned enrollment and default enrollment easier to implement.	States with Medicaid managed care for dually eligible beneficiaries	Arizona and New Jersey

TABLE 6A-1. (continued)

Strategy	Description	Possible in	Examples of states using this strategy
Require D-SNPs to operate with exclusively aligned enrollment	Exclusively aligned enrollment occurs when a state limits enrollment in a D-SNP to full-benefit dually eligible beneficiaries who receive their Medicaid benefits from the D-SNP or a Medicaid managed care plan offered by the same parent company. Requiring D-SNPs to enroll only members who are also enrolled in their aligned Medicaid plan ensures that Medicaid and Medicare benefits are provided through a single entity. To implement this strategy, states must either have overlap between plans offering Medicaid managed care and D-SNPs or directly capitate D-SNPs for Medicaid coverage.	All states	Idaho, Massachusetts, Minnesota, and New Jersey
Allow or require D-SNPs to use default enrollment	D-SNPs that meet the requirements at 42 CFR 422.66(c)(2) may use default enrollment to enroll newly dually eligible beneficiaries into a D-SNP through the same parent organization as their current Medicaid managed care plan, as long as the individuals will continue to be enrolled in Medicaid managed care once they are Medicare eligible. This strategy would ensure an uninterrupted transition from Medicaid-only coverage to dual status, in which an individual's Medicaid and Medicare benefits are coordinated by the same parent organization. Beneficiaries can choose to opt out.	States with Medicaid managed care for dually eligible beneficiaries	Arizona, Colorado, Kentucky, New York, Oregon, Pennsylvania, Tennessee, Utah, and Virginia
Automatically assign D-SNP enrollees to Medicaid plans under the same parent organization	In states with overlap between the organizations offering D-SNPs and Medicaid managed care plans for dually eligible beneficiaries, this strategy ensures an individual's Medicaid and Medicare benefits are coordinated by the same parent organization. Beneficiaries can choose to opt out.	States with Medicaid managed care for dually eligible beneficiaries	Arizona, ³ Minnesota, and New Jersey
Incorporate Medicaid quality improvement priorities into the D-SNP contract	States that directly capitate D-SNPs for Medicaid benefits can incorporate their Medicaid quality improvement priorities into their D-SNP contracts because the direct capitation means they are bound by the same regulations that guide Medicaid managed care. Regulations at 42 CFR 438.330 and 42 CFR 438.340 require states to develop and implement Medicaid Quality Assessment and Performance Improvement programs. This strategy could improve the quality of care provided to dually eligible beneficiaries.	States with Medicaid managed care for dually eligible beneficiaries	Minnesota

TABLE 6A-1. (continued)

Strategy	Description	Possible in	Examples of states using this strategy
Automate crossover claims payment processes for Medicaid payment of Medicare cost sharing	States with Medicaid managed care programs for dually eligible beneficiaries can work with their D-SNPs and Medicaid managed care plans to set up automated crossover claims payment processes for Medicaid payment of Medicare cost sharing. This arrangement applies only to cases in which the dually eligible beneficiary is covered by different plans for Medicaid and Medicare benefits because plans covering both do not make such payments. This can simplify billing and payment for providers who serve dually eligible beneficiaries.	States with Medicaid managed care for dually eligible beneficiaries	None

Notes: D-SNP is dual eligible special needs plan.

¹ Pennsylvania and Virginia require separate plan benefit packages for full- and partial-benefit dually eligible beneficiaries.

² D-SNPs that operated in Tennessee prior to 2014 are exempt from the state’s selective contracting requirement.

³ Arizona does this on a limited basis.

Source: Mathematica, 2021, analysis for MACPAC of state contracts with D-SNPs for contract years 2020 and 2021 as well as interviews with stakeholders and review of federal regulations.

APPENDIX 6B: Implementing Default Enrollment

States can use default enrollment to automatically enroll Medicaid beneficiaries into a dual eligible special needs plan (D-SNP) aligned with their current Medicaid managed care plan when the beneficiary first becomes dually eligible for Medicaid and Medicare. This can increase enrollment of full-benefit dually eligible beneficiaries in D-SNPs.

To use default enrollment, states must have certain infrastructure in place. They must have Medicaid managed care plans and D-SNPs operating under the same parent company or must be contracting directly with D-SNPs to cover all Medicaid benefits. States must also have experience enrolling populations that are likely to become dually eligible, such as adults and individuals with disabilities, in comprehensive Medicaid managed care.

Who Can Be Default Enrolled?

Medicaid beneficiaries who become eligible for Medicare due to age or disability become dually eligible for both programs as long as they retain their Medicaid eligibility. However, Medicaid beneficiaries not eligible due to disability or use of long-term services and supports (LTSS) may lose Medicaid when they turn age 65 or otherwise become eligible for Medicare because the method for determining their financial eligibility changes from modified adjusted gross income (MAGI) to another methodology. For example, the non-MAGI methodology applies an asset test, but the MAGI methodology does not. Becoming eligible for Medicare prompts a Medicaid eligibility redetermination to find out if the beneficiary still qualifies for Medicaid. Individuals who do not retain full-benefit Medicaid coverage upon enrolling

