

December 11, 2025

CYSHCN Transitions to Adult Medicaid Coverage

Summary of the Transformed Medicaid Statistical Information System (T-MSIS) analysis and interview findings

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Medicaid and CHIP Payment and Access Commission

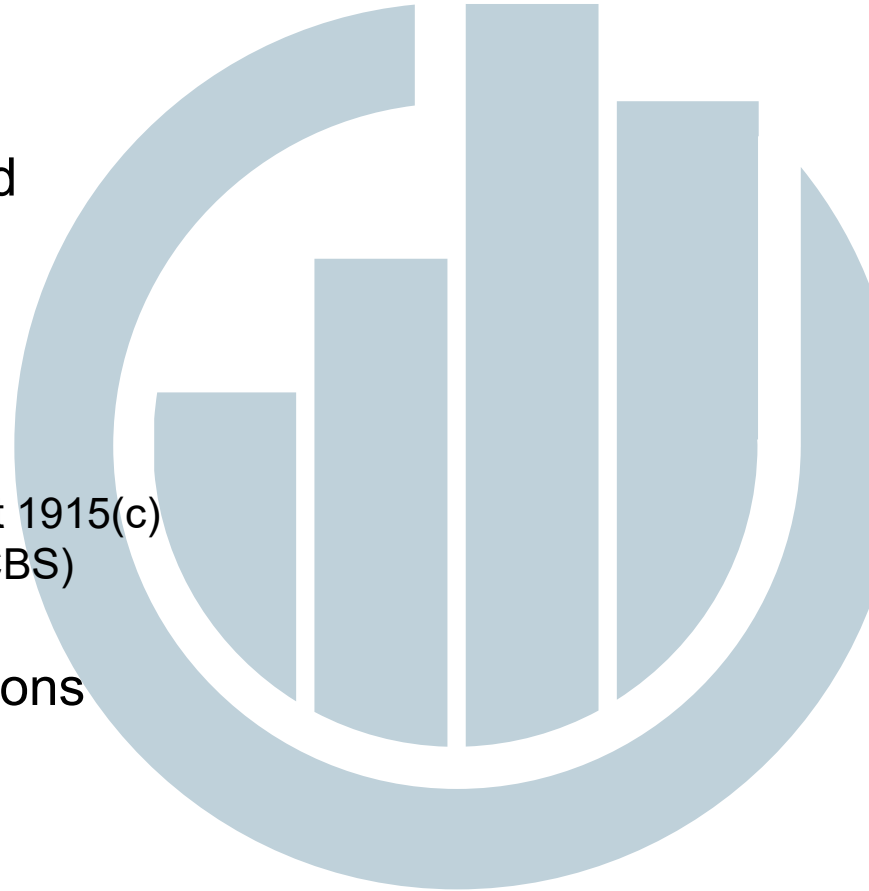
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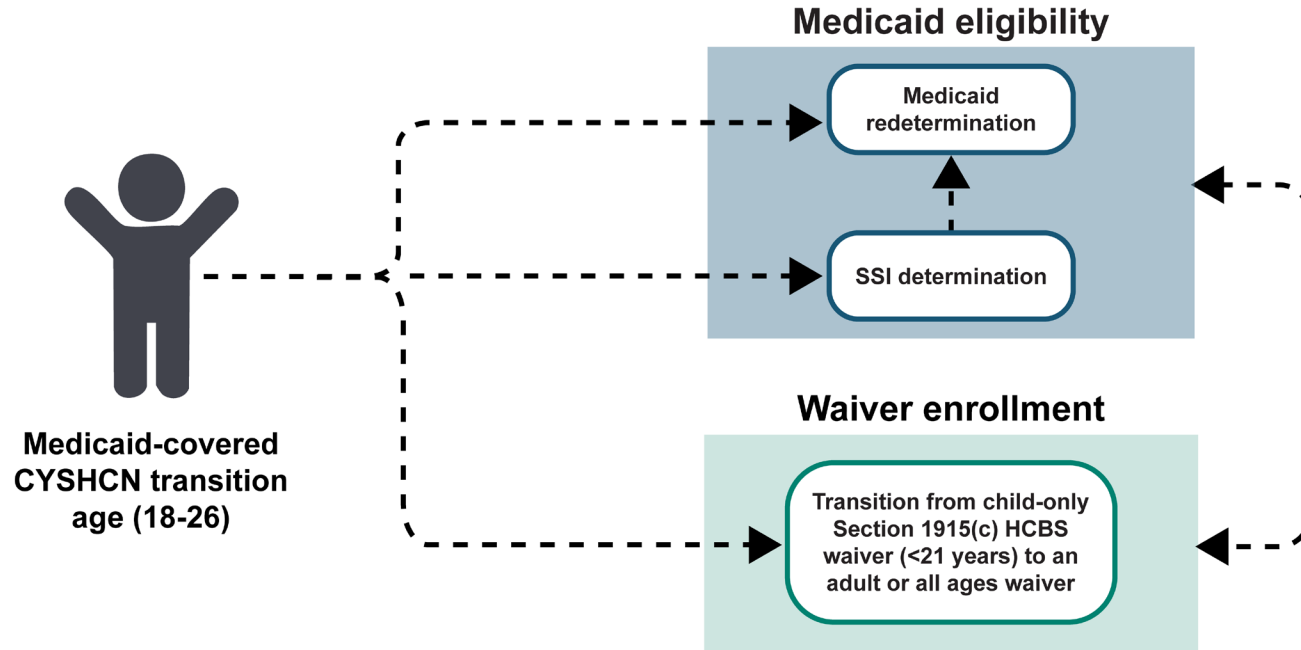
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Overview

