

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

Medicaid plays an important role in covering health care services for almost half of all children and youth with special health care needs (CYSHCN). Almost half of CYSHCN are covered by Medicaid or a combination of Medicaid and private insurance (37.2 percent and 7.6 percent, respectively) (MACPAC 2024). CYSHCN are broadly defined by the Maternal and Child Health Bureau (MCHB) in the Health Research & Services Administration as those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition; require health and related services of a type or amount beyond that required by children generally; and have one or more health or functional limitations (MCHB 2025, Black et al. 2024). Given the range of health care conditions and needs for this population, CYSHCN can be enrolled in Medicaid on the basis of income or disability. Findings from the 2017 National Health Interview Survey estimate that about 15 percent of CYSHCN are eligible for Medicaid on the basis of disability, and the other 85 percent of CYSHCN are eligible through another Medicaid pathway (Musumeci and Chidambaram 2019).

When CYSHCN transition to adult Medicaid, they must navigate many changes to their coverage, benefits, and care, and they may experience challenges that can lead to gaps and loss of coverage. Some of the documented challenges include the lack of timely notices from Medicaid about eligibility, lack of family and caregiver awareness of documentation needed to remain covered as an adult, and limited support from case workers and navigators for these beneficiaries (McManus et al. 2024). Recent research indicates that disenrollment among Medicaid-covered individuals peaks at age 19 when they are aging out of child Medicaid (Cliff et al. 2026, McMahan et al. 2025, Smith et al. 2025). Additionally, rates of public insurance for youth with disabilities is greater for those ages 12–18 compared to those ages 19–25 (58 percent compared to 43 percent, respectively), suggesting a decrease in public insurance coverage for individuals who have aged into adult coverage (McManus et al. 2024). Gaps in coverage, even for short periods, are associated with delays in receipt of care, an increase in unmet health needs, fewer office-based doctor visits, and an increase in the risk of hospitalization (Rennane et al. 2023, Brantley and Ku 2022, Hemmeter 2011).

Although findings from the literature indicate that Medicaid-covered CYSHCN experience challenges with transitioning to adult Medicaid coverage and maintaining continuity of coverage, there are few reported data on the transition-age CYSHCN population or their adult coverage outcomes. To address this gap in the data, we examined Medicaid-covered CYSHCN and their transitions to adult Medicaid coverage using 2017–2019 enrollment data from the Transformed Medicaid Statistical Information System (T-MSIS). We defined transition-age as Medicaid-covered children within 12 months of aging out of child Medicaid eligibility. Specifically, we examined (1) the number of children eligible on the basis of disability aging out of child Medicaid eligibility at age 19 years (21 years in 4 states), (2) the percent who remain Medicaid-covered continuously 12 months after transitioning to adult Medicaid coverage, (3) the percent who experience a gap in coverage when transitioning to adult Medicaid coverage, and (4) the average number of months they experience a gap in coverage.

Our findings indicate that 17.6 percent of transition-age CYSHCN enrolled in disability-related eligibility pathways disenrolled from Medicaid or experienced a gap in Medicaid coverage during the year leading up to aging out of child Medicaid (Table 3). Of those who disenrolled, 33.9 percent re-enrolled within 12 months (i.e., they churned on and off coverage) and the remainder were still disenrolled after 12 months. The rate of enrollment, churn, and disenrollment also differed between children enrolled in Supplemental Security Income (SSI)-related pathways and those enrolled in other disability-related pathways (defined in the methods section below). For example, the



percent who remained covered after reaching the transition-age was greater for beneficiaries enrolled in SSI-related eligibility pathways compared to those enrolled in other disability-related eligibility pathways (85.1 percent compared to 72.4 percent) (Table 2). Of those who disenrolled, about two-thirds of those enrolled in SSI-related eligibility pathways and in other disability-related pathways remained disenrolled after 12 months and did not re-enroll in Medicaid.

Our findings show that the majority of beneficiaries enrolled in the same eligibility pathway or a modified adjusted gross income (MAGI) eligibility pathway when they transitioned to adult Medicaid.¹ For example, of those who remained enrolled, the majority of those enrolled in SSI-related pathways as a child remained in the same eligibility pathway as an adult (85.9 percent) (Figure 1). Of the remainder, the majority transitioned to a MAGI eligibility group. Additionally, of all beneficiaries who churned, 50.3 percent re-enrolled in a MAGI eligibility group (Figure 2). Further, in states that expanded Medicaid to adults with incomes up to 138 percent of the federal poverty level (FPL), 13.5 percent of beneficiaries remained continuously enrolled and 50.1 percent of those who churned enrolled in an expansion pathway as adults (Figure 8).

The percentage of beneficiaries across all pathways who remained enrolled during the transition or churned was greater in states that adopted Medicaid expansion compared to those enrolled in states that did not. For example, a larger percentage of beneficiaries enrolled in SSI-related pathways and other disability-related pathways as a child in states with expansion remained enrolled during the transition (88.3 percent and 74.6 percent, respectively) compared to those in non-expansion states (78.7 percent and 59.7 percent, respectively) (Figure 7). Additionally, a smaller percentage of beneficiaries enrolled in states with expansion disenrolled and did not re-enroll within 12 months compared to those in non-expansion states.

In this brief, we present the findings from our analysis of CYSHCN and their transitions to adult Medicaid. The brief begins by providing an overview of the methods used to conduct this analysis. Then, it describes the Medicaid-covered transition-age population and their transitions to adult coverage, which includes those who remain continuously covered and those who disenroll and churn. It also describes state policies related to transitions to adult Medicaid coverage and how transition outcomes may differ between individuals enrolled in states with varying SSI eligibility determination policies and states with and without the optional adult expansion pathway. Finally, the brief includes a discussion of the findings and study limitations.

Methods

MACPAC worked with Acumen to examine data from T-MSIS for calendar years 2017 through 2019. To observe changes in coverage and disenrollment, we used data from the years before the COVID-19 public health emergency (2020–2023), when states paused Medicaid redeterminations.² The analytic population includes transition-age Medicaid children enrolled in a disability-related eligibility group code, using their last-best month in 2017, and were enrolled for all previous 12 months.^{3,4} This includes children who were enrolled in multiple eligibility pathways across the 12-month period. For the analysis, we grouped children into three groups: “SSI-related pathways,” “other SSI-related pathways,” and “other disability-related pathways” (Appendix A, Table A-1). Transition age is defined as children within 12 months of aging out of child Medicaid eligibility. In most states, this age is 19, but four states (the District of Columbia, Florida, Maine, and Massachusetts) have extended child eligibility to age 21 through a state plan option (42 CFR 435.222 and 42 CFR 435.223). We excluded beneficiaries who were not enrolled in a disability-related eligibility group as a child, who were missing an eligibility group code, and who moved to another state between January 2018 and December 2019 from the analytic population.

Using this analytic population, we calculated the number eligible on the basis of disability aging out of child Medicaid eligibility; the percentage who remained Medicaid-covered continuously for 12 months after aging out of child Medicaid and transitioning to adult Medicaid coverage; the percentage who disenrolled and remained disenrolled for 12 months; the percentage who disenrolled and reenrolled (churned) within 12 months after aging out; and for those who churned, the average number of months they experienced a gap in coverage. The analysis



also identified the adult eligibility pathway for those who remained enrolled as an adult or churned. The adult eligibility group is determined using the individual's eligibility group in the first month of enrollment after the transition. If the eligibility group was different than the one they were enrolled in as a child, they were grouped in one of four categories (adults, MAGI); adults, non-MAGI, disabled; adults, non-MAGI, non-disabled; and other) (Appendix, Table A-1). In states that have adopted the Medicaid expansion pathway, we identified the number who enrolled in this specific MAGI pathway as an adult. Furthermore, for those who churned, the analysis calculated the average number of months between disenrollment and reenrollment.

