

Medicaid Disenrollment Among Young Adults With and Without Complex Medical Conditions

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 Supplemental content

IMPORTANCE Loss of health insurance coverage is common as Medicaid-enrolled children transition to adulthood and increases morbidity and mortality, especially for individuals with complex medical conditions (CMCs).

OBJECTIVE To measure risk of Medicaid disenrollment in young adults with and without CMCs and variation by medical condition and state of residence.

DESIGN, SETTING, AND PARTICIPANTS This retrospective observational study was conducted among individuals in 47 state Medicaid programs born 1991-2001 with 11 or more months of comprehensive Medicaid coverage in 2016 using the 2016-2019 Transformed Medicaid Information Systems Analytic Files, a census of Medicaid administrative medical claims (N = 9 409 619). Individuals with CMCs were identified in 2016 using the Pediatric Medical Complexity Algorithm. Age-based risk of disenrollment and reenrollment for individuals aged 16 to 26 years with and without CMCs was estimated from 2017-2019 using discrete-time survival models. Cumulative risk of disenrollment in individuals aged 19 to 21 years was measured using Kaplan-Meier curves. Analyses were stratified by state and medical condition. Data were analyzed from October 2024 to September 2025.

MAIN OUTCOMES AND MEASURES The primary outcome was probability of disenrollment, defined as 2 or more months with no days of comprehensive benefits. The secondary outcome was reenrollment, defined as any days of comprehensive benefits within 12 months of disenrollment. Correlates of disenrollment were measured at individual and state levels.

RESULTS A total of 305 323 individuals (3.2%) were identified as having a CMC in 2016. Disenrollment peaked at age 19 years; conditional probability of disenrollment was 13.4% (95% CI, 13.2%-13.6%) among individuals with CMCs and 35.6% (95% CI, 35.6%-35.7%) among individuals without CMCs. Probability varied by state, ranging from 2.6% (95% CI, 2.0%-3.2%) to 37.0% (95% CI, 34.7%-39.4) for individuals with CMCs and from 7.3% (95% CI, 6.7%-7.9%) to 83.9% (95% CI, 83.5%-84.3%) for those without CMCs. Among individuals with a CMC, mental health and cardiac conditions had the highest probability of disenrollment at age 19 years. Cumulative risk of disenrollment was 37.9% (95% CI, 37.3%-38.6%) among individuals with CMCs and 74.2% (95% CI, 74.1%-74.3%) among those without. Higher conditional probability of disenrollment was correlated with being male, eligibility via income, living in a Medicaid nonexpansion state, and living in a state with 50% or more managed care penetration. Of disenrolled individuals, 38.0% (95% CI, 37.6%-38.4%) of those with CMCs and 29.1% (95% CI, 29.0%-29.1%) of those without CMCs reenrolled within 12 months.

CONCLUSIONS AND RELEVANCE In this cohort study, disruptions in Medicaid coverage were common for emerging adults with and without CMCs and varied by state and condition.

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Eligibility for health insurance changes as children transition to adulthood, creating the opportunity for loss or disruption in coverage. Loss of insurance has been shown to reduce health care access and increase risk of morbidity and mortality.¹⁻³ Health insurance loss can hinder the receipt of chronic disease management and valuable preventive care and increases the likelihood that serious illness is diagnosed at a more advanced stage.^{4,5}

Insurance instability may be especially problematic for individuals with high health care needs. Children with complex medical conditions (CMCs) are among the most complicated and vulnerable patients in the US health care system.⁶⁻⁹ Clinical innovations are helping more of these children live well into adulthood, yet health and social supports for this population as they age are lacking.¹⁰⁻¹⁴ To the extent that they exist, many of these supports are tied to insurance coverage. Existing work shows that as medically complex individuals age into adulthood, they are at heightened risk for gaps in insurance coverage and have poorer health care outcomes compared to those in pediatric care.^{13,15-24} As a primary payer for more than half of children with medical complexity, state Medicaid programs play a crucial role in health care access for individuals with CMCs.^{25,26} Disruptions around the time of categorical eligibility changes—such as aging out of childhood programs—are known challenges for care continuity and access, yet these disruptions have been difficult to study at scale.^{13,26-29}