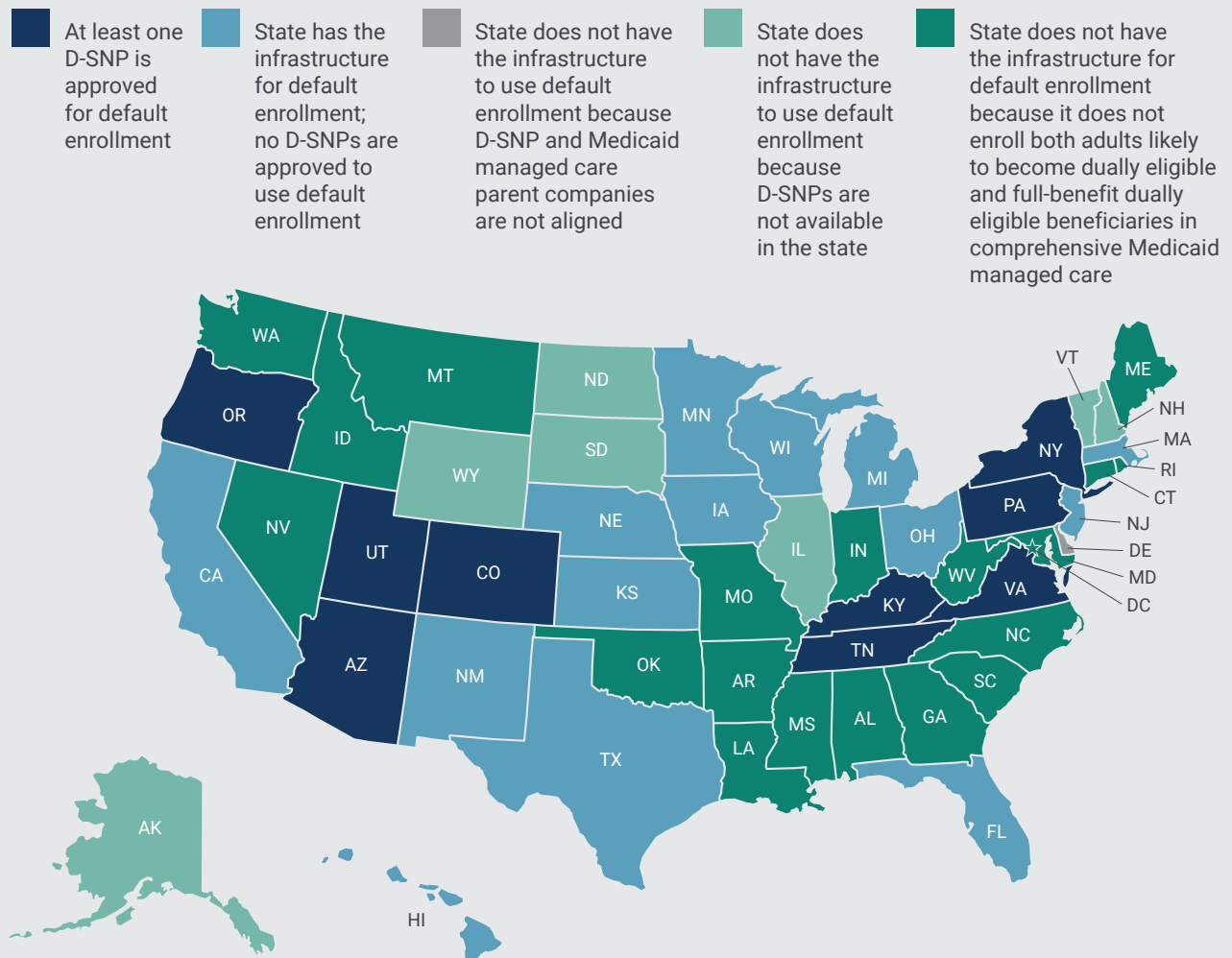
in Medicare are not eligible for default enrollment into a D-SNP.

States vary in how they approach Medicaid redetermination and default enrollment. For example, states may exclude certain eligibility groups from default enrollment because they are unlikely to retain Medicaid eligibility after becoming eligible for Medicare or because of the difficulty completing the Medicaid redetermination process in time to meet the 60-day beneficiary notification requirement for default enrollment. In these states, only beneficiaries who are eligible for Medicaid based on a non-MAGI methodology, such as beneficiaries eligible for Medicaid based on disability or Supplemental Security Income, would be default enrolled into D-SNPs.

State Infrastructure Necessary to Use Default Enrollment

Twenty-three states have the basic infrastructure necessary to use default enrollment, and D-SNPs are approved for default enrollment in nine of these states (Figure 6B-1). These 23 states enroll full-benefit dually eligible beneficiaries in Medicaid managed care. They also enroll individuals likely to become dually eligible, such as individuals with certain disabilities, in Medicaid managed care. These states also have at least one parent company that operates both Medicaid managed care plans and D-SNPs or that contracts directly with D-SNPs to cover all Medicaid benefits for their members.

FIGURE 6B-1. States with the Infrastructure Necessary to Use Default Enrollment, 2021



Notes: D-SNP is dual eligible special needs plan. Several states enroll beneficiaries in a form of managed care, but we do not consider those state programs to provide comprehensive managed care coverage, so we have excluded those states. This includes Arkansas, which enrolls certain dually eligible beneficiaries into the Provider-Led Arkansas Shared Savings Entity program for beneficiaries with developmental disabilities and those who use certain behavioral health services. Also, Louisiana and Washington enroll dually eligible beneficiaries in behavioral health organizations (BHOs), but we do not consider BHOs comprehensive Medicaid managed care; however, it is possible for some BHOs and D-SNPs to align to create a highly integrated dual eligible special needs plan.

In addition to not having D-SNPs available in the state, Alaska, North Dakota, South Dakota, and Wyoming do not enroll full-benefit dually eligible beneficiaries in Medicaid managed care.

Source: MACPAC and Mathematica, 2021, analysis of data on special needs plans and Medicaid managed care plans from CMS and state websites.

APPENDIX 6C: Dual Eligible Special Needs Plans Aligned with Medicaid Managed Care Plans

States in which dual eligible special needs plans (D-SNPs) are aligned with comprehensive Medicaid managed care plans offered by the same parent company are best positioned to maximize contracting strategies to improve integration in D-SNPs. States vary in the extent to which plans are aligned (Figure 6C-1). As an alternative for states that do not have D-SNPs aligned with Medicaid plans, states can contract directly with D-SNPs to cover Medicaid benefits and can require that the D-SNP be designated as a highly integrated dual eligible special needs plan (HIDE SNP) or fully integrated dual eligible special needs plan (FIDE SNP).

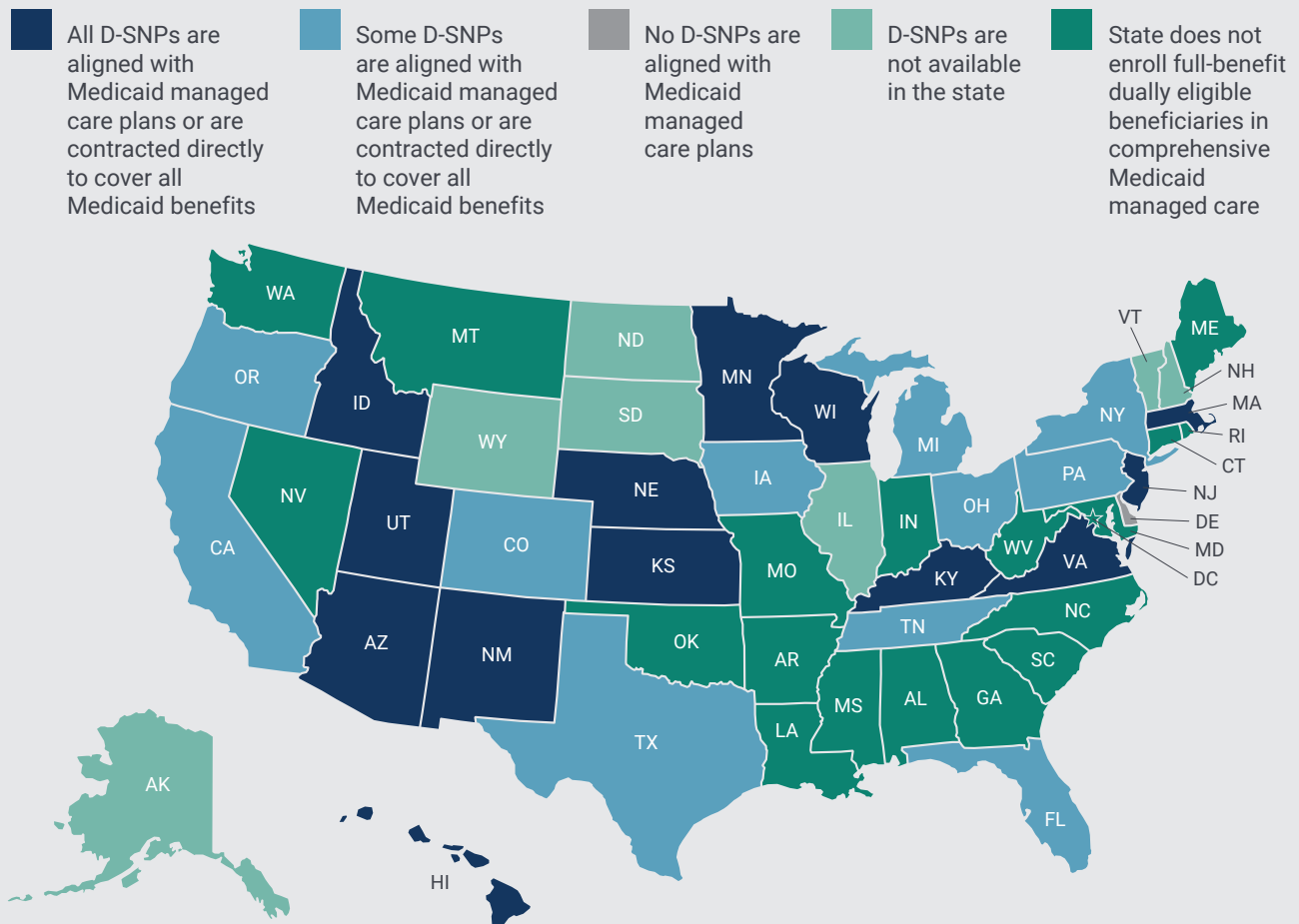
Twenty-five states have both D-SNPs and Medicaid managed care for dually eligible beneficiaries. Of these, 24 states have at least one parent company that operates a D-SNP aligned with a Medicaid managed care plan, or the state has contracted directly with a D-SNP designated as a HIDE SNP or FIDE SNP. Among the latter include the following:

