Chapter 1:

Children and Youth with Special Health Care Needs Transitions of Care

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Recommendations

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

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

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

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

Children and Youth with Special Health Care Needs Transitions of Care

Key Points

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

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

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

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

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

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

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

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

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

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

Medicaid-Covered CYSHCN

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

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

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

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

Transition of care process

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

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

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

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

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

The following are examples:

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

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

BOX 1-1. (continued)

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

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

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

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

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

Structured health care transitions

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

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

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

Data availability and limitations

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

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

Federal Transition of Care Requirements

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

Medicaid

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

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

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

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

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

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

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

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

Health Resources & Services Administration

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

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

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

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

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

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

State Role in Transitions

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

Transition of care approach

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

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

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

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

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

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

Coverage of services to support transitions of care

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

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

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

Data collection on transitions of care

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

Collaboration with state Title V agencies

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

Challenges with Medicaid-Covered CYSHCN Transitions to Adult Care

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

Lack of clearly documented and communicated state transitions of care strategy

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

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

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

Not all CYSHCN receive a transition of care plan

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

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

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

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

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

Lack of data collection on transitions of care and outcomes

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

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

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

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

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

Commission Recommendations

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

Recommendation 1.1

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

Rationale

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

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

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

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

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

Implications

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

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

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

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

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

Recommendation 1.2

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

Rationale

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

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

Implications

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

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

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

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

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

Recommendation 1.3

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

Rationale

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

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

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

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

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

Implications

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

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

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

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

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

Recommendation 1.4

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

Rationale

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

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

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

Implications

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

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

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

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

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

Looking Ahead

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

Endnotes

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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APPENDIX 1A: Methods

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

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

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

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

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

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

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

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

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

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

Endnotes

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

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

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

Commission Vote on Recommendations

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

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

The Commission voted on these recommendations on April 11, 2025.

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

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

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

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

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

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