- Background on Medicaid eligibility and waiver transitions
- T-MSIS analysis
- Stakeholder interview findings
 - Factors in the transitions to adult Medicaid coverage and between child-only and adult 1915(c) home- and community-based services (HCBS) waivers
- Key challenges and policy considerations
- Next steps



CYSHCN Medicaid Eligibility and Waiver Transitions



T-MSIS Analysis

Methods

- **Purpose:** There are few reported data on transition-age children and youth with special health care needs (CYSHCN) or their coverage transition outcomes. To address this gap, we examined Medicaid-covered CYSHCN and their transitions to adult Medicaid coverage using 2017–2019 enrollment data from T-MSIS
- **Population of focus:** Transition-age CYSHCN (within 12 months of aging out of child Medicaid) enrolled in disability-related eligibility pathways
 - Supplemental Security Income (SSI)-related: Current SSI recipients
 - Other SSI-related: Beneficiaries who would be eligible for SSI, but not receiving
 - Other disability-related: Other non-Modified Adjust Gross Income (MAGI) groups
- **Transition outcomes**
 - Continuous enrollment: Enrolled for 12 months after aging out of child Medicaid eligibility
 - Churn: Disenrolled in the year prior to aging out and re-enrolled in Medicaid within 12 months
 - Disenrollment: Disenrolled during the year prior to aging out and do not re-enroll

Transitions to Adult Medicaid Coverage Among Transition-Age CYSHCN by Eligibility Group

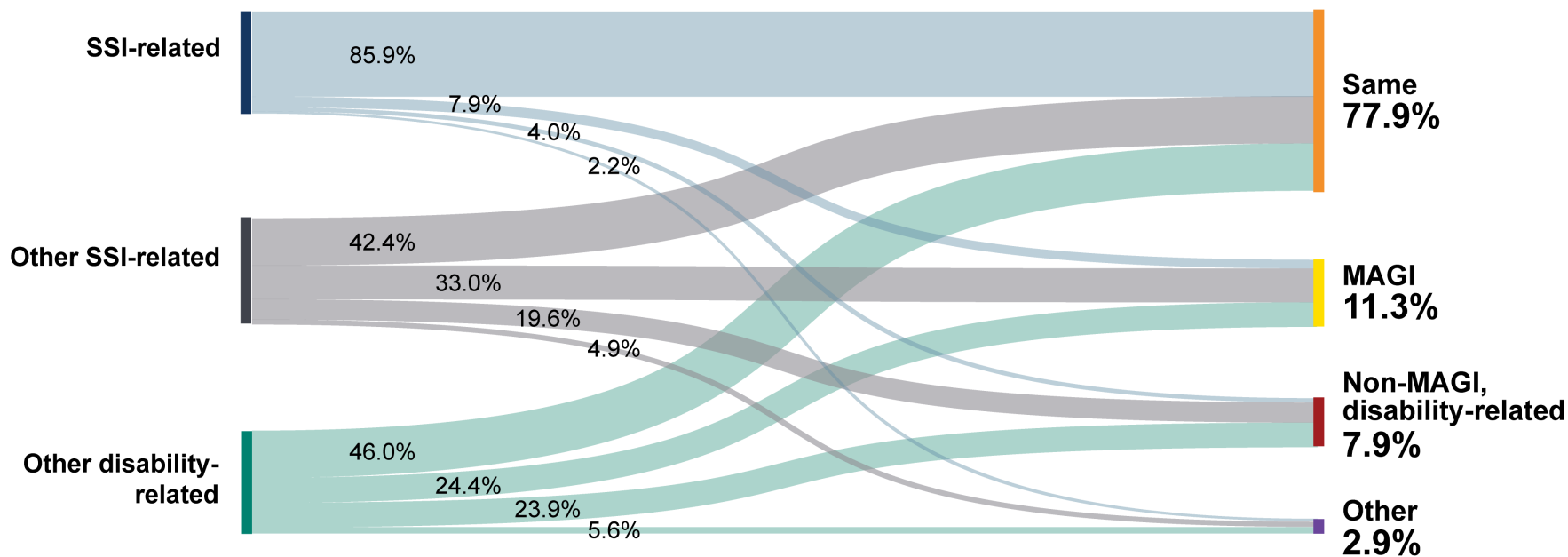
Eligibility pathways	Number of transition-age CYSHCN	Share who remained continuously enrolled	Share who disenrolled	Share who disenrolled and churned within 12 months
All disability-related	83,904	82.4%	17.6%	33.9%
SSI-related eligibility	65,062	85.1	14.9	34.2
Other SSI-related	1,049	84.9	15.1	51.9
Other disability-related	17,793	72.4	27.6	32.7