- In 13 states, all D-SNPs cover Medicaid benefits for their members either directly or through an aligned Medicaid managed care plan.
 - In 4 of the 13 states, D-SNPs use exclusively aligned enrollment.
- In 11 states, some but not all D-SNPs are aligned with a Medicaid managed care plan.
 - These states could selectively contract with D-SNPs that offer aligned Medicaid managed care plans during their next D-SNP procurement cycle if they wanted to ensure that all D-SNPs operating in

the state are aligned with a Medicaid managed care plan.

In 25 states and the District of Columbia, alignment is not possible because full-benefit dually eligible beneficiaries are not enrolled in comprehensive Medicaid managed care or D-SNPs are not available or both (Figure 6C-1).

FIGURE 6C-1. Dual Eligible Special Needs Plans Aligned with Medicaid Managed Care Plans by State, 2021



Notes: D-SNP is dual eligible special needs plan. States that use selective contracting include Arizona, Hawaii, Minnesota, New Jersey, Tennessee, and Virginia. Tennessee uses selective contracting for new D-SNP enrollment, but some grandfathered D-SNPs that are not aligned with a Medicaid managed care plan still operate in the state.

States that use exclusively aligned enrollment include Idaho, Massachusetts, Minnesota, and New Jersey.

Some fully integrated dual eligible special needs plans (FIDE SNPs) cover Medicaid services directly rather than through an aligned Medicaid managed care plan. Florida contracts directly with D-SNPs to cover all Medicaid managed care services, except home- and community-based services (HCBS), which are provided by a Medicaid managed care plan. Some D-SNPs are aligned with Medicaid managed care plans that cover HCBS and are designated as FIDE SNPs or highly integrated dual eligible special needs plans. Massachusetts contracts directly with D-SNPs to cover Medicaid and Medicare benefits, and all D-SNPs are designated as FIDE SNPs.

In addition to not having D-SNPs available in the state, Alaska, North Dakota, South Dakota, and Wyoming do not enroll full-benefit dually eligible beneficiaries in Medicaid managed care.

Several states enroll beneficiaries in a form of managed care, but we do not consider those state programs to provide comprehensive managed care coverage, so we have excluded those states. This includes Arkansas, which enrolls certain dually eligible beneficiaries into the Provider-Led Arkansas Shared Savings Entity program for individuals with

FIGURE 6C-1. (continued)

developmental disabilities and individuals who use certain behavioral health services. Also, Louisiana and Washington enroll dually eligible beneficiaries in behavioral health organizations (BHOs), but we do not consider BHOs comprehensive Medicaid managed care. However, it is possible for some BHOs and D-SNPs to align to create a highly integrated dual eligible special needs plan.

Rhode Island and South Carolina enroll full-benefit dually eligible beneficiaries into Medicare-Medicaid plans through the Financial Alignment Initiative demonstration, but outside the demonstration, dually eligible beneficiaries are not enrolled in Medicaid managed care plans that could align with D-SNPs.

Source: MACPAC and Mathematica, 2021, analysis of data on special needs plans and Medicaid managed care plans from CMS and state websites.

