

January 29, 2026

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

*Policy options*

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Ava Williams and Linn Jennings



Medicaid and CHIP Payment and Access Commission

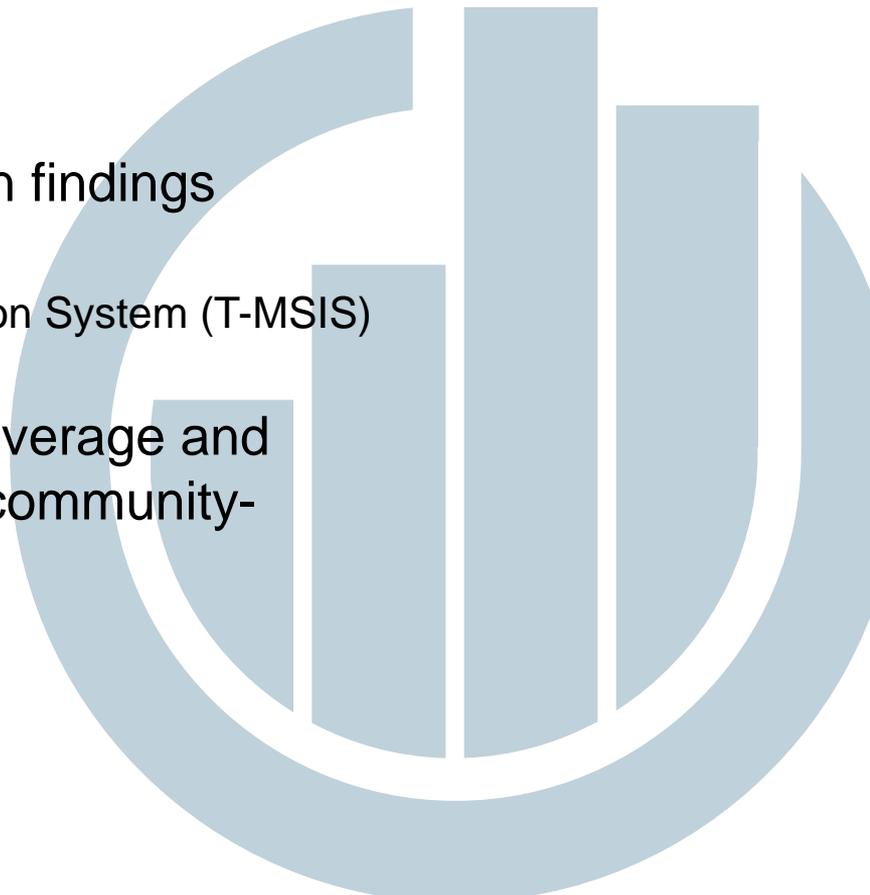
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# Overview

- Summary of state flexibilities based on findings
  - Stakeholder interviews
  - Transformed Medicaid Statistical Information System (T-MSIS) analysis
- Challenges with transitions to adult coverage and between Section 1915(c) home- and community-based services (HCBS) waivers
- Policy options
- Next steps