Recent work shows more than 40% of children are ever uninsured by their 18th birthday, but less is known about gaps during the transition to adulthood.³⁰ Most evidence is limited to small sample sizes or specific complex populations.^{23,24} In this cohort study, we seek to fill this gap by quantitatively estimating, in a national Medicaid population, risk and correlates of Medicaid disenrollment during the transition to adulthood around age 19 years for individuals with and without CMCs in 46 states and Washington, DC. We estimate both discrete and cumulative risks of disenrollment nationally and by state and, for individuals with CMCs, discretely by medical condition to generate national benchmarks and facilitate comparisons. Such evidence on a national scale informs policymakers, state Medicaid programs, and health systems regarding specific risks for coverage loss and can foster assessment of health care access for a vulnerable patient population.

Methods

Data and Setting

We used the 2016-2019 Transformed Medicaid Statistical Information System Analytic Files (TAF), which are harmonized data from all US Medicaid programs.³¹ The data include the universe of medical claims and monthly enrollment information for all Medicaid enrollees. Using the 2016 data, we identified enrollees born in 1991-2001 (ages 15-25 years) who had comprehensive Medicaid benefits, including through a Children's Health Insurance Program. To ensure a valid claims history for CMC identification, we retained enrollees with 11 to 12 months of enrollment, 57% of the total enrollees (eTable 1 in *Supplement 1*). We followed reporting guidelines for using

Key Points

Question What is the probability of disenrollment from Medicaid for emerging adults, and how does it vary by medical condition and state of residence?

Findings In this cohort study, risk of disenrollment among individuals aged 16 to 26 years old in 2017-2019 peaked at age 19 years, when probability of disenrollment for 2 or more months was 13% among individuals with complex medical conditions and 36% among those without. Disenrollment risk varied widely by which state an individual lives in and, for individuals with complex conditions, which specific condition.

Meaning Due to differences in eligibility and operations of state Medicaid programs, age-based risk of disenrollment is high, with substantial variation across states and by medical diagnosis.

TAF data developed by the Medicaid Data Learning Network and the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline (eTable 3 in *Supplement 1*).³² This study was approved by the University of Chicago Institutional Review Board.

The TAF are sourced from state Medicaid programs and have variable quality across states and year. To reduce bias from poor data quality, each variable in the analysis was systematically checked against the national resource for TAF data quality, the Data Quality Atlas (DQ Atlas), which reports data quality for measures common in claims data for the full Medicaid population by state.³³ We additionally performed our own quality checks when information from the DQ Atlas was not available or to investigate issues highlighted by the DQ Atlas in this study's specific age group (eTable 2 in *Supplement 1*). Two states that had poor quality data for identifying people with CMCs were dropped (Maryland and Arkansas), as well as 2 states that had unreliable enrollment data (Maine and Rhode Island).

Identifying Individuals With Complex Medical Conditions

We used the Pediatric Medical Complexity Algorithm (PMCA) to identify teenagers and young adults in 2016 data with CMCs.^{34,35} As described in previous work, the PMCA was chosen over other possible algorithms to identify individuals with CMCs because it has been validated for use in Medicaid claims data, it focuses on child onset conditions, and its sensitivity and specificity have been validated with 1 year of medical history.³⁶ We used the "conservative coding" recommended by prior work and described in eTable 4 in *Supplement 1*.³⁷ We created an indicator for any complex condition, as well as the type (malignant, progressive) and body system(s) involved. Previous research has shown using the PMCA identifies approximately the same population prevalence of complexity as other commonly used algorithms.³⁷

