

Improving Continuity of Coverage for CYSHCN During Transitions to Adult Medicaid Coverage: MACPAC's Recommendations to Congress

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AGENDA

Speaker Introductions: Peggy McManus, Got Transition

Welcome: Holly Henry, Director, Lucile Packard Foundation

Presentation: Linn Jennings and Ava Williams, MACPAC

Q & A: Please add questions to the chat, and we will discuss.

October 7th, 2026

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

June 2026 chapter and recommendations

Ava Williams and Linn Jennings



Medicaid and CHIP Payment and Access Commission

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What is MACPAC?

- The Medicaid and CHIP Payment and Access Commission (MACPAC) is a non-partisan legislative branch agency that provides policy and data analysis and makes recommendations to Congress, the Secretary of the U.S. Department of Health and Human Services, and the states on issues affecting Medicaid and State Children's Health Insurance Program (CHIP)
 - MACPAC serves as an independent source of information on Medicaid and CHIP, publishing Reports to Congress, issue briefs and data reports throughout the year to support policy analysis and program accountability
- The U.S. Comptroller General appoints MACPAC's 17 commissioners, who come from diverse regions across the United States and bring broad expertise and a wide range of perspectives on Medicaid and CHIP
- MACPAC's authorizing statute also requires the Commission to submit reports to Congress by March 15 and June 15 of each year
 - In carrying out its work, the Commission holds public meetings and regularly consults with state officials, congressional and executive branch staff, beneficiaries, health care providers, researchers, and policy experts

June 2025 Recommendations on CYSHCN Transitions of Care

- Congress should require states to develop and implement a strategy for transitions from pediatric to adult care for CYSHCN that addresses the development of an individualized transition of care plan
- States should collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan
- The Centers for Medicare & Medicaid Services (CMS) should:
 - issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs
 - amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care

Overview

- Project overview and methodology
- Medicaid-covered CYSHCN
- Transitions from child to adult Medicaid
- Transition outcomes
- Federal Medicaid requirements
- State role in supporting coverage transitions
- Challenges
- Recommendations