To stratify the data by race and ethnicity, we used the T-MSIS Analytic Files (TAF) Race/Ethnicity Imputation (REI) companion file for more complete beneficiary race and ethnicity information. The TAF data element for race and ethnicity is unusable or unreliable in many states (CMS 2023a). The REI file supplements state-reported data by estimating race and ethnicity based on beneficiary information in the TAF Annual Demographic and Eligibility file (first name, surname, self-reported race and ethnicity, and American Indian or Alaska Native certification); data from the TAF geocoded address companion file for beneficiaries; and geographic, race and ethnicity, and surname data from the Census Bureau. Beneficiary user counts stratified by race and ethnicity should be interpreted as approximations because the calculations use both self-reported and imputed probabilities of a person being classified as a given race and ethnicity. In addition, total user counts that are calculated by summing the values of the different race and ethnicity amounts may not be equivalent to the true totals because they are approximations.

Medicaid Coverage of Transition-Age CYSHCN

State Medicaid programs cover CYSHCN through a variety of mandatory and optional eligibility pathways, including disability-related pathways. These include SSI-related or state optional disability pathways. The optional pathways include the state medically needy pathway, the coverage group established by the Family Opportunity Act, Section 1915(i) state plan home- and community-based services (HCBS) benefit pathway, and the Katie Beckett pathway for children with disabilities (Musumeci and Chidambaram 2019).^{5, 6}

Between 2017 and 2018, there were 83,904 transition-age CYSHCN enrolled in disability-related pathways (Table 1). The majority of CYSHCN were enrolled in SSI-related pathways or other SSI-related pathways (78.8 percent).

TABLE 1. Transition-Age Medicaid-Covered CYSHCN by Medicaid Eligibility Pathway, Calendar Years 2017–2019

Eligibility group	Number of transition-age CYSHCN	Percent of total transition-age CYSHCN
All disability-related eligibility pathways	83,904	100.0%
SSI-related eligibility pathways	65,062	77.5
Other SSI-related pathway	1,049	1.3
Other disability-related pathway	17,793	21.2

Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

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



Transitions to Adult Medicaid

When Medicaid-covered CYSHCN approach aging into adult Medicaid, they must be redetermined to maintain Medicaid coverage. During this transition to adult Medicaid, many remain covered by Medicaid, but others may disenroll from Medicaid for a short time and re-enroll (churn) or not re-enroll. There are a number of reasons why individuals may disenroll or churn on and off of Medicaid. For example, the beneficiary may no longer be eligible for Medicaid (e.g., due to an increase in income or other changes in circumstances), gain coverage through an employer, or experience administrative challenges that prevent them from maintaining enrollment (Corallo et al. 2021).

Continuity of coverage

The majority of Medicaid-covered CYSHCN enrolled in a disability-related eligibility pathway remained enrolled after aging out of child Medicaid eligibility (82.4 percent) (Table 2). However, there were differences among beneficiaries enrolled in different types of eligibility pathways. Our findings show that 85.1 percent of CYSHCN enrolled in SSI-related pathways and 84.9 percent of CYSHCN enrolled in other SSI-related pathways remained enrolled in Medicaid as adults, which was greater compared to the percent of CYSHCN enrolled in other disability-related pathways who remained enrolled as adults (72.4 percent). Across states, there were also differences in the percent who remained enrolled in Medicaid as adults, with percentages ranging from 64.5 percent to 95.6 percent (Appendix B, Table B-1).

TABLE 2. Transition-Age Medicaid-Covered CYSHCN by Eligibility Pathway and Percentage Enrolled as Adults, Calendar Years 2017–2019

Eligibility group	Number of transition-age CYSHCN	Percent of transition-age beneficiaries who remain Medicaid-covered as adults
All disability-related eligibility pathways	83,904	82.4%
SSI-related eligibility pathways	65,062	85.1
Other SSI-related pathway	1,049	84.9
Other disability-related pathway	17,793	72.4

Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

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

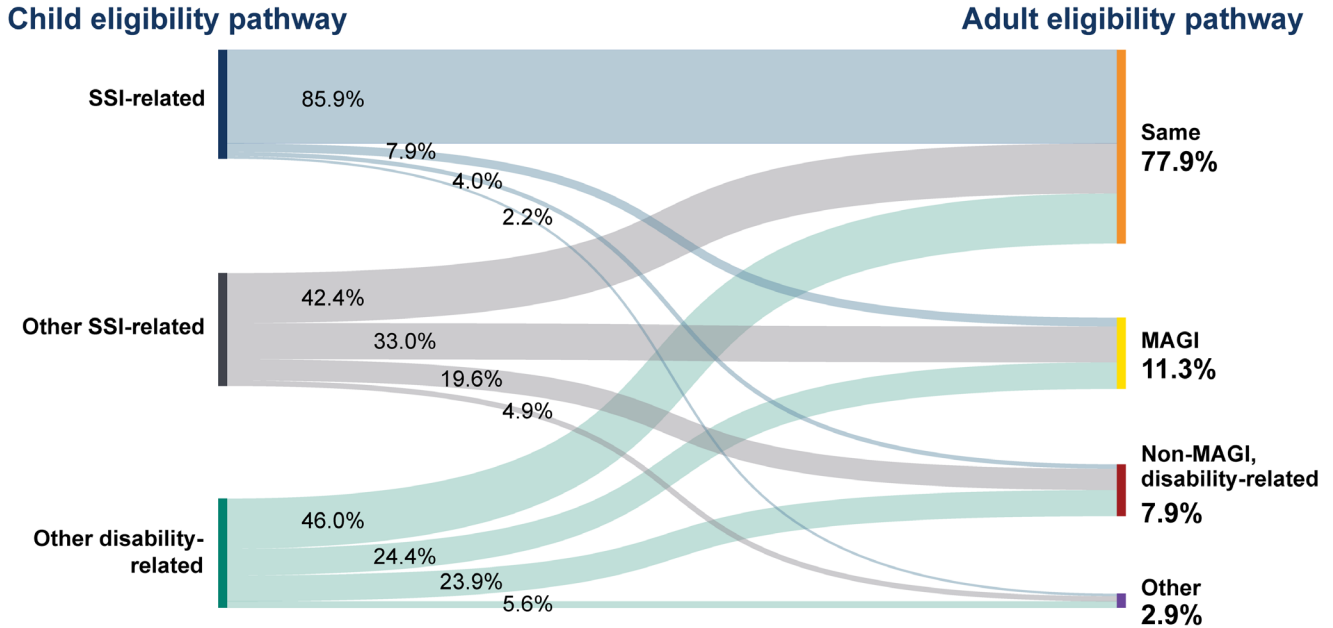
CYSHCN enrolled in a disability-related eligibility pathway redetermined Medicaid eligible as an adult may be enrolled in the same eligibility pathway as an adult (e.g., SSI-related pathways as a child and adult) or a different one from their child pathway. Figure 1 visualizes the transition between child and adult eligibility pathways. In the left column, the percentages represent those enrolled in a child eligibility pathway group (e.g., SSI-related pathways) who transitioned to an adult pathway (e.g. same eligibility pathway, MAGI pathway, etc.). In the right column, there are four adult eligibility pathway categories, and the percentages represent the percent of all CYSHCN who transitioned to each of these categories.

Findings from our analysis indicate that the majority of beneficiaries who were enrolled in SSI-related pathways remained enrolled in the same SSI eligibility pathway as an adult (85.9 percent) (Figure 1). Of the 14.1 percent enrolled in SSI-related pathways who changed eligibility group, the majority transitioned to a MAGI pathway. In



contrast, of those enrolled in other SSI-related or disability-related pathways as a child, fewer than 50 percent remained enrolled in the same eligibility pathway as an adult (42.4 percent and 46.0 percent, respectively).