Source. SSI is Supplemental Security Income. CYSHCN is children with special health care needs. Churn refers to individuals who disenrolled and re-enrolled within 12 months MACPAC analysis of T-MSIS, 2017–2019.

Transition-Age CYSHCN who Remained Continuously Enrolled

Child eligibility pathway

Adult eligibility pathway



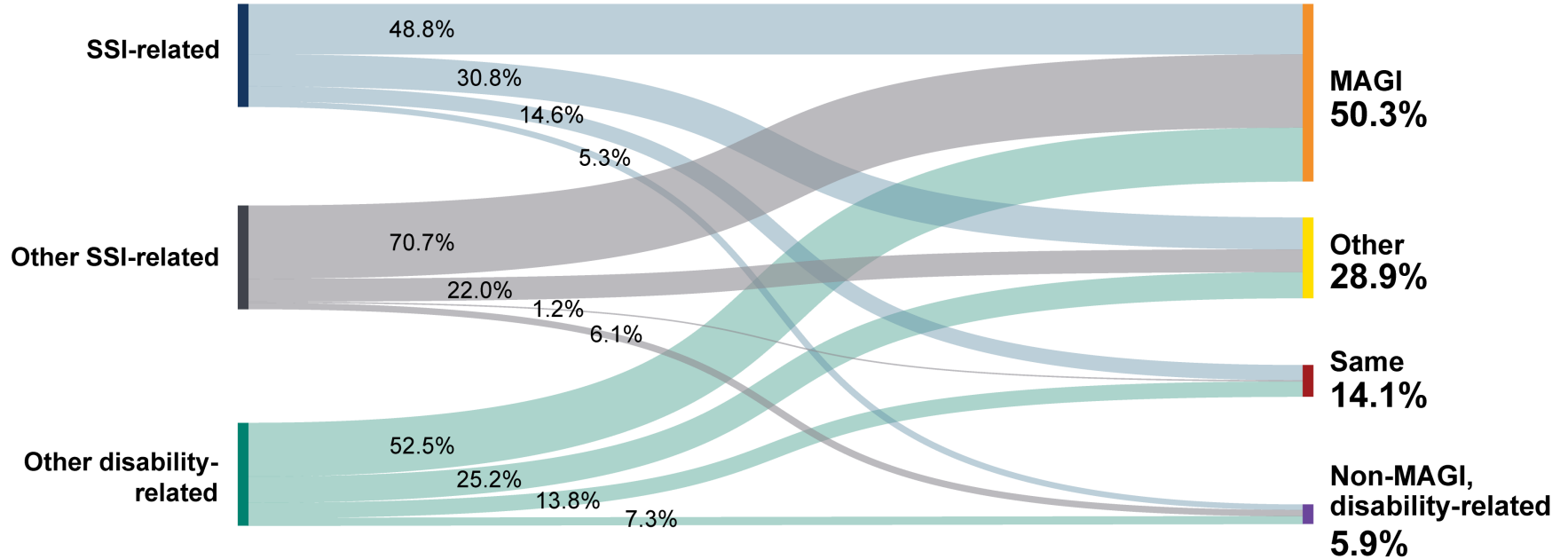
Notes. SSI is Supplemental Security Income. MAGI is Modified Adjusted Gross Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. The child eligibility pathways show percentages of children and youth with special health care needs (CYSHCN) who transitioned to an adult eligibility group. The adult eligibility pathway percentages represent the percent of all transition-age children who transitioned to each adult eligibility pathway group.

