

Chapter 5:

Children and Youth with Special Health Care Needs Transitions to Adult Coverage

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Recommendations

- 5.1** The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 435.919(b)(6) to require states to send a notice a minimum of 60 days in advance of children and youth with special health care needs (CYSHCN) aging out of child Medicaid eligibility to inform them that the renewal process has been initiated. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.
- 5.2** State Medicaid agencies should provide children and youth with special health care needs (CYSHCN) who are aging out of child Medicaid eligibility with a minimum of 30 days to respond to requests for information to complete Medicaid redeterminations in accordance with 42 CFR 435.919(c)(1). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.
- 5.3** To ensure the accuracy of information provided by the Social Security Administration (SSA) to Medicaid beneficiaries enrolled in Supplemental Security Income (SSI)-related eligibility pathways who are being notified that they are losing eligibility for SSI, the Secretary of the U.S. Department of Health and Human Services, through the Centers for Medicare & Medicaid Services, should coordinate with SSA to review and update model notice language pertaining to Medicaid in SSA's Program Operations Manual System manual paragraphs. The model language should clearly indicate that the individual may retain their Medicaid coverage while the state Medicaid agency takes steps to redetermine the individual on a new basis of eligibility. Additionally, the model language should describe, in general terms, the steps the individual needs to follow to complete the Medicaid redetermination that are specific to 1634, SSI criteria, and 209(b) states.
- 5.4** State Medicaid agencies should implement optional Medicaid eligibility for children and youth with special health care needs (CYSHCN) up to age 21 who are not otherwise eligible for and enrolled in mandatory coverage or optional full Medicaid coverage under the state plan (42 CFR 435.222 and 42 CFR 435.223). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

- 5.5** To ensure children and youth with special health care needs (CYSHCN) receive a full 12-month continuous eligibility period in their final year of child Medicaid eligibility, Congress should amend § 1902(e)(12) of the Social Security Act to require states to provide CYSHCN with a 12-month continuous eligibility period that lasts a full 12 months from the date of the eligibility determination, even if during the continuous eligibility period, an individual reaches the upper age limit for the eligibility pathway by which they are eligible for Medicaid. This 12-month continuous eligibility period should apply to all CYSHCN who receive coverage from a mandatory or optional child eligibility pathway, including optional pathways covering youth above age 18. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.
- 5.6** 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 supporting children and youth with special health care needs (CYSHCN) with Medicaid redeterminations and transitioning to adult Medicaid coverage. The guidance should address authorities to cover case management, transition planning for child-only Section 1915(c) home- and community-based services waivers, and the state optional pathway to cover children up to age 21. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

Key Points

- Medicaid-covered children and youth with special health care needs (CYSHCN) often navigate multiple, sometimes overlapping, transitions as they reach adulthood. In addition to transitioning from child to adult Medicaid eligibility, they may simultaneously undergo the Supplemental Security Income (SSI) age-18 redetermination and transition from child-only to adult 1915(c) home- and community-based services waivers.
- State Medicaid agencies leverage a number of authorities to ease the Medicaid redetermination process. The majority of CYSHCN (82.4 percent) enrolled in disability-related pathways remained enrolled in Medicaid as adults without experiencing a gap in coverage. However, some CYSHCN experience challenges with this transition. Of the 17.6 percent who disenroll when aging out of child Medicaid, one-third re-enrolled in Medicaid within 12 months.
- Key challenges with the transition to adult Medicaid coverage include insufficient time to prepare and respond to Medicaid redetermination notices; lack of clarity about changes to SSI and how it affects Medicaid eligibility; and inconsistent and sometimes insufficient support with the Medicaid redetermination and other simultaneous transitions.

CHAPTER 5: Children and Youth with Special Health Care Needs Transitions to Adult Coverage

Almost a quarter of all children meet the criteria for having special health care needs, and Medicaid covers more than 40 percent of these children and youth (Black et al. 2024). Children and youth with special health care needs (CYSHCN) are broadly defined by the Maternal and Child Health Bureau (MCHB) 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 (MCHB 2025, Black et al. 2024).¹ CYSHCN are often high users of care and may interact with many types of providers (e.g., primary and specialized, care coordinators, case managers) and need prescriptions for their treatment (Schiff et al. 2022). Additionally, Medicaid-covered CYSHCN may be involved with and receive supports from several agencies at the federal, state, and local levels (MACPAC 2025).

When Medicaid-covered CYSHCN approach adulthood, they may need to navigate multiple program age-related transitions (often between age 18 and 26) that occur simultaneously or near simultaneously. These can include transitions from child to adult Medicaid eligibility (most often at age 19); the end of the early and periodic screening, diagnostic, and treatment (EPSDT) requirement (ends at age 21); transitions between Section 1915(c) home- and community-based services (HCBS) waivers (often between age 17 and 22); the age-18 Supplemental Security Income (SSI) redetermination (between age 18 and 19); the end of Title V Maternal and Child Health program services (often by age 21); the end of special education school services (often by age 22); and the end of child welfare support and Medicaid coverage for those who aged out of foster care (age 26) (MACPAC 2025, McManus et al. 2024).² Thus,

during this transition period, CYSHCN may experience a so-called services cliff due to a reduction or loss of multiple services and supports (Steinway et al. 2017).

The Commission sought to understand Medicaid's role in supporting CYSHCN transitions between child and adult care and Medicaid eligibility and how these transitions may overlap and interact with other program transitions. This work focuses on a narrow scope of Medicaid-covered CYSHCN (about 3.6 percent) who are eligible for Medicaid through either SSI-related eligibility pathways or the Katie Beckett pathway for children with disabilities (enacted under the Tax Equity and Fiscal Responsibility Act of 1982) through state plan or waiver authority, or enrolled in a waiver because they qualify to receive an institutional level of care (MACPAC 2021).³

In MACPAC's June 2025 report to Congress, the Commission made recommendations to address barriers in the transition from pediatric to adult care for Medicaid-covered CYSHCN, their families, and their caregivers identified in our research. These recommendations direct: (1) Congress to require states to develop and implement a strategy for CYSHCN transitions from pediatric to adult care that includes developing individualized transition of care plans, (2) the U.S. Department of Health and Human Services (HHS) to direct the Centers for Medicare & Medicaid Services (CMS) to issue guidance on existing authorities for covering transition of care services, (3) HHS to direct CMS to require states to collect and report to CMS on CYSHCN transition-related data, and (4) HHS to direct CMS to require interagency agreements between state Medicaid and Title V agencies to specify the roles and responsibilities of these agencies in supporting CYSHCN transitions from pediatric to adult care (MACPAC 2025).

This chapter describes findings from our examination of CYSHCN transitions between child and adult Medicaid coverage and how this transition overlaps with the Social Security Administration (SSA) age-18 SSI redetermination and the transition between child-only and adult Section 1915(c) HCBS waivers. In this work, the Commission sought to understand the federal requirements for the Medicaid redetermination process and authorities that state Medicaid agencies

can use to ease transitions from child to adult Medicaid coverage for CYSHCN, their families, and their caregivers. We conducted a literature review, federal and state policy scan, stakeholder interviews, and analyses of the Transformed Medicaid Statistical Information System (T-MSIS) and the American Community Survey (ACS).

Research demonstrates that CYSHCN and their families and caregivers experience challenges when transitioning to adult Medicaid that can lead to gaps and loss of coverage (McManus et al. 2024, Okumura et al. 2022, White et al. 2018). For example, recent research indicates that disenrollment among Medicaid-covered individuals peaks at age 19 when they are aging out of child Medicaid (Cliff et al. 2026, McMahan et al. 2025, Smith et al. 2025). Additionally, findings from our analysis of T-MSIS and ACS show that 17.6 percent of Medicaid-covered transition-age youth enrolled in disability pathways disenrolled when aging out. Among young adults with self-reported disabilities, the percentage of Medicaid-covered individuals was lower for those age 19 and 20 to 25 years (39.5 percent and 35.9 percent, respectively) compared to those age 17 to 18 years (48.2 percent) (Appendices 5A and 5B). Disenrollment can be attributed to no longer meeting Medicaid eligibility criteria, transitioning to other sources of coverage, and administrative barriers that prevent beneficiaries from maintaining coverage when they are eligible (Sugar et al. 2021). Gaps and loss of coverage, even for short periods, are associated with delays in receipt of care, an increase in unmet health needs, fewer office-based doctor visits, and an increase in the risk of hospitalization, which can have both short- and long-term health implications (Rennane et al. 2023, Brantley and Ku 2022, Horne et al. 2022, Hemmeter 2011). Additionally, churning (disenrolling and reenrolling in Medicaid within a short period of time) may increase overall Medicaid costs for beneficiaries of all ages due to pent-up demand for care and increased emergency department (ED) utilization after gaps in coverage (Sugar et al. 2021). For example, findings from a 2022 MACPAC study of health care utilization for adults following a gap in Medicaid coverage show that rates of hospitalization and ED use were more than twice as high compared to baseline utilization before disenrollment (MACPAC 2022).

States have many flexibilities and authorities that they can leverage to ease and support the transition to adult Medicaid coverage, including those related to the eligibility redetermination process, optional child and adult eligibility pathways, and the operationalization of their Section 1915(c) HCBS waiver programs. Our findings demonstrate that many states use some of these existing flexibilities and authorities, and our analysis of 2017 through 2019 T-MSIS data indicate that the majority of Medicaid-covered CYSHCN enrolled in disability-related pathways (82.4 percent) remain continuously enrolled during this transition to adult Medicaid coverage (Appendix 5A, Tables 5A-1 and 5A-2). However, our research also identified that despite these state efforts to ease the transition to adult Medicaid, some CYSHCN experience challenges with this transition that can lead to disruptions in their coverage. Challenges include insufficient time to prepare for and respond to Medicaid redetermination notices, lack of clarity in notices from SSA about changes to SSI and SSI-related Medicaid eligibility, navigating eligibility transitions, and variation in the level of support received with Medicaid redeterminations.

The Commission makes six recommendations to address these challenges and improve continuity of coverage as CYSHCN transition to adult Medicaid coverage. The Commission's recommendations are:

- 5.1 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 435.919(b)(6) to require states to send a notice a minimum of 60 days in advance of children and youth with special health care needs (CYSHCN) aging out of child Medicaid eligibility to inform them that the renewal process has been initiated. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

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- 5.6 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 supporting children and youth with special health care needs (CYSHCN) with Medicaid redeterminations and transitioning to adult Medicaid coverage. The guidance should address authorities to cover case management, transition planning for child-only Section 1915(c) home- and community-based services waivers, and the state optional pathway to cover children up to age 21. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI

as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

This chapter begins with background on the Medicaid-covered CYSHCN population, including their eligibility pathways and benefits. It then describes the transition from child to adult Medicaid coverage, including the federal requirements for Medicaid redeterminations and transitions between Section 1915(c) HCBS waivers, and key findings on adult Medicaid coverage transition outcomes. Then it presents findings on the state role in facilitating the transition to adult Medicaid coverage and approaches to easing this process. Next it describes the four key challenges beneficiaries experience with the transition to adult Medicaid coverage. Finally, the chapter presents the Commission's six recommendations and associated rationale as well as implications for federal spending, states, enrollees, plans, and providers.

Medicaid-Covered CYSHCN

More than 40 percent of CYSHCN are covered by Medicaid or a combination of Medicaid and private insurance (37.2 percent and 7.6 percent, respectively) (MACPAC 2024). Medicaid-covered CYSHCN can enroll on the basis of income or disability, which includes mandatory SSI-related pathways and state optional disability pathways. Optional disability-related pathways include the state medically needy pathway option, state plan options established by the Family Opportunity Act of 2005 (P.L. 109-171), the Section 1915(i) state plan HCBS benefit pathway, and the optional Katie Beckett pathway for children with disabilities or Katie Beckett waiver (Musumeci and Chidambaram 2019).⁴

Most Medicaid beneficiaries enrolled in mandatory SSI-related eligibility pathways are also eligible for SSI, but the Medicaid enrollment processes vary between states.⁵ Based on legislative flexibilities that Congress has afforded to states, states can use three approaches when determining Medicaid eligibility for SSI-enrolled individuals:

- **1634 states (35 states and the District of Columbia):** Section 1634 of the Social Security Act (the Act) allows SSA to enter into an agreement with state Medicaid agencies in which SSA determines Medicaid eligibility for individuals who are eligible for SSI. In these states, referred to as "1634 states," a determination of eligibility for SSI confers Medicaid eligibility, and the beneficiary remains Medicaid eligible as long as they remain SSI eligible (42 CFR 435.541). SSI-eligible individuals are not required to submit a separate Medicaid application.
- **SSI criteria states (8 states):** Medicaid programs in these states use SSI methodology when determining Medicaid eligibility on the basis of disability. These states do not have a Section 1634 agreement with SSA, so if an individual applies to SSA for SSI, they must also submit a separate Medicaid application to the state Medicaid agency to enroll in Medicaid because SSI eligibility does not automatically confer categorical eligibility for Medicaid (42 CFR 435.541).
- **209(b) states (8 states):** Section 209(b) of the Act, Amendments of 1972, allows states to use Medicaid eligibility criteria (related to income and assets, disability, or both) that are more restrictive than SSI program criteria. Individuals who are eligible for SSI must separately apply to Medicaid to be determined eligible for Medicaid coverage.