FIGURE 1. Transition-Age Medicaid-Covered CYSHCN Who Remained Continuously Enrolled in Medicaid as Adults by Child and Adult Eligibility Pathways, Calendar Years 2017–2019



Notes: SSI is Supplemental Security Income. MAGI is modified adjusted gross income. Transition-age children and youth with special health care needs (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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The child eligibility pathways show percentages of CYSHCN who transitioned to an adult eligibility group. The adult eligibility pathway percentages represent the percentage of all transition-age children who transitioned to each adult eligibility pathway group (e.g., of all transition-age CYSHCN, 77.9 percent maintain coverage in the same eligibility pathway). The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

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

Disenrollment and churn

Overall, 17.6 percent of CYSHCN enrolled in a disability eligibility pathway disenrolled during the 12-month period prior to aging out child Medicaid eligibility (Table 3). Of those who disenrolled, 66.1 percent remained disenrolled after 12 months and 33.9 percent churned within 12 months. Our findings show that among the three disability eligibility groups, CYSHCN enrolled through SSI-related pathways had the lowest overall rate of churn (5.1 percent) and those enrolled in other disability-related pathways had the highest overall rate of churn (9.0 percent). For those who remained disenrolled after 12 months, CYSHCN who had been enrolled in other SSI-related pathways had the lowest overall rate of disenrollment (7.2 percent) and CYSHCN enrolled in other disability-related pathways had the highest overall rate of disenrollment (18.6 percent). Across states, there were also differences in the rate of churn and disenrollment, with rates of churn ranging from 0.0 to 18.4 percent and the rates of individuals remaining disenrolled for all 12 months when aging out of child Medicaid ranging from 1.1 to 30.8 percent (Appendix B, Table B-1).

TABLE 3. Disenrollment and Churn When Transitioning to Adult Medicaid Coverage Among Transition-Age Medicaid-Covered CYSHCN by Eligibility Group, Calendar Years 2017–2019

Eligibility group	Number of transition-age CYSHCN	Disenrolled after aging out of child Medicaid		Churned within 12 months		Disenrolled after aging out of child Medicaid and remain disenrolled for the following 12 months	
		Number of transition-age CYSHCN	Share of all transition-age CYSHCN	Share of all transition-age CYSHCN	Share of transition-age CYSHCN who disenrolled	Share of all transition-age CYSHCN	Share of transition-age CYSHCN who disenrolled
All disability-related pathways	83,904	14,756	17.6%	6.0%	33.9%	11.6%	66.1%
SSI-related eligibility pathways	65,062	9,681	14.9	5.1	34.2	9.8	65.8
Other SSI-related pathway	1,049	158	15.1	7.8	51.9	7.2	48.1
Other disability-related pathway	17,793	4,917	27.6	9.0	32.7	18.6	67.3

Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

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

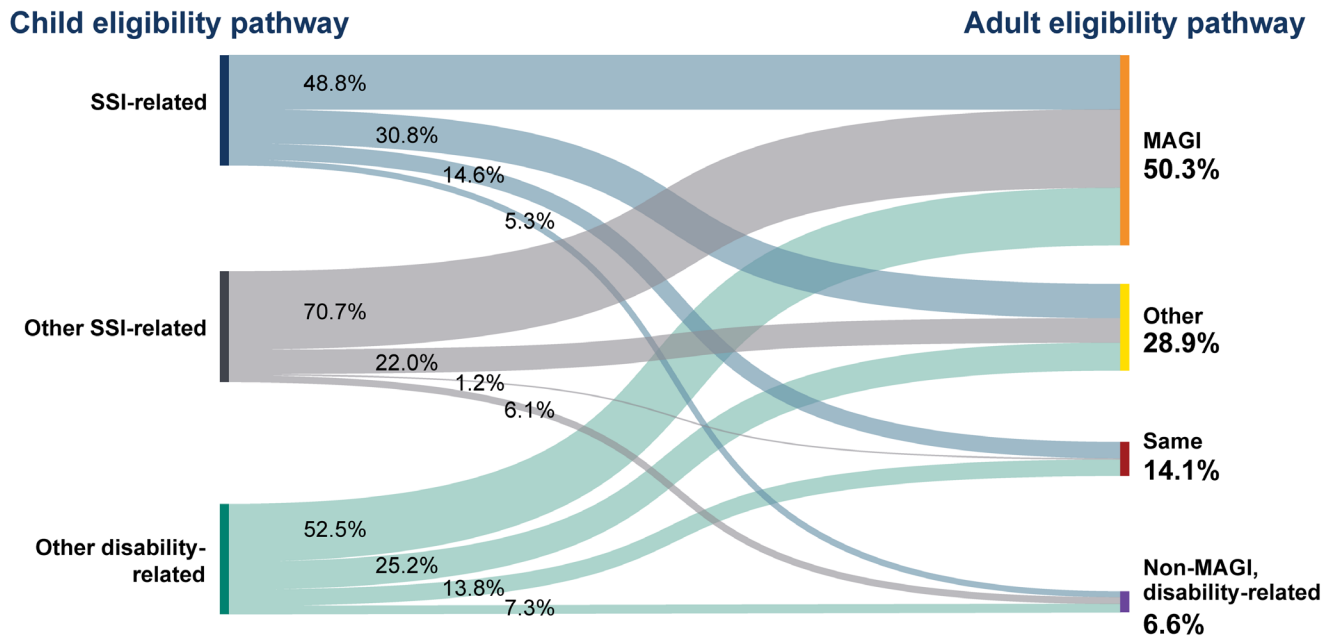
Figure 2 visualizes the transition between child and adult eligibility pathways for those who disenrolled and re-enrolled in Medicaid within 12 months (churned). In the left column, the percentages represent those enrolled a child eligibility pathway group (e.g., SSI-related) who transitioned to an adult pathway (e.g. MAGI, same pathway, etc.). In the right column, there are four adult eligibility pathway categories, and the percentages represent the percent of all CYSHCN who transitioned to each of these categories. For example, of all CYSHCN who churned when transitioning to adult Medicaid, 50.3 percent moved to a MAGI eligibility pathway.

The majority of CYSHCN who churned within 12 months, re-enrolled in an adult eligibility pathway that differed from their child pathway (85.1 percent enrolled in another pathway as an adult and 14.1 percent remained enrolled in the same pathway) (Figure 2). This is in contrast to the findings displayed in Figure 1, where the majority of those who remained enrolled in Medicaid during the transition to adult coverage remained covered in the same eligibility pathway (77.9 percent) and only 22.1 percent changed their eligibility pathway.

Across all three child eligibility groups, the majority after churning re-enrolled in a MAGI eligibility pathway (50.3 percent) (Figure 2). For example, of those enrolled as a child in SSI-related pathways, 48.8 percent re-enrolled in a MAGI pathway as an adult. Similarly, of those enrolled as a child in another SSI eligibility pathway or other disability pathway, 70.7 percent and 52.5 percent, respectively, re-enrolled in a MAGI pathway as an adult.



FIGURE 2. Transition-Age Medicaid-Covered CYSHCN Who Churned by Child and Adult Eligibility, Calendar Years 2017–2019