Source. MACPAC analysis of T-MSIS, 2017–2019.

Transition-Age CYSHCN who Churned

Child eligibility pathway

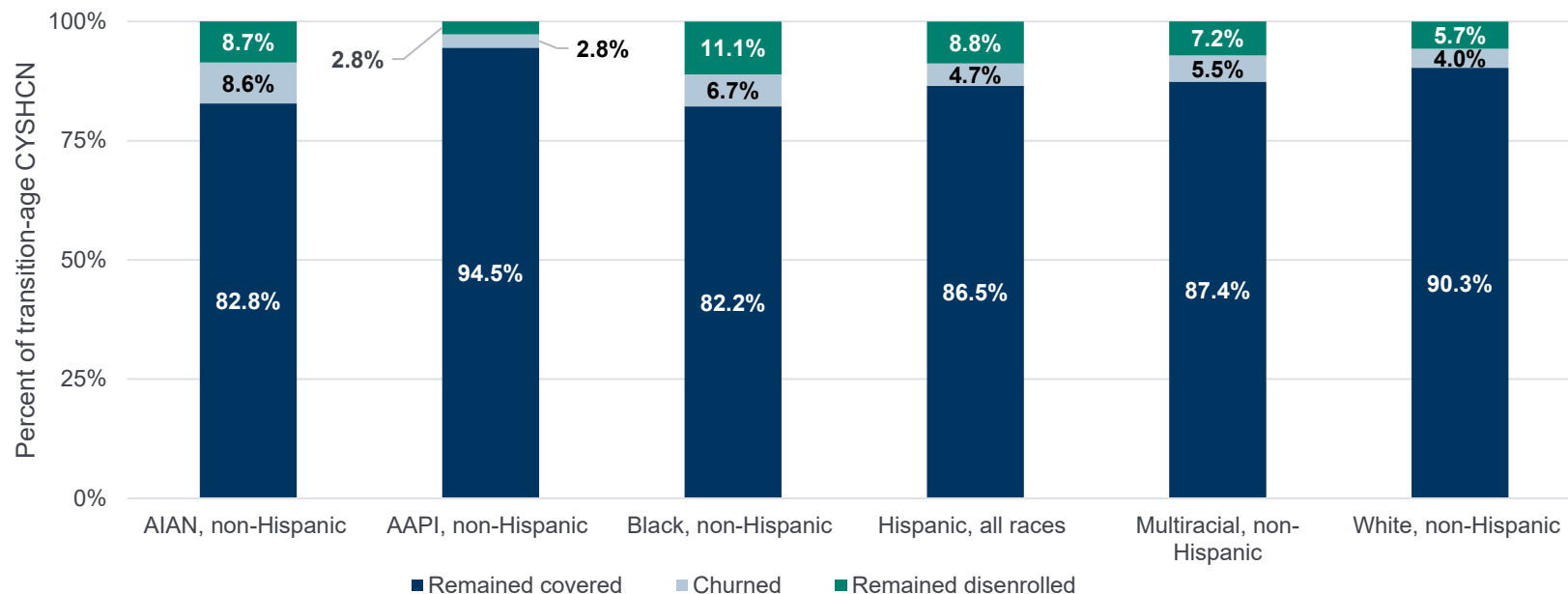
Adult eligibility pathway



Notes. SSI is Supplemental Security Income. MAGI is Modified Adjusted Gross Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. The child eligibility pathways show percentages of children and youth with special health care needs (CYSHCN) who disenrolled and then re-enrolled in Medicaid by adult eligibility group. The adult eligibility pathway percentages represent the percent of all transition-age children who transitioned to each adult eligibility pathway group.

Source. MACPAC analysis of T-MSIS, 2017–2019.