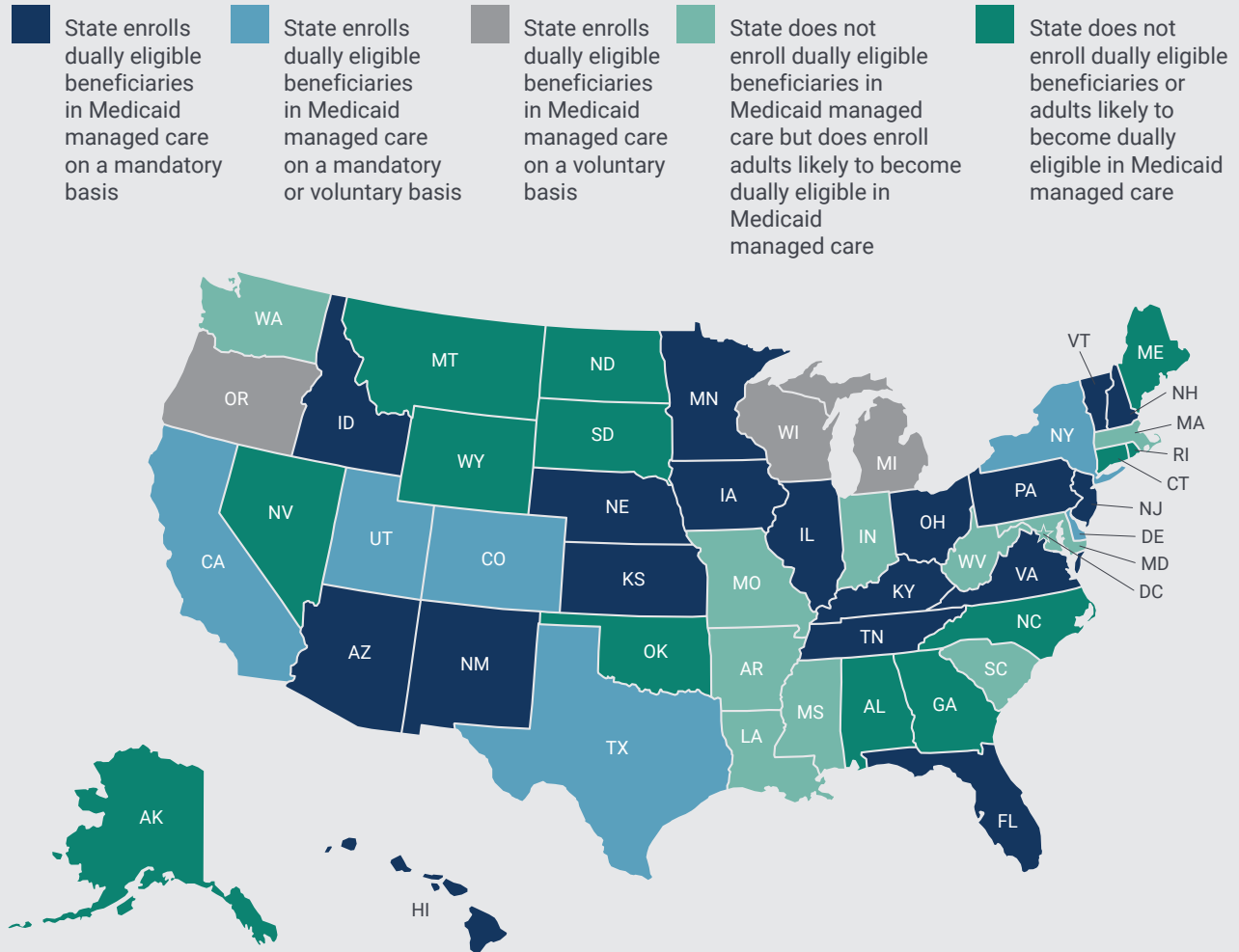
APPENDIX 6D: States Enrolling Full- Benefit Dually Eligible Beneficiaries in Medicaid Managed Care

States that enroll full-benefit dually eligible beneficiaries in Medicaid managed care have a greater ability to use contracting strategies to improve integration in dual eligible special needs plans (D-SNPs) (Figure 6D-1). States may enroll dually eligible beneficiaries in Medicaid managed care on a mandatory or voluntary basis. For example, states may enroll beneficiaries in certain counties or in select populations in mandatory Medicaid managed care, while other dually eligible beneficiaries are enrolled voluntarily in Medicaid managed care. States that enroll dually eligible beneficiaries in Medicaid managed care on a mandatory basis have a greater ability to use contracting strategies to improve integration and increase enrollment in D-SNPs.

On the other hand, states that do not have experience enrolling the dually eligible population in Medicaid managed care would have more difficulty implementing certain contracting strategies. Twenty-three states and the District of Columbia do not enroll full-benefit dually eligible beneficiaries in Medicaid managed care. These states could have a difficult time using the Medicare Improvements for Patients and Providers Act of 2008 (MIPPA, P.L. 110-275) strategies because they may lack the staff, tools, and experience necessary, such as procurement, rate setting, quality management, and plan oversight, to contract directly with D-SNPs to cover Medicaid benefits for dually eligible beneficiaries.

Of the 23 states that do not enroll full-benefit dually eligible beneficiaries in Medicaid managed care, 10 states and the District of Columbia do enroll populations that may become dually eligible in Medicaid managed care. These states may be able to leverage their experience with Medicaid managed care procurement for this population to contract directly with D-SNPs to cover Medicaid benefits for full-benefit dually eligible beneficiaries.

FIGURE 6D-1. States that Enroll Dually Eligible Beneficiaries in Medicaid Managed Care, 2021



Notes: For this figure, Medicaid managed care refers to comprehensive Medicaid managed care, and dually eligible beneficiaries refers to full-benefit dually eligible beneficiaries.

Alaska and Connecticut do not have any Medicaid managed care enrollment.

Several states enroll beneficiaries in a form of managed care, but we do not consider those state programs to provide comprehensive managed care coverage, so we have excluded those states. This includes Arkansas, which enrolls certain dually eligible beneficiaries into the Provider-Led Arkansas Shared Savings Entity program for beneficiaries with developmental disabilities and those who use certain behavioral health services, but we do not consider this program comprehensive Medicaid managed care. Louisiana and Washington enroll dually eligible beneficiaries in behavioral health organizations (BHOs), but we do not consider BHOs comprehensive Medicaid managed care. However, it is possible for some BHOs and dual eligible special needs plans (D-SNPs) to align to create a highly integrated dual eligible special needs plan.

Massachusetts does not have a stand-alone, comprehensive Medicaid managed care program for dually eligible beneficiaries and instead contracts directly with D-SNPs to cover all Medicaid benefits for the plans' members; all D-SNPs in the state are designated as fully integrated dual eligible special needs plans.

FIGURE 6D-1. (continued)

Minnesota and Nebraska enroll select populations of dually eligible beneficiaries in Medicaid managed care on a mandatory basis.

Nevada and North Dakota enroll adults eligible under the Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) into Medicaid managed care but do not enroll adults likely to become dually eligible or dually eligible beneficiaries in Medicaid managed care.

Rhode Island and South Carolina voluntarily enroll full-benefit dually eligible beneficiaries into Medicare-Medicaid plans through the Financial Alignment Initiative demonstration, but dually eligible beneficiaries outside the demonstration are not enrolled in Medicaid managed care.

Source: MACPAC and Mathematica, 2021, analysis of state use of managed care for the dually eligible population.

Appendix

Authorizing Language (§ 1900 of the Social Security Act)