Outcomes: Measuring Disenrollment and Reenrollment

This study's main outcome measure, disenrollment, was defined as the loss of comprehensive Medicaid for 2 or more months, regardless of whether or when the individual reentered a Medicaid program. Likelihood of disenrollment from

2017 to 2019 was measured using variables that give the number of days enrollment and type of plan in each month. Following earlier work, individuals with missing data, 0 days of enrollment, or codes that indicate enrollment in a restricted or limited benefit plan were considered disenrolled in that month.³⁸ As a more conservative definition of disenrollment, disenrollment was defined as loss of comprehensive Medicaid for 6 or more months. In all specifications, enrollees with 1 month of missing eligibility data were retained in the data, as conversations with Medicaid program officials suggest these are likely data or administrative mistakes.³⁸

Reenrollment was defined as an enrollee who disenrolled in 2017-2018 and reappeared in the data with comprehensive Medicaid within 12 months of the original disenrollment date.

Each of these outcome variables was assessed at the national level for individuals with and without CMCs. Additionally, we report these variables for each state with sufficient data quality and for each condition identified by the PMCA. Individuals are assigned to the state program they were enrolled in in 2016.

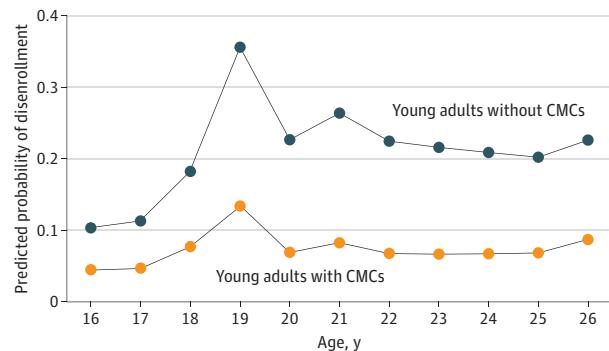
Statistical Analysis

To measure the probability of disenrollment at each age, we estimated a discrete-time survival analysis model in which an enrollee is at risk of disenrollment in each year, indexed at an enrollee's birth month. The model specification is a logit regression and estimates probability of disenrollment at each age from 16 to 26 years conditional on being enrolled at the previous age. Individuals who died or who remained in the sample through the study period are right censored. Individuals who move to other states were retained.

Our main estimates adjust for differences in rates of disenrollment by state over time using indicator covariates for state \times year. We enter age in categories and interact it with an indicator for diagnosis of a CMC. To measure correlations of disenrollment with individual and state policy characteristics, models were estimated separately for individuals with and without CMCs that include individual Medicaid eligibility type (disability, income based, other); Social Security Insurance (SSI) receipt; self-reported gender, age, and, at the state level, existence of a medically needy pathway to enrollment, a waiver covering transition-age services; Medicaid expansion status; and managed care penetration.^{13,26,27,39,40} To estimate probability of reenrollment, a similar regression model was used, limited to individuals who disenrolled in 2017 or 2018. In all discrete-time models, conditional probabilities or marginal effects are reported as noted in Figures and the Table. Regression specification and additional details about estimation and covariates are provided in the eMethods in [Supplement 1](#). We used robust standard errors and Stata version 18.0 (StataCorp) for all analyses.

Finally, we measured the cumulative probability of disenrollment from 2017-2019 for the subset of individuals who turned 19 years old in 2017 using Kaplan-Meier curves. We indexed enrollees' probability of disenrollment to the month before they turned 19 years old (beginning December 2016) and measured cumulative disenrollment through 2019, up

Figure 1. Conditional Probability of Medicaid Disenrollment by Age



This Figure shows the conditional probability of disenrollment from Medicaid (2017-2019) at each age for individuals with and without complex medical conditions (CMCs), adjusted for differences in levels and trends across states with state \times year fixed-effects with a logistic regression (N = 9 409 619). Confidence intervals are not visible due to large sample sizes for each group. See specific details of regression that generated estimates in the eMethods in [Supplement 1](#). Source: Authors' analysis of Transformed Medicaid Statistical Information System Analytic Files (TAF) data.

to 36 months. Survival probabilities of these curves are interpreted as the percentage of individuals continuously enrolled from ages 19 to 21 years.