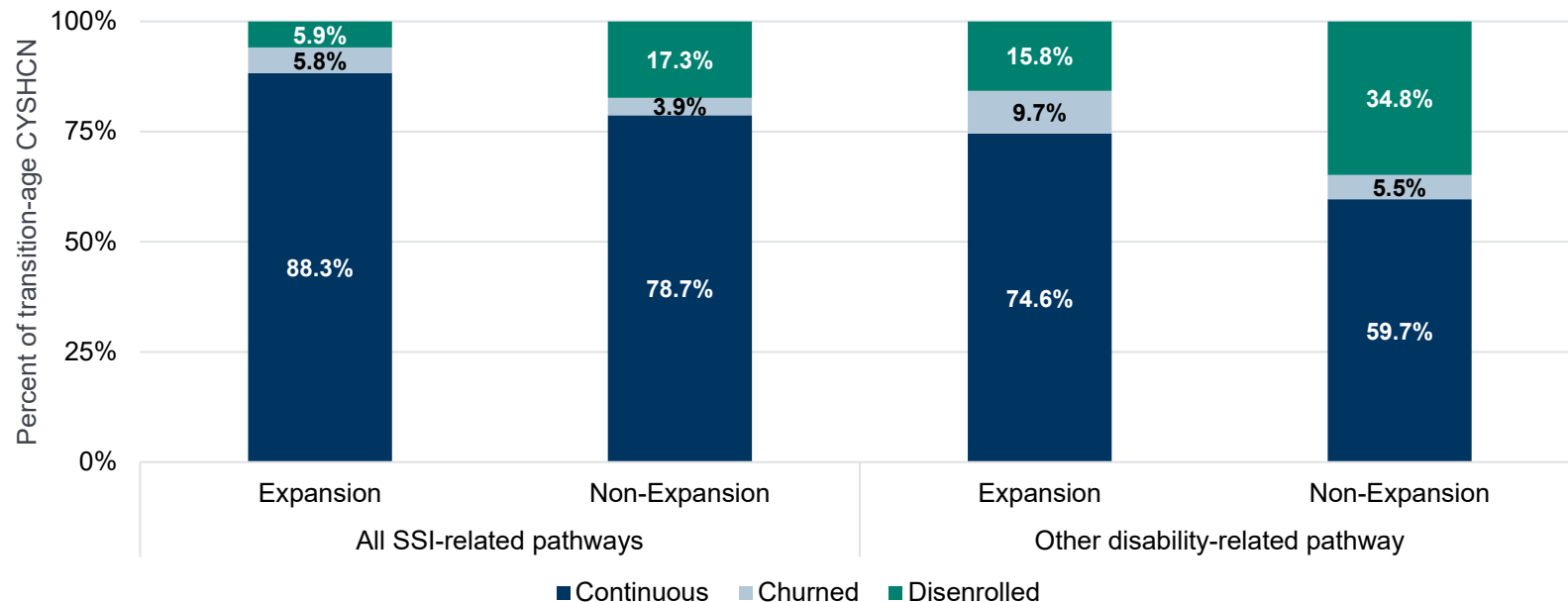
Coverage Transitions for those Enrolled in SSI-Related Pathways by Race and Ethnicity



Notes. SSI is Supplemental Security Income. CYSHCN is children and youth with special health care needs. Churn refers to individuals who disenrolled and re-enrolled within 12 months. AIAN is American Indian and Alaska Native. AAPI is Asian American and Pacific Islander. Race and ethnicity estimates are calculated using the Transformed Medicaid Statistical Information System (T-MSIS) Analytical Files race/ethnicity imputed compiled files.

Source. MACPAC analysis of T-MSIS, 2017–2019.