States may choose to cover optional benefits under the state plan or through waiver programs. For example, states can use waiver authority to cover services not covered under the state plan, including HCBS. Furthermore, Section 1915(c) HCBS waiver authority allows states to cover a broad array of HCBS to eligible individuals, which can include CYSHCN, or a subset of them, who meet an institutional level of care. At the time of our review in 2025, 34 states operated a total of 51 age-limited child-only 1915(c) HCBS waiver programs with state-determined age-related eligibility limits (e.g., age 0–5 or up to age 21) and condition-specific eligibility criteria (e.g., specific diagnoses). Additionally, all Medicaid-covered children up to age 21 who are enrolled in Medicaid through the categorically needy pathway are entitled to benefits under the EPSDT requirement (42 CFR 441.56).

Section 1905(a)(4)(B) and (r) of the Act requires states to provide EPSDT-eligible children coverage for all medically necessary services that could be covered under the mandatory and optional services in section 1905(a), regardless of whether such services are covered under the state plan. The EPSDT requirement extends beyond the upper age limit for most children's eligibility pathways, so youth who receive these benefits up to age 21 are often receiving Medicaid coverage as adults.

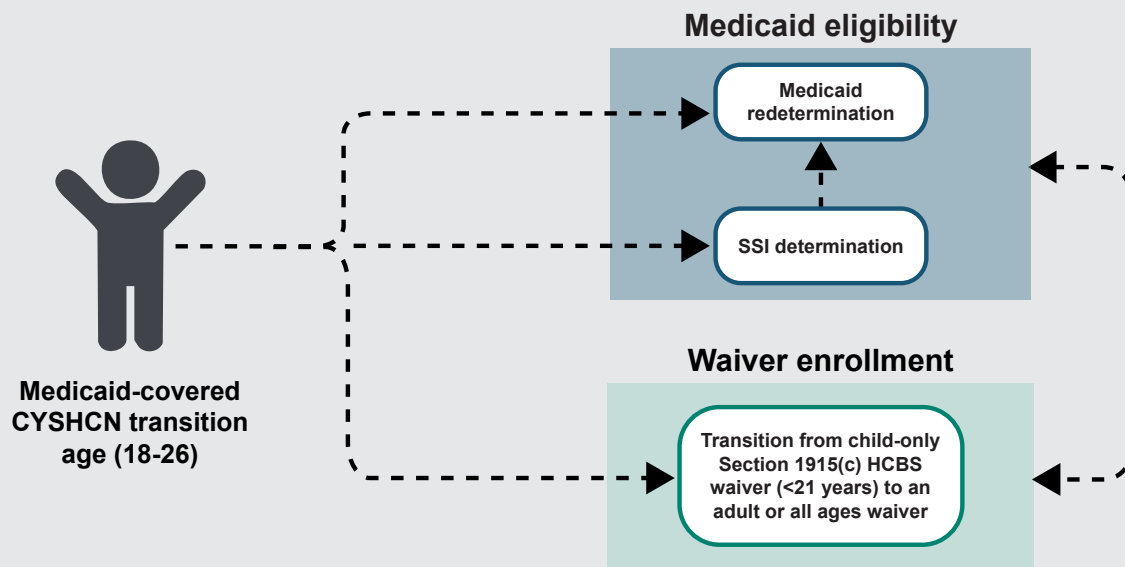
States may also choose to expand financial eligibility for waiver services through optional pathways, such as the medically needy pathway or the special income-level pathway (MACPAC 2023). Additionally, Public Law 119-21, an Act to Provide for Reconciliation Pursuant to Title II of H. Con. Res. 14 amended Section 1915(c) of the Act to create a new HCBS waiver option for states to establish a

standalone 1915(c) HCBS waiver that does not require beneficiaries to meet an institutional level of care.⁶

Transitions from Child to Adult Medicaid Coverage

When Medicaid-covered CYSHCN age into adulthood, they often navigate multiple transitions between age 18 and 26, including the transition from child to adult Medicaid coverage (Figure 5-1). During this transition period, CYSHCN can be enrolled in and receive services and supports from several programs, including Section 1915(c) HCBS waivers, SSI, state Title V programs, special education services, and child welfare. The timing of the child-to-adult transitions associated with these programs may

FIGURE 5-1. Children and Youth with Special Health Care Needs Medicaid Eligibility and Waiver Enrollment



Notes: SSI is Supplemental Security Income. CYSHCN is children and youth with special health care needs. HCBS is home- and community-based services.

Source: MACPAC analysis, 2025.

overlap and interact with the Medicaid redetermination at age 19 in most states (MACPAC 2025, McManus et al. 2024). For example, for youth enrolled in SSI-related Medicaid pathways reaching adulthood, the Medicaid redetermination may overlap with the SSI age-18 redetermination (Box 5-1). The outcome of the SSI redetermination affects the beneficiary's Medicaid eligibility pathway. Additionally, beneficiaries enrolled in an age-limited child Section 1915(c) HCBS waiver may need to transition to an adult or all ages waiver to maintain access to HCBS services. In some cases, waiver enrollment can confer Medicaid eligibility for individuals who would not otherwise be eligible for Medicaid through a mandatory pathway. Thus, the outcome of the 1915(c) HCBS waiver transition can affect the beneficiary's Medicaid eligibility as well.

Transition to adult Medicaid outcomes

Research demonstrates that disenrollment from Medicaid is greatest for youth when they reach age 19, when they are transitioning out of child Medicaid eligibility and may be experiencing multiple simultaneous or near simultaneous transitions (Cliff et al. 2026, MACPAC 2025, McMahon et al. 2025, Smith

et al. 2025). Findings from our analysis of the 2023 ACS demonstrate that there are differences in insurance coverage between youth (age 17–18) and young adults (age 19–25) with self-reported disabilities (Appendix 5B, Table 5B-1). For example, the percentage of individuals who were Medicaid covered was greater for those age 17 to 18 (48.2 percent) compared to those age 19 (39.5 percent) and 20 to 25 (35.9 percent). Across these same groups, a higher percentage of young adults (age 19 and 20–25) reported having private coverage (50.1 percent and 49.5 percent, respectively) or being uninsured (8.7 percent and 12.0 percent, respectively) compared to those age 17 to 18 (44.3 percent and 5.8 percent, respectively).

Findings from our analysis of 2017 through 2019 T-MSIS eligibility and enrollment data indicate that 17.6 percent of Medicaid-covered youth enrolled in disability-related pathways disenrolled when aging out of child Medicaid and experienced a disruption in Medicaid coverage (Appendix 5A, Table 5A-2). Of those who disenrolled, about 34 percent churned back onto Medicaid within 12 months, and the remaining 66 percent did not reenroll within 12 months.

BOX 5-1. Supplemental Security Income Age-18 Redeterminations

Individuals eligible for Supplemental Security Income (SSI) as a child must have their SSI eligibility redetermined at age 18 to continue to receive SSI benefits as an adult (SSA 2024a). The Social Security Administration (SSA) is required to initiate the age-18 redetermination for SSI within a year after an individual turns 18 years old (20 CFR 416.987). Starting at age 14, SSA sends an annual notice email to individuals about the age-18 redetermination so the enrollee and their family can prepare for the transition. The annual notice includes a link to educational resources that describe the age-18 redetermination and how to appeal if they are determined ineligible as an adult (SSA 2024a, n.d.b).

The SSI disability criteria differ for children (up to age 18) and adults (18 and older). Child disability is determined based on functional limitations, abilities of children compared to those of children without impairments, and deemed parent income (SSA 2001). The adult disability determination is defined by functional impairments, which are assessed based on the ability to work and perform substantial gainful activity, and only the individual's income is counted (SSA 2023). Due to the differences in child and adult disability and financial criteria for SSI, not all individuals eligible for SSI as children are determined eligible as an adult. In 2023, more than 66,000 children eligible for SSI were redetermined as an adult at age 18. Of these children, 48 percent were determined eligible for SSI as adults, and 52 percent were not. Of those who were not determined eligible, 42 percent appealed the decision (SSA 2024b).

Our analysis also identified the eligibility pathways that the young adults enroll in as adults. For example, the majority of transition-age youth enrolled in disability-related pathways (e.g., SSI-related pathways) who remained continuously enrolled then enrolled in the same pathway as an adult (77.9 percent) (Appendix 5A, Figure 5A-1). In contrast, of those who churned, only 14.1 percent reenrolled in the same pathway, and 50.3 percent reenrolled in a modified adjusted gross income (MAGI) pathway (including the adult expansion pathway) (Appendix 5A, Figure 5A-2). Additional findings from this analysis are published in the 2026 MACPAC issue brief *CYSHCN Transitions to Adult Medicaid Coverage* (MACPAC 2026).

Our T-MSIS analysis also identified state variation in the percentage of youth enrolled in disability-related pathways who remained continuously enrolled as they transitioned to adult Medicaid coverage (ranging from 64.5 to 95.6 percent) (MACPAC 2026). For example, we identified differences in the share who remained continuously enrolled, churned, and disenrolled between those enrolled in states that had adopted Medicaid expansion and those enrolled in states that did not (Appendix 5A, Figure 5A-3). A larger percentage of beneficiaries in expansion states who were enrolled in SSI-related pathways and other disability-related pathways as a child remained continuously enrolled as an adult compared to those in non-expansion states (88.3 percent compared to 78.7 percent and 74.6 percent compared to 59.7 percent, respectively). In addition to Medicaid expansion, many other state Medicaid policies could contribute to state variation, such as state Medicaid redetermination procedural differences (e.g., number of days for beneficiaries to respond to requests for information) and state adoption of optional pathways and child-only 1915(c) HCBS waivers that allow individuals to be enrolled beyond age 18 (Cliff et al. 2026, Musumeci et al. 2025, Alker et al. 2024).

Federal Medicaid redetermination requirements

Federal Medicaid redeterminations for children must occur every 12 months; more frequent redeterminations are not permitted. Federal law requires states to provide 12 months of continuous eligibility for all children younger than age 19 (§ 1902(e)(12)(A) of the Act). For

Medicaid redeterminations, state Medicaid agencies must first attempt to confirm ongoing eligibility using reliable information available to the agency without requiring information from the individual, known as “ex parte” or “administrative renewal” (42 CFR 435.916(b)(1)). Furthermore, as a part of the 2024 Streamlining Medicaid, Children’s Health Insurance Program, and Basic Health Program Application, Eligibility Determination, Enrollment, and Renewal Processes final rule (E&E), CMS added section 42 CFR 435.919 to define state redetermination responsibilities related to changes in circumstance, including anticipated changes (e.g., aging out of a child eligibility pathway). These requirements are yet to be implemented due to the moratorium put in place by the 2025 Budget Reconciliation Act, but states have the option to implement these provisions (Box 5-2). In accordance with 42 CFR 435.919(6), states should initiate and complete the redetermination process in advance of the child turning 19 years old. Federal rules do not specify how much lead time is required or require states to inform beneficiaries that the redetermination process has been initiated, but many states initiate redeterminations between 60 and 90 days before the end of the eligibility period (CMS 2024a).

States are required to send beneficiaries notices about the agency’s decision or a request for information if additional information is needed from the beneficiary to complete the redetermination. For example, if the state identifies information that will lead to termination, reduced benefits (e.g., change in eligibility pathway), or increases in premiums or cost sharing, the state is required to contact the beneficiary and offer them an opportunity to provide new information before making changes to their eligibility (42 CFR 435.917, 42 CFR 435.952(d)). States that request information from beneficiaries are required to complete timely redetermination (42 CFR 435.912), including providing MAGI beneficiaries with a minimum of 30 days to respond to requests for information (42 CFR 435.916(b)(2) and 435.919(c)). The 2024 E&E final rule expanded this requirement to include non-MAGI beneficiaries. The implementation of this provision of the final rule was paused by the 2025 Budget Reconciliation Act, but states still have the option to implement it (Box 5-2). If an individual does not respond to the request for information within the required time frame, before termination, the state must assess all possible eligibility pathways (42 CFR 435.916(d)(1) and 42 CFR 435.911).

BOX 5-2. Moratorium on Certain Provisions in the 2024 Eligibility and Enrollment Final Rule

The 2024 Centers for Medicare & Medicaid Services (CMS) *Streamlining Medicaid, Children's Health Insurance Program, and Basic Health Program Application, Eligibility Determination, Enrollment, and Renewal Processes* (E&E) final rule implemented changes to help with Medicaid enrollment and promote retention and redetermination of eligible individuals. The finalized provisions include aligning application and renewal requirements for Medicaid beneficiaries enrolled in a non-modified adjusted gross income (MAGI) pathway with those applicable to the MAGI population (CMS 2024b).

