September 18, 2025

CYSHCN Transitions to Adult Coverage

Federal and state policy scan findings

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Overview

- Project aims
- Background on children and youth with special health care needs (CYSHCN)
- Federal Medicaid and Supplemental Security Income (SSI) redetermination requirements
- Transition to adult Medicaid coverage and waiver enrollment processes
- Next steps



Project Aims

The project on CYSHCN transitions to adult Medicaid coverage examines:

- Federal Medicaid requirements for states renewing coverage for youth aging out of child eligibility and how these policies interact with the Social Security Administration's (SSA) age-18 redetermination for SSI and Medicaid waiver enrollment processes,
- Federal authorities states can use to improve continuity of coverage during these transitions
- Challenges beneficiaries experience with transitioning to adult Medicaid eligibility
- Barriers to transitioning to adult Medicaid eligibility that can be addressed in federal policy



Medicaid-Covered CYSHCN

- Almost half of CYSHCN are covered by Medicaid or a combination of Medicaid and private insurance
 - About 15 percent of CYSHCN are eligible for Medicaid on the basis of disability
- CYSHCN enroll in Medicaid through a variety of mandatory and optional eligibility pathways
 - Disability-related pathways include SSI-related pathways and state optional disability pathways, such as the state medically needy, the Family Opportunity Act, Section 1915(i) state plan home- and community-based services (HCBS) benefit, and the Katie Beckett pathway for children with disabilities



Disability-Related Pathways

- SSI-related pathways: Individuals eligible for and receiving SSI
 payments are often automatically covered by Medicaid, but this process
 varies by state
 - 1634 states (35 states): SSI eligibility confers Medicaid eligibility. Individuals are not required to submit a separate Medicaid application (42 CFR 435.541)
 - SSI criteria states (8 states): SSI eligibility does not automatically confer eligibility for Medicaid. Individuals must submit a separate Medicaid application (42 CFR 435.541)
 - 209(b) states (8 states): States may use Medicaid eligibility criteria that are more restrictive than SSI criteria. Individuals must separately apply to Medicaid (42 CFR 435.540)
- Other disability-related pathways: State can cover children with disabilities through the optional Tax Equity and Fiscal Responsibility Act state plan pathway, also referred to as the Katie Beckett state plan option, or under Section 1915(c) HCBS authority



1915(c) HCBS Waivers

- States have the option to use waiver authorities and state plan options to provide HCBS
- States can use Section 1915(c) waivers to limit eligibility to specific age groups and populations
 - 51 age-limited child-only 1915(c) HCBS waivers across 34 states
 - 28 states have an HCBS Katie Beckett-like waiver that covers children who qualify to receive an institutional level of care but whose family income exceeds income eligibility

Federal Medicaid and SSI Redetermination Requirements



Federal Medicaid Redetermination Requirements

- Most states conduct annual eligibility redeterminations, and states must begin the process in advance of the end of the eligibility period (42 CFR 435.916(a) and (c))
 - Federal requirements do not specify how far in advance to notify beneficiaries, but many states begin this process 60 days prior to the eligibility period ending
- States must first attempt to confirm ongoing eligibility on an ex parte basis
 - If additional information is needed, the state must notify the beneficiary and provide them with a renewal form
 - If a state identifies information that will lead to changes in eligibility, the agency must contact the beneficiary and offer them an opportunity to provide new information
 - Prior to termination, the state "must consider all bases for eligibility" (42 CFR 435.916(d)(1))
- For individuals eligible for Medicaid on the basis of disability, the redetermination process includes the state confirming the disability determination in accordance with 1634, SSI-criteria, or 209(b) rules (42 CFR 435.40)



Federal SSI Redetermination Requirements

- Individuals determined eligible for SSI as a child must be redetermined at age 18 to continue to receive SSI benefits as an adult
 - The Social Security Administration (SSA) is required to initiate the age-18 redetermination for SSI within a year after an individual turns 18 years
 - SSA notifies children with SSI before their age-18 redetermination and sends annual notices beginning at age 14 years
- The SSI criteria differ for children and adults, so not all children remain eligible as adults
 - In 2023, 48.0 percent of children who were redetermined at age 18 were determined eligible for SSI as adults. Of those who were not determined eligible, 42.2 percent appealed the decision.