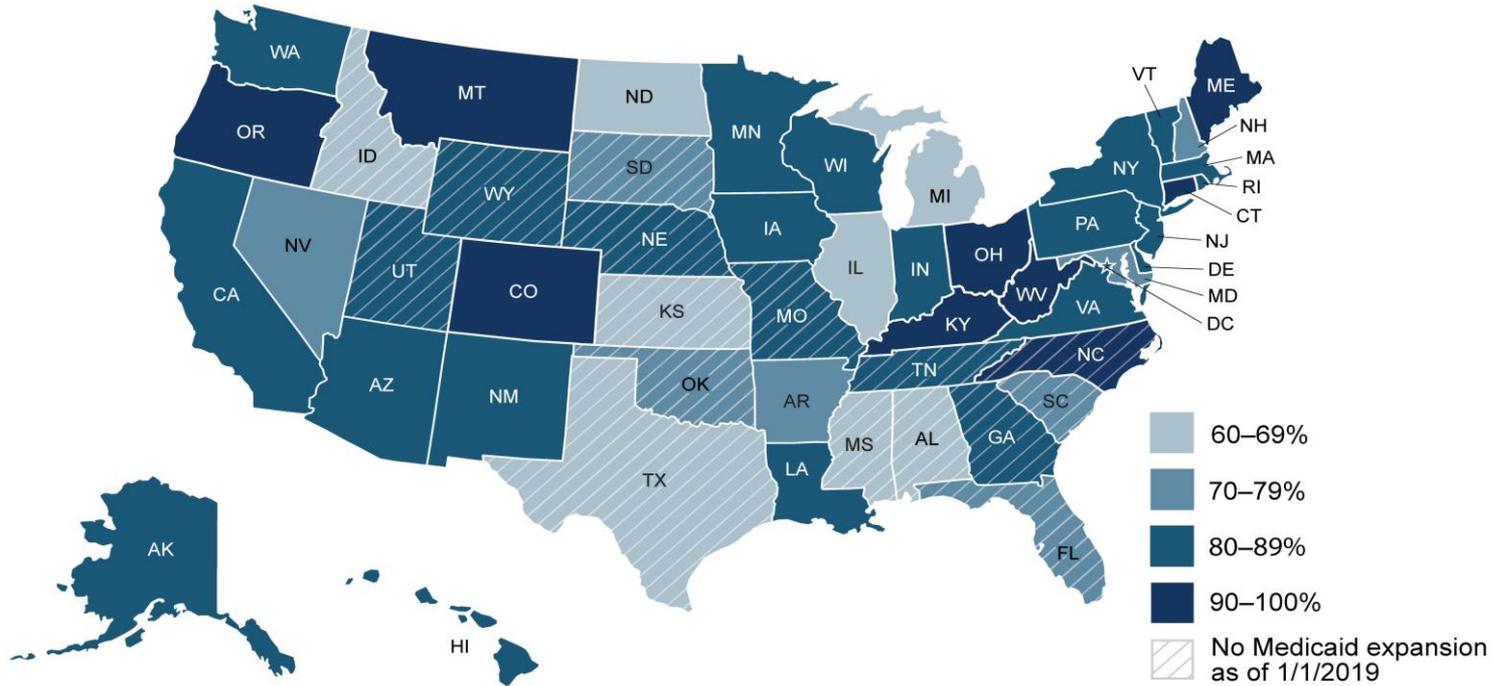
# State Flexibilities Can Affect Transitions to Adult Coverage

- State eligibility and redetermination policies and processes
  - Type of Supplemental Security Information (SSI) determination [state](#) affects how the state uses the SSI disability determination for Medicaid eligibility
  - How far in advance states can send notices about upcoming redeterminations
  - Extend childhood eligibility to age 21 (42 CFR 435.223)
  - Adopt optional eligibility pathways (e.g., expansion)

## T-MSIS Findings on Transitions to Adult Medicaid

- The majority of CYSHCN (82.4 percent) enrolled in disability-related pathways remained enrolled in Medicaid as adults
  - Varied by the disability-related eligibility pathway enrolled in as a child, beneficiary race and ethnicity, and the beneficiary's enrollment state
- More CYSHCN in expansion states remained continuously enrolled compared to those in non-expansion states
  - Of those enrolled in expansion states, 13 percent were continuously enrolled and 48 percent of those who churned enrolled in the expansion pathway

# CYSHCN Continuously Enrolled when Transitioning to Adult Medicaid Coverage



**Notes:** 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, Maine, Massachusetts, and Florida. These states have extended child Medicaid eligibility to age 21.

# State Flexibilities that Can Affect Transitions Between 1915(c) HCBS Waivers

- State waiver design and operationalization can affect transitions from child to adult waivers
  - Must specify state-designed transition planning for age-limited waivers (e.g., coverage of case management)
  - Reserve capacity can be used to ensure beneficiaries aging out of a child waiver can enroll in an adult waiver
  - Can design their minimum and maximum waiver age limits to overlap

# **CYSHCN Challenges with Transition to Adult Medicaid Coverage**

## Insufficient Time to Prepare and Respond to Medicaid Redetermination Notices

- States must first attempt redeterminations on an ex parte basis, and not contact beneficiaries unless more information is needed
  - 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
  - Notices often lack clear and actionable steps in plain language