Medicaid and CHIP Payment and Access Commission

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

- (C) ENROLLMENT AND RETENTION PROCESSES.—Medicaid and CHIP enrollment and retention processes, including a determination of the degree to which Federal and State policies encourage the enrollment of individuals who are eligible for such programs and screen out individuals who are ineligible, while minimizing the share of program expenses devoted to such processes.
 - (D) COVERAGE POLICIES.—Medicaid and CHIP benefit and coverage policies, including a determination of the degree to which Federal and State policies provide access to the services enrollees require to improve and maintain their health and functional status.
 - (E) QUALITY OF CARE.—Medicaid and CHIP policies as they relate to the quality of care provided under those programs, including a determination of the degree to which Federal and State policies achieve their stated goals and interact with similar goals established by other purchasers of health care services.
 - (F) INTERACTION OF MEDICAID AND CHIP PAYMENT POLICIES WITH HEALTH CARE DELIVERY GENERALLY.—The effect of Medicaid and CHIP payment policies on access to items and services for children and other Medicaid and CHIP populations other than under this title or title XXI and the implications of changes in health care delivery in the United States and in the general market for health care items and services on Medicaid and CHIP.
 - (G) INTERACTIONS WITH MEDICARE AND MEDICAID.—Consistent with paragraph (11), the interaction of policies under Medicaid and the Medicare program under title XVIII, including with respect to how such interactions affect access to services, payments, and dually eligible individuals.
 - (H) OTHER ACCESS POLICIES.—The effect of other Medicaid and CHIP policies on access to covered items and services, including policies relating to transportation and language barriers and preventive, acute, and long-term services and supports.
- (3) RECOMMENDATIONS AND REPORTS OF STATE-SPECIFIC DATA.—MACPAC shall—
- (A) review national and State-specific Medicaid and CHIP data; and
 - (B) submit reports and recommendations to Congress, the Secretary, and States based on such reviews.
- (4) CREATION OF EARLY-WARNING SYSTEM.—MACPAC shall create an early-warning system to identify provider shortage areas, as well as other factors that adversely affect, or have the potential to adversely affect, access to care by, or the health care status of, Medicaid and CHIP beneficiaries. MACPAC shall include in the annual report required under paragraph (1)(D) a description of all such areas or problems identified with respect to the period addressed in the report.
- (5) COMMENTS ON CERTAIN SECRETARIAL REPORTS AND REGULATIONS.—
- (A) CERTAIN SECRETARIAL REPORTS.—If the Secretary submits to Congress (or a committee of Congress) a report that is required by law and that relates to access policies, including with respect to payment policies, under Medicaid or CHIP, the Secretary shall transmit a copy of the report to MACPAC. MACPAC shall review the report and, not later than 6 months after the date of submittal of the Secretary’s report to Congress, shall submit to the appropriate committees

of Congress and the Secretary written comments on such report. Such comments may include such recommendations as MACPAC deems appropriate.

- (B) REGULATIONS.—MACPAC shall review Medicaid and CHIP regulations and may comment through submission of a report to the appropriate committees of Congress and the Secretary, on any such regulations that affect access, quality, or efficiency of health care.

(6) AGENDA AND ADDITIONAL REVIEWS.—

- (A) IN GENERAL.—MACPAC shall consult periodically with the chairmen and ranking minority members of the appropriate committees of Congress regarding MACPAC’s agenda and progress towards achieving the agenda. MACPAC may conduct additional reviews, and submit additional reports to the appropriate committees of Congress, from time to time on such topics relating to the program under this title or title XXI as may be requested by such chairmen and members and as MACPAC deems appropriate.

(B) REVIEW AND REPORTS REGARDING MEDICAID DSH.—

- (i) IN GENERAL.—MACPAC shall review and submit an annual report to Congress on disproportionate share hospital payments under section 1923. Each report shall include the information specified in clause (ii).
- (ii) REQUIRED REPORT INFORMATION.—Each report required under this subparagraph shall include the following:
- (I) Data relating to changes in the number of uninsured individuals.
 - (II) Data relating to the amount and sources of hospitals’ uncompensated care costs, including the amount of such costs that are the result of providing unreimbursed or under-reimbursed services, charity care, or bad debt.
 - (III) Data identifying hospitals with high levels of uncompensated care that also provide access to essential community services for low-income, uninsured, and vulnerable populations, such as graduate medical education, and the continuum of primary through quaternary care, including the provision of trauma care and public health services.
 - (IV) State-specific analyses regarding the relationship between the most recent State DSH allotment and the projected State DSH allotment for the succeeding year and the data reported under subclauses (I), (II), and (III) for the State.
- (iii) DATA.—Notwithstanding any other provision of law, the Secretary regularly shall provide MACPAC with the most recent State reports and most recent independent certified audits submitted under section 1923(j), cost reports submitted under title XVIII, and such other data as MACPAC may request for purposes of conducting the reviews and preparing and submitting the annual reports required under this subparagraph.
- (iv) SUBMISSION DEADLINES.—The first report required under this subparagraph shall be submitted to Congress not later than February 1, 2016. Subsequent reports shall be submitted as part of, or with, each annual report required under paragraph (1)(C) during the period of fiscal years 2017 through 2024.

- (7) AVAILABILITY OF REPORTS.—MACPAC shall transmit to the Secretary a copy of each report submitted under this subsection and shall make such reports available to the public.
- (8) APPROPRIATE COMMITTEE OF CONGRESS.—For purposes of this section, the term “appropriate committees of Congress” means the Committee on Energy and Commerce of the House of Representatives and the Committee on Finance of the Senate.
- (9) VOTING AND REPORTING REQUIREMENTS.—With respect to each recommendation contained in a report submitted under paragraph (1), each member of MACPAC shall vote on the recommendation, and MACPAC shall include, by member, the results of that vote in the report containing the recommendation.
- (10) EXAMINATION OF BUDGET CONSEQUENCES.—Before making any recommendations, MACPAC shall examine the budget consequences of such recommendations, directly or through consultation with appropriate expert entities, and shall submit with any recommendations, a report on the Federal and State-specific budget consequences of the recommendations.
- (11) CONSULTATION AND COORDINATION WITH MEDPAC.—
- (A) IN GENERAL.—MACPAC shall consult with the Medicare Payment Advisory Commission (in this paragraph referred to as “MedPAC”) established under section 1805 in carrying out its duties under this section, as appropriate and particularly with respect to the issues specified in paragraph (2) as they relate to those Medicaid beneficiaries who are dually eligible for Medicaid and the Medicare program under title XVIII, adult Medicaid beneficiaries (who are not dually eligible for Medicare), and beneficiaries under Medicare. Responsibility for analysis of and recommendations to change Medicare policy regarding Medicare beneficiaries, including Medicare beneficiaries who are dually eligible for Medicare and Medicaid, shall rest with MedPAC.
- (B) INFORMATION SHARING.—MACPAC and MedPAC shall have access to deliberations and records of the other such entity, respectively, upon the request of the other such entity.
- (12) CONSULTATION WITH STATES.—MACPAC shall regularly consult with States in carrying out its duties under this section, including with respect to developing processes for carrying out such duties, and shall ensure that input from States is taken into account and represented in MACPAC’s recommendations and reports.
- (13) COORDINATE AND CONSULT WITH THE FEDERAL COORDINATED HEALTH CARE OFFICE.—MACPAC shall coordinate and consult with the Federal Coordinated Health Care Office established under section 2081 of the Patient Protection and Affordable Care Act before making any recommendations regarding dually eligible individuals.
- (14) PROGRAMMATIC OVERSIGHT VESTED IN THE SECRETARY.—MACPAC’s authority to make recommendations in accordance with this section shall not affect, or be considered to duplicate, the Secretary’s authority to carry out Federal responsibilities with respect to Medicaid and CHIP.
- (c) MEMBERSHIP.—
- (1) NUMBER AND APPOINTMENT.—MACPAC shall be composed of 17 members appointed by the Comptroller General of the United States.