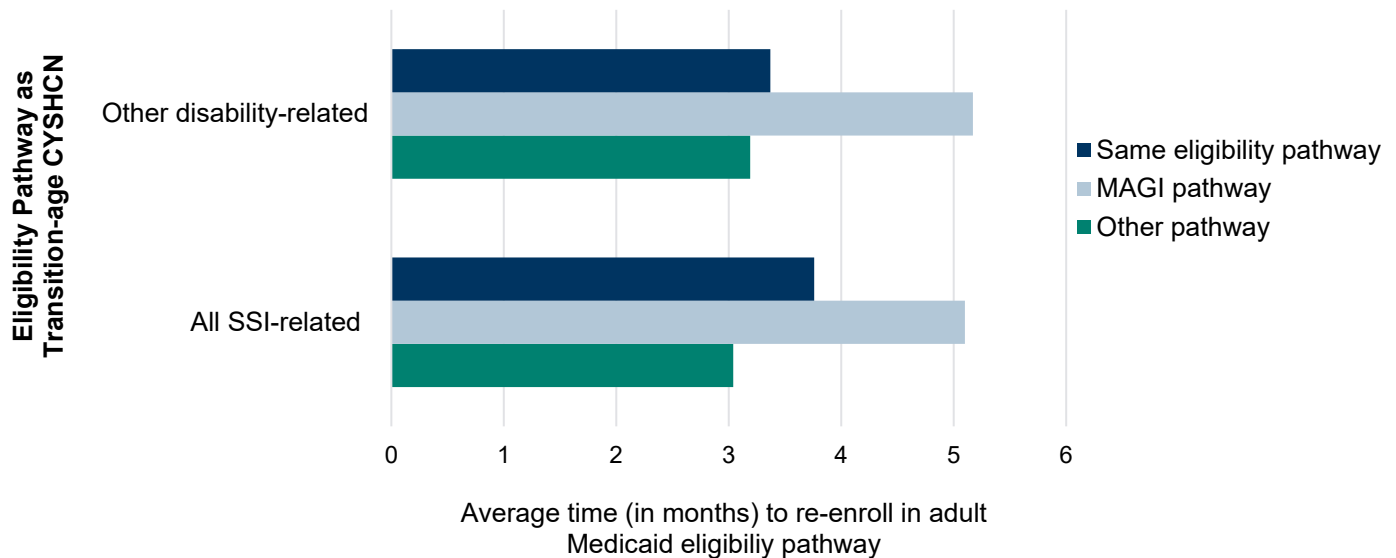


Notes: Percentages may not add to 100 percent due to rounding. SSI is Supplemental Security Income. MAGI is modified adjusted gross income. CYSHCN is children and youth with special health care needs. The child eligibility pathways show percentages of children who transitioned to each adult eligibility pathway group. The adult eligibility pathway percentages represent the percentage of all transition-age children who transitioned to each adult eligibility pathway group (e.g., of all transition-age children, 14.1 percent maintain coverage in the same eligibility pathway). Transition-age children and youth with special health care needs 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. A crosswalk of eligibility groups to the eligibility pathway codes in Transformed Medicaid Statistical Information System (T-MSIS) are included in Appendix A, Table A-1.

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

CYSHCN who had been enrolled in SSI-related pathways and in other disability-related pathways experienced similar gaps in coverage when they disenrolled from child coverage and reenrolled as adults (Figure 3). For example, the average number of months between disenrollment and re-enrollment was greatest for those who enrolled as an adult in a MAGI pathway (5.2 months). For those who re-enrolled in the same eligibility pathway or another pathway as an adult, the average time to re-enroll was between 3 and 4 months.

FIGURE 3. Average Time Between Disenrollment from Child Coverage and Reenrollment in Adult Medicaid Coverage Among Transition-Age Medicaid-Covered CYSHCN, Calendar Years 2017–2019



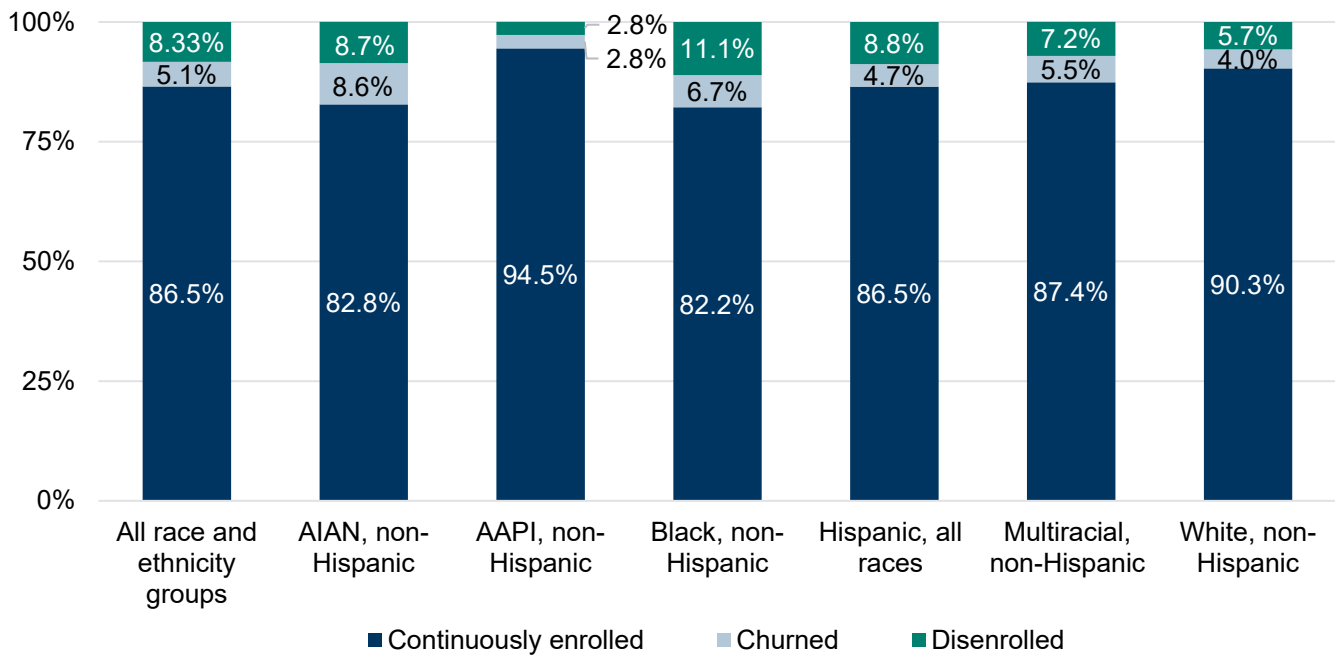
Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. MAGI is modified adjusted gross income. Transition-age CYSHCN are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

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

Variation in continuity of coverage

The rate of beneficiaries who remained enrolled in Medicaid after their transition varied among racial and ethnic groups, and differed by the eligibility pathway the transition-age child was enrolled in prior to the transition (Figures 4 and 5). For example, among those who were enrolled in SSI-related eligibility pathways, the percent who remained enrolled ranged between 82.2 and 94.5 percent across racial and ethnic groups (Figure 4). Black, non-Hispanic and American Indian and Alaska Natives experienced the lowest rate of Medicaid coverage after their transition (82.2 and 82.8 percent, respectively) and Black, non-Hispanic experienced the highest rate of individuals who remained disenrolled after 12 months (11.1 percent) compared to all other groups (ranging from 2.8 to 8.8 percent).

FIGURE 4. Transition-Age Medicaid-Covered CYSHCN Enrolled in SSI-Related Pathways who Remained Covered, Churned, and Disenrolled When Aging Out of Child Medicaid, by Eligibility Pathway and Race and Ethnicity, Calendar Years 2017–2019

