

April 9, 2026

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

Draft chapter and recommendations

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Medicaid and CHIP Payment and Access Commission

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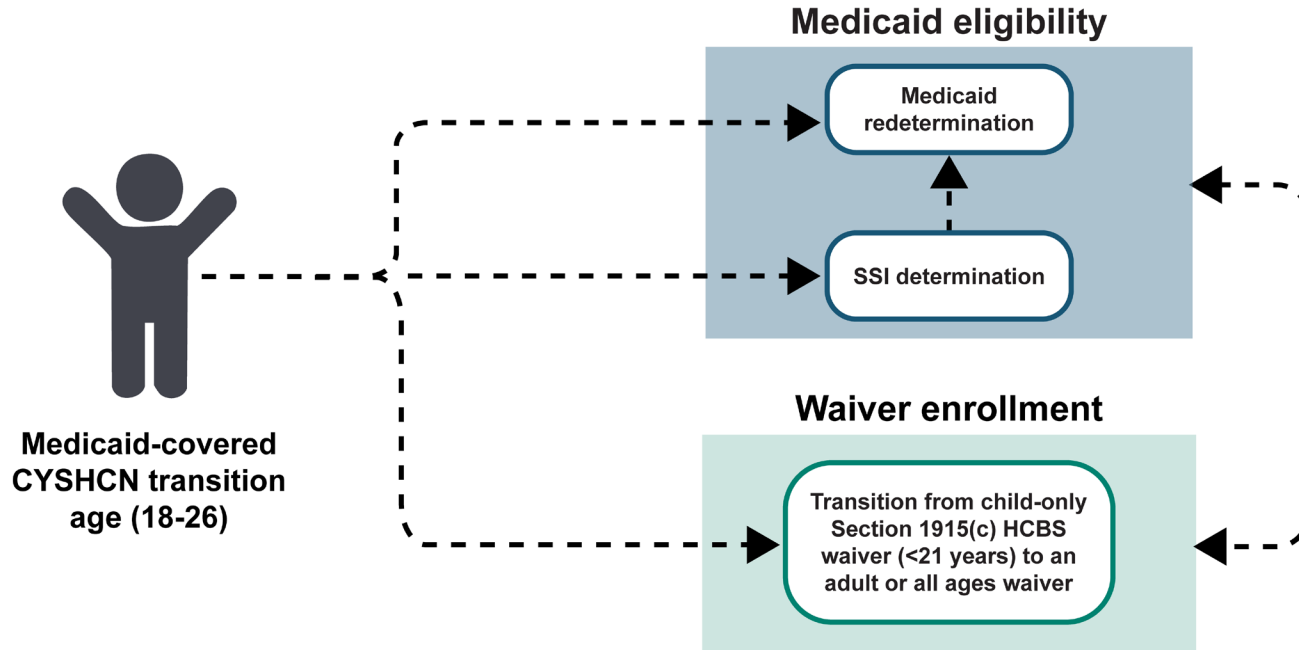
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Overview

- Transitions from child to adult Medicaid
- State role in transitions of coverage
- Challenges
- Recommendations



CYSHCN Medicaid Eligibility and Waiver Transitions



State Role in Transitions of Coverage

- For all Medicaid redeterminations, states must first attempt to confirm ongoing eligibility on a ex parte basis
 - 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
- States have flexibility to ease coverage transitions, including:
 - Providing advance notice of upcoming redetermination
 - Extending child eligibility up to age 21

Challenge

Insufficient time to prepare and respond to Medicaid redetermination notices

To CMS: Require states to send a notice to CYSHCN aging out of child Medicaid eligibility a minimum of 60 days in advance of the end of the eligibility period

To state Medicaid agencies: Provide CYSHCN a minimum of 30 days to respond to requests for information

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

To CMS: Coordinate with SSA to review and update notice language to individuals who lose SSI about the effect on Medicaid eligibility