(2) QUALIFICATIONS.—

- (A) IN GENERAL.—The membership of MACPAC shall include individuals who have had direct experience as enrollees or parents or caregivers of enrollees in Medicaid or CHIP and individuals with national recognition for their expertise in Federal safety net health programs, health finance and economics, actuarial science, health plans and integrated delivery systems, reimbursement for health care, health information technology, and other providers of health services, public health, and other related fields, who provide a mix of different professions, broad geographic representation, and a balance between urban and rural representation.
- (B) INCLUSION.—The membership of MACPAC shall include (but not be limited to) physicians, dentists, and other health professionals, employers, third-party payers, and individuals with expertise in the delivery of health services. Such membership shall also include representatives of children, pregnant women, the elderly, individuals with disabilities, caregivers, and dually eligible individuals, current or former representatives of State agencies responsible for administering Medicaid, and current or former representatives of State agencies responsible for administering CHIP.
- (C) MAJORITY NONPROVIDERS.—Individuals who are directly involved in the provision, or management of the delivery, of items and services covered under Medicaid or CHIP shall not constitute a majority of the membership of MACPAC.
- (D) ETHICAL DISCLOSURE.—The Comptroller General of the United States shall establish a system for public disclosure by members of MACPAC of financial and other potential conflicts of interest relating to such members. Members of MACPAC shall be treated as employees of Congress for purposes of applying title I of the Ethics in Government Act of 1978 (Public Law 95–521).

(3) TERMS.—

- (A) IN GENERAL.—The terms of members of MACPAC shall be for 3 years except that the Comptroller General of the United States shall designate staggered terms for the members first appointed.
 - (B) VACANCIES.—Any member appointed to fill a vacancy occurring before the expiration of the term for which the member’s predecessor was appointed shall be appointed only for the remainder of that term. A member may serve after the expiration of that member’s term until a successor has taken office. A vacancy in MACPAC shall be filled in the manner in which the original appointment was made.
- (4) COMPENSATION.—While serving on the business of MACPAC (including travel time), a member of MACPAC shall be entitled to compensation at the per diem equivalent of the rate provided for level IV of the Executive Schedule under section 5315 of title 5, United States Code; and while so serving away from home and the member’s regular place of business, a member may be allowed travel expenses, as authorized by the Chairman of MACPAC. Physicians serving as personnel of MACPAC may be provided a physician comparability allowance by MACPAC in the same manner as Government physicians may be provided such an allowance by an agency under section 5948 of title 5, United States Code, and for such purpose subsection (i) of such section shall apply to MACPAC in the same manner as it applies to the Tennessee Valley Authority. For purposes of pay (other than pay of members of MACPAC) and employment benefits, rights, and privileges, all personnel of MACPAC shall be treated as if they were employees of the United States Senate.

- (5) CHAIRMAN; VICE CHAIRMAN.—The Comptroller General of the United States shall designate a member of MACPAC, at the time of appointment of the member as Chairman and a member as Vice Chairman for that term of appointment, except that in the case of vacancy of the Chairmanship or Vice Chairmanship, the Comptroller General of the United States may designate another member for the remainder of that member’s term.
- (6) MEETINGS.—MACPAC shall meet at the call of the Chairman.
- (d) DIRECTOR AND STAFF; EXPERTS AND CONSULTANTS.—Subject to such review as the Comptroller General of the United States deems necessary to assure the efficient administration of MACPAC, MACPAC may—
- (1) employ and fix the compensation of an Executive Director (subject to the approval of the Comptroller General of the United States) and such other personnel as may be necessary to carry out its duties (without regard to the provisions of title 5, United States Code, governing appointments in the competitive service);
 - (2) seek such assistance and support as may be required in the performance of its duties from appropriate Federal and State departments and agencies;
 - (3) enter into contracts or make other arrangements, as may be necessary for the conduct of the work of MACPAC (without regard to section 3709 of the Revised Statutes (41 USC 5));
 - (4) make advance, progress, and other payments which relate to the work of MACPAC;
 - (5) provide transportation and subsistence for persons serving without compensation; and
 - (6) prescribe such rules and regulations as it deems necessary with respect to the internal organization and operation of MACPAC.
- (e) POWERS.—
- (1) OBTAINING OFFICIAL DATA.—MACPAC may secure directly from any department or agency of the United States and, as a condition for receiving payments under sections 1903(a) and 2105(a), from any State agency responsible for administering Medicaid or CHIP, information necessary to enable it to carry out this section. Upon request of the Chairman, the head of that department or agency shall furnish that information to MACPAC on an agreed upon schedule.
 - (2) DATA COLLECTION.—In order to carry out its functions, MACPAC shall—
 - (A) utilize existing information, both published and unpublished, where possible, collected and assessed either by its own staff or under other arrangements made in accordance with this section;
 - (B) carry out, or award grants or contracts for, original research and experimentation, where existing information is inadequate; and
 - (C) adopt procedures allowing any interested party to submit information for MACPAC’s use in making reports and recommendations.

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

Biographies of Commissioners

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.

Melanie Bella, MBA (Chair), is head of partnerships and policy at Cityblock Health, which facilitates health care delivery for low-income urban populations, particularly Medicaid beneficiaries and those dually eligible for Medicaid and Medicare. Previously, she served as the founding director of the Medicare-Medicaid Coordination Office at the Centers for Medicare & Medicaid Services (CMS), where she designed and launched payment and delivery system demonstrations to improve quality and reduce costs. Ms. Bella also was the director of the Indiana Medicaid program, where she oversaw Medicaid, the State Children's Health Insurance Program (CHIP), and the state's long-term care insurance program. Ms. Bella received her master of business administration from Harvard University.

Tricia Brooks, MBA, is a research professor at the McCourt School of Public Policy at Georgetown University and a senior fellow at the Georgetown University Center for Children and Families (CCF), an independent, non-partisan policy and research center whose mission is to expand and improve health coverage for children and families. At CCF, Ms. Brooks focuses on issues relating to policy, program administration, and quality of Medicaid and CHIP coverage for children and families. Prior to joining CCF, she served as the founding CEO of

New Hampshire Healthy Kids, a legislatively created non-profit corporation that administered CHIP in the state, and served as the Medicaid and CHIP consumer assistance coordinator. Ms. Brooks holds a master of business administration from Suffolk University.

Brian Burwell is vice president of health care policy and research at Ventech Solutions, where his work includes research, consulting services, policy analysis, and technical assistance in financing and delivery of long-term services and supports (LTSS), and data analysis related to integrated care models for dually eligible beneficiaries and managed LTSS. Previously, Mr. Burwell was a senior executive in the government health and human services unit at IBM Watson Health. He received his bachelor of arts from Dartmouth College.

Martha Carter, DHSc, MBA, APRN, CNM, is an independent consultant. She is the founder and former CEO of FamilyCare Health Centers, a community health center that serves four counties in south-central West Virginia. Dr. Carter practiced as a certified nurse-midwife in Kentucky, Ohio, and West Virginia for 20 years and is a member of the West Virginia Alliance for Creative Health Solutions, a practice-led research and advocacy network. Dr. Carter was a Robert Wood Johnson Foundation Executive Nurse Fellow in 2005–2008 and received the Robert Wood Johnson Foundation Community Health Leader award in 1999. She holds a doctorate of health sciences from A.T. Still University in Mesa, Arizona, and a master of business administration from West Virginia University.