Results

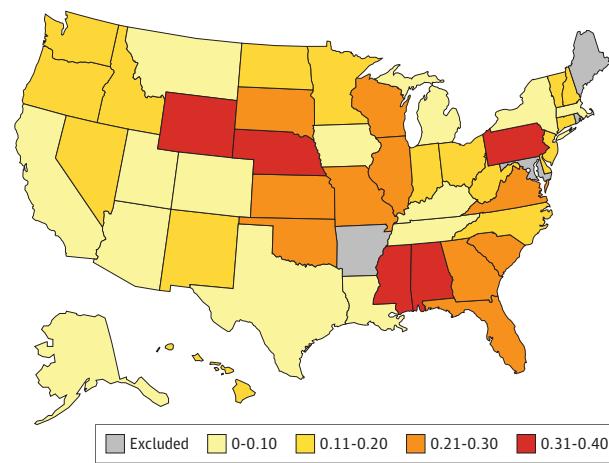
Cohort Size and Description

Our total population was 9 409 619 individuals in 46 states and Washington, DC, 305 323 (3.2%) of whom are defined as individuals with CMCs (eTable 5 in [Supplement 1](#)). Individuals with a CMC were less likely to be female and more likely to be Medicaid eligible through a disability-based instead of an income-based pathway relative to those without a CMC. Individuals with and without CMCs were equally likely to live in states with policies that might promote coverage retention, including Medicaid expansion, medically needy eligibility pathways, and transition waivers. More details about this cohort, including state-specific prevalence of individuals with CMCs, are in eTable 6 in [Supplement 1](#) and previously published work.³⁶

Probability of Disenrollment by Age

The unadjusted rate of disenrollment was 57.3% among individuals without CMCs and 27.1% among individuals with CMCs (eTable 7 in [Supplement 1](#)). Conditional probability of disenrollment peaked at age 19 years among individuals with and without CMCs (Figure 1; eTable 8 in [Supplement 1](#)). Our main estimates found the conditional probability of disenrollment was 13.4% (95% CI, 13.2%-13.6%) for individuals at age 19 years with a CMC and 35.6% (95% CI, 35.6%-35.7%) for individuals without a CMC, compared with 4.5% (95% CI, 4.4%-4.7%) and 10.3% (95% CI, 10.3%-10.4%), respectively, at age 16 years ($P < .001$ for both comparisons; eTable 8 in [Supplement 1](#)). After age 19 years, the probability of disenrollment declined for both groups, although it remained elevated above the risk at age 16 years (all comparisons statistically significant).

Figure 2. Conditional Probability of Disenrollment for Individuals With Complex Medical Conditions at Age 19 Years by State



This US map shows the conditional probability of disenrollment for individuals with complex medical conditions at age 19 years. Probabilities are generated with predictions from state-specific logistic regressions that include age in categories, an interaction term to allow for differences at each age for individuals with and without a complex medical condition and calendar year fixed-effects. Individuals are assigned the state they resided in in 2016. Source: Authors' analysis of Transformed Medicaid Statistical Information System Analytic Files (TAF) data (2016-2019).