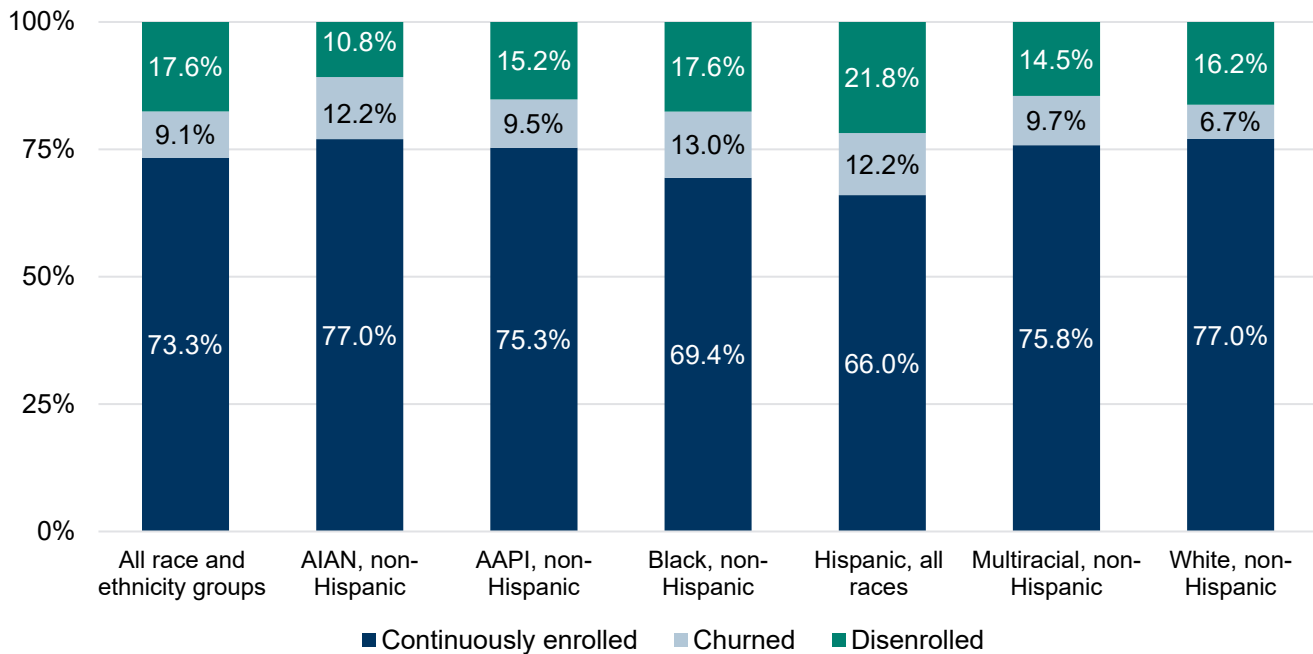


Notes: Percentages may not add to 100 percent due to rounding. CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. AIAN is American Indian and Alaska Native. AAPI is Asian American and Pacific Islander. Transition-age CYSHCN are defined as children enrolled 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1. Race and ethnicity estimates are calculated using the T-MSIS Analytical Files race/ethnicity imputed compiled files.

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

The percent of CYSHCN enrolled in other disability-related pathways who remained covered by Medicaid was lower compared to those enrolled in SSI-related pathways and ranged between 66.0 and 77.0 percent across racial and ethnic groups (Figure 5). Black, non-Hispanic and Hispanic transition-age CYSHCN experienced the lowest rate of Medicaid coverage after their transition (69.4 and 66.0 percent, respectively). Additionally, Black, non-Hispanic and Hispanic transition-age CYSHCN experienced the highest rate of individuals who remained disenrolled after 12 months (17.6 and 21.8 percent) compared to all other groups (ranging from 10.8 to 16.2 percent).

FIGURE 5. Transition-Age Medicaid-Covered CYSHCN Enrolled in Other Disability-Related Pathways who Remained Covered, Churned, and Disenrolled When Aging out of Child Medicaid, by Race and Ethnicity, Calendar Years 2017–2019



Notes: Percentages may not add to 100 percent due to rounding. AIAN is American Indian and Alaska Native. AAPI is Asian American and Pacific Islander. CYSHCN is children and youth with special health care needs. 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1. Race and ethnicity estimates are calculated using the T-MSIS Analytical Files race/ethnicity imputed compiled files.

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

State Policies Related to Transitions to Adult Medicaid Coverage

Our findings suggest that there may be a relationship between certain state policy choices and CYSHCN coverage transition outcomes, particularly whether states allow SSI eligibility to automatically confer Medicaid eligibility and have expanded eligibility to adults.

Medicaid eligibility for SSI enrollees

Almost all states are required to provide Medicaid coverage to individuals who receive SSI payments, but SSI eligibility does not always automatically confer Medicaid eligibility (42 CFR 435.120). States have the choice to enter into an agreement with the Social Security Administration (SSA) to allow SSA to determine Medicaid eligibility or to require SSI eligible individuals to separately apply to Medicaid. In 35 states, an individual determined eligible for SSI will automatically qualify for Medicaid coverage and is not required to submit a separate Medicaid application (referred to as “1634 states”) (42 CFR 435.541).⁷ Additionally, when these beneficiaries are annually redetermined for Medicaid coverage, the state Medicaid agency does not need to take



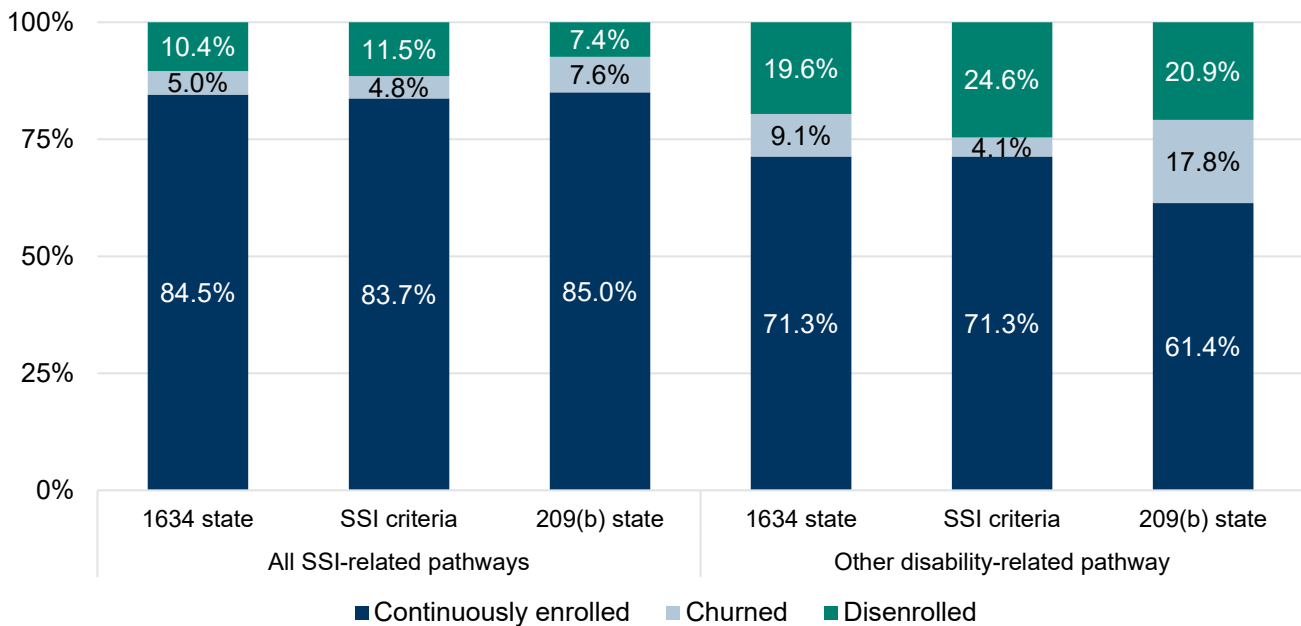
any action to complete the redetermination on an ex parte basis (CMS 2024). Eight states are “SSI criteria states” and use the SSI disability determination to determine Medicaid eligibility for individuals who apply to Medicaid and require SSI eligible individuals to submit a separate Medicaid application to be enrolled in Medicaid. SSI eligibility does not automatically confer categorical eligibility for Medicaid, so when these beneficiaries are annually redetermined for Medicaid coverage, the state Medicaid agency must confirm SSI eligibility with SSA (42 CFR 435.541) (CMS 2024).

States may choose to use more restrictive requirements for Medicaid (related to income and assets, disability, or both) than the SSI disability determination (called “209b states”), so the enrollment and redetermination processes are different for SSI eligible individuals in these states (42 CFR 435.121).⁸ Eight states are “209(b) states” and individuals who are eligible for SSI payments must separately apply to Medicaid to be determined eligible for Medicaid coverage. The state must redetermine eligibility in the same manner as all individuals eligible on the basis of disability (CMS 2024).

Our analysis found that the percent of transition-age CYSHCN enrolled in SSI-related pathways who remained enrolled in Medicaid after transitioning out of child Medicaid are similar across 1634, SSI criteria, and 209(b) states (ranged between 83.7 and 85.0 percent) (Figure 6). However, in 1634 and SSI criteria states, a larger percentage of these beneficiaries disenrolled and did not re-enroll within 12 months compared to those enrolled in 209(b) states (10.4 and 11.5 percent compared to 7.4 percent).

Among CYSHCN enrolled in other disability-related pathways, there were some differences in the percent who remained enrolled, churned, and remained disenrolled among 1634, SSI criteria, and 209(b) states. Findings indicate that a greater percentage of these CYSHCN in 1634 and SSI criteria states remained enrolled in Medicaid after transitioning out of child Medicaid compared to those enrolled in 209(b) states (71.3 percent compared to 61.4 percent) (Figure 6). Additionally, a larger percentage of those enrolled in 209(b) states churned compared to those in 1634 and SSI criteria states (17.8 percent compared to 9.1 percent and 4.1 percent, respectively).