Navigating eligibility transitions

To state Medicaid agencies: Implement the state option to extend child eligibility up to age 21 for CYSHCN who are not otherwise eligible for a mandatory coverage or optional Medicaid coverage

To Congress: Require states to provide CYSHCN with a continuous eligibility (CE) period that lasts 12 months from the date of the eligibility determination. The full 12-month CE period applies to beneficiaries who receive coverage from either a mandatory or optional state child eligibility pathway

Variation in the level of support received with Medicaid redetermination

To CMS: Issue guidance on existing authorities for supporting transitions to adult Medicaid coverage, including the state option to extend child eligibility up to age 21

Recommendations

Notes: CYSHCN is children and youth with special health care needs. CMS is Centers for Medicare & Medicaid Services. SSI is supplemental security income. SSA is Social Security Administration.

Recommendations

Rationale and Implications

Draft 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 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

Implications

- **Federal spending:** The Congressional Budget Office (CBO) does not estimate a direct effect on federal spending
- **States:** May increase administrative burden if states are not already sending this type of notice, and there may be administrative burden with identifying CYSHCN and target notices to this population
- **Enrollees:** Receive advance notice and more time to prepare for their upcoming redetermination
- **Plans:** May have fewer beneficiaries who are experiencing disruptions in coverage
- **Providers:** Transition coordinators may have more advance notice of upcoming redeterminations. Providers may be able to provide care to their beneficiaries with fewer disruptions

Draft 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 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

- 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
 - This is often just one of many transitions that the family is navigating as the CYSHCN ages into adulthood, so families can feel overwhelmed during this transition period

Implications

- **Federal spending:** CBO does not estimate a direct effect on federal spending
- **States:** Some administrative burden to revise notice procedures and language to accommodate the 30-day response period
- **Enrollees:** More time to submit required information
- **Plans:** May have fewer beneficiaries who are experiencing disruptions in coverage
- **Providers:** May have more time to send beneficiaries requested medical records

Draft 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 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))

Implications

- **Federal spending:** Awaiting estimate from CBO
- **States:** May need to provide input on the notice language to ensure the language is accurate and clarifies the effect of a loss of SSI on Medicaid coverage
- **Enrollees:** Greater clarity about the effect of losing SSI eligibility on Medicaid eligibility
- **Plans:** May have fewer enrollees who are experiencing coverage disruptions
- **Providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft 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

- 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

Implications

- **Federal spending:** Awaiting estimate from CBO
- **States:** Effect on state budget is dependent on how broadly or narrowly a state defines optional pathway eligibility criteria
- **Enrollees:** An additional pathway to remain Medicaid covered may reduce disenrollment among CYSHCN during transition to adulthood
- **Plans:** May have fewer enrollees who are experiencing coverage disruptions
- **Providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft Recommendation 5.5

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

Implications

- **Federal spending:** Awaiting estimate from CBO
- **States:** Extends the number of months that states cover CYSHCN under a child mandatory or optional state pathway
- **Enrollees:** Decrease in administrative burden in the final 12 months prior to aging out of child Medicaid
- **Plans:** May have fewer enrollees who are experiencing coverage disruptions
- **Providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft 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

- 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

Implications

- **Federal spending:** CBO does not estimate a direct effect on federal spending
 - CMS would have to commit time and resources to issuing guidance
- **States:** Improved understanding of authorities to support CYSHCN with Medicaid redetermination and transition to adult Medicaid
- **Enrollees:** Increased access to support with Medicaid redeterminations
- **Plans:** May be administrative effort to develop payment policy and guidance for providers supporting beneficiaries with Medicaid redeterminations
- **Providers:** May engage in supporting CYSHCN with the transition to adult Medicaid coverage

Next Steps

- Publish chapter in the June 2026 Report to Congress
- Commissioner questions:
 - Any additional questions about the recommendation language and implications?
 - Do Commissioners have feedback on tone and clarity in the draft chapter?

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