When disenrollment spells were defined as 6 months without Medicaid, the overall pattern looked similar, although attenuated. Unadjusted total disenrollment was 20.2% among individuals with CMCs and 47.1% among individuals without CMCs. At age 19 years, conditional probability of disenrollment was 10.2% (95% CI, 10.0%-10.4%) among individuals with CMCs and 29.0% (95% CI, 29.0%-29.1%) among individuals without CMCs (eTable 8 in *Supplement 1*). Estimates did not change substantially using states with only high-quality data (eTable 9 in *Supplement 1*).³³

Variation by Medical Condition

Compared with our main results, patterns of disenrollment by age were similar across types of complex conditions and body system involvement (eFigure 1 in *Supplement 1*). However, the magnitude of each spike at age 19 years differed by condition (eFigure 2, eTable 10 in *Supplement 1*). For example, the conditional probability of disenrollment for individuals with a mental health condition was 25.9% (95% CI, 25.8%-26.1%) at age 19 years compared with 6.0% (95% CI, 5.4%-6.6%) for individuals with genetic conditions.

Variation by State

States varied considerably in patterns and likelihood of disenrollment across age. At age 19 years, the conditional probability of disenrollment for individuals with CMCs was near or above 30% in some states (Alabama, Pennsylvania, Mississippi, Nebraska, Wyoming, South Dakota, and Georgia) and less than 10% in others (eg, Kentucky, Colorado, Michigan, Louisiana) (Figure 2; eFigure 3 in *Supplement 1*). States with high disenrollment among individuals with CMCs tended to

have high disenrollment among those without CMCs (eg, Alabama, Mississippi, South Dakota, and Georgia) (eTable 11 in *Supplement 1*). Utah is an exception; the probability of disenrollment among individuals with a CMC at age 19 was relatively low (8.3%; 95% CI, 5.6%-11.0%) but among individuals without a CMC was relatively high (74.3%; 95% CI, 73.3%-75.3%).

In contrast to national patterns, not all states had a disenrollment spike at age 19 years (eFigure 4 in *Supplement 1*). North Carolina and New York, for example, had a higher probability of disenrollment at age 21 years than at age 19 years for both individuals with and without a CMC. Other states, including Colorado and Iowa, had spikes in disenrollment at age 19 years only among individuals without CMCs. Still other states (eg, Arizona and Oregon) showed markedly higher risks of disenrollment for adults (>19 years) compared with adolescents but no age-specific spike.

Individual and State Characteristics Associated With Disenrollment

Being female, eligibility through SSI or another disability pathway, and, for individuals with CMCs, having more than 1 body system involved were all associated with a decrease in the conditional probability of disenrollment (Table), although with varying magnitudes. For example, for the CMC population, being female reduced risk of disenrollment by 0.4 percentage points (ppts) (95% CI, -0.5 to -0.3 ppts), while being enrolled through SSI reduced risk by 11.8 ppts (95% CI, -12.0 to -11.7 ppts; $P < .001$ for both comparisons).

Living in a state with Medicaid expansion was associated with a 4.8 ppt (95% CI, -5.0 to -4.7 ppts) reduction in probability of disenrollment among individuals with CMCs and a 13.0 ppt (95% CI, -13.1 to -13.0 ppts) reduction among individuals without CMCs, about a 60% relative decrease for both groups. States with managed care penetration above 50% had increased risk of disenrollment from Medicaid among both individuals with and without CMCs. For the largest group, states with managed care penetration of 66% to 80%, risk of disenrollment increased by 2.3 ppt (95% CI, 2.0-2.6 ppts) for individuals with CMCs and 4.3 ppt (95% CI, 4.2-4.4 ppts) for individuals without CMCs relative to no managed care penetration.

Cumulative Probability of Disenrollment: Overall and by State

Cumulative disenrollment from ages 19 to 21 years for individuals with CMCs was 37.9% (95% CI, 37.3%-38.6%) and 74.2% (95% CI, 74.1%-74.3%) for individuals without CMCs (Figure 3; eTable 12 in *Supplement 1*). Consistent with conditional probabilities, drops in disenrollment were concentrated shortly after enrollees' 19th birthday and continued steadily through the next 36 months.