FIGURE 6. Coverage Outcomes for Transition-Age Medicaid-Covered CYSHCN by Eligibility Pathway and State Medicaid Eligibility Determination Based on SSI, Calendar Years 2017–2019



Notes: Percentages may not add to 100 percent due to rounding. CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. § 209(b) refers to Section 209(b) of the Social Security Act Amendments of 1972. § 1634 refers to Section 1634 of the Social Security Act. SSI criteria are used to determine Medicaid eligibility in both Section 1634 and SSI-criteria states. In Section 1634 states, the federal eligibility determination process for SSI automatically qualifies an individual for Medicaid; in SSI-criteria states, individuals must submit information to the state for a separate eligibility determination. Section 209(b) states may use eligibility criteria (related to income and assets, disability, or both) that are more restrictive than SSI program criteria, but they may not use more restrictive criteria than those in effect in the state on January 1, 1972. If a Section 209(b) state does not have a separate medically needy standard, it must allow individuals with higher incomes to spend down to the Section 209(b) income level shown here by deducting incurred medical expenses from the amount of income that is counted for Medicaid eligibility purposes.

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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1. Race and ethnicity estimates are calculated using the T-MSIS Analytical Files race/ethnicity imputed compiled files.

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

State option to expand Medicaid to all adults under 65

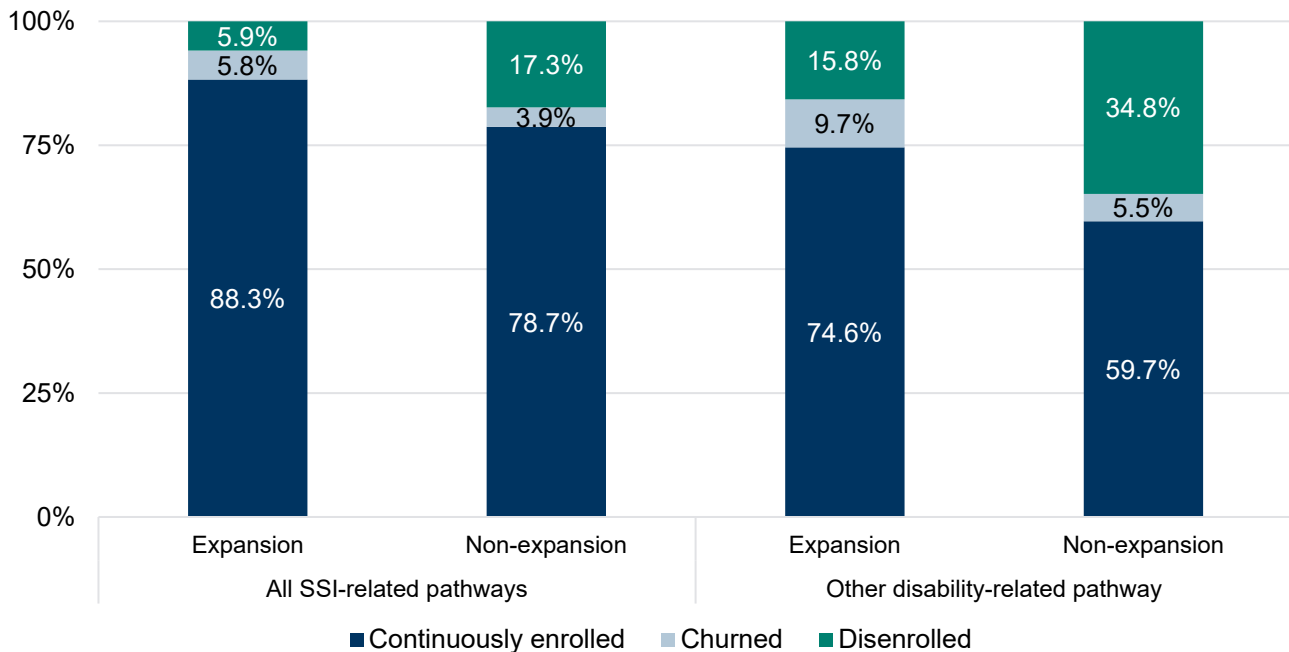
State Medicaid programs may choose to adopt the adult expansion pathway to extend Medicaid eligibility to all adults under age 65 (including parents and adults without dependent children).⁹ As of January 1, 2019 (which aligns with the years of our data analysis), 34 states and the District of Columbia adopted the adult expansion (KFF 2025a). In states that adopted the adult expansion, eligible individuals can obtain Medicaid without receiving SSI payments. This means individuals can remain Medicaid covered with higher income and assets than they would be permitted to be eligible on the basis of disability (Burns and Dague 2017).

Our analysis found differences by state expansion status in the percentage of CYSHCN who had been enrolled in disability-related pathways that remain enrolled in Medicaid as adults (Figure 7).¹⁰ A larger percentage of beneficiaries enrolled in SSI-related pathways as a child in states with expansion remained enrolled as adults compared to those in non-expansion states (88.3 percent compared 78.7 percent). Additionally, a larger percentage of beneficiaries enrolled in SSI-related pathways as a child in states without the expansion pathway remained disenrolled when aging out of child Medicaid compared to those enrolled in states with the expansion pathway (17.3 percent compared to 5.9 percent).

We observed a similar trend for CYSHCN enrolled in other disability-related pathways. A larger percentage of those who were enrolled in expansion states remained enrolled in Medicaid as adults compared to those in non-expansion states (74.6 percent compared to 59.7 percent). Further, a larger percentage of those enrolled in non-expansion states remained disenrolled when aging out of child Medicaid compared to those in expansion states (34.8 percent compared to 15.8 percent).



FIGURE 7. Coverage Outcomes for Transition-Age Medicaid-Covered CYSHCN by Eligibility Pathway and State Adoption of Medicaid Expansion, Calendar Years 2017–2019



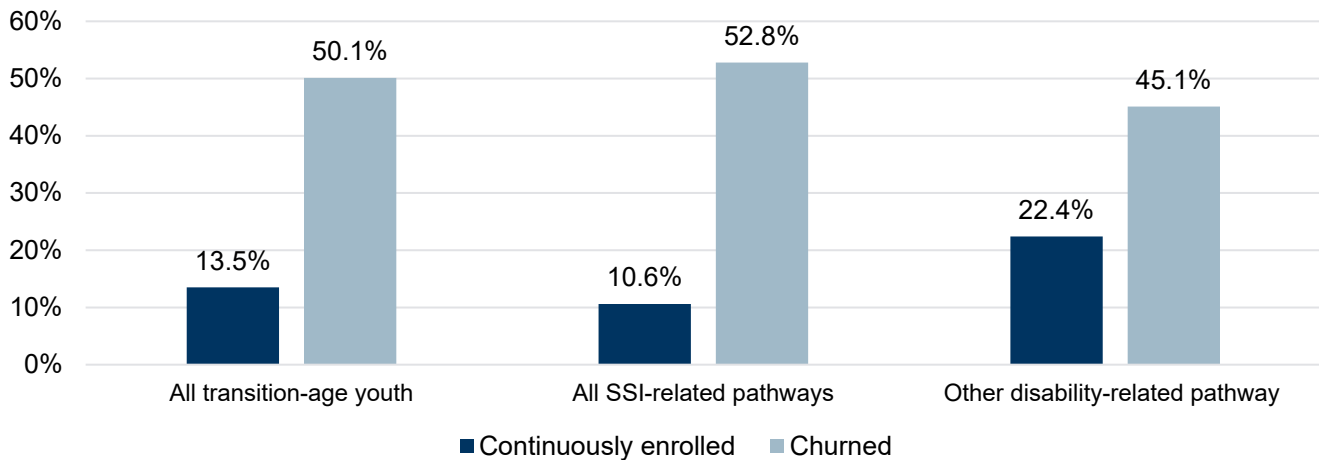
Notes: Percentages may not always add up to 100 percent due to rounding. CYSHCN is children and youth with special health care needs, SSI is Supplemental Security Income. CYSHCN is children and youth with special health care needs. Transition-age CYSHCN are defined as children enrolled in disability 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

Expansion refers to the 34 states and the District of Columbia that, as of January 1, 2019, adopted Medicaid expansion and extended Medicaid eligibility to all adults younger than age 65 (including parents and adults without dependent children) with incomes below 133 percent of the federal poverty level. Non-expansion refers to states that have not adopted Medicaid expansion as of January 1, 2019 (KFF 2025a).