## Lack of Clarity in Notices from the Social Security Administration (SSA)

- SSA sends a notice of termination to individuals who are no longer eligible for SSI and, in states where SSI eligibility confers Medicaid eligibility, it includes information about the effect on Medicaid eligibility
  - There are no federal requirements for SSA and state Medicaid agencies to coordinate on SSA notice language and the information related to Medicaid eligibility
- Beneficiaries and families experience challenges with understanding notice information about how losing SSI affects Medicaid eligibility
  - SSA notices often lack clear and actionable steps for retaining Medicaid coverage
  - State Medicaid agencies are not required to inform the beneficiary of changes in SSI eligibility unless the state needs additional information to complete the redetermination

# Insufficient Support 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
  - CYSHCN and their families do not always have a dedicated case manager or care coordinator to support them with their Medicaid redetermination

# Navigating Eligibility Transitions

- States must provide 12 months continuous eligibility for all children under age 19
- State flexibilities that can ease Medicaid redeterminations include:
  - Use of SSI eligibility to determine Medicaid eligibility (e.g. 1634, SSI criteria, and 209(b) states)
  - Extend 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
  - Beneficiaries and their families can feel overwhelmed with completing the Medicaid redetermination, especially if they are navigating other benefit program transitions

## Optional Medicaid Eligibility Pathways for Adults who are Not Eligible on the Basis of Disability

- States may cover optional adult Medicaid eligibility pathways, and adoption of these pathways can affect coverage transitions
  - Medicaid beneficiaries can also enroll in waiver programs, which sometimes confer Medicaid eligibility through state optional pathways
- Many Medicaid-covered adults with disabilities are not SSI-eligible and must enroll in non-SSI related pathways to remain Medicaid-covered
  - A larger percentage of transition-age children enrolled in disability pathways remained enrolled as adults in states that had adopted Medicaid expansion than those in states that had not adopted it



# Policy Options

## Challenge

## Policy options

**Insufficient time to prepare and respond to Medicaid redetermination notices**

**Policy option 1:** Recommendation to 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

**Policy option 2:** Recommendation to state Medicaid agencies to implement the minimum of 30 days to respond to requests for information for CYSHCN aging out of child Medicaid

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

**Policy option 3:** Recommendation to Congress to require state Medicaid agencies to coordinate with SSA to review and update notice language for individuals who lose SSI and are enrolled in SSI-related

**Insufficient support from state Medicaid programs with navigating multiple simultaneous transitions**

**Policy option 4:** Recommendation to CMS to issue guidance on existing authorities for supporting for transitions to adult Medicaid coverage

**Navigating eligibility transitions**

**Policy option 5:** Recommendation to state Medicaid agencies to implement the state option to extend child eligibility up to age 21 for CYSHCN

**Policy option 6:** Recommendation to CMS to issue guidance to states on extending child Medicaid eligibility up to age 21

**Policy option 7:** Recommendation to Congress to extend the 12-month continuous eligibility period for CYSHCN from age 19 to through age 19

**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.

# Advance Notice for Anticipated Change in Circumstance

- **Policy option 1:** The Centers for Medicare & Medicaid Services (CMS) should require states to send a notice a minimum of 60 days in advance of CYSHCN aging out of child Medicaid eligibility
  - States are not required to notify beneficiaries of an upcoming redetermination, but most states begin this process 60 to 90 days prior to the end of the eligibility period
  - CYSHCN who are SSI eligible, receive an SSA notice a year in advance of their age-18 SSI redetermination, and there is no analogous requirement for state Medicaid agencies in advance of CYSHCN aging out of child Medicaid

# Advance Notice for Anticipated Change in Circumstance, cont.

- **Policy option 2:** State Medicaid agencies should implement a minimum of 30 days to respond to requests for information to complete Medicaid redeterminations for CYSHCN aging out of child Medicaid eligibility groups
  - The 2024 CMS Eligibility and Enrollment (E&E) rule requires states provide beneficiaries with a minimum of 30 calendar days to respond to requests for information for changes in circumstances. However, the implementation of this requirement is paused by the 2025 Budget Reconciliation Act (P.L. 119-21) through fiscal year 2035