The Public Law 119-21, an Act to Provide for Reconciliation Pursuant to Title II of H. Con. Res. 14 put a moratorium on the implementation of provisions in the 2024 E&E final rule that were not in effect as of July 4, 2025, until fiscal year 2035. The 2025 Budget Reconciliation Act prevents CMS from enforcing these new federal requirements, although states can still adopt many of these changes by exercising their own authority to design their program (Erzouki 2025). For example, the E&E final rule amended 42 CFR 435.916(b)(2) and added 435.919(c) to require state Medicaid agencies to provide non-MAGI beneficiaries with a minimum of 30 days to respond to requests for information. This new requirement aligns non-MAGI and MAGI requirements, and states were expected to implement this change by June 3, 2027 (CMS 2024b). Although CMS cannot enforce the required implementation of this provision, states still have the authority to implement this change. Throughout the chapter, we discuss some Medicaid redetermination requirements that are subject to the 2025 Budget Reconciliation Act.

Additionally, if the individual is eligible for multiple categories, they must have a choice in the pathway selection (42 CFR 435.404).

Medicaid redetermination for beneficiaries eligible on the basis of disability. For CYSHCN enrolled in SSI-related pathways as a child, the Medicaid redetermination process varies based on whether they are enrolled in a 1634, SSI criteria, or 209(b) state and whether they remain SSI enrolled as an adult. In 1634 and SSI criteria states, state Medicaid agencies use SSI criteria for disability determinations. If SSA has made a disability determination for an individual in these types of states, the state generally must use SSA's disability determination, rather than conducting a separate disability determination, when redetermining Medicaid eligibility (42 CFR 435.541). For example, in 1634 states, if a beneficiary was enrolled in SSI as a child and remains enrolled in SSI as an adult, the individual continues to be automatically eligible for Medicaid, and the state does not need to take any action to complete an ex parte redetermination. In SSI criteria states, the state can

complete the ex parte process by confirming SSI eligibility with SSA. In contrast, in 209(b) states, in which SSI eligibility does not confer Medicaid eligibility, the state cannot complete a Medicaid redetermination only on the basis of SSI disability (CMS 2024a).

Medicaid redetermination for beneficiaries not eligible on the basis of disability. The Medicaid redetermination process is different for those who had SSI as a child and lose SSI as an adult and beneficiaries who were not enrolled in an SSI as a child. If a beneficiary is not redetermined eligible for SSI as an adult, SSA will notify the state Medicaid agency, prompting it to conduct a change in circumstance redetermination (42 CFR 435.919). In 1634 states, Medicaid beneficiaries do not apply separately to Medicaid, so when an individual loses SSI, the state must first attempt to redetermine them on an ex parte basis, but they may not have sufficient information to complete the redetermination. In these cases, beneficiaries must provide the state with additional information to complete the redetermination on a new basis. In SSI criteria and 209(b) states,

beneficiaries submit a separate Medicaid application, so in some cases the state may be able to complete redeterminations on an ex parte basis.

When a Medicaid beneficiary loses SSI, SSA will send the individual a notice informing them of this loss. SSA is required to send notices to individuals about changes to their SSI eligibility, which must include information about SSI determinations and decisions and rights to appeal and explain the reason for the decision (SSA 2025a). In states where SSI eligibility confers Medicaid eligibility, the notice includes information on their SSI-related Medicaid coverage (20 CFR 416.987 and 20 CFR 416.1336). The SSA notice specifies that these individuals no longer qualify for Medicaid based on SSI rules and that there may be other pathways for Medicaid eligibility. Additionally, the notice may include state-specific Medicaid eligibility information (e.g., state Medicaid agency contact information) and instruct individuals to contact the state Medicaid agency to determine if they are still eligible for Medicaid (SSA 2025b, 2011).

Transition planning requirements for age-limited 1915(c) HCBS waivers

States operating age-limited 1915(c) HCBS waivers must provide transition planning for beneficiaries enrolled in these waivers to support beneficiaries with maintaining continuity of services to the extent feasible. The Section 1915(c) HCBS technical guide indicates that transition planning may include certain activities (e.g., identifying and informing individuals about waivers they may qualify for), but it does not specify or prescribe specific parameters for planning procedures related to Medicaid redeterminations and continuity of coverage (CMS 2024c). Findings from our review of all child-only 1915(c) HCBS waivers indicate that most of these waivers specify who is responsible (e.g., case manager, care coordinator, or service coordinator) for notifying and supporting the beneficiary and family with the transition to an adult or all ages 1915(c) HCBS waiver. Additionally, a few waivers specify that beneficiaries who are not eligible for adult waiver services can receive transition support.

State Role in Supporting CYSHCN Transitions to Adult Medicaid

State Medicaid agencies can leverage a number of authorities to ease the Medicaid redetermination process and transitions between child-only and adult 1915(c) HCBS waivers and support continuity of coverage.

Medicaid eligibility and redetermination flexibilities

Findings from our state scan and stakeholder interviews demonstrate that many states leverage existing flexibilities and authorities to ease Medicaid eligibility and redeterminations processes for beneficiaries transitioning to adult Medicaid. State approaches include using the SSI disability determination for Medicaid eligibility determinations, sending advance notice of upcoming Medicaid redeterminations, adopting state optional pathways, and using various authorities to provide CYSHCN with support during the transition.

Type of disability determination state (e.g., 1634, SSI criteria, and 209(b)). One of the factors affecting whether states can complete ex parte disability-related redeterminations is the state's use of SSI eligibility criteria when making Medicaid determinations. For example, 1634 and SSI criteria states use the SSA disability determination as the basis for Medicaid eligibility (42 CFR 435.541). Additionally, state officials in 1634 and SSI criteria states shared that beneficiaries who are SSI eligible as children and remain enrolled as adults will remain eligible and enrolled in the same SSI-related Medicaid eligibility pathway. However, in 1634 states, the Medicaid agency may ask beneficiaries who had SSI as a child and are no longer eligible as an adult to provide additional information to complete a Medicaid redetermination on a different basis. For example, one 1634 state shared that they may be able to use data from SSA to complete an ex parte redetermination, but often more information is needed from the beneficiary.

In these states, SSI enrollees do not submit a separate Medicaid application, so when they lose SSI, the state Medicaid agency may be missing information to assess eligibility. In contrast, SSI criteria states, where beneficiaries submit a separate Medicaid application, have more information about the beneficiary, such as household income, so the state may be able to complete the redetermination without requesting additional information from the beneficiary.

Advance notice of upcoming Medicaid redetermination. States are not required to send beneficiaries notices in advance of their Medicaid redetermination unless additional information is needed, but recent state survey findings indicate that 20 states contact beneficiaries in advance of initiating the renewal (Brooks 2025). Interviewed states and national and state-level advocates shared that sending beneficiaries and families advance notice of the upcoming age-19 Medicaid redetermination helps them prepare for this process and ensure they have the information needed to maintain Medicaid coverage. Similarly, one interviewed state official shared that their state sends beneficiaries letters and emails as early as a year in advance of the beneficiary aging out of their child eligibility pathway to improve their awareness of the upcoming redetermination.

State optional pathways. States have the flexibility to adopt optional eligibility pathways to cover beneficiaries who may not otherwise be eligible for any mandatory pathways. Findings from our work indicate that many beneficiaries aging out of child Medicaid coverage and losing SSI eligibility enroll in the optional adult expansion pathway in states that have adopted it (Appendix 5A, Figures 5A-3 and 5A-4) (MACPAC 2026). For example, findings from our T-MSIS analysis show that about 20 percent of individuals enrolled in SSI-related pathways as children who transitioned to adult coverage (continuously or churned) did not remain enrolled in analogous pathways as adults, and about half of these beneficiaries enrolled in an adult MAGI pathway. Of those who enrolled in a MAGI pathway, about half enrolled in the expansion pathway if they lived in a state that had adopted this option. Additionally, several interviewees indicated that CYSHCN who were enrolled in disability-related Medicaid pathways and who lose SSI as an adult also

retain Medicaid coverage through the adult expansion pathway. The income eligibility threshold for the expansion group is greater than that of SSI, and it does not have asset limits, which allows many adults with disabilities with incomes above the SSA limit to qualify for Medicaid (Machledt 2024).⁷ Furthermore, two states shared that beneficiaries awaiting an adult SSI determination or who are on a Medicaid waiver waitlist may be able to maintain Medicaid coverage under the adult expansion pathway.

Four states have implemented an optional child eligibility pathway that allows states to extend childhood eligibility up to age 21 (42 CFR 435.222 and 42 CFR 435.223).⁸ For this eligibility pathway, individuals must also have a household income at or below the standard established by the state for the particular age group or reasonable classification of individuals and not be eligible for mandatory coverage under the state plan.⁹ Additionally, in expansion states, individuals cannot enroll in this pathway if they are eligible for the expansion pathway, and the child eligibility pathway household income criteria must be above the maximum income eligibility for the expansion pathway (133 percent of the federal poverty level (FPL)) (CMS n.d.). The states that have implemented this optional child eligibility pathway provide coverage to targeted populations. For example, the District of Columbia, Florida, and Massachusetts extended eligibility for children age 19 and 20 who are not eligible for or enrolled in another mandatory pathway with state-specific income criteria (CMS 2014, 2013a, 2013b). In 2023, Maine extended eligibility for children age 19 and 20 and increased the upper income limit for all children younger than 21 to 300 percent FPL. Maine's state plan amendment specified that individuals are eligible for this pathway only when they are not eligible or enrolled in any other mandatory or state optional pathway (CMS 2023a).

Findings from our work indicate that extending child eligibility up to age 21 can increase coverage stability during the transition to adulthood and reduce the risk of delayed or missed care due to churn. Interviewed states that have extended child eligibility to older than age 18 shared that delaying the coverage transition to adult Medicaid gives beneficiaries and families more time to navigate the many other program transitions

that occur during this period. Some of these transitions include those that may affect a beneficiary's ability to remain Medicaid-covered (e.g., applying to SSI as an adult, enrolling in an adult 1915(c) HCBS waiver). Additionally, interviewed advocates and some states noted that extending eligibility up to age 21 would align with the EPSDT age limit and other services received outside of Medicaid. For example, some CYSHCN receive services and supports from state Title V programs, such as coordination and case management services as well as educational resources, typically up to age 21 (McManus et al. 2024).

Support with Medicaid redeterminations. State Medicaid agencies and other entities can help beneficiaries with the Medicaid redetermination process and ease the transition to adult Medicaid coverage. State Medicaid agencies, managed care organizations, waiver case managers, other state agencies, and community-based organizations such as family-to-family networks often provide such support.¹⁰ For example, advocates shared that family-to-family networks can provide beneficiaries and families with educational resources and assist them with the paperwork for both SSI and Medicaid redeterminations. Additionally, state 1915(c) HCBS waiver programs often cover case management services, which can include supporting beneficiaries with transitions. The role of the case manager can vary by waiver, but often they are responsible for supporting beneficiaries' transitions between benefit programs (e.g., Medicaid and SSI) and helping them understand waiver program rules and requirements (Saraswathula and Colello 2025). Furthermore, states can provide case management and targeted case management (TCM) through their state plan to specific populations, including CYSHCN, to support their transitions of coverage and care (42 CFR 440.169). However, MACPAC's earlier work on transitions from pediatric to adult care found that states do not currently use TCM to provide transition of coverage or care-related services for CYSHCN (MACPAC 2025).

Our findings indicate that having a dedicated case manager or care coordinator is particularly important because of the role they can play in helping beneficiaries and families navigate waiver enrollment processes, SSI redeterminations, and Medicaid coverage transitions. Many interviewees shared that children enrolled in waivers, in comparison to those

who are not, are often able to maintain coverage as adults because of the case management services they receive through the waiver. Waiver case managers can serve beneficiaries in many ways, including helping families understand the Medicaid and SSI redetermination processes, request required medical forms, and fill out and submit required documentation. However, advocates and state Medicaid officials noted that ongoing workforce issues can affect the amount of support beneficiaries receive during this transition, even when they are enrolled in a waiver program. Advocates noted that beneficiaries who are not enrolled in an HCBS waiver may not receive any dedicated support from the state.

Section 1915(c) HCBS waiver program flexibilities

States have flexibility in how they design and operationalize their 1915(c) HCBS waiver programs. Findings from our state policy review and stakeholder interviews indicate that many states have taken many different approaches to leveraging these flexibilities (e.g., transition planning procedures, reserve capacity, waitlists) to ease the transition between child-only and adult 1915(c) HCBS waivers.

Section 1915(c) HCBS waiver program design.

Some states with multiple 1915(c) HCBS waivers have designed corresponding child and adult waiver programs to promote continuity of care for beneficiaries transitioning from the child to adult waiver. For example, one state designed its corresponding child-only and adult 1915(c) HCBS waivers to have overlapping age eligibility and allows beneficiaries enrolled in the child-only waiver (enrollment up to age 21) to choose to enroll in the adult waiver beginning as early as age 18 (minimum allowable age). This approach allows beneficiaries to have flexibility in choosing when to transition between waivers and gives them multiple years to complete the transition. Another state allows beneficiaries enrolled in a child-only waiver to remain enrolled until they enroll in a new waiver or are determined ineligible for all other state Medicaid waiver programs, even if enrollment extends past the child-only waiver upper age limit. Furthermore, some states shared that they allow individuals to remain enrolled in child-only 1915(c) HCBS waivers as adults as long as they were

enrolled as a child and did not disenroll before the age-out upper limit.