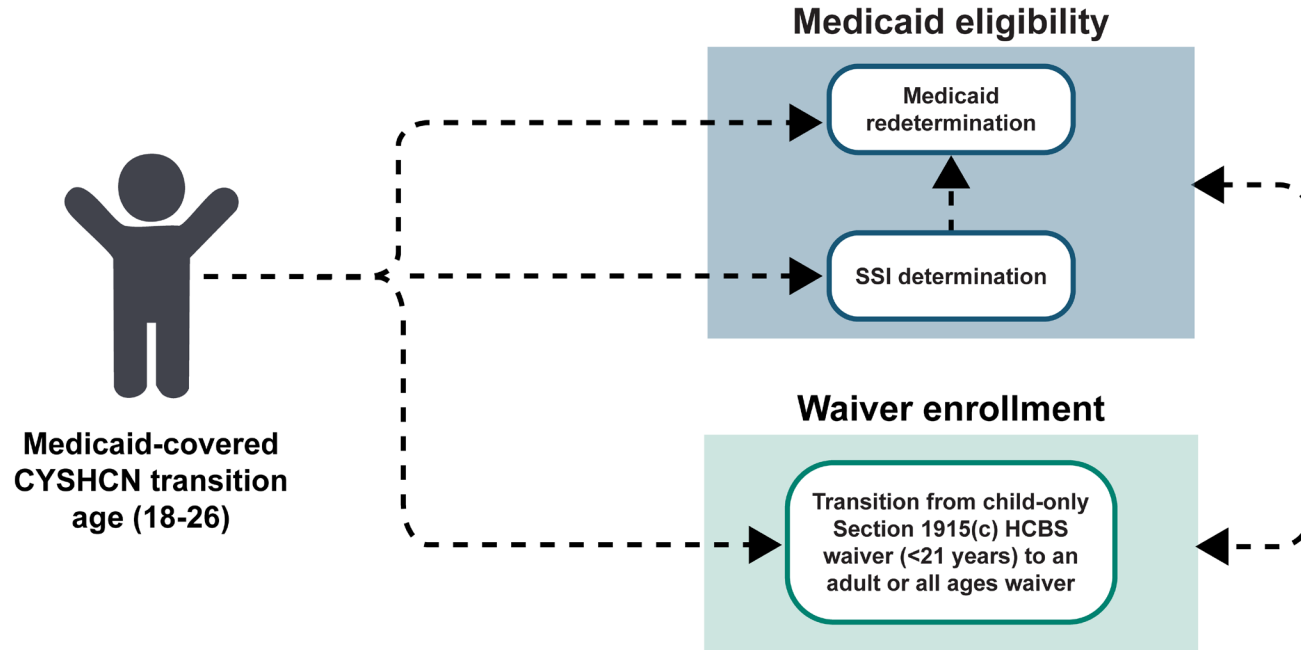
Project Overview and Approach

- Study aims:
 - Examine how federal and state Medicaid policies address transitions in coverage for CYSHCN aging out of child basis of eligibility to adult basis of eligibility to prevent gaps in coverage
 - Identify barriers to coverage transitions for CYSHCN that could be addressed in federal Medicaid policy
- Approach:
 - Federal policy review
 - Findings from the state policy scan completed as part of our first phase of work on CYSHCN transitions of care (review of state 1915(c) home- and community-based services (HCBS) waivers and managed care contracts)
 - Stakeholder interviews (e.g., federal and state officials, national research experts, and national and state-level advocates)
 - [Issue brief](#) on findings on CYSHCN transitions to adult Medicaid coverage, analysis of the Transformed Medicaid Statistical Information System (T-MSIS), 2017-2019

Medicaid-Covered CYSHCN

- CYSHCN can enroll based on income or disability, including Supplemental Security Income (SSI)-related pathways and optional disability pathways (e.g., Katie Beckett pathway)
- States can use three approaches when determining Medicaid eligibility for SSI-enrollees
 - 1634 states use SSI disability determination, and SSI enrollment automatically confers Medicaid eligibility
 - SSI criteria states use SSI disability determination for Medicaid determination on basis of disability, requires a separate Medicaid application
 - 209(b) states can use disability eligibility criteria that are more restrictive than SSI criteria, requires a separate Medicaid application

CYSHCN Medicaid Eligibility and Waiver Transitions



Data Findings

T-MSIS Analysis: Transition Outcomes

- **Purpose:** There are few reported data on transition-age CYSHCN or their coverage transition outcomes. To address this gap, we examined Medicaid-covered CYSHCN and their transitions to adult Medicaid coverage using 2017–2019 enrollment data from T-MSIS
- **Population of focus:** Transition-age CYSHCN (within 12 months of aging out of child Medicaid) enrolled in disability-related eligibility pathways
 - SSI-related: Current SSI recipients
 - Other SSI-related: Beneficiaries who would be eligible for SSI, but not receiving
 - Other disability-related: Other non-Modified Adjust Gross Income (MAGI) groups
- **Transition outcomes**
 - Continuous enrollment: Enrolled for 12 months after aging out of child Medicaid eligibility
 - Churn: Disenrolled in the year prior to aging out and re-enrolled in Medicaid within 12 months
 - Disenrollment: Disenrolled during the year prior to aging out and do not re-enroll