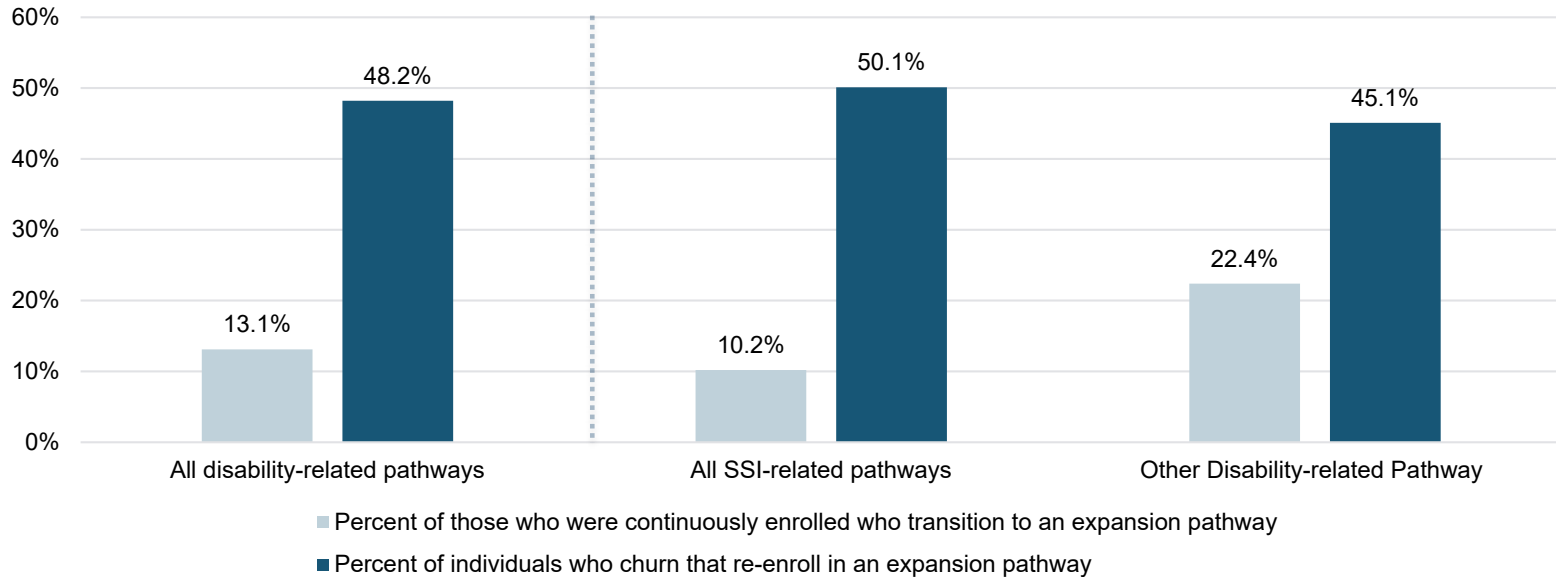
Coverage Outcomes for Transition-Age CYSHCN by Eligibility Pathway and State Adoption of Medicaid Expansion



Notes. SSI is Supplemental Security Income. CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. As of January 2019, 35 states and the District of Columbia had adopted Medicaid expansion and extended Medicaid eligibility to all adults under age 65 (including parents and adults without dependent children) with incomes below 133 percent of the federal poverty level (FPL). Non-expansion refers to states that have not adopted Medicaid expansion as of January 1, 2019.

Source. MACPAC analysis of T-MSIS, 2017–2019.

Transition-Age CYSHCN who Transition to an Expansion Eligibility Pathway as an Adult



Notes. CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. Churn refers to individuals who disenrolled and re-enrolled within 12 months. As of January 2019, 35 states and the District of Columbia had adopted Medicaid expansion and extended Medicaid eligibility to all adults under age 65 (including parents and adults without dependent children) with incomes below 133 percent of the federal poverty level (FPL).

Source. MACPAC analysis of T-MSIS, 2017–2019.

Key Takeaways

- The majority of CYSHCN remained continuously enrolled in Medicaid when transitioning to adult Medicaid (82.4 percent)
 - However, the percent who remained continuously enrolled varied by the disability-related eligibility pathway enrolled in as a child, beneficiary race and ethnicity, the beneficiary's enrollment state, and state adoption of Medicaid expansion
- The adult eligibility pathways that CYSHCN transitioned to differed between those who remained continuously enrolled and those who churned
 - Over 75 percent of CYSHCN continuously enrolled stayed in the same pathway as an adult, whereas about 50 percent of those who churned, enrolled in an adult MAGI pathway
 - Of those enrolled in expansion states, 13 percent of those who were continuously enrolled and 48 percent of those who churned enrolled in the expansion pathway