Transition planning. States with age-limited Section 1915(c) HCBS waivers must specify waiver transition planning procedures for individuals aging out of the waiver to support beneficiaries with maintaining continuity of services. States have flexibility in defining the transition planning activities, which can include identifying and informing individuals about public programs and waivers that they may qualify for and providing them with priority consideration for other state Medicaid waivers (CMS 2024c). Some state officials shared that they designate case managers to help beneficiaries with identifying and applying for waivers and with completing the functional and level of care assessments.¹¹ Additionally, state officials shared that case managers can inform the beneficiary and their family about upcoming Medicaid and SSI redeterminations and provide resources and referrals to community-based organizations that may be able to provide additional support. Furthermore, some states specify in their transition planning procedures that the designated case manager will help the beneficiary and family apply for other benefits programs if they are no longer eligible for Medicaid or a waiver as an adult.

Reserve capacity. With approval from CMS, states can designate a predetermined number of reserve capacity spots in their Section 1915(c) HCBS waiver for individuals who are transitioning from another waiver, including those aging out of a child-only waiver (CMS 2024c). For example, two interviewed states shared that they reserve capacity in their adult 1915(c) HCBS waivers for beneficiaries age 18 to 21 years who are transitioning from a child-only intellectual and developmental disability or autism waiver. States are permitted to have waitlists for their waivers, which can delay the transition to adult waivers; however, reserve capacity can be used to allow some beneficiaries to bypass the waitlist. For example, one interviewed state shared that they automatically enroll beneficiaries aging out of their child developmental disability waiver into the adult developmental disability waiver, even though the adult waiver has a waitlist. Several advocates and states with reserve capacity shared that, in general, reserving capacity in their adult waivers works well and helps beneficiaries maintain needed waiver enrollment and services.

Challenges with CYSHCN Transitions to Adult Medicaid

Our findings show that state Medicaid programs have taken steps to improve transitions to adult Medicaid and support CYSHCN and their families with navigating Medicaid redeterminations and other related program transitions. Additionally, findings indicate that the majority of children transition to adult Medicaid coverage without experiencing a gap in coverage. Of those who disenroll, almost half churn back onto Medicaid through the state optional expansion pathway. However, our research also found that some CYSHCN and their families experience challenges with this transition that can lead to a loss or gap in coverage.

Insufficient time to prepare and respond to Medicaid redetermination notices

Beneficiaries and families may not receive a notification or reminder of the upcoming redetermination in advance of the age-19 Medicaid redetermination or have sufficient time to provide documentation to complete this redetermination process. Advocates shared that sometimes beneficiaries receive their redetermination request for information notice too late to respond within the required time frame, after the deadline, or do not receive the notice at all. For example, in our state interviews, we heard that there can be delays in receiving mail in rural areas, contributing to beneficiaries receiving notices after the response deadlines. If a beneficiary does not complete the steps detailed in the notice in a timely way, their coverage may be terminated. In 1634 states where Medicaid eligibility is automatic for SSI-eligible individuals, the beneficiary and family have never applied to Medicaid, so they may not be aware of the Medicaid redetermination process or the requirement that they have to send information to the Medicaid agency to maintain Medicaid coverage. Additionally, advocates described that the redetermination request for information notices sent to beneficiaries often lack clear and actionable steps in plain language, leading

to beneficiary and family confusion about how to respond to maintain coverage. The notices terminating coverage may similarly lack clear language about their change in eligibility and benefits.

Lack of clarity in notices from SSA about changes to SSI and Medicaid eligibility

Beneficiaries and families experience challenges with understanding how a loss of SSI affects their Medicaid eligibility. Advocates described SSA notices as sometimes lacking clear and actionable steps to retain Medicaid coverage in 1634 states. In our research, interviewees shared that the notification from SSA sometimes incorrectly states that a loss of SSI eligibility results in a termination of Medicaid. When an individual has a change in circumstance (e.g., loss of SSI, change in income), the state Medicaid agency is required to redetermine their eligibility based on other pathways before terminating coverage (42 CFR 435.916(d)(1)). Furthermore, in accordance with Section 1902(e)(12) of the Act, the state is not permitted to terminate coverage of those who are younger than age 19 until the individual reaches the end of their 12-month enrollment period, except in cases when the individual attains age 19 or moves out of state. Interviewees indicated a need for improving the language in SSA notices about losing SSI eligibility to ensure the information about the effect on Medicaid eligibility is accurate. Furthermore, the information should help with beneficiary and family understanding of potential changes to Medicaid eligibility status, the required beneficiary actions for maintaining Medicaid coverage, and the state process for determining eligibility for another eligibility pathway.

Navigating multiple simultaneous transitions

CYSHCN and their families may experience gaps in coverage because they lack the time needed to complete the Medicaid redetermination while also navigating other benefits program transitions. National and state-level advocates shared that beneficiaries and their families can feel overwhelmed with completing the Medicaid redetermination while they also take steps to enroll in a waiver program

and applying for SSI as an adult, and families may need more time to complete all of these enrollment processes. For example, many children with disabilities do not apply for or qualify for SSI until they are an adult (e.g., those enrolled in the Katie Beckett pathway), and interviewees shared that the SSI eligibility determination can sometimes be a multiyear process. If a beneficiary applies for Medicaid while awaiting an SSI disability determination, the state Medicaid agency is required to make its own disability determination if they do not receive one from SSA within 90 days after the Medicaid application submission (42 CFR 435.541). However, state advocates shared that even with these state requirements, delays with the SSI determination can still lead to disruptions in coverage and care for these beneficiaries if they are not eligible for Medicaid through another pathway as an adult. Additionally, those in 1634 states who had SSI as a child and do not qualify for SSI as an adult may be going through the Medicaid redetermination process for the first time as a non-SSI-eligible beneficiary. These beneficiaries, as with any beneficiary being redetermined for Medicaid, may need to provide additional information to the state Medicaid agency to be redetermined on a different basis.

The Medicaid redetermination may also occur simultaneously as the transition from child to adult 1915(c) HCBS waivers, and the outcomes of these two processes may affect each other. Waiver enrollment relies on the beneficiary being enrolled in Medicaid, so if an individual does not complete their redetermination and they lose coverage or the state determines they are not eligible on any other basis, the beneficiary will be disenrolled from the waiver. However, in some cases, waiver enrollment can confer Medicaid eligibility for individuals who would not otherwise be eligible (CMS 2025b). Advocates shared that beneficiaries who are on a 1915(c) HCBS waiver waitlist may be unable to enroll in Medicaid while on the waitlist if they are not eligible for Medicaid on any other basis.

Insufficient support with the Medicaid redetermination

Advocates shared that the level of support (e.g., dedicated case manager or care coordinator) that CYSHCN and their families receive when navigating

the Medicaid redetermination when aging out of child Medicaid varies among states and waivers within states. One of the key components of structured transition plans for those transitioning between pediatric and adult care is having a transition coordinator or a point of contact during this period to help prepare for and support the transition (Gabriel et al. 2017). Findings from our stakeholder interviews indicate that it is also important to have a transition coordinator or dedicated case manager to support families with Medicaid redeterminations. Several state advocates and state officials shared that beneficiaries enrolled in waivers receive support with the Medicaid redetermination from their waiver case managers and that, in general, they have smoother transitions than beneficiaries who are not enrolled in waivers and do not have an assigned case manager. For example, some state advocates shared that case managers often submit the information needed for the Medicaid redetermination on behalf of beneficiaries enrolled in 1915(c) HCBS waivers to ease the redetermination process. Additionally, one interviewee emphasized the importance of beneficiaries having a dedicated case manager to help them prepare for these transitions several years in advance of aging out of child eligibility. The advance planning helps ensure the family is prepared for all of the changes and supports a more seamless coverage transition.

Commission Recommendations

The Commission makes six recommendations to improve Medicaid redeterminations and continuity of coverage for beneficiaries as they transition to adult Medicaid.

Recommendation 5.1

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 435.919(b)(6) to require states to send a notice a minimum of 60 days in advance of children and youth with special health care needs (CYSHCN) aging out of child Medicaid eligibility to inform them that the

renewal process has been initiated. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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

Research demonstrates that beneficiaries and families need advance notice of the upcoming transition from child to adult Medicaid so that they are aware of and can prepare for the steps needed to maintain Medicaid coverage as an adult. Without adequate time to prepare, beneficiaries and families may not complete the redetermination process within the allotted time, potentially leading to termination of coverage. For example, in our stakeholder interviews, one state advocate shared that it would help families if the Medicaid agency sent out information about what to expect, such as changes related to eligibility criteria and what information the beneficiary and family may need to provide, so that families can prepare in advance for this process. Additionally, advocates shared that it would be helpful if the notices from state Medicaid agencies could also provide basic information about other determinations that may occur during the same period and affect Medicaid coverage, such as the SSI age-18 redetermination and 1915(c) HCBS waiver enrollment.

Currently, there is no federal requirement for state Medicaid agencies to notify beneficiaries that they are initiating the redetermination process unless the state needs additional information from the beneficiary to complete the redetermination (42 CFR 435.916) or the state identifies information that will lead to termination, reduced benefits, or increases in premiums or cost sharing (42 CFR. 435.952(d)). Federal rules and guidance also do not specify how much lead time is required to initiate this process, but many states initiate the redetermination between 60 and 90 days before the end of the eligibility period (CMS 2024a). Although not required, some states send advance notices to inform beneficiaries about the redetermination process so that they can prepare. For example, one state

shared that they send a notice a year in advance of the end of the beneficiary's eligibility period, and others shared that they send beneficiaries notices one to two months in advance.

In the Commission's view, states should provide beneficiaries with an informational notice about their age-19 Medicaid redetermination as far in advance as practicable before the state begins the beneficiary's age-19 eligibility redetermination to inform beneficiaries and ensure they and their families have sufficient time to prepare for their transition to adult Medicaid coverage.¹² The informational notice should provide the beneficiary and family with information about what to expect as part of the renewal process at age 19, including that they may be asked to provide information to complete the redetermination as an adult. Additionally, the state should write the informational notice in plain language, clearly explain that it requires no action from the beneficiary in advance of the redetermination process, and commit to send a separate request to the beneficiary for information if it needs additional information to complete the redetermination. In establishing rules and subregulatory guidance, CMS should emphasize that sending an informational notice 60 days in advance of the beneficiary turning age 19 is a minimum and encourage states to send these informational notices as early as is feasible. For example, states that already begin this process more than 60 days in advance should notify beneficiaries when they begin the redetermination process.

Implications

Federal spending. The Congressional Budget Office (CBO) estimates this recommendation would not have a direct effect on federal Medicaid spending. CMS would have to commit time and resources to issue guidance related to this new requirement.

States. States would be required to send a new notice to beneficiaries, which may require eligibility system programming changes to develop and generate this type of notice. Additionally, there may be administrative burden to identify CYSHCN and target notices to this population.

Enrollees. This policy may help ensure beneficiaries, their families, and caregivers are more prepared for the Medicaid redetermination at age 19, which

may ease the redetermination process and improve continuity of coverage.

Plans. To the extent that an informational notice provided before the renewal eases the beneficiary's Medicaid redetermination process and continuity of coverage as an adult, plans may have fewer beneficiaries who are experiencing disruptions in coverage.

Providers. Transition coordinators and other care and coverage coordinators may also have more advance notice of upcoming redeterminations, which may improve their ability to support beneficiaries. To the extent that the advance notice eases the beneficiary's Medicaid redetermination process and continuity of coverage as an adult, providers may be able to provide care to their beneficiaries with fewer disruptions.

Recommendation 5.2

State Medicaid agencies should provide children and youth with special health care needs (CYSHCN) who are aging out of child Medicaid eligibility with a minimum of 30 days to respond to requests for information to complete Medicaid redeterminations in accordance with 42 CFR 435.919(c)(1). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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

Under current rules established in 2024, states are required to implement a 30-day minimum for beneficiaries to respond to requests for information before the state takes an adverse action, including terminating coverage, to ensure beneficiaries have adequate time to respond without overburdening the state (CMS 2024b). However, the 2025 Budget Reconciliation Act prevents CMS from enforcing this requirement but does not eliminate the state option to provide a longer response time. In effect, the pre-2024 policies are restored, and states can opt to implement a 30-day response time.

Research demonstrates that many beneficiaries and their families have challenges with responding to requests for information within the time they are currently given, which may contribute to loss of or gaps in coverage among CYSHCN who are aging out of child Medicaid. For example, currently, 14 states provide beneficiaries with only 10 days to respond to these types of requests (Brooks et al. 2025). In our stakeholder interviews, some advocates shared that beneficiaries may receive their notice too late to respond to within the required time frame, which can lead to delays with the redetermination or termination of coverage. Furthermore, advocates shared that the coverage transition is often just one of many that the family is navigating and that families often feel overwhelmed by the amount of information requests they have to respond to within a short time frame.