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

Our analysis found that many transition-age CYSHCN who transitioned to adult Medicaid enrolled in the expansion eligibility pathway in expansion states (Figure 8). Across disability pathway groups, between 45.1 and 52.8 percent of transition-age CYSHCN who churned and experienced a gap in coverage when aging out of child eligibility re-enrolled in the expansion pathway. A smaller percentage of those who remained continuously enrolled after aging out of child eligibility also transitioned to the adult expansion pathway. The percentage of those who transitioned to the expansion pathway ranged from 10.6 percent of those enrolled in an SSI-related pathway as a child to 22.4 percent of those enrolled in another disability-related pathway.

FIGURE 8. Transition-Age Medicaid-Covered CYSHCN by Eligibility Pathway Who Transition to an Expansion Eligibility Pathway as an Adult, Calendar Years 2017–2019



Notes: CYSHCN is children and youth with special health care needs. SSI is Supplemental Security Income. Transition-age children and youth with special health care needs 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, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. A crosswalk of eligibility groups to the eligibility pathway codes in Transformed Medicaid Statistical Information System (T-MSIS) are included in Appendix A, Table A-1.

Expansion refers to the 34 states and the District of Columbia that, as of January 1, 2019, adopted Medicaid expansion and extended Medicaid eligibility to all adults younger than age 65 (including parents and adults without dependent children) with incomes below 133 percent of the federal poverty level. Non-expansion refers to states that have not adopted Medicaid expansion as of January 1, 2019 (KFF 2025a).

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

Discussion

In recent years, a number of studies have examined rates of continuous coverage and churn for Medicaid-covered populations using T-MSIS and survey data, but none of these studies have focused specifically on children with disabilities transitioning to adult Medicaid coverage and their transition between child and adult eligibility pathways. When CYSHCN transition to adult Medicaid, they must navigate many changes to their coverage, benefits, and care. These changes can lead to challenges with maintaining coverage as an adult, which research has shown is associated with increases in unmet health needs and risk of hospitalization, and these outcomes can be worse for those with complex health needs (Rennane et al. 2023, Brantley and Ku 2022). Many of these challenges are unique to the transition period for these youth and can be compounded by having to navigate multiple age-related transitions that occur simultaneously or near simultaneously with the coverage transition, including educational-, employment-, and health care-related transitions (MACPAC 2025, McManus et al. 2024, Okumura et al. 2022, White et al. 2018, Steinway et al. 2017).

Our study estimates that 17.6 percent of transition-age CYSHCN enrolled in disability-related pathways experienced a period of disenrollment when transitioning to adult coverage, which is greater than prior estimates of annual rate disenrollment for all children with disabilities. These estimates vary between studies due to difference in population definitions and exclusions. Previous studies using T-MSIS and NSCH indicate that about 2.0–5.2 percent of individuals with disabilities (including those not enrolled in disability-related pathways) were Medicaid-covered for fewer than 12 months continuously (MACPAC 2023, 2021). Additionally, in a prior MACPAC study of churn from the same period as our study (2017–2019), it was estimated that 7.2 percent of full-benefit



Medicaid-covered children enrolled in disability-related pathways disenrolled for at least 1 month in 2018 (MACPAC 2021).¹¹

One of the limitations of this study is that we are unable to identify all CYSHCN enrolled in Medicaid. Although many CYSHCN are enrolled in SSI-related and other disability-related pathways, many may also be enrolled in MAGI eligibility pathways. As was noted above, only about 15 percent of CYSHCN are eligible for Medicaid on the basis of disability, and the other 85 percent of CYSHCN are eligible through another Medicaid pathway (Musumeci and Chidambaram 2019). It is challenging to identify CYSHCN not enrolled in disability-related pathways and may require identification based on receipt of specialized or high-risk care for physical or behavioral health needs or using claims and encounter data to assess if they are in an active course of treatment for a complex illness (CMS 2023b).

Another limitation is that our analysis cannot determine the reason for disenrollment or their coverage status after losing Medicaid. For example, we do not know whether beneficiaries who experienced churn or disenrollment transitioned to other sources of coverage or became uninsured. CYSHCN experience many other transitions that can occur simultaneously or near simultaneously as the Medicaid coverage transition, including the SSI age-18 redetermination, transitioning from pediatric to adult systems of care, and school- and employment-related changes. Navigating multiple transitions can be burdensome for families and may lead to challenges with maintaining coverage during this period (MACPAC 2025, McManus et al. 2024). Additionally, disenrollment and churn may be an indicator of administrative barriers that disrupt coverage for beneficiaries who continue to meet income and other eligibility requirements. Such disruptions in coverage result in unnecessary administrative costs for states and delays in care for beneficiaries, which may increase health costs in the long run (Sugar et al. 2021).

The associations that we observed between state policy choices and rates of enrollment, disenrollment, and churn after the transition do not necessarily imply causation. Other factors that we did not examine include state differences in rates of completing redeterminations on an ex parte basis, in particular for populations with disabilities, and state efforts to streamline the redetermination processes that may affect a beneficiary's continuity of coverage during this transition period.

Endnotes

¹ MAGI is a standardized method of counting income used for beneficiaries under age 65 who are not eligible for Medicaid on the basis of a disability (ASPE 2013).

² During the COVID-19 public health emergency, the Families First Coronavirus Response Act (P.L. 116-127) provided states with a temporary 6.2 percentage point increase in the federal medical assistance percentage (FMAP) if they met certain conditions, including a continuous coverage requirement for most Medicaid beneficiaries who were enrolled in the program as of or after March 18, 2020. The Consolidated Appropriations Act of 2023 (CAA, P.L. 117-328) decoupled the end of the continuous coverage requirement from the public health emergency. The CAA established an end date of March 31, 2023, for the requirement and a phase-down of the enhanced matching rate over the remainder of 2023 for states that met certain renewal processing and data reporting requirements.

³ Acumen defined the last-best month as the most recent month containing a valid non-CHIP eligibility group code or a valid basis of eligibility (if eligibility group is missing or invalid). If the beneficiary has at least one validly enrolled month (i.e., at least one last-best month), they considered them validly enrolled for the given year. When using the final action eligibility file to define valid enrollment, Acumen further subset the enrollment records to the time when the date of birth and the date of death indicate the beneficiaries are still alive.



⁴ Acumen defined the last-best month as the most recent month containing a valid non-CHIP eligibility group code or a valid basis of eligibility (if eligibility group is missing or invalid). If the beneficiary has at least one validly enrolled month (i.e., at least one last-best month), they considered them validly enrolled for the given year. When using the final action eligibility file to define valid enrollment, Acumen further subset the enrollment records to the time when the date of birth and the date of death indicate the beneficiaries are still alive.

⁵ The Family Opportunity Act allows children with disabilities whose family income is below 300 percent of the federal poverty level to buy into Medicaid. A state can use a higher income standard, but federal financial participation is not available for the individuals with incomes that exceed 300 percent FPL (CMS n.d.). As of 2025, 9 states (Colorado, Iowa, Kentucky, Louisiana, Massachusetts, New Jersey, North Dakota, Texas, and Utah) have adopted the option authorized in the Family Opportunity Act (KFF 2025b).

⁶ The Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA, P.L. 97-248) changed Medicaid income counting rules to allow severely disabled children to receive their care at home while retaining their Medicaid coverage (Smith et al. 2000). This expanded the Katie Beckett waiver. Under this optional state plan pathway (called the “Katie Beckett eligibility pathway”), states count only the income and financial resources of a child with a disability who needs long-term services and supports. Many states converted their Katie Beckett waivers to the state plan option, and some provided institutional long-term services and supports or Section 1915(c) waiver benefits to individuals eligible under this pathway who meet institutional criteria (MACPAC 2022, CISWH 2016).