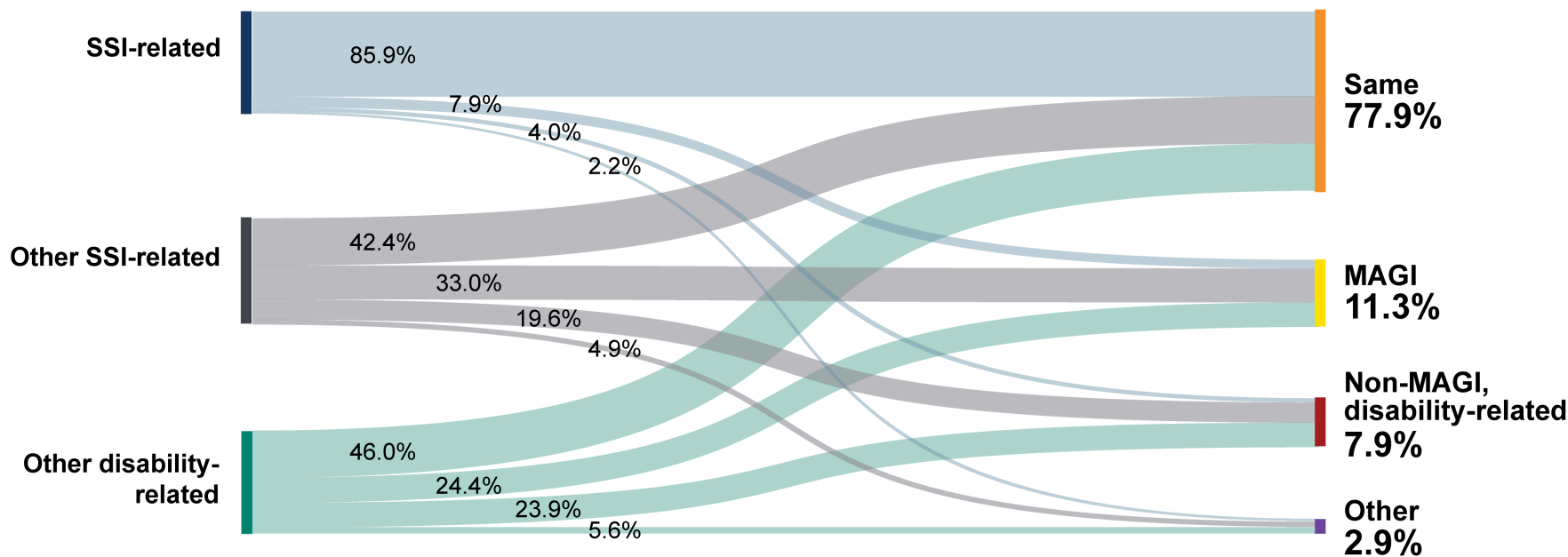
Key Takeaways

- The majority of CYSHCN remained continuously enrolled in Medicaid when transitioning to adult Medicaid (82.4 percent)
 - However, the percent who remained continuously enrolled varied by the disability-related eligibility pathway enrolled in as a child, beneficiary race and ethnicity, the beneficiary's enrollment state, and state adoption of Medicaid expansion
- The adult eligibility pathways that CYSHCN transitioned to differed between those who remained continuously enrolled and those who churned
 - Over 75 percent of CYSHCN continuously enrolled stayed in the same pathway as an adult, whereas about 50 percent of those who churned, enrolled in an adult MAGI pathway
 - Of those enrolled in expansion states, 13.5 percent of those who were continuously enrolled and 50.1 percent of those who churned enrolled in the expansion pathway

Transition-Age CYSHCN who Remained Continuously Enrolled

Child eligibility pathway

Adult eligibility pathway



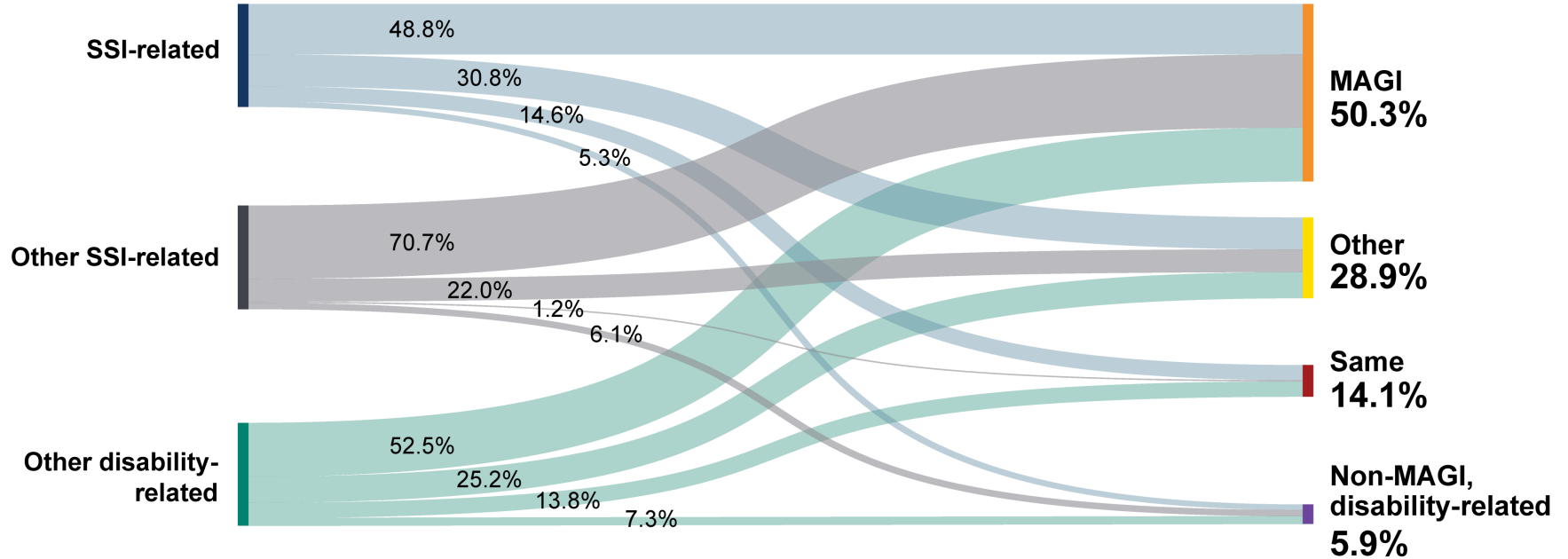
Notes. SSI is Supplemental Security Income. MAGI is Modified Adjusted Gross Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. The child eligibility pathways show percentages of children and youth with special health care needs (CYSHCN) who transitioned to an adult eligibility group. The adult eligibility pathway percentages represent the percent of all transition-age children who transitioned to each adult eligibility pathway group.