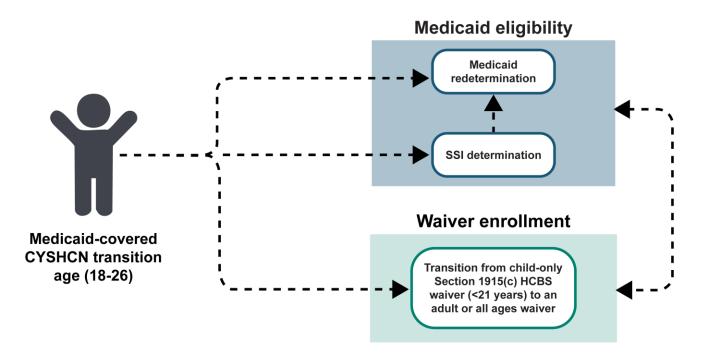
HCBS Waiver Transition Planning

- Beneficiaries enrolled in age-limited Section 1915(c) HCBS waiver should receive transition planning to support continuity of services
 - Transition planning may include identifying and informing individuals about public programs and waivers that they may qualify for and providing them with priority consideration for other state waivers
- Findings from our waiver review identified variation in:
 - How far in advance planning begins
 - Who is responsible for supporting beneficiaries and their families with the transition
 - What types of supports they provide
 - The use of reserve capacity for children aging out of waivers

Transitions to Adult Medicaid Coverage and Between Child-Only and Adult HCBS Waivers

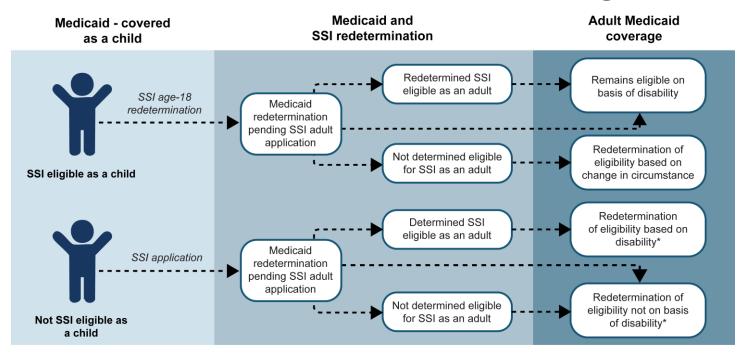


CYSHCN Medicaid Eligibility and Waiver Transitions





Transition Between Child and Adult Medicaid Coverage Process



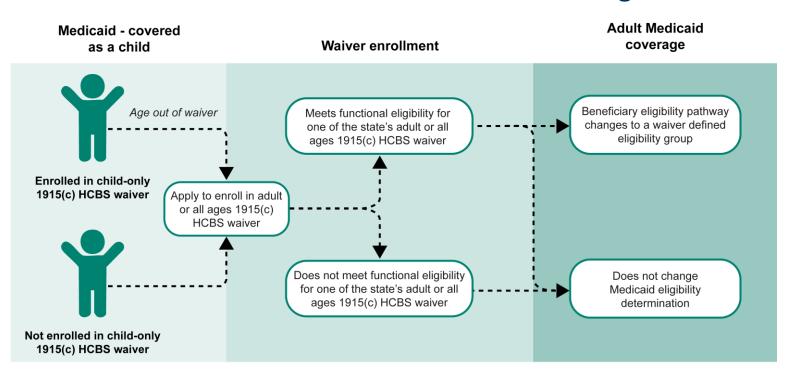
Notes. SSI is Supplemental Security Income.

Source. MACPAC analysis, 2025

^{*} Eligibility on basis of disability is defined as the same definition of disability as for SSI with the exception of 8 states that use a more restrictive definition to determine eligibility



Transition Between Child and Adult Medicaid Coverage Process





Next Steps

- Commissioner feedback on the federal and state policy findings and how these policies affect the CYSHCN transition to adult Medicaid coverage and between child-only and adult HCBS waivers
- Return in October to present findings from:
 - Quantitative analysis of these transitions using data from the Transformed Medicaid Statistical Information System (T-MSIS)
 - Stakeholder interviews

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