

March 5, 2026

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

Draft recommendations

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Medicaid and CHIP Payment and Access Commission

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Overview

- Summary of challenges
- Draft recommendations
- Next steps



Key Challenges

- Insufficient time to prepare and respond to Medicaid redetermination notices
 - Without advance notice of the redetermination, CYSHCN and families may lack sufficient time to provide needed documentation
- Lack of clarity about the effect of a loss of Supplemental Security Income (SSI) on Medicaid eligibility in notices from the Social Security Administration (SSA)
- Navigating eligibility transitions
 - Many beneficiaries churn or disenroll when they age out of child Medicaid
 - Beneficiaries and their families can feel overwhelmed with completing the Medicaid redetermination, especially if they are navigating other benefit program transitions
- Variation in support with Medicaid redeterminations
 - Beneficiaries do not always have a dedicated case manager or care coordinator to support them with their Medicaid redetermination

Draft Recommendations

Challenge

Recommendations

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

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.

Draft Recommendation 1

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

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
- CMS should amend 42 CFR 435.919(b)(6) to require states to send a notice informing CYSHCN that the renewal process has been initiated a minimum of 60 days in advance of the end of the eligibility period

Implications

- **Federal:** CMS would have to commit time and resources to issuing guidance
- **States:** May increase administrative burden if states are not already sending this type of notice, and may be administrative burden to identify 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 and care
- **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 2

State Medicaid agencies should provide children and youth with special health care needs (CYSHCN) with a minimum of 30 days to respond to requests for information to complete Medicaid redeterminations in accordance with 42 CFR 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 attain 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 aging out of child Medicaid.

Rationale

- Many beneficiaries experience challenges with responding to notices within the timeframe
 - Beneficiaries may receive the notice too late to respond within the required timeframe, after the deadline, or do not receive the notice at all
- State Medicaid agencies that do not already provide beneficiaries with a minimum of 30 days to respond to requests for information should implement this minimum response time

Implications

- **Federal:** No anticipated effect
- **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 and care
- **Providers:** May have more time to send beneficiaries requested medical records

Draft Recommendation 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 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 the 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
- Under this recommendation, CMS would coordinate with SSA on developing and reviewing model notice language about how a loss of SSI affects Medicaid eligibility, which 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:** CMS would have to commit time and resources to reviewing and updating SSA notice language
- **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 and providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft Recommendation 4

State Medicaid agencies should implement the state option in 42 CFR 435.222 and 42 CFR 435.223 to provide Medicaid up to age 21 for children and youth with special health care needs (CYSHCN) who are not otherwise eligible for and enrolled in a mandatory coverage or optional full Medicaid coverage under the state plan. CYSHCN includes, 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

- CYSHCN aging out of child Medicaid can experience a loss of or gap in coverage, leading to unmet health care needs and delays in care
- States should implement the state optional pathway to extend child Medicaid eligibility up to age 21 for individuals who are not eligible for another mandatory or optional pathway and would disenroll at age 19
 - Provides CYSHCN and families with more time to complete multiple program transitions and improves coverage stability
 - Aligns child eligibility with the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement

Implications

- **Federal:** CMS would have to commit time and resources to reviewing state plan amendments
- **States:** The 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 and providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft Recommendation 5

To ensure that children and youth with special health care needs (CYSHCN) receive a full 12-month continuous eligibility period (CE) in their final year of child Medicaid eligibility, Congress should amend section 1902(e)(12) to require states to provide CYSHCN with a continuous eligibility 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. CYSHCN includes, 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 are required to provide 12-months CE for children under age 19, but this requirement ends when the beneficiary turns 19
 - Research shows that disenrollment from Medicaid peaks at age 19, when youth transition out of child Medicaid eligibility
- Under this recommendation, Congress would amend the 12-month CE requirement in two ways:
 - The end of the 12-month CE requirement should be tied to the end of the eligibility pathway's upper age limit rather than to the maximum age limit to ensure beneficiaries who are covered under a state child optional pathway that provides coverage up to age 20 or 21 receive 12-month CE up to the extended age
 - Beneficiaries should be continuously eligible for the full 12-month period even if it extends beyond the CYSHCN eligibility pathway's upper age limit to ensure beneficiaries receive a complete 12-month CE period after their final redetermination as a child

Implications

- **Federal:** Providing 12-months CE through the end of the child's eligibility pathway's upper age limit would increase the number of months of continuous coverage. Additionally, CMS would have to commit time and resources to issuing rules
- **States:** Extends the number of months that states cover these children 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 and providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Draft Recommendation 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, transitions 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 attain 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 aging out of child Medicaid.

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 (e.g., targeted case management, case management through a Section 1915(c) HCBS waiver, etc.) states can use to provide CYSHCN with a dedicated case manager or care coordinator to ease the Medicaid redetermination
 - Child-only 1915(c) HCBS waiver transition planning procedures that are specifically related to Medicaid redeterminations
 - State implementation of the state optional pathway to extend eligibility up to age 21 (42 CFR 435.222 or 42 CFR 435.223)

Implications

- **Federal:** 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 need to develop payment policy and guidance for providers to support implementation of provider payment changes
- **Providers:** May engage in supporting CYSHCN with the transition to adult Medicaid coverage

Next Steps

- Staff welcome feedback on the draft policy recommendations, rationale, and implications
- Staff will return in April with the draft chapter and a vote on the recommendations
- Discussion questions
 - Do the draft recommendations address the identified challenges and Commissioner feedback?
 - Does the presented evidence support the draft recommendations?
 - Are there other factors for staff to consider while developing the chapter and recommendation rationale?

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