Redefining disenrollment as 6 or more months without comprehensive Medicaid resulted in similar patterns with slightly lower magnitudes: 31.4% (95% CI, 30.7%-32.1%) of individuals with CMCs and 66.0% (95% CI, 65.9%-66.1%) of individuals without CMCs disenrolled (eFigure 5, eTable 12 in *Supplement 1*). Using only states with high-quality enroll-

Table. Associations of Age, Individual, and State Policy Characteristics With Medicaid Disenrollment

Characteristic	Marginal effect (95% CI) ^a	
	Teens and young adults with CMCs	Teens and young adults without CMCs
Age, y		
16	1 [Reference]	1 [Reference]
17	0.002 (0.000 to 0.004)	0.010 (0.001 to 0.011)
18	0.032 (0.03 to 0.034)	0.080 (0.080 to 0.081)
19	0.089 (0.087 to 0.092)	0.245 (0.245 to 0.246)
20	0.031 (0.029 to 0.034)	0.125 (0.124 to 0.126)
21	0.048 (0.046 to 0.051)	0.162 (0.161 to 0.162)
22	0.033 (0.031 to 0.036)	0.129 (0.128 to 0.13)
23	0.033 (0.03 to 0.035)	0.126 (0.126 to 0.127)
24	0.032 (0.03 to 0.035)	0.121 (0.12 to 0.121)
25	0.032 (0.03 to 0.035)	0.115 (0.114 to 0.115)
26	0.055 (0.052 to 0.058)	0.142 (0.142 to 0.143)
Individual characteristics		
Sex		
Male	1 [Reference]	1 [Reference]
Female	-0.004 (-0.005 to -0.003)	-0.038 (-0.038 to -0.038)
Body system involvement		
1	1 [Reference]	NA
2	-0.01 (-0.011 to -0.009)	NA
3	-0.024 (-0.026 to -0.021)	NA
4	-0.031 (-0.037 to -0.025)	NA
≥5	-0.047 (-0.06 to -0.034)	NA
Eligibility pathway		
Income	1 [Reference]	1 [Reference]
SSI	-0.118 (-0.12 to -0.117)	-0.161 (-0.161 to -0.160)
Other disability	-0.099 (-0.101 to -0.097)	-0.100 (-0.102 to -0.099)
State policy characteristics ^b		
Medicaid expansion state	-0.048 (-0.05 to -0.047)	-0.130 (-0.131 to -0.130)
Medically needy pathway of enrollment	-0.001 (-0.003-0.000)	-0.041 (-0.042 to -0.041)
Transition waiver	-0.036 (-0.038 to -0.035)	-0.038 (-0.039 to -0.037)
Managed care penetration, %		
0	1 [Reference]	1 [Reference]
1-50	-0.003 (-0.007 to 0.000)	0.016 (0.015 to 0.017)
51-65	0.029 (0.025 to 0.033)	0.046 (0.045 to 0.048)
66-80	0.023 (0.020 to 0.026)	0.043 (0.042 to 0.044)
81-100	0.030 (0.027 to 0.034)	0.048 (0.047 to 0.049)
Constant	0.080	0.202
No. observations	878 122	22 296 761
No. individuals	277 330	8 122 091

Abbreviations: CMC, complex medical condition; NA, not applicable; SSI, Social Security Insurance.

^a Marginal effects can be interpreted as the change in probability of disenrollment from the reference group in each row; negative values signify a decline in disenrollment. Regressions of complex and noncomplex populations run separately using a logit specification that includes all covariates listed and calendar year fixed-effects. The following states were excluded due to insufficient data or a high degree of missingness about eligibility groups in 2016: Transformed Medicaid Statistical Information System Analytic Files (TAF) data: Maryland, Arkansas, Rhode Island, Maine, Tennessee, New Jersey, Vermont, North Dakota, Iowa, Washington, DC, Kansas, Oregon, and Alabama.

^b These covariates are binary indicators where reference group is states without each policy characteristic.

ment data did not substantially change estimates (eFigure 5 in [Supplement 1](#)).