States that do not already provide beneficiaries with a minimum of 30 days to respond to requests for information should implement this minimum response time for CYSHCN aging out of child Medicaid eligibility. The Commission emphasized that 30 days is meant to be a minimum, and states are encouraged to allow more time for beneficiaries to respond. The longer response time would ensure beneficiaries, their families, and their caregivers have adequate time to gather any requested information.

Implications

Federal spending. The CBO estimates this recommendation would not have a direct effect on federal Medicaid spending. There is no anticipated effect on CMS, as it does not need to approve these state changes.

States. There would be some administrative burden for states to revise notice procedures and language to accommodate the 30-day response period.

Enrollees. This policy provides beneficiaries, their families, and caregivers more time to submit required information to the state Medicaid agency, which would help them maintain their Medicaid coverage into adulthood.

Plans. Plans may have fewer beneficiaries who are experiencing disruptions in coverage and care.

Providers. We do not anticipate any direct implications for providers. To the extent that providers

send beneficiaries requested medical records as part of the Medicaid redeterminations, providers would have more time to complete this process.

Recommendation 5.3

To ensure the accuracy of information provided by the Social Security Administration (SSA) to Medicaid beneficiaries enrolled in Supplemental Security Income (SSI)-related eligibility pathways who are being notified that they are losing eligibility for SSI, the Secretary of the U.S. Department of Health and Human Services, through the Centers for Medicare & Medicaid Services, should coordinate with SSA to review and update model notice language pertaining to Medicaid in SSA's Program Operations Manual System manual paragraphs. The model language should clearly indicate that the individual may retain their Medicaid coverage while the state Medicaid agency takes steps to redetermine the individual on a new basis of eligibility. Additionally, the model language should describe, in general terms, the steps the individual needs to follow to complete the Medicaid redetermination that are specific to 1634, SSI criteria, and 209(b) states.

Rationale

When Medicaid-beneficiaries who were receiving SSI lose SSI eligibility, they receive a notice from SSA, not state Medicaid agencies, about their SSI denial and information about SSI-related Medicaid eligibility (20 CFR 416.1336 and 42 CFR 435.917). Unlike SSA, which is required to send notices to individuals about changes to SSI eligibility and potential effects on Medicaid eligibility, state Medicaid agencies are not required to send a notice to the beneficiary about these changes unless the state needs additional information from the beneficiary to complete the redetermination (42 CFR 435.916) (SSA 2025a). Findings from stakeholder interviews indicate that the information the beneficiary receives from SSA about how a loss of SSI affects Medicaid eligibility is sometimes unclear, leading to beneficiary and family confusion about their Medicaid enrollment status and the steps they need to take to maintain eligibility. For example, national and state-level advocates shared that these notices may not always explain that Medicaid coverage is not immediately terminated or include information about the state Medicaid

agency's general next steps for redetermining Medicaid coverage. This can lead to challenges that are unique for beneficiaries in 1634 states, where SSI eligibility automatically confers Medicaid eligibility and beneficiaries have not had to directly apply to Medicaid for coverage. These beneficiaries may have to send information directly to the state Medicaid agency for an eligibility determination for the first time and may not understand how the redetermination process works.

There are no federal requirements for SSA and CMS to coordinate on the SSA notice language sent to beneficiaries who lose SSI. Given that most beneficiaries only receive a notice from SSA about how a loss of SSI may affect Medicaid eligibility, it is important that the Medicaid eligibility information in this notice is accurate and clear. Currently, the SSA Program Operations Manual System includes template notice language to send to individuals who lose SSI at the age-18 redetermination and specific language for those residing in 1634 and non-1634 states (SSA 2025b, 2011). For example, in 1634 states, where Medicaid eligibility is automatic and beneficiaries do not have to apply to Medicaid separately, these notices specify that these individuals no longer qualify for Medicaid based on SSI rules and that there may be other pathways for Medicaid eligibility. In non-1634 states, the notice language on Medicaid eligibility instructs individuals to contact the state Medicaid agency to determine if they are still eligible for Medicaid (SSA 2011). The template notice language does not include information about continued Medicaid eligibility during the Medicaid redetermination process or information about what the beneficiary should expect during this process, such as how and when they will be contacted by the Medicaid agency.

To ensure Medicaid beneficiaries receive SSA notices that include easily understood and accurate information about how a loss of SSI could affect their Medicaid coverage, CMS should coordinate with SSA on developing model notice language on the effects on Medicaid eligibility. In the development of the model notice language, CMS should seek input from states and advocates to ensure that the model language is accurate and understandable to Medicaid beneficiaries. The model notice language should indicate potential implications for Medicaid coverage so beneficiaries are aware that Medicaid

coverage is not immediately terminated. CMS should also coordinate with SSA to develop model template language tailored for the different types of Medicaid determination states (i.e., 1634, SSI criteria, and 209(b)). For example, in 1634 states, the model notice language should specify that Medicaid eligibility is no longer automatic and that the individual will now need to directly communicate with the state Medicaid agency on issues regarding their Medicaid coverage. Furthermore, CMS should consider including language in the notice to describe the general steps of the Medicaid redetermination process and the type of information a beneficiary may need to provide to the state Medicaid agency to complete the redetermination (e.g., household income).

Implications

Federal spending. The CBO estimates this recommendation would not have a direct effect on federal Medicaid spending. CMS would have to commit time and resources to review and update the SSA notice language in partnership with SSA and ensure ongoing coordination with SSA to update notice language to reflect evolving federal Medicaid eligibility and enrollment policies.

States. As part of CMS's efforts to develop model notice language, state Medicaid agencies may be asked to provide input on the notice language to ensure it is accurate and clarifies the effect of a loss of SSI on Medicaid coverage.

Enrollees. This policy would help ensure that beneficiaries, their families, and caregivers have greater clarity about the effect of losing SSI eligibility on Medicaid eligibility and the steps they need to take to ensure that if the beneficiary remains Medicaid eligible, they are able to maintain coverage. To the extent that CMS seeks input from beneficiaries, some beneficiaries may have an opportunity to engage in the development of this model notice language.

Plans. To the extent that improved notice language eases the beneficiary's Medicaid redetermination process and continuity of coverage as an adult, plans may have fewer beneficiaries who are experiencing disruptions in coverage.

Providers. To the extent that improved notice language eases the beneficiary's Medicaid

redetermination process and continuity of coverage as an adult, providers may be able to provide care to their beneficiaries with fewer disruptions.

Recommendation 5.4

State Medicaid agencies should implement optional Medicaid eligibility for children and youth with special health care needs (CYSHCN) up to age 21 who are not otherwise eligible for and enrolled in mandatory coverage or optional full Medicaid coverage under the state plan (42 CFR 435.222 and 42 CFR 435.223). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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

This recommendation is intended to ease the transition from child to adult Medicaid coverage for CYSHCN and improve their coverage stability when aging into adulthood. Recent national and state-level research indicates that Medicaid-covered CYSHCN are at a much higher risk of experiencing disenrollment and short disruptions of coverage when they are aging into adult coverage compared to when they are Medicaid covered as children (Cliff et al. 2026, MACPAC 2026, McMahon et al. 2025, Smith et al. 2025, and McManus et al. 2024). CYSHCN and their families can experience unique challenges with completing the Medicaid redetermination at age 19, as they are also often navigating multiple program transitions (e.g., child-only to adult 1915(c) HCBS waivers, age-18 SSI redetermination), which can overwhelm and overburden families and lead to an increased risk of losing coverage (MACPAC 2025, McManus et al. 2024). Furthermore, many CYSHCN have complex medical conditions and are considered some of the most vulnerable Medicaid-covered children. They rely on specialized pediatric care and continue to need these specialized services as adults, so coverage disruptions are particularly challenging for these children, as accessing their specialized care relies

on coverage. As they age into adulthood and are transitioning from a pediatric model of care to the adult care system, maintaining coverage stability is even more important for maintaining continuity of care (Cliff et al. 2026, 2025; Validova et al. 2023; Musumeci and Chidambaram 2019).

Delaying the transition to adult Medicaid coverage is one of many approaches state Medicaid agencies can take to improve coverage stability for CYSHCN who are at risk of disenrolling and becoming uninsured when they age out of child Medicaid. Findings from stakeholder interviews, literature review, and MACPAC's chapter in the June 2025 report to Congress indicate that extending child eligibility to age 21 could benefit CYSHCN and their families in two primary ways (MACPAC 2025). First, delaying this coverage transition would ensure CYSHCN and families, including those who may not be eligible as an adult, have coverage stability while navigating multiple transitions that occur between age 18 and 21. Second, the extended eligibility can act as a bridge between child and adult coverage by providing families with more time to complete transition steps that can directly affect an individual's ability to meet adult Medicaid eligibility criteria. For example, state officials from two states that have extended child eligibility shared that in some cases, additional time is needed so beneficiaries and families can complete the adult SSI application process, which they shared can take multiple years, or determine guardianship for the beneficiary. Without being able to maintain Medicaid through an extended child eligibility pathway, some CYSHCN may experience long- and short-term coverage disruptions, which can be detrimental to their health. Furthermore, interviewed advocates and some states also raised the importance of extending eligibility up to age 21 to align with the EPSDT requirement and other services received outside of Medicaid.

Currently, states have the flexibility to extend Medicaid coverage for children up to age 21 (42 CFR 435.222 and 42 CFR 435.223), and CMS further clarified the use of this pathway in the 2024 E&E final rule (CMS 2024b). Four states have implemented this state option and have established varying eligibility criteria for this extended eligibility pathway (CMS 2023b). For example, all three expansion states must establish a baseline household income that exceeds the

maximum income limit for the expansion pathway (133 percent FPL), so all three states established different household income ranges using 133 percent FPL as their minimum income (upper household income ranges from 150 to 300 percent FPL). Additionally, Maine (an expansion state) specifies that children can enroll in this pathway only if they are not eligible or enrolled in any mandatory or state optional full-benefit pathways (CMS 2023a).

This recommendation directs states to implement this state optional pathway for CYSHCN who are not eligible for or enrolled in another mandatory or state optional pathway under the state plan and would otherwise disenroll when aging out of child Medicaid. The Commission weighed several factors that states should consider when implementing this optional pathway. First, this optional pathway provides states with a number of flexibilities in how it is designed, and states should consider how to implement an extended pathway that best meets the needs of their beneficiaries who are at risk of becoming uninsured at age 19. Second, some Commissioners raised concerns about the state fiscal impact of expanding coverage to individuals who may otherwise disenroll. In the implementation of this state option, states should consider how narrowly or broadly to define the eligibility criteria for this pathway and the effect on the state's budget, especially as states are balancing many other state priorities. On the other hand, there was some discussion of the state fiscal impact of covering health care costs for uninsured individuals, especially for youth with complex medical conditions who are at an increased risk of ED use due to missed care. Estimates of public funding sources for uncompensated care suggest that state and local programs fund about 35.9 percent of these costs (Coughlin et al. 2021).

Implications

Federal spending. The CBO estimates this recommendation would not have a direct effect on federal Medicaid spending. CMS would have to commit time and resources to reviewing state plan amendments.

States. This existing state option gives states the flexibility to determine the eligibility criteria for this optional pathway, including the population, age

groups, and household income level. The state budget implications are dependent on how broadly or narrowly a state decides to define these criteria.

Enrollees. The implementation of this policy may allow beneficiaries who would otherwise disenroll at age 19 to remain eligible, if they meet the state's optional pathway eligibility criteria. This extended coverage up to age 21 could also provide families with more time to complete a non-Medicaid transition that could directly affect an individual's ability to meet adult Medicaid eligibility criteria (e.g., applying for SSI as an adult).

Plans. To the extent that this extends coverage and improves continuity of coverage during this transition period, plans may have fewer beneficiaries who are experiencing disruptions in coverage.

Providers. To the extent that states choose to implement this option, CYSHCN who would otherwise disenroll from Medicaid at age 19 would be able to remain Medicaid covered and receive continuous care from their providers.

Recommendation 5.5

To ensure children and youth with special health care needs (CYSHCN) receive a full 12-month continuous eligibility period in their final year of child Medicaid eligibility, Congress should amend § 1902(e)(12) of the Social Security Act to require states to provide CYSHCN with a 12-month continuous eligibility period that lasts a full 12 months from the date of the eligibility determination, even if during the continuous eligibility period, an individual reaches the upper age limit for the eligibility pathway by which they are eligible for Medicaid. This 12-month continuous eligibility period should apply to all CYSHCN who receive coverage from a mandatory or optional child eligibility pathway, including optional pathways covering youth above age 18. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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

Findings from our T-MSIS analysis indicate that about 17.6 percent of transition-age youth enrolled in disability-related pathways disenroll when aging out of child eligibility pathways, and of those who disenroll, about one-third churn back onto Medicaid within 12 months. CYSHCN often have complex medical conditions, requiring care coordination and frequent appointments with primary care and specialized providers, and are particularly vulnerable to coverage disruptions (Cliff et al. 2026). Gaps in coverage, even for short periods, are associated with delays in receipt of care, an increase in unmet health needs, fewer office-based doctor visits, an increase in the risk of hospitalization, and higher administrative costs (Rennane et al. 2023, Brantley and Ku 2022, Hemmeter 2011). Additionally, gaps in coverage can lead to increases in health care use after regaining coverage. For example, findings from a 2022 MACPAC study of health care utilization for adults following a gap in coverage show that hospitalization and ED rates were more than twice as high after the churn period as the baseline utilization before disenrollment (MACPAC 2022).