# Rationale

- Findings show that many CYSHCN who age out of child Medicaid experience a gap in coverage during this transition period
- Beneficiaries and families experience challenges with completing the Medicaid redetermination and other benefit program transitions simultaneously, and advocates shared that beneficiaries need:
  - Advance notice of the Medicaid redetermination at age 19 so they are aware of this process and can prepare
  - More time to provide additional information needed to complete the Medicaid redetermination as an adult

# Coordination between Medicaid and SSA on Notice Language

- **Policy option 3:** Congress should require state Medicaid agencies to coordinate with SSA on notice language
  - Require state Medicaid agencies to coordinate with SSA to review and update SSA's Program Operations Manual System template language for notices sent to individuals enrolled in SSI-related Medicaid who lose SSI when they are redetermined at age 18

# Rationale

- Beneficiaries aging out of child Medicaid who lose SSI do not receive SSA notices with easily understood or consistently accurate information about the steps needed to maintain Medicaid coverage
- State Medicaid agencies should coordinate with SSA to update the SSA notice language sent to beneficiaries who lose SSI to include clear and accurate information about:
  - Medicaid eligibility status during the Medicaid redetermination
  - What the beneficiary should expect during the Medicaid redetermination process, including how the state Medicaid agency may contact them to provide updated information to complete the Medicaid redetermination

# Guidance on Existing Authorities to Provide Coverage Transition Support

- **Policy option 4:** CMS should Issue guidance to states on existing Medicaid authorities for supporting transitions to adult Medicaid coverage
  - Using existing authorities to provide CYSHCN with a dedicated case manager or care coordinator to ease the Medicaid redetermination process and the beneficiary's transition to adult Medicaid
  - Including transition planning procedures in their 1915(c) HCBS waivers that are specifically related to supporting beneficiaries through the Medicaid redetermination process

# Rationale

- CYSHCN transitioning to adult Medicaid may need more support with navigating the Medicaid redetermination
  - Advocates shared that the level of support available varies across and within states based on the beneficiary's level of need and enrollment in managed care plans and other benefits programs
- Advocates shared that beneficiaries with dedicated case managers or care coordinators often receive more support than those without one
  - Beneficiaries enrolled in 1915(c) HCBS waivers often receive case management support with transition planning between waivers

# Extending Child Eligibility

- **Policy option 5:** State Medicaid agencies should implement the state option to extend child eligibility up to age 21 for CYSHCN
  - Recommend states implement the existing state plan option to extend child Medicaid eligibility up to age 21 for CYSHCN (42 CFR 435.223)
  - Four states have implemented this option, and CMS clarified that states can extend coverage for individuals under age 21 who meet the criteria for non-modified adjusted gross income (MAGI) eligibility groups
- **Policy option 6:** CMS should issue guidance to states on extending child Medicaid eligibility up to age 21 using the state option

## Extending Child Eligibility, cont.

- **Policy option 7:** Congress should extend the 12-month continuous eligibility (CE) period to through age 19 for CYSHCN
  - The 12 month CE period ends at age 19, so a beneficiary's final 12-month CE period may be less than 12 months depending on how many months occur between their annual redetermination and their 19<sup>th</sup> birthday
  - 12 month CE reduces churn and transition-age CYSHCN would remain Medicaid-enrolled as a child for a final full 12-month CE period through age 19

# Rationale

- Research shows that disenrollment from Medicaid is greatest for youth (ages 18–19) transitioning out of child Medicaid eligibility
  - Similar trends are found for Medicaid disenrollment and churn among young adults with disabilities
- Extending child Medicaid eligibility up to age 21 may ease the coverage transition for beneficiaries and their families and reduce the risk of a gap or loss of coverage
  - Interviewed advocates and some states raised the importance of extending eligibility up to age 21 to align with the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement

# Next Steps

- Commissioner feedback on the policy options and which to advance for the June Report to Congress
- Discussion questions
  - Are there outstanding questions about the policy options that staff can answer?
  - Do the policy options address the identified challenges and does the presented evidence support the policy options?
  - Are there other factors for staff to consider while developing recommendation language and the rationale?

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