⁷ Section 1634 of the Social Security Act (the Act) allows SSA to enter into an agreement with state Medicaid agencies to determine Medicaid eligibility for individuals who are eligible for SSI based on disability. States that enter into these agreements are often referred to as 1634 states. Therefore, a determination of eligibility for SSI confers Medicaid eligibility, and the beneficiary at the age of transition remains Medicaid eligible as long as they remain SSI eligible (42 CFR 435.541).

⁸ Section 209(b) of the Act Amendments of 1972 allows states to use Medicaid eligibility criteria (related to income and assets, disability, or both) that are more restrictive than SSI program criteria. States may not use more restrictive criteria than those in effect in the state on January 1, 1972 (42 CFR 435.540).

⁹ The Patient Protection and Affordable Care Act (ACA, P.L. 111-148, as amended) 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). The June 2012 Supreme Court ruling in *National Federation of Independent Business (NFIB) v. Sebelius* effectively made the expansion an option for states.

¹⁰ For the purposes of this analysis focusing on transitions to adult coverage in 2019, we used state expansion status as of January 1, 2019 (KFF 2025a).

¹¹ In MACPAC’s 2021 analysis of disenrollment and churn, these were calculated based on a 12-month enrollment period rather than disenrollment at a point in time (age of transitioning out of child Medicaid) (MACPAC 2021).



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APPENDIX A: Eligibility Pathway Groups

TABLE A-1. Child and Adult Eligibility Pathway Eligibility Group Assignment

Types of eligibility pathways	Eligibility category	Eligibility pathways
Child eligibility pathways	SSI-related pathways	Individuals receiving SSI; aged, blind and disabled individuals in 209(b) states; individuals receiving mandatory state supplements; optional state supplement recipients—1634 states and SSI criteria states with 1616 agreements; and optional state supplement recipients—209(b) and SSI criteria states without 1616 agreements.
	Other SSI-related pathway	Institutionalized individuals continuously eligible since 1973; individuals who lost eligibility for SSI/SSP due to an increase in OASDI benefits in 1972; individuals who would be eligible for SSI/SSP but for OASDI COLA increases since April 1977; and disabled widows and widowers ineligible for SSI, working disabled under 1619(b).
	Other disability-related pathway	Qualified disabled children under age 19; Family Opportunity Act children with disabilities; individuals eligible for HCBS; and medically needy children, parents, and caretakers and aged, blind, and disabled individuals.
Adult eligibility pathways	MAGI	Expansion pathway; transitional medical assistance; extended Medicaid; and pregnant women.
	Non-MAGI, disabled	SSI pathways; other disability pathways that overlap with those listed for child eligibility pathways; essential spouses; blind or disabled eligible in 1973; disabled adult children; qualified Medicare beneficiaries; qualified disabled and working individuals; aged, blind, or disabled individuals eligible for but not receiving cash assistance; ticket to work, individuals eligible for HCBS; and medically needy aged, blind, or disabled.
	Non-MAGI, non-disabled	Certain individuals needing treatment for breast or cervical cancer and medically needy parents and other caretakers.
	Other	Any other adult eligibility pathway.

Notes: SSI is Supplemental Security Income. SSP is state supplemental payment. OASDI is Old-Age, Survivors, and Disability Insurance. COLA is cost-of-living adjustment. HCBS is home- and community-based services. MAGI is modified adjusted gross income. The 1616 agreements are agreements state Medicaid agencies may have under section 1616 of the Social Security Act with the Social Security Administration (SSA) to have SSA administer the state Medicaid agency's supplementary payment programs (CMS n.d.). Child and adult eligibility groups were categorized using similar methods as other recent churn analyses using Transformed Medicaid Statistical Information System (T-MSIS) (Mann et al. 2022, MACPAC 2021). The child eligibility groups were based on age criteria (up to age 19).

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



APPENDIX B: State-Level Results

Table B-1 includes state-level estimates for transition-age Medicaid-covered CYSHCN who remained enrolled, churned, and disenrolled when aging out of child Medicaid eligibility. The national total is slightly different from the state-level total, so national analyses and state-level analyses will have different total populations. These totals are different for a couple of reasons. First, the analytic population only includes beneficiaries who were covered for 12 months prior to being enrolled during their transition-age, and the 12 months of continuous enrollment can be across multiple states for the population denominator used in the national total, but these individuals would not be included in any of the state-level population denominators. Second, in T-MSIS, some beneficiaries appear to be concurrently enrolled in more than one state, so they are only counted once in the national total.

TABLE B-1. Transition-Age Medicaid-Covered CYSHCN who Remained Covered, Churned, and Disenrolled When Aging Out of Child Medicaid by State, Calendar Years 2017–2019

State	All transition-age Medicaid-covered CYSHCN transitioning to adult Medicaid coverage		
	Remained continuously enrolled when aging out of child Medicaid	Churned within 12 months	Disenrolled and did not reenroll within 12 months
Alabama	67.6%	4.2%	28.3%
Alaska	86.3	4.3	9.4
Arizona	87.6	5.2	7.1
Arkansas	70.6	10.3	19.0
California	87.4	6.0	6.6
Colorado	90.5	3.5	6.1
Connecticut	95.6	3.3	1.1
Delaware	80.2	7.3	12.5
District of Columbia	88.9	0.0	11.1
Florida	74.8	4.0	21.1
Georgia	88.1	3.5	8.4
Hawaii	85.3	6.3	8.4
Idaho	67.2	5.2	27.6
Illinois	67.0	16.2	16.8
Indiana	88.7	4.6	6.7
Iowa	89.6	4.6	5.8
Kansas	78.5	3.5	18.0
Kentucky	94.2	0.0	5.8
Louisiana	89.8	5.2	5.0
Maine	91.0	4.5	4.5
Maryland	73.9	18.4	7.7
Massachusetts	87.9	1.9	10.2
Michigan	68.4	13.2	18.4
Minnesota	87.5	6.7	5.8
Mississippi	64.5	4.6	30.8
Missouri	82.1	5.5	12.3



State	All transition-age Medicaid-covered CYSHCN transitioning to adult Medicaid coverage		
	Remained continuously enrolled when aging out of child Medicaid	Churned within 12 months	Disenrolled and did not reenroll within 12 months
Montana	90.7	6.2	3.1
Nebraska	86.6	1.3	12.2
Nevada	78.8	7.5	13.7
New Hampshire	71.5	14.6	13.8
New Jersey	81.2	9.5	9.3
New Mexico	80.5	13.7	5.8
New York	84.8	8.7	6.4
North Carolina	92.8	1.4	5.8
North Dakota	65.1	15.9	19.0
Ohio	92.7	2.7	4.6
Oklahoma	77.5	9.8	12.7
Oregon	90.6	3.0	6.4
Pennsylvania	77.9	8.6	13.5
Rhode Island	83.4	7.5	9.1
South Carolina	78.7	4.4	16.9
South Dakota	76.2	3.9	19.9
Tennessee	89.0	1.1	9.8
Texas	68.1	5.8	26.2
Utah	85.0	5.8	9.2
Vermont	89.3	0.0	10.7
Virginia	84.4	7.3	8.3
Washington	84.2	8.5	7.4
West Virginia	92.3	2.8	4.9
Wisconsin	83.7	7.5	8.8
Wyoming	80.0	5.0	15.0

Notes: CYSHCN is children and youth with special health care needs. Transition-age CYSHCN are defined as children enrolled in disability pathways who are within 12 months of aging out of child Medicaid eligibility. CYSHCN who churned are beneficiaries who disenrolled and re-enrolled in Medicaid within 12 months. Child Medicaid eligibility ends at age 19 in most states, with the exception of the District of Columbia, Florida, Maine, and Massachusetts, which have extended child Medicaid eligibility to age 21. The Transformed Medicaid Statistical Information System (T-MSIS) eligibility pathway codes included in each eligibility group are included in Appendix A, Table A-1.

Source: MACPAC analysis of Transformed Medicaid Statistical Information System (T-MSIS), 2017–2019.