Frederick Cerise, MD, MPH, is president and CEO of Parkland Health and Hospital System, a large public safety-net health system in Dallas, Texas. Previously, he oversaw Medicaid and other programs for the state of Louisiana as secretary of the Department of Health and Hospitals. Dr. Cerise also held the position of medical director and other leadership roles at various health care facilities operated by Louisiana State University. He began his career as an internal medicine physician and spent 13 years treating patients and teaching

medical students in Louisiana's public hospital system. Dr. Cerise received his degree in medicine from Louisiana State University and his master of public health from Harvard University.

Kisha Davis, MD, MPH, (Vice Chair), is vice president of health equity for Aledade. Previously, Dr. Davis was Maryland medical director for VaxCare Corporation; worked as a family physician at CHI Health Care in Rockville, Maryland; and served as program manager at CFAR in Philadelphia, Pennsylvania, where she supported projects for family physicians focused on payment reform and practice transformation to promote health system change. Dr. Davis has also served as the medical director and director of community health at CHI and as a family physician at a federally qualified health center (FQHC) in Maryland. As a White House Fellow at the U.S. Department of Agriculture, she established relationships among leaders of FQHCs and the Women, Infants, and Children nutrition program. Dr. Davis received her degree in medicine from the University of Connecticut and her master of public health from Johns Hopkins University.

Toby Douglas, MPP, MPH, is senior vice president, national Medicaid, at Kaiser Permanente. Previously, Mr. Douglas was senior vice president for Medicaid solutions at Centene Corporation, and prior to that, a long-standing state Medicaid official. He served as director of the California Department of Health Care Services and was director of California Medicaid for six years, during which time he also served as a board member of the National Association of Medicaid Directors and as a CHIP director. Earlier in his career, Mr. Douglas worked for the San Mateo County Health Department in California, as a research associate at the Urban Institute, and as a VISTA volunteer. He received his master of public policy and master of public health from the University of California, Berkeley.

Robert Duncan, MBA, is executive vice president of Children's Wisconsin, where he oversees the strategic contracting for systems of care, population health, and the development of value-based contracts. He also is 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. Previously, he 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.

Darin Gordon is president and CEO of Gordon & Associates in Nashville, Tennessee, where he provides health care-related consulting services to a wide range of public- and private-sector clients. Previously, he was director of Medicaid and CHIP in Tennessee for 10 years, where he oversaw various program improvements, including the implementation of a statewide value-based purchasing program. During this time, he served as president and vice president of the National Association of Medicaid Directors for four years. Before becoming director of Medicaid and CHIP, he was the chief financial officer and director of managed care programs. Mr. Gordon received his bachelor of science from Middle Tennessee State University.

Christopher Gorton, MD, MHSA, was formerly president of public plans at Tufts Health Plan, a non-profit health plan in Massachusetts, Rhode Island, and New Hampshire, as well as CEO of a regional health plan that was acquired by the Inova Health System of Falls Church, Virginia. Other positions held include vice president for medical management and worldwide health care strategy for Hewlett Packard Enterprise Services and president and chief medical officer for APS Healthcare, a behavioral health plan and care management organization based in Silver Spring, Maryland. After beginning his career as a practicing pediatrician in FQHCs in Pennsylvania and Missouri, Dr. Gorton served as chief medical officer in the Pennsylvania Department of Public Welfare. Dr. Gorton received

his degree in medicine from Columbia University's College of Physicians and Surgeons and his master of health systems administration from the College of Saint Francis in Joliet, Illinois.

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 LTSS 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 care needs, Founders Council of the United States of Care, and a board member of Health Law Advocates, a Massachusetts-based non-profit 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.

Verlon Johnson, MPA, is senior vice president of corporate strategy at CNSI, 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 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.

Stacey Lampkin, FSA, MAAA, MPA, is an actuary and principal with Mercer Government Human Services Consulting, where she has led actuarial work for several state Medicaid programs. She previously served as an actuary and assistant deputy secretary for Medicaid finance and analytics at Florida's Agency for Health Care Administration and as an actuary at Milliman. She has also served as a member of the Federal Health Committee of the American Academy of Actuaries (AAA), as vice chairperson of AAA's uninsured work group, and as a member of the Society of Actuaries project oversight group for research on evaluating medical management interventions. Ms. Lampkin is a fellow of the Society of Actuaries and a member of the AAA. She received her master of public administration from Florida State University.

William Scanlon, PhD, is an independent consultant working with West Health, among others. He began conducting health services research on the Medicaid and Medicare programs in 1975, with a focus on such issues as the provision and financing of long-term care services and provider payment policies. He previously held positions at Georgetown University and the Urban Institute, was managing director of health care issues at the U.S. Government Accountability Office, and served on the Medicare Payment Advisory Commission. Dr. Scanlon received his doctorate in economics from the University of Wisconsin, Madison.

Laura Herrera Scott, MD, MPH, is vice president of clinical strategy and product at Anthem, where she has developed payer and data alignment policies to support efforts to advance population health. Previously, she held several leadership positions in the Maryland Department of Health and Mental Hygiene and the Veterans Health Administration. Dr. Herrera Scott's work has focused on payment reform and delivery system transformation to improve health status and outcomes in underserved communities. She received her degree in medicine from SUNY Health Science Center at Brooklyn and her master of public health from the Johns Hopkins Bloomberg School of Public Health.

Katherine Weno, DDS, JD, is an independent public health consultant. Previously, she held positions at the Centers for Disease Control and Prevention, including senior advisor for the National Center for Chronic Disease Prevention and Health Promotion and director of the Division of Oral Health. Dr. Weno also served as the director of the Bureau of Oral Health in the Kansas Department of Health and Environment. Previously, she was the CHIP advocacy project director at Legal Aid of Western Missouri and was an associate attorney at Brown, Winick, Graves, Gross, Baskerville, and Schoenebaum in Des Moines, Iowa. Dr. Weno started her career as a dentist in Iowa and Wisconsin. She earned degrees in dentistry and law from the University of Iowa.

Biographies of Staff

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

James Boissonault, MA, is the chief information officer. Prior to joining MACPAC, he was the information technology (IT) director and security officer for OnPoint Consulting. At OnPoint, he worked on several federal government projects, including projects for the Missile Defense Agency, the U.S. Department of the Treasury, and the U.S. Department of Agriculture. He has nearly two decades of IT and communications experience. Mr. Boissonault holds a master of arts in Slavic languages and literatures from The University of North Carolina and a bachelor of arts in Russian from the University of Massachusetts.

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

Kacey Buderl, MPA, is a senior analyst. Prior to joining MACPAC, she worked in the Center for Congressional and Presidential Studies at American University and completed internships in the office of U.S. Senator Ed Markey and at the U.S. Department of Health and Human Services (HHS). Ms. Buderl holds a master of public administration and a bachelor of arts in political science, both from American University.