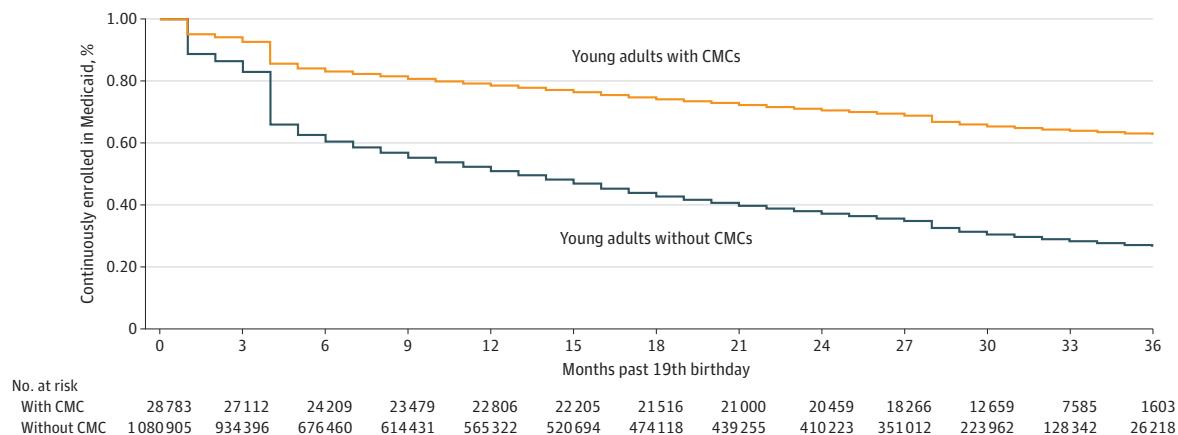
Cumulative disenrollment varied considerably by state. For individuals with CMCs, Kentucky has the lowest rate of disenrollment, retaining 89.8% of enrollees, and 2 other states (Iowa and Utah) retained more than 75% (Figure 4; eTable 12 in [Supplement 1](#)). In contrast, 5 states retained less than half of the 19- to 21-year-old population with CMCs. For the population without CMCs, the rate of retention was much lower; in most states, fewer than half of 19-year-old enrollees were continuously enrolled through age 21 years regardless of whether

disenrollment was defined as 2 or more or 6 or more months without Medicaid (eFigures 6-8 in [Supplement 1](#)).

Probability of Reenrollment

Probability of reenrollment was 29.1% (95% CI, 29.0%-29.1%) among individuals without CMCs and 38.0% (95% CI, 37.6%-38.4%) among individuals with CMCs (eTable 13 in [Supplement 1](#)). Individuals who reenrolled were disenrolled for a median (IQR) period of 5 months (3-8), with the plurality of individuals disenrolled for 2 months (eFigure 9 in [Supplement 1](#)). Individuals living in Medicaid expansion states and