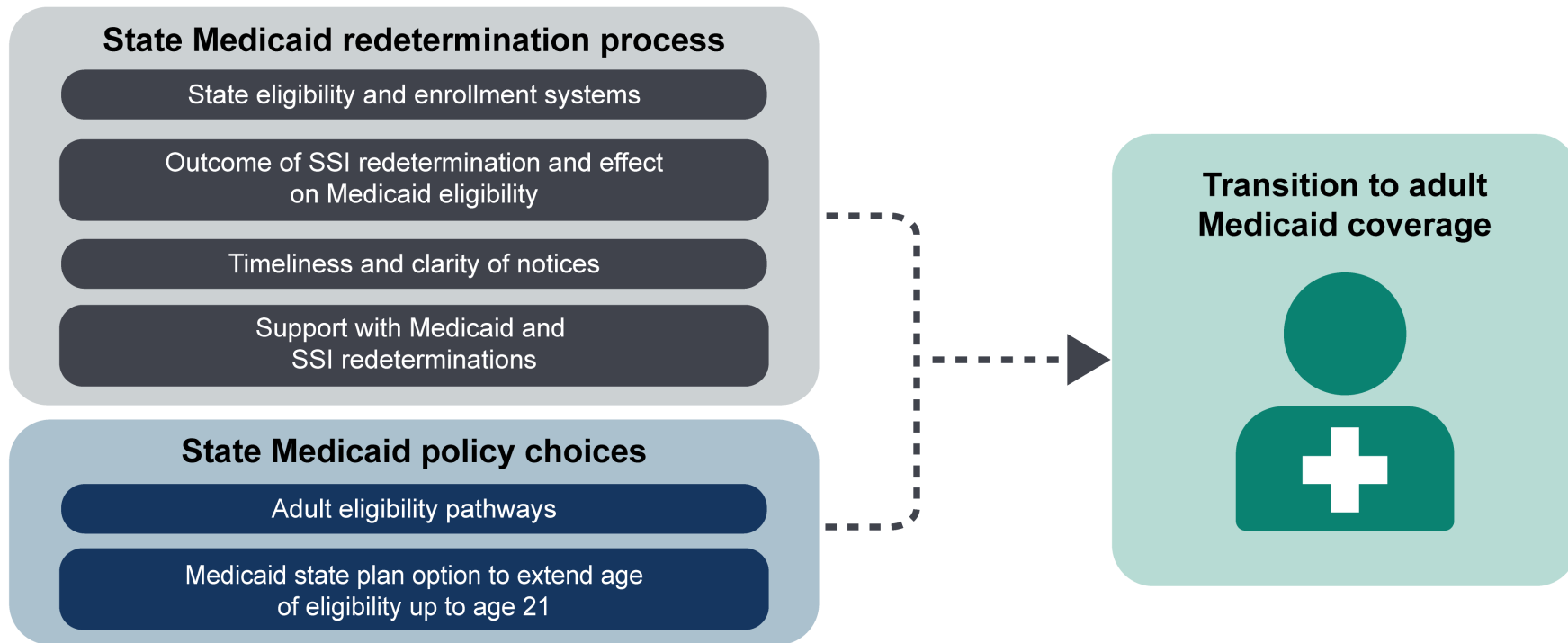
Commissioner Discussion

- Technical questions on the analysis
- Comments and questions about the T-MSIS findings



Stakeholder Interview Findings

Factors that Affect the Medicaid Coverage Transition



Factors that Affect the Medicaid Coverage Transition, cont.

State eligibility and enrollment systems

- Ex parte redeterminations for beneficiaries with disabilities and those who are changing between eligibility groups can be challenging:
 - Separate eligibility systems for MAGI and non-MAGI beneficiaries
 - Non-MAGI systems may be outdated and unable to conduct ex parte redeterminations

Outcome of SSI redeterminations and effect on Medicaid eligibility

- If a beneficiary remains eligible for SSI as an adult, they often do not experience any changes to their adult Medicaid eligibility pathway
- If a beneficiary is not eligible for SSI as an adult, they will need to be redetermined on all other bases before their Medicaid is terminated (42 CFR 435.916(d)(1))
 - The Medicaid redetermination process varies based on the type of redetermination state (e.g., 1634, SSI criteria, 209(b))

Factors that Affect the Medicaid Coverage Transition, cont.

Timelines and clarity of notices

- There are no federal requirements for how far in advance a redetermination notice requesting additional information should be sent
 - Sometimes beneficiaries receive these notices too late to respond within the required timeframe or do not receive the notice at all
- Redetermination notices and notices related to SSI often lack clear actionable steps

Support with Medicaid and SSI redeterminations

- The amount of support beneficiaries receive during the Medicaid or SSI redetermination process can vary depending on which entity is providing the support
 - For example, beneficiaries enrolled in HCBS waivers often receive transition support from case managers, while beneficiaries not enrolled in a waiver may not receive any support with the Medicaid or SSI redetermination

Factors that Affect the Medicaid Coverage Transition, cont.