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

Transition-Age CYSHCN who Churned

Child eligibility pathway

Adult eligibility pathway



Notes. SSI is Supplemental Security Income. MAGI is Modified Adjusted Gross Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. The child eligibility pathways show percentages of children and youth with special health care needs (CYSHCN) who disenrolled and then re-enrolled in Medicaid by adult eligibility group. The adult eligibility pathway percentages represent the percent of all transition-age children who transitioned to each adult eligibility pathway group.

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

Key Findings

Federal and state policy scan and stakeholder interviews

Federal Medicaid Requirements

- States are required to provide 12-months continuous eligibility (CE) for all children under age 19
- For all Medicaid redeterminations, states must first attempt to confirm ongoing eligibility on an ex parte basis
 - States often begin this process 60 to 90 days in advance of the end of the eligibility period, and states are required to notify the beneficiary if additional information is needed to complete the redetermination
 - If the state is unable to complete the beneficiary redetermination or identifies information that will lead to termination, the state must provide beneficiaries with the opportunity to provide additional information

State Role in Supporting CYSHCN Coverage Transitions

Medicaid eligibility and redeterminations related to SSI

- If a beneficiary remains eligible for SSI as an adult, they often do not experience any changes to their adult Medicaid eligibility pathway
- The Medicaid redetermination process varies based on the type of redetermination state (e.g., 1634, SSI criteria, 209(b))

Timelines and clarity of notices

- States are not required to send a notice in advance of an upcoming renewal, but some states send beneficiaries a notice to help them prepare for this process
 - Without advance notice of the age 19 redetermination, some beneficiaries are unaware of the redetermination
- Redetermination notices and notices related to SSI often lack clear actionable steps

State Role in Supporting CYSHCN Coverage Transitions, cont.

Extended age eligibility for child coverage

- Four states have extended child eligibility up to age 21 through a state plan option (42 CFR 435.223), which can improve beneficiary coverage stability and ease their transition process as they navigate multiple transitions

Support with Medicaid and SSI redeterminations

- The amount of support beneficiaries receive during the Medicaid or SSI redetermination process can vary depending on which entity is providing the support
 - For example, beneficiaries enrolled in HCBS waivers often receive transition support from case managers, while beneficiaries not enrolled in a waiver may not receive any support with the Medicaid or SSI redetermination

State Role in Supporting CYSHCN 1915(c) HCBS Waiver Transitions

Transition planning

- States are required to specify transition planning for age-limited 1915(c) HCBS waivers and can specify activities that include identifying and helping beneficiaries apply for waivers that they may qualify for and providing support with Medicaid redeterminations
 - The robustness of transition planning varies across waivers, and transition planning may be insufficient to facilitate smooth transitions between waivers

Corresponding child-only and adult 1915(c) HCBS waiver programs

- States have the flexibility to design their HCBS waiver programs in order to support transitions
- Some states have designed corresponding child and adult waiver programs to promote continuity of care for transitioning beneficiaries
 - For example, one state allows beneficiaries enrolled in a child-only waiver to transition waiver enrollment at age 18 or 21, because the child only waiver upper age limit (21 years) overlaps with the comparable adult waiver minimum age (18 years)

Challenges with CYSHCN Transitions to Adult Medicaid

- Insufficient time to prepare and respond to Medicaid redetermination notices
 - Many states begin the process 60 to 90 days in advance, and there is no requirement to notify beneficiaries that the redetermination is beginning
 - Without advance notice of the redetermination, beneficiaries and families may lack sufficient time to provide needed documentation
- Lack of clarity in notices from the Social Security Administration (SSA) about changes to SSI and Medicaid eligibility
 - There are no federal requirements related to Medicaid and SSA coordinating or combining notices related to changes in SSI eligibility and how this affects Medicaid coverage
 - Beneficiaries experience challenges with understanding notices from Medicaid and SSA about how changes to SSI eligibility affect Medicaid eligibility

Challenges with CYSHCN Transitions to Adult Medicaid, cont.