Beginning in 2024, states are required to provide 12 months of continuous eligibility for all children younger than age 19 until the earlier of four events: the individual's 12-month eligibility period ends, the individual attains age 19, the individual requests voluntary disenrollment, or the individual is no longer a resident of such state (Section 1902(e)(12)(A) of the Act). Congress made the continuous eligibility policy mandatory in response to research that showed that continuous eligibility reduces rates of churn and improves access to care and short- and long-term health outcomes for children (CMS 2023c). With the current requirement, beneficiaries remain continuously eligible for 12 months up to age 19 and must be redetermined before reaching the end of the eligibility period upon turning age 19.

This recommendation is intended to address churn among CYSHCN during their transition to adult Medicaid coverage and improve continuity of coverage into adulthood by amending the 12-month continuous eligibility requirement for CYSHCN in two ways. First, the continuous eligibility requirement should be amended so that beneficiaries receive the full

12-months of continuous eligibility, even if during the continuous eligibility period the CYSHCN reaches their eligibility pathway's upper age limit, rather than having the continuous eligibility period end when an individual attains the eligibility period's upper age limit. This change aligns with the state option to extend 12-month postpartum coverage, which ensures that those eligible for 12 months of postpartum coverage continue to receive continuous eligibility even if the postpartum period extends beyond the regularly scheduled renewal date (CMS 2021). Additionally, this policy applies to those who age out of an eligibility pathway. For example, for Medicaid- and CHIP-covered pregnant individuals younger than age 19, the 12-month postpartum coverage period would apply even if the beneficiary turns age 19 and extend beyond the eligibility pathway's upper age limit (CMS 2021). Second, the continuous eligibility requirement should apply to child eligibility pathways that extend beyond age 18 to account for some states' extension of child coverage. Under current requirements, states are not permitted to provide 12 months of continuous eligibility to children after age 18, even if children are enrolled in a child eligibility pathway that extends up to age 21.

In considering this recommendation, the Commission discussed the importance of continuity of coverage for this population and weighed several factors in amending the current 12-month continuous eligibility requirement for children. CYSHCN transitioning to adulthood navigate many simultaneous program transitions between age 18 and 21, and providing 12 months of continuous eligibility in the final year of child eligibility could reduce beneficiary and family burden with completing multiple redeterminations. Additionally, this recommendation could improve continuity of coverage into adulthood, including for those enrolled in state optional pathways that extend child eligibility up to age 21, and reduce the risk of adverse health outcomes due to gaps in coverage. Commissioners raised that there are financial implications related to churn and policies that aim to reduce it. For example, a number of studies show that churning may increase overall Medicaid costs for beneficiaries of all ages due to pent-up demand for care and increased ED use after gaps in coverage (Sugar et al. 2021). Furthermore, some studies have shown that churn can lead to increases in state Medicaid agency administrative costs due to additional redeterminations

and renewals (Sugar et al. 2021). However, some studies raised that policies to reduce churn, such as providing 12 months or longer CE to children, have been shown to increase federal and state costs because of increased enrollment and potentially covering individuals who are no longer eligible for Medicaid (CBO 2024, Buettgens 2023).

Implications

Federal spending. The CBO estimates this recommendation would increase federal direct spending between \$250 million and \$2 billion.

States. This policy would require states to provide CYSHCN with 12 months of continuous eligibility through the end of the child's eligibility pathway's upper age limit, which extends the number of months that states cover these children under a child mandatory or optional state pathway. In states that have extended Medicaid coverage to individuals up to age 20 or 21, they would now also be required to provide CYSHCN covered under this optional pathway with 12 months of continuous eligibility.

Enrollees. This policy may reduce administrative burden in the final 12 months before aging out of child Medicaid by having the continuous eligibility period continue for 12 months, even if it extends beyond age 19. Additionally, those covered under a state optional pathway that extends Medicaid coverage to individuals up to age 20 or 21 will receive 12 months of continuous eligibility through the end of the eligibility pathway's upper age limit.

Plans. To the extent that this improves continuity of coverage during this transition period, plans may have fewer beneficiaries who are experiencing disruptions in coverage and care.

Providers. To the extent that CYSHCN are less likely to disenroll or churn during this transition period, they will be able to remain connected to and receive continuous care from their providers.

Recommendation 5.6

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 supporting children

and youth with special health care needs (CYSHCN) with Medicaid redeterminations and transitioning to adult Medicaid coverage. The guidance should address authorities to cover case management, transition planning for child-only Section 1915(c) home- and community-based services waivers, and the state optional pathway to cover children up to age 21. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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

Findings from the stakeholder interviews demonstrate that many young adults transitioning to adult Medicaid coverage do not receive sufficient support with navigating the Medicaid eligibility redetermination at age 19. For example, interviewees shared that many CYSHCN need a dedicated case manager or care coordinator to explain the steps needed to complete the financial and disability determinations at age 19, when most beneficiaries are redetermined as an adult. Several state advocates and state officials shared that, in general, beneficiaries enrolled in child-only 1915(c) HCBS waivers who have a dedicated case manager receive support with preparing for the Medicaid financial eligibility redetermination and waiver functional eligibility assessments years in advance and have smoother transitions to adult Medicaid than beneficiaries who are not enrolled in these waivers. However, the level of support with both the Medicaid redetermination and the transition to adult 1915(c) HCBS waivers that beneficiaries enrolled in child-only 1915(c) HCBS waivers receive can vary among states and even between state waiver programs because there may not be enough staff to support all families through these multiple transition processes.

Currently, there is no CMS guidance to states on existing authorities and flexibilities that are specific to how states can ease CYSHCN transitions to adult coverage. In the Commission's view, in developing the guidance, CMS should at minimum address the following:

- authorities states can use to provide CYSHCN with a dedicated case manager or care coordinator to support them with understanding the steps needed to complete the financial and disability determinations that need to be completed for the age-19 Medicaid redetermination (e.g., TCM, case management through a 1915(c) HCBS waiver);
- transition planning procedures states can include in state age-limited Section 1915(c) HCBS waivers to support beneficiaries and their families through the Medicaid redetermination process (e.g., support with preparing for the upcoming redetermination as an adult, understanding how the adult eligibility criteria may differ from those for children, and preparing the beneficiary and family for what information they may need to provide the state Medicaid agency); and
- implementation of the state option to extend child eligibility up to age 21 under 42 CFR 435.222 or 42 CFR 435.223 and examples of how states have implemented this optional pathway (e.g., reasonable classifications of individuals younger than age 21 that states have chosen for this pathway, income eligibility criteria) and the potential state financial implications of covering these children.

Additionally, CMS may wish to consider addressing other state options to ease transitions, including providing a 90-day reconsideration period for non-MAGI beneficiaries, in the guidance. States are required to provide beneficiaries eligible under MAGI rules, and have the option to provide other beneficiaries, with a 90-day reconsideration period for those who have Medicaid terminated due to failure to provide information (42 CFR 435.916(b)(2)(iii) and 42 CFR 435.919(d)). If beneficiaries send the information within 90 days, their Medicaid eligibility would be back dated to the date that coverage was terminated (CMS 2024d). The 2024 E&E final rule requires states to implement a 90-day reconsideration period for non-MAGI beneficiaries as well, but this provision was paused through 2035, so the requirement is not enforceable by CMS (2025 Budget Reconciliation Act).¹³

Implications

Federal spending. The CBO estimates this recommendation would not have a direct effect on federal Medicaid spending. CMS would have to commit time and resources to issuing guidance.

States. The guidance will provide states with greater clarity on the available existing authorities to support CYSHCN transitions to adult Medicaid.

Enrollees. This policy may improve beneficiary and family support with Medicaid redeterminations and the transition to adult Medicaid coverage.

Plans. There may be administrative effort for plans to develop payment policy and guidance for providers supporting beneficiaries with Medicaid redeterminations.

Providers. To the extent that states choose to provide support to CYSHCN with the Medicaid redetermination through managed care organizations, providers may engage in supporting CYSHCN with the transition to adult Medicaid coverage.

Looking Ahead

Over the past two analytic cycles, the Commission focused on CYSHCN and their coverage and care transitions as they age into adulthood. This work culminated in two chapters published in the June 2025 and 2026 reports to Congress with a total of 10 recommendations for improving CYSHCN transitions and their continuity of care and coverage. Looking ahead, we are continuing our commitment to building our body of work on access to coverage and care for CYSHCN, including forthcoming work focused on those with complex behavioral health needs and those involved in the child welfare system.

Endnotes

¹ In 2024, MCHB broadened its approach to screening for CYSHCN as part of the National Survey of Children's Health. The expanded definition of CYSHCN includes those who are identified by the screener and those who did not qualify based on the screener but have at least one health condition and functional difficulty. This expanded approach increases the national percentage of CYSHCN by about 5 percent (DRC 2025, Black et al. 2024).

² MCBH 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). The Health Resources & Services Administration (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).

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, and states may refer to programs by a variety of names. The Tax Equity and Fiscal Responsibility Act of 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). In addition, some states provide similar services to the same population under Section 1915(c) waivers rather than under the state plan. 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, 43 states and the District of Columbia use the Katie Beckett eligibility pathway or have a comparable 1915(c) waiver (Musumeci et al. 2022).

⁴ State Medicaid programs can cover children with disabilities younger than age 19 whose family income may otherwise be too high to qualify for Medicaid or SSI through the optional TEFRA state plan pathway, which is also referred to as the Katie Beckett state plan option, or under Section 1915(c)

HCBS authority. The Katie Beckett state plan pathway uses the SSI definition of disability and counts only the child's income and assets (42 CFR 435.225). The Katie Beckett state plan option allows these children to receive services in their home and affords greater employment flexibility to beneficiary families (Colello and Morton 2019, CISWH 2016). Some states provide similar services to the same population under Section 1915(c) HCBS waivers rather than under the state plan.

⁵ To qualify for SSI, children and adults are required to meet federal medical and financial criteria, which include income and asset limits, and the disability criteria are different for children and adults. To be eligible for SSI as a child, they must have "a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." As an adult, the disability criteria are instead based on their ability to perform work at a substantial gainful activity level (Hemmeter et al. 2009). This is defined based on monthly earnings, and this amount is defined based on the nature of a person's disability and is adjusted with changes in the national average wage index (SSA n.d.a).

⁶ This new waiver option will be available to states on July 1, 2028, and may provide beneficiaries with another pathway to Medicaid eligibility and access to additional services not covered under the state plan (CMS 2025a).

⁷ The resource limit for SSI was set in 1972 and was not indexed to inflation, so the resource limit is currently only one-sixth of the 1972 value. The limits contribute to rates of churn and rates of ineligibility (Romig et al. 2023).

⁸ As of 2023, the District of Columbia, Florida, Maine, and Massachusetts have adopted this option and cover beneficiaries age 19 and 20 (CMS 2023c).

⁹ In 2024, CMS's E&E final rule added 42 CFR 435.223 to clarify that states can extend coverage for individuals younger than age 21 who meet the criteria for non-MAGI eligibility groups (CMS 2024b). The reasonable classifications of individuals younger than age 21 are those described in any clause of Section 1902(a)(10)(A)(ii) of the Act.

¹⁰ 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).

¹¹ Functional eligibility is determined using an assessment tool, and generally, individuals must be found to have an institutional level of care (LOC) to qualify for an HCBS waiver. An LOC assessment is used to determine what services a beneficiary needs while on the waiver, and this assessment is completed annually. Functional assessments are often completed by the agency that oversees the waiver or a third-party vendor, who shares the results with the state Medicaid agency (MACPAC 2016).

¹² We define an informational notice as information sent to the beneficiary to prepare them for the upcoming redetermination that requires no action from the beneficiary. This type of informational notice is different from a notice, as defined in 42 CFR 431.210, or an advance notice, as defined in 431.211, which is required when the state is taking an action under 431.206(c).

¹³ Before the 2024 E&E final rule, states were required to provide beneficiaries under MAGI rules with a 90-day reconsideration period and had the option to provide this same reconsideration period to non-MAGI beneficiaries (CMS 2024b).