Moira Forbes, MBA, is the principal policy director focusing on payment policy and the design, implementation, and effectiveness of program integrity activities in Medicaid and the State Children's Health Insurance Program (CHIP). Previously, she served as director of the division of health and social service programs in the Office of Executive Program Information at HHS and as a vice president in the Medicaid practice at The Lewin Group. She has extensive experience with federal and state policy analysis, Medicaid program operations, and delivery system design. Ms. Forbes was elected to the National Academy of Social Insurance in 2019. She has a master of business administration from The George Washington University and a bachelor's degree in Russian and political science from Bryn Mawr College.

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

Tamara Huson, MSPH, is an analyst. Prior to joining MACPAC, she worked as a research assistant in the Department of Health Policy and Management at The University of North Carolina. She also worked for the American Cancer Society and completed internships with the North Carolina General Assembly and the Foundation for Health Leadership

and Innovation. Ms. Huson holds a master of science in public health from The University of North Carolina at Chapel Hill and a bachelor of arts in biology and global studies from Lehigh University.

Joanne Jee, MPH, is a policy director and the congressional liaison. Her work focuses on CHIP and children's coverage. Prior to joining MACPAC, she was a program director at the National Academy for State Health Policy, where she focused on children's coverage issues. Ms. Jee also has been a senior analyst at GAO, a program manager at The Lewin Group, and a legislative analyst in the HHS Office of Legislation. Ms. 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 an analyst. Prior to joining MACPAC, she 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. She 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.

Allissa Jones, MTA, is the executive assistant. Prior to joining MACPAC, Ms. Jones worked as an intern for Kaiser Permanente, where she helped coordinate health and wellness events in the Washington, DC, area. Ms. Jones holds a master of tourism administration from The George Washington University and a bachelor of science with a concentration in health management from Howard University.

Erin McMullen, MPP, is a principal analyst. Prior to joining MACPAC, she served as the chief of staff in the Office of Health Care Financing at the Maryland Department of Health. Ms. McMullen also has been a senior policy advisor in the Office of Behavioral Health and Disabilities at the Maryland Department of Health and a legislative policy analyst for the

Maryland General Assembly's Department of Legislative Services. Ms. McMullen holds a master of public policy from American University and a bachelor's degree in economics and social sciences from Towson University.

Jerry Mi is a research assistant. Prior to joining MACPAC, Mr. Mi interned for the U.S. House of Representatives Committee on Energy and Commerce, the Health Resources and Services Administration, the Food and Drug Administration, and the National Institutes of Health. Mr. Mi graduated from the University of Maryland with an undergraduate degree in biological sciences.

Michelle KIELTY Millerick, MPH, is a senior analyst. Prior to joining MACPAC, she was a senior manager of provider and pharmacy programs at the Massachusetts Medicaid program (MassHealth). Prior to that, she worked in the Government Relations Office at Dana-Farber Cancer Institute, where her work focused on health policy and advocacy issues affecting specialty cancer care. Ms. Millerick holds a master of public health from Boston University with a dual concentration in health policy & management and health law, bioethics & human rights, as well as a bachelor of science in health sciences from Boston University's Sargent College of Health and Rehabilitation Sciences.

Breshay Moore is the communications specialist. Prior to joining MACPAC, Ms. Moore worked as a communications intern for Better Markets, a non-profit organization in Washington, DC, where she supported press engagement and updated media databases. She also was a junior transcriber at Verb8tm Captioning & Transcription Software and Services, Inc., where she translated audio for company partners and clients. Ms. Moore graduated from Towson University with a bachelor of arts in mass communications.

Robert Nelb, MPH, is a principal analyst focusing on issues related to Medicaid payment and delivery system reform. Prior to joining MACPAC, he served as a health insurance specialist at the Centers for Medicare & Medicaid Services, leading projects related to CHIP and Medicaid Section 1115 demonstrations. Mr. Nelb has a master of public health and a bachelor's degree in ethics, politics, and economics from Yale University.

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

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

Aaron Pervin, MPH, is a senior analyst. Prior to joining MACPAC, Mr. Pervin worked for Results for Development, an international consulting firm that advises foreign governments on health finance and provider payment issues related to insurance coverage for low-income and vulnerable populations. Earlier, Mr. Pervin worked for the Commonwealth of Massachusetts at the Health Policy Commission, where his work focused on alternative payment arrangements and delivery

system reform. Mr. Pervin holds a master of public health from Harvard University and a bachelor of arts in political science from Reed College.

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

Kimberley Pringle is the administrative assistant. Prior to joining MACPAC, she was the executive assistant to the executive director of the NOVA Foundation for Northern Virginia Community College in Annandale, Virginia. Ms. Pringle attended Atlantic Community College where she received a certificate in computer technology.

Melinda Becker Roach, MS, is a senior analyst. Prior to joining MACPAC, Ms. 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. Ms. Roach previously served as a legislative advisor on personal staff in the U.S. House of Representatives. She 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.

Brian Robinson, CGFM, is a financial analyst. Prior to joining MACPAC, he worked as a business intern at the Joint Global Climate Change Research Institute, a partnership between the University of Maryland and Pacific Northwest National Laboratory. Mr. Robinson holds a bachelor of science in accounting from the University of Maryland.

Anne L. Schwartz, PhD, is the executive director. She previously served as deputy editor at *Health Affairs*; vice president at Grantmakers In Health, a national organization providing strategic advice and educational programs for foundations and corporate giving programs working on health issues;

and special assistant to the executive director and senior analyst at the Physician Payment Review Commission, a precursor to the Medicare Payment Advisory Commission. Earlier, she held positions on committee and personal staff for the U.S. House of Representatives. Dr. Schwartz earned a doctorate in health policy from the School of Hygiene and Public Health at Johns Hopkins University.

Ashley Semanskee, MPA, is an analyst. Prior to joining MACPAC, she worked as a research assistant at the Kaiser Family Foundation and interned at the U.S. Senate Committee on Finance, where she worked on health reform and prescription drug legislation. Ms. Semanskee holds a master of public affairs from Princeton School of Public and International Affairs and a bachelor of arts in human biology from Stanford University.

Kristal Vardaman, PhD, MSPH, is a policy director. Previously, she was a senior analyst at GAO and a consultant at Avalere Health. Dr. Vardaman earned a doctorate in public policy and administration from The George Washington University. She also holds a master of science in public health from The University of North Carolina at Chapel Hill and a bachelor of science from the University of Michigan.

Eileen Wilkie is the administrative officer and is responsible for coordinating human resources, office maintenance, travel, and Commission meetings. Previously, she held similar roles at National Public Radio and the National Endowment for Democracy. Ms. Wilkie has a bachelor's degree in political science from the University of Notre Dame.

Amy Zettle, MPP, is a senior analyst. Prior to joining MACPAC, Ms. Zettle served as the legislative director for the Health and Human Services Committee at the NGA. Ms. Zettle has been a federal affairs director at Cigna and a health care analyst at the Potomac Research Group. Ms. Zettle holds a master of public policy from the University of Maryland and a bachelor of arts in economics from John Carroll University.




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MACPAC

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1800 M Street NW
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