

May 7, 2026

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

Recommendations and updated implications

Linn Jennings and Ava Williams



Medicaid and CHIP Payment and Access Commission

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Overview

- Summary of recommendations
- Updated recommendation implications
- Next steps



Recommendations

| Recommendation | CBO federal spending estimate |
|--|--|
| Recommendation 1: Directs CMS to 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. | No effect on federal direct spending |
| Recommendation 2: Directs state Medicaid agencies to provide CYSHCN a minimum of 30 days to respond to requests for information. | No effect on federal direct spending |
| Recommendation 3: Directs CMS to coordinate with SSA to review and update notice language to individuals who lose SSI about the effect on Medicaid eligibility. | No effect on federal direct spending |
| Recommendation 4: Directs state Medicaid agencies to 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. | No effect on federal direct spending |
| Recommendation 5: Directs Congress to require states to provide CYSHCN with a continuous eligibility (CE) period that lasts for a full 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 option state child eligibility pathway. | Would increase federal direct spending between \$250 million and \$2 billion |
| Recommendation 6: Directs CMS to issue guidance on existing authorities for supporting transitions to adult Medicaid coverage, including the state option to extend child eligibility up to age 21. | No effect on federal direct spending |

Notes: CBO is Congressional Budget Office. 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 3-5

Updated Implications

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.

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 review and update the SSA notice language and ensure ongoing coordination with SSA
- **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:** May allow for 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.

Implications

- **Federal spending:** 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:** May affect state budget, which is dependent on how broadly or narrowly a state defines optional pathway eligibility criteria
- **Enrollees:** 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 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.

Implications

- **Federal spending:** CBO estimates this recommendation would increase federal direct spending between \$250 million and \$2 billion
- **States:** Extends the number of months that states cover CYSHCN under a child mandatory or optional state pathway
- **Enrollees:** May decrease in administrative burden in the final 12 months prior to aging out of child Medicaid
- **Plans:** May have fewer enrollees who experience coverage disruptions
- **Providers:** May be able to provide improved care to their beneficiaries due to fewer coverage disruptions

Next Steps

- Commissioner vote on all six recommendations
- Publish chapter in the June 2026 report to Congress

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Vote on Recommendations for June Report to Congress

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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.

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.

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.

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.

Draft 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.

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.