Adult eligibility pathways

- Beneficiaries who remain enrolled in SSI as an adult most often remain Medicaid eligible through an SSI-related pathway
- Those who are ineligible for SSI need to enroll in a different eligibility pathway to maintain coverage, and many qualify for the optional adult expansion pathway

Extended age eligibility for child coverage

- Five states have extended child eligibility for all or a subset of children through a state plan option (42 CFR 435.223) or a 1115 demonstration waiver
- Extended child eligibility can ease the transition process for beneficiaries as they navigate other benefit program transitions

Factors that affect 1915(c) HCBS Waiver Transitions

State Medicaid waiver process

Transition planning for age-limited waivers

Functional and LOC assessments required for beneficiary to enroll in waiver

State Medicaid waiver policy choices

Available child-only and adult 1915(c) HCBS waiver programs

Reserve capacity

Waitlists

Transition between 1915(c) HCBS waivers



Factors that affect 1915(c) HCBS Waiver Transitions, cont.

Transition planning

- States are required to specify transition planning for age-limited 1915(c) waivers, but the robustness of transition planning varies across waivers
- Transition planning may be insufficient to facilitate smooth transitions between waivers

Functional and level of care (LOC) assessments

- Beneficiaries can experience challenges with these assessments because they may not receive proper notice, be aware of how long these assessments take, or understand that they are required to enroll in a new waiver
- Advocates have noted that annual LOC assessments can be burdensome for individuals with certain conditions because there are few changes to their disabilities each year

Factors that affect 1915(c) HCBS Waiver Transitions, cont.

Available child-only and adult 1915(c) HCBS waiver programs

- States have the flexibility to design their HCBS waiver programs in order to support transitions
 - For example, one state allows beneficiaries enrolled in a child-only waiver to transition waiver enrollment at age 18 or 21, because the child only waiver upper age limit (21 years) overlaps with the comparable adult waiver minimum age (18 years)

Reserve capacity

- Some states use reserve capacity in adult waivers to ease transitions between child-only and adult HCBS waivers

Waitlists

- Many states have a waitlist for their waivers and this can lead to a gap in waiver enrollment and affect Medicaid coverage



Key Challenges and Policy Considerations for States

State Optional Medicaid Eligibility Pathways for Adults with Disabilities

- The SSI application process can be challenging and the SSI disability and financial criteria are different for children and adults
 - Child disability: functional limitations and abilities of CYSHCN compared to children without impairments
 - Adult disability: the ability to work and perform substantial gainful activity
- Research indicates that many adult beneficiaries with disabilities are not eligible for Medicaid through SSI even if they were eligible as children
 - The disability determination for SSI is different for children and adults, and about half of eligible children remain eligible as an adult
 - An individual may meet the disability criteria, but they may not meet the income and asset limits
- Findings demonstrate that some young adults who are no longer eligible for SSI as an adult are able to maintain coverage through other adult Medicaid pathways, such as the adult expansion group

Insufficient Support with Navigating Multiple Simultaneous Transitions

- Beneficiaries may not receive sufficient support or advance notice with the Medicaid redetermination and waiver transition process, leading to gaps in coverage
- States have implemented policies to support and reduce beneficiary burden with the Medicaid redetermination:
 - Notices about redeterminations 30 to 60 days in advance
 - Extending child Medicaid eligibility
 - Case managers to support the waiver application and Medicaid redetermination processes
- States that extended child eligibility up to age 21 raised that this additional time helps beneficiaries navigate their multiple transitions, and maintain coverage into young adulthood

Lack of Clarity in Eligibility Notices from Medicaid and Social Security Administration (SSA)

- Beneficiaries experience challenges with understanding notices from Medicaid and SSA about how changes to SSI eligibility affect Medicaid eligibility
- There are no federal requirements related to Medicaid and SSA coordinating or combining notices related to changes in SSI eligibility and how this affects Medicaid coverage
 - When a beneficiary is no longer eligible for SSI, SSA notifies them that SSI changes may affect Medicaid coverage, but there are no Medicaid requirements to notify the beneficiary unless additional information is needed to complete the change in circumstance redetermination (42 CFR 435.917)
- Interviewees raised the importance of improving notices related to changes in SSI eligibility to ensure beneficiaries have the information they need to be redetermined for Medicaid on a different basis

Next Steps

- Commissioner feedback on:
 - Are there outstanding questions about the T-MSIS and interview findings that staff can answer?
 - Does the evidence support the need for particular federal or state policy changes that MACPAC could consider?
 - Aside from the information presented above, are there other factors that should be considered in developing policy options?
- Return in January to present potential policy options

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DECEMBER MEETING



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