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APPENDIX 5A: Transformed Medicaid Statistical Information System (T-MSIS)

Methods and Findings

MACPAC worked with Acumen to examine data from the Transformed Medicaid Statistical Information System (T-MSIS) for calendar years 2017 through 2019. To observe changes in coverage and disenrollment, we used data from the years before the COVID-19 public health emergency (2020–2023), when states paused Medicaid redeterminations.¹ The analytic population includes transition-age Medicaid children enrolled in a disability-related eligibility group code, using their last-best month in 2017, and were enrolled for all previous 12 months.^{2,3} This includes children who were enrolled in multiple eligibility pathways across the 12-month period. For the analysis, we grouped children into three groups: “SSI-related pathways,” “other SSI-related pathways, and “other disability-related pathways” (Appendix 5A, Table 5A-1). Transition age is defined as children within 12 months of aging out of child Medicaid eligibility. In most states this age is 19, but four states (the District of Columbia, Florida, Maine, and Massachusetts) have extended child eligibility to age 21 through a state plan option (42 CFR 435.222 and 42 CFR 435.223). We excluded beneficiaries who were not enrolled in a disability-related eligibility group as a child, who were missing an eligibility group code, and who moved to another state between January 2018 and December 2019 from the analytic population.

Using this analytic population, we calculated the number eligible on the basis of disability aging out of child Medicaid eligibility; the percentage who remained Medicaid covered continuously for 12 months after aging out of child Medicaid and transitioning to adult Medicaid coverage; the percentage who disenrolled and remained disenrolled for 12 months; the percentage who disenrolled and reenrolled (churned) within 12 months after aging out; and for those who churned, the average number of months they experienced a gap in coverage. The analysis also identified the adult eligibility pathway for those who remained enrolled as an adult or churned. The adult eligibility group is determined using the individual’s eligibility group in the first month of enrollment after the transition. If the eligibility group was different than the one they were enrolled in as a child, they were grouped in one of four categories (adults, modified adjusted gross income (MAGI); adults, non-MAGI, disabled; adults, non-MAGI, non-disabled; and other) (Table 5A-1). Additionally, in states that have adopted the Medicaid expansion pathway, we identified the number that enrolled in this specific MAGI pathway as an adult. Furthermore, for those who churned, the analysis calculated the average number of months between disenrollment and reenrollment.

TABLE 5A-1. Child and Adult Eligibility Pathway Eligibility Group Assignment

Types of eligibility pathways	Eligibility category	Eligibility pathways
Child eligibility pathways	SSI-related	Individuals receiving SSI; aged, blind and disabled individuals in 209(b) states; individuals receiving mandatory state supplements; optional state supplement recipients—1634 states and SSI criteria states with 1616 agreements; and optional state supplement recipients—209(b) and SSI criteria states without 1616 agreements.
	Other SSI-related	Institutionalized individuals continuously eligible since 1973; individuals who lost eligibility for SSI/SSP due to an increase in OASDI benefits in 1972; individuals who would be eligible for SSI/SSP but for OASDI COLA increases since April 1977; and disabled widows and widowers ineligible for SSI, working disabled under 1619(b).
	Other disability-related	Qualified disabled children under age 19; Family Opportunity Act children with disabilities; individuals eligible for HCBS; and medically needy children, parents, and caretakers and aged, blind, and disabled individuals.
Adult eligibility pathways	MAGI	Expansion pathway; transitional medical assistance; extended Medicaid; and pregnant women.
	Non-MAGI, disabled	SSI pathways; other disability pathways that overlap with those listed for child eligibility pathways; essential spouses; blind or disabled eligible in 1973; disabled adult children; qualified Medicare beneficiaries; qualified disabled and working individuals; aged, blind, or disabled individuals eligible for but not receiving cash assistance; ticket to work, individuals eligible for HCBS; and medically needy aged, blind, or disabled.
	Non-MAGI, non-disabled	Certain individuals needing treatment for breast or cervical cancer and medically needy parents and other caretakers.
	Other	Any other adult eligibility pathway.

Notes: SSI is Supplemental Security Income. SSP is state supplemental payment. OASDI is Old-Age, Survivors, and Disability Insurance. COLA is cost-of-living adjustment. HCBS is home- and community-based services. MAGI is modified adjusted gross income. The 1616 agreements are agreements state Medicaid agencies may have under section 1616 of the Social Security Act with the Social Security Administration (SSA) to have SSA administer the state Medicaid agency's supplementary payment programs (CMS n.d.). Child and adult eligibility groups were categorized using similar methods as other recent churn analyses using Transformed Medicaid Statistical Information System (T-MSIS) (Mann et al. 2022, MACPAC 2021). The child eligibility groups were based on age criteria (up to age 19).

Source: MACPAC analysis of T-MSIS, 2017–2019.

T-MSIS findings

The tables and figures below present findings from the analysis of the 2017 through 2019 T-MSIS eligibility and enrollment data referenced in the chapter. Additional findings are published in the 2026 MACPAC issue brief CYSHCN Transitions to Adult Medicaid Coverage (MACPAC 2026).

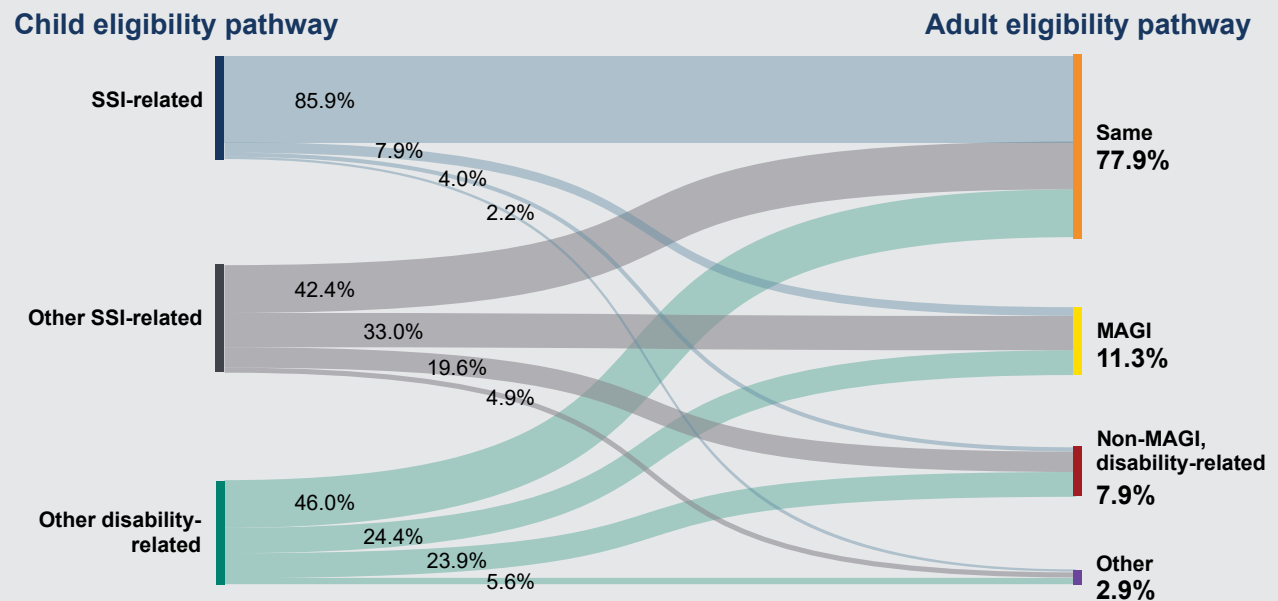
TABLE 5A-2. Disenrollment and Churn When Transitioning to Adult Medicaid Coverage among Transition-Age Children and Youth with Special Health Care Needs by Eligibility Group, 2017–2019

Eligibility group	Transition-age CYSHCN		Disenrolled after aging out of child Medicaid		Churned within 12 months		Disenrolled after aging out of child Medicaid and remain disenrolled for the following 12 months	
	Number of transition-age CYSHCN	Share who remained continuously enrolled	Number of transition-age CYSHCN	Share of all transition-age CYSHCN	Share of all transition-age CYSHCN	Share of transition-age CYSHCN who disenrolled	Share of all transition-age CYSHCN	Share of transition-age CYSHCN who disenrolled
All disability-related pathways	83,904	82.4%	14,756	17.6%	6.0%	33.9%	11.6%	66.1%
SSI related	65,062	85.1	9,681	14.9	5.1	34.2	9.8	65.8
Other SSI related	1,049	84.9	158	15.1	7.8	51.9	7.2	48.1
Other disability related	17,793	72.4	4,917	27.6	9.0	32.7	18.6	67.3

Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. Transition-age CYSHCN are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Table 5A-1.

Source: MACPAC analysis of T-MSIS, 2017–2019.

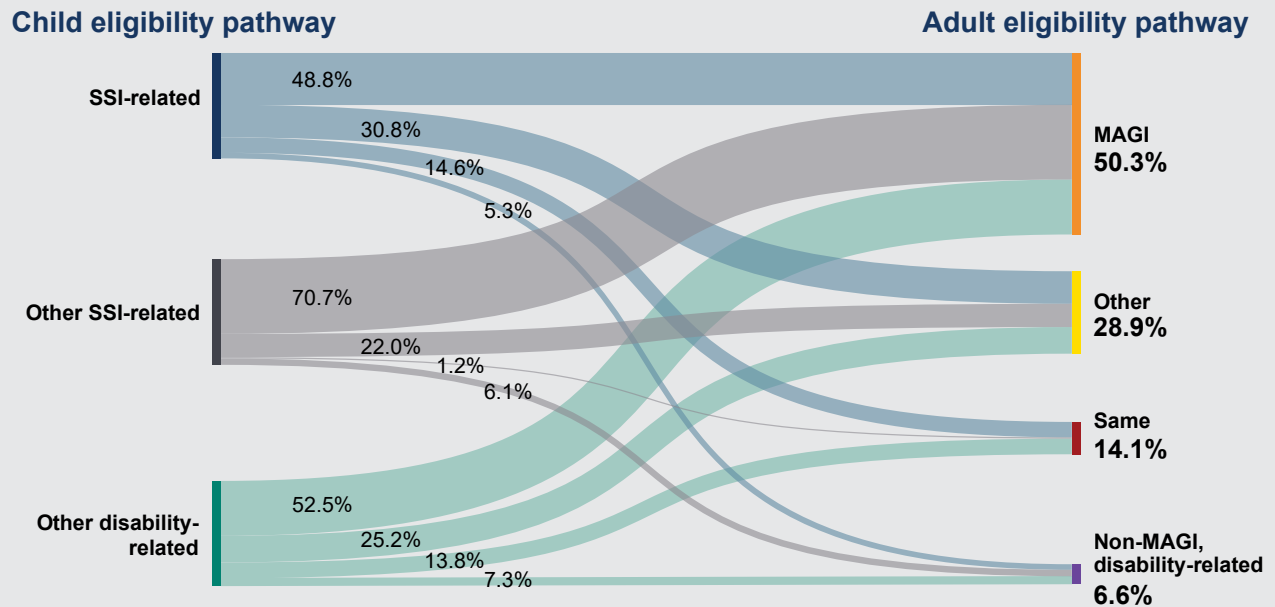
FIGURE 5A-1. Transition-Age Medicaid-Covered Children and Youth with Special Health Care Needs Who Remained Continuously Enrolled in Medicaid as Adults by Child and Adult Eligibility Pathways, 2017–2019



Notes: SSI is Supplemental Security Income. MAGI is modified adjusted gross income. Transition-age children and youth with special health care needs (CYSHCN) are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The child eligibility pathways show percentages of CYSHCN who transitioned to an adult eligibility group. The adult eligibility pathway percentages represent the percentage of all transition-age children who transitioned to each adult eligibility pathway group (e.g., of all transition-age CYSHCN, 77.9 percent maintain coverage in the same eligibility pathway). The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Table 5A-1.

Source: MACPAC analysis of T-MSIS, 2017–2019.

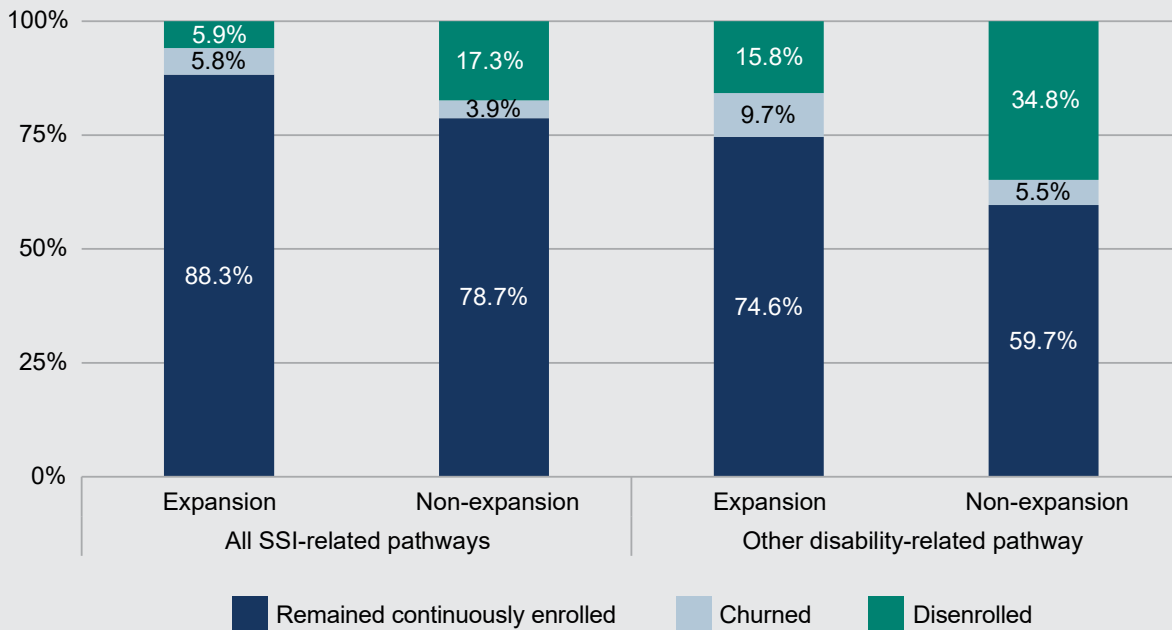
FIGURE 5A-2. Transition-Age Children and Youth with Special Health Care Needs Who Churned by Child and Adult Eligibility, 2017–2019



Notes: SSI is Supplemental Security Income. MAGI is modified adjusted gross income. The child eligibility pathways show percentages of children who transitioned to each adult eligibility pathway group. The adult eligibility pathway percentages represent the percentage of all transition-age children who transitioned to each adult eligibility pathway group (e.g., of all transition-age children, 14.1 percent maintain coverage in the same eligibility pathway). Transition-age children and youth with special health care needs are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. A crosswalk of eligibility groups to the eligibility pathway codes in Transformed Medicaid Statistical Information System (T-MSIS) are included in Table 5A-1.

Source: MACPAC analysis of T-MSIS, 2017–2019.

FIGURE 5A-3. Coverage Outcomes for Transition-Age Children and Youth with Special Health Care Needs by Eligibility Pathway and State Adoption of Medicaid Expansion, 2017–2019

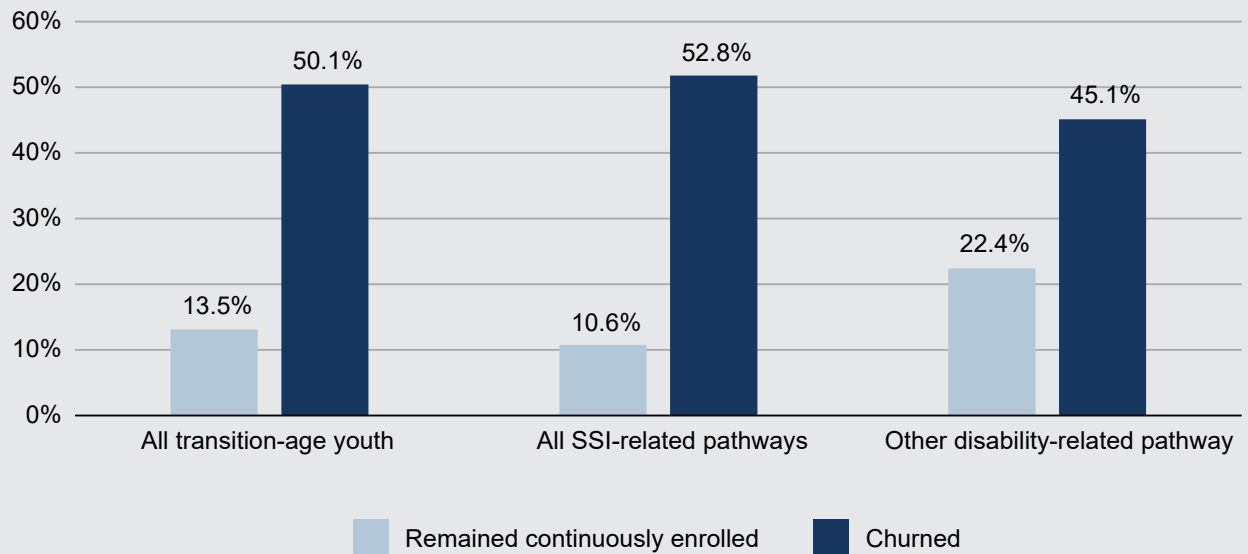


Notes: SSI is Supplemental Security Income. Transition-age children and youth with special health care needs are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. A crosswalk of eligibility groups to the eligibility pathway codes in Transformed Medicaid Statistical Information System (T-MSIS) are included in Table 5A-1.

Expansion refers to the 35 states and the District of Columbia that, as of January 1, 2019, adopted Medicaid expansion and extended Medicaid eligibility to all adults younger than age 65 (including parents and adults without dependent children) with incomes below 133 percent of the federal poverty level. Non-expansion refers to states that have not adopted Medicaid expansion as of January 1, 2019 (KFF 2025).

Source: MACPAC analysis of T-MSIS, 2017–2019.

FIGURE 5A-4. Transition-Age Children and Youth with Special Health Care Needs by Eligibility Pathway Who Transition to an Expansion Eligibility Pathway as an Adult, 2017–2019



Notes: SSI is Supplemental Security Income. Transition-age children and youth with special health care needs are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. A crosswalk of eligibility groups to the eligibility pathway codes in Transformed Medicaid Statistical Information System (T-MSIS) are included in Table 5A-1.

Source: MACPAC analysis of T-MSIS, 2017–2019.

Endnotes

¹ During the COVID-19 public health emergency, the Families First Coronavirus Response Act (P.L. 116-127) provided states with a temporary 6.2 percentage point increase in the federal medical assistance percentage (FMAP) if they met certain conditions, including a continuous coverage requirement for most Medicaid beneficiaries who were enrolled in the program as of or after March 18, 2020. The Consolidated Appropriations Act of 2023 (CAA, P.L. 117-328) decoupled the end of the continuous coverage requirement from the public health emergency. The CAA established an end date of March 31, 2023, for the requirement and a phase-down of the enhanced matching rate over the remainder of 2023 for states that met certain renewal processing and data reporting requirements.

² Acumen defined the last-best month as the most recent month containing a valid non-CHIP eligibility group code or a valid basis of eligibility (if eligibility group is missing or invalid). If the beneficiary has at least one validly enrolled month (i.e., at least one last-best month), they considered them validly enrolled for the given year. When using the final action eligibility file to define valid enrollment, Acumen further subset the enrollment records to the time when the date of birth and the date of death indicate the beneficiaries are still alive.

³ The cohort of transition-age children and youth with special health care needs was defined as individuals between age 18 and 19 as of December 2017. Individuals who remained continuously enrolled in the year leading up to their 19th birthday and for the 12 months following their 19th birthday are considered continuously enrolled. Individuals who disenrolled for any period of time in 2018 (which includes individuals who were within 12 months of their 19th birthday) is defined as the disenrolled group. Those who disenrolled and reenrolled within 12 months of the month of disenrollment are defined as the “churn group.”

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APPENDIX 5B: American Community Survey Methods and Findings

MACPAC worked with the State Health Access Data Assistance Center to examine survey data from the 2023 American Community Survey (ACS). We used these survey data to better understand the demographic characteristics and insurance coverage of youth and young adults with disabilities, defined based on self-reported disability and reported receipt of Supplemental Security Income (SSI) payments. We stratified and compared these results by those with and without self-reported disabilities, age groups (17–18 years old, 19 years old, and 20–25 years old), insurance type (Medicaid, private, and no insurance), and those who receive and do not receive SSI. We defined someone as having a self-reported disability if they reported having one or more of these six functional limitations: deaf or difficulty hearing, blind or difficulty seeing, difficulty concentrating and making decisions, difficulty with walking or climbing stairs, difficulty dressing or bathing, and difficulty with doing errands alone.

Findings

In this section we include the table from the analysis of the 2023 ACS referenced in the chapter.

TABLE 5B-1. Selected Demographic and Socioeconomic Characteristics of Youth and Young Adults with Self-Reported Disability by Age Group, 2023

Selected characteristics	17–18 years	19 years	20–25 years
Race and ethnicity			
Hispanic	24.1%	23.2%	21.5%*
White, non-Hispanic	49.7	51.4	54.9*
Black, non-Hispanic	13.9	12.0*	12.7*
American Indian and Alaska Native, non-Hispanic	0.8	0.5	0.7
Asian, non-Hispanic	2.9	3.2	3.1
Native Hawaiian and other Pacific Islander, non-Hispanic	–	–	0.2*
Other single and multiple races, non-Hispanic	8.6	9.4	6.9*
Insurance coverage			
Any Medicaid	48.2	39.5*	35.9*
Private only	44.3	50.1*	49.5*
Other (military or VA)	1.7	1.7	2.5*
Uninsured	5.8	8.7*	12.0*
Benefits programs			
Receives income from SSI	11.3	11.2	11.8
Self-reported disability			
Reports having 2 or more functional limitations	38.8	38.4	37.9
Reports having 3 or more functional limitations	13.4	14.0	12.5

Notes: SSI is Supplemental Security Income. VA is Veterans Affairs insurance. Disability status is defined using the self-reported disability status. Has a disability means the respondent reported yes for at least one of six functional limitations.

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

– Estimate not reported because it is too small of a sample size or it is unreliable because it has a relative standard error greater than or equal to 30 percent.

Source: MACPAC analysis of the American Community Survey, 2023.

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 May 7, 2026.

Children and Youth with Special Health Care Needs Transitions to Adult Coverage

5.1 The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 435.919(b)(6) to require states to send a notice a minimum of 60 days in advance of children and youth with special health care needs (CYSHCN) aging out of child Medicaid eligibility to inform them that the renewal process has been initiated. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

5.1 voting result	#	Commissioner
Yes	17	Allen, Bjork, Brown, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Karl, Killingsworth, McCarthy, McFadden, Nardone, Snyder
No	0	

5.2 State Medicaid agencies should provide children and youth with special health care needs (CYSHCN) who are aging out of child Medicaid eligibility with a minimum of 30 days to respond to requests for information to complete Medicaid redeterminations in accordance with 42 CFR 435.919(c)(1). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

5.2 voting result	#	Commissioner
Yes	17	Allen, Bjork, Brown, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Karl, Killingsworth, McCarthy, McFadden, Nardone, Snyder
No	0	

5.3 To ensure the accuracy of information provided by the Social Security Administration (SSA) to Medicaid beneficiaries enrolled in Supplemental Security Income (SSI)-related eligibility pathways who are being notified that they are losing eligibility for SSI, the Secretary of the U.S. Department of Health and Human Services, through the Centers for Medicare & Medicaid Services, should coordinate with SSA to review and update model notice language pertaining to Medicaid in SSA's Program Operations Manual System manual paragraphs. The model language should clearly indicate that the individual may retain their Medicaid coverage while the state Medicaid agency takes steps to redetermine the individual on a new basis of eligibility. Additionally, the model language should describe, in general terms, the steps the individual needs to follow to complete the Medicaid redetermination that are specific to 1634, SSI criteria, and 209(b) states.

5.3 voting result	#	Commissioner
Yes	17	Allen, Bjork, Brown, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Karl, Killingsworth, McCarthy, McFadden, Nardone, Snyder
No	0	

5.4 State Medicaid agencies should implement optional Medicaid eligibility for children and youth with special health care needs (CYSHCN) up to age 21 who are not otherwise eligible for and enrolled in mandatory coverage or optional full Medicaid coverage under the state plan (42 CFR 435.222 and 42 CFR 435.223). CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

5.4 voting result	#	Commissioner
Yes	16	Allen, Bjork, Brown, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Karl, Killingsworth, McFadden, Nardone, Snyder
No	1	McCarthy

5.5 To ensure children and youth with special health care needs (CYSHCN) receive a full 12-month continuous eligibility period in their final year of child Medicaid eligibility, Congress should amend § 1902(e)(12) of the Social Security Act to require states to provide CYSHCN with a 12-month continuous eligibility period that lasts a full 12 months from the date of the eligibility determination, even if during the continuous eligibility period, an individual reaches the upper age limit for the eligibility pathway by which they are eligible for Medicaid. This 12-month continuous eligibility period should apply to all CYSHCN who receive coverage from a mandatory or optional child eligibility pathway, including optional pathways covering youth above age 18. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

5.5 voting result	#	Commissioner
Yes	14	Allen, Bjork, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Killingsworth, McFadden, Nardone, Snyder
No	3	Brown, Karl, McCarthy

5.6 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 supporting children and youth with special health care needs (CYSHCN) with Medicaid redeterminations and transitioning to adult Medicaid coverage. The guidance should address authorities to cover case management, transition planning for child-only Section 1915(c) home- and community-based services waivers, and the state optional pathway to cover children up to age 21. CYSHCN include, but are not limited to, children who are enrolled in Medicaid through Supplemental Security Income (SSI)-related eligibility pathways who are not eligible for SSI as adults and are transitioning to non-SSI related pathways when they reach age 19, 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.

5.6 voting result	#	Commissioner
Yes	17	Allen, Bjork, Brown, Duncan, Gerstorff, Giardino, Hartman, Heaphy, Hill, Ingram, Johnson, Karl, Killingsworth, McCarthy, McFadden, Nardone, Snyder
No	0	