- Navigating eligibility transitions
 - State flexibilities that can ease Medicaid redeterminations include use of SSI eligibility to determine Medicaid eligibility and extending child eligibility up to age 21 (42 CFR 435.223)
 - Many beneficiaries churn or disenroll when they age out of child Medicaid, and they may need more time to complete the Medicaid redetermination at age 19
- Variation in the level of support received with Medicaid redeterminations
 - States can provide case management to support with transitions to adult Medicaid coverage using existing authorities, including 1915(c) HCBS waivers and targeted case management
 - Beneficiaries do not receive sufficient support, especially when navigating multiple transitions



Final Recommendations

CMS Should Issue New Guidance

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

- States need guidance on the use of existing authorities to support CYSHCN with the Medicaid redetermination and transitioning to adult Medicaid
- In the development of guidance, CMS should address:
 - Existing authorities to provide CYSHCN a dedicated case manager or care coordinator (e.g., targeted case management, case management through a Section 1915(c) HCBS waiver, etc.)
 - Transition planning procedures allowed in age-limited Section 1915(c) HCBS waivers
 - State implementation of the state optional pathway to extend eligibility up to age 21

CMS and States Should Improve Beneficiary Notices

Advance notice: *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 were 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.*

Time to respond: *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 were 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

- Beneficiaries and families need advance notice of the upcoming Medicaid redetermination to prepare for the transition to adult coverage
 - A notice about what to expect, such as changes related to eligibility criteria and what information the beneficiary and family may need to provide, would help families prepare
- States should provide beneficiaries with as much advance notice of their upcoming eligibility redetermination as possible and consider sending a notice as early as a year in advance, as is done by SSA in advance of the SSI age-18 redetermination
- CYSHCN aging out of child Medicaid may experience challenges responding to notices requesting additional information for the Medicaid redetermination within the required timeframe
 - They may receive the notice too late to respond within the required timeframe, after the deadline, or do not receive the notice at all

CMS and SSA Should Coordinate to Improve SSI Notices

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 beneficiaries lose SSI, they receive a notice from SSA about their SSI denial and information about Medicaid eligibility
 - These notices may not provide clear or consistently accurate information about the effect on Medicaid coverage, leading to beneficiary and family confusion
- There are no federal Medicaid or SSA requirements for SSA and CMS to coordinate on SSA notice language sent to beneficiaries who lose SSI
- The notice language about how a loss of SSI affects Medicaid eligibility should include:
 - Potential implications for Medicaid coverage so beneficiaries are aware that it is not immediately terminated
 - Information pertinent to the type of Medicaid determination state (i.e., 1634, SSI criteria, and 209(b))

States Should Adopt Option to Extend Child Eligibility

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

- Medicaid-covered CYSHCN are at a 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
 - CYSHCN can have complex medical conditions and often need specialized pediatric care and continue to need specialized services as adults; coverage disruptions can result in delays in necessary care
- Delaying the transition to adult Medicaid coverage can improve coverage stability for CYSHCN during a period of multiple program transitions, including the SSI age-18 redetermination
 - Aligns child eligibility with the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement

Congress Should Extend 12-Month Continuous Eligibility Through Final Year of Eligibility

To ensure children and youth with special health care needs (CYSHCN) receive a full 12-month continuous eligibility (CE) 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 CE period that lasts a full 12 months from the date of the eligibility determination, even if during the CE period, an individual reaches the upper age limit for the eligibility pathway by which they are eligible for Medicaid. This 12-month CE 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.
 - Gaps in coverage, even for short periods, are associated with delays in receipt of care, an increase in the risk of hospitalization, and higher administrative costs
- Beginning in 2024, states are required to provide 12-months continuous eligibility (CE) for children under age 19 to reduce rates of churn among children
 - CE requirement ends when beneficiary turns 19, even if this occurs before the end of full 12-month CE period

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Chapter



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Issue Brief



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THANK YOU!

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