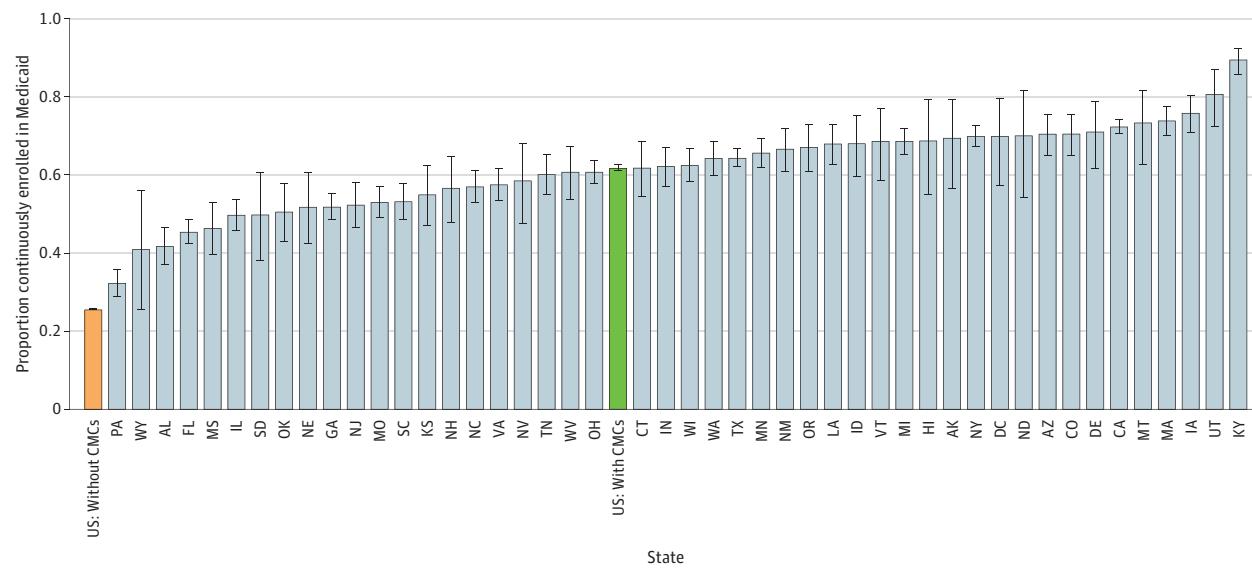
Figure 3. Kaplan-Meier Curve of Cumulative Disenrollment: Ages 19 to 22 Years



This Kaplan-Meier curve shows the cumulative rate of disenrollment for individuals who turn 19 years in 2017, from 1 month prior to their 19th birthday for up to 37 months (December 2019). Disenrollment was defined as ≥ 2 months without comprehensive Medicaid. Disenrollment was measured at the

monthly level and included every 3 months in the x-axis for clarity of presentation. Source: Authors' analysis of Transformed Medicaid Statistical Information System Analytic Files (TAF) data (2016-2019). CMC indicates complex medical condition.

Figure 4. Proportion of Enrollees With Complex Medical Conditions (CMCs) Continuously Enrolled: Ages 19-21 Years



This Figure shows the proportion of individuals with a CMC continuously enrolled in a state Medicaid program 36 months after their 19th birthday. The percentage of continuous enrollment was measured with Kaplan-Meier curves run separately for each state; curves are in eFigure 7 in [Supplement 1](#), and estimates are in eTable 12 in [Supplement 1](#). Enrollees who died or continued

enrollment through the end of the sample period (December 2019) are right censored. Continuous enrollment was defined as consecutive months of enrollment with gaps of 0-1 months. Source: Authors' analysis of Transformed Medicaid Statistical Information System Analytic Files (TAF) data.

those with CMCs were more likely to reenroll compared with individuals without CMCs living in nonexpansion states (eFigure 10, eTable 13 in [Supplement 1](#)).

what protected but still experience significant coverage losses. Disenrollment spikes nationally at age 19 years, although levels and patterns vary by state and, for individuals with CMCs, by specific diagnosis. These results imply that 2 people born with different but equally severe conditions in different states may have a substantially different chance of retaining Medicaid coverage as they become adults.

The increase in disenrollment at age of adulthood is likely driven by changes in eligibility as individuals shift from child

Discussion

We find considerable attrition in Medicaid among emerging adults. Those with medically complex conditions are some-

to adult categories. However, it could also be caused by differences in renewal or redetermination policies or by changes in social supports, such as aging out of pediatric care or school systems that may help with enrollment. Differences among states likely reflect differences in Medicaid eligibility policies or operational procedures in each state. For example, in North Carolina, Massachusetts, New York, and Florida, there are specific eligibility rules that apply to 19- to 20-year-olds. In these states, disenrollment spikes at age 21 years rather than 19 years or, in the case of Florida, at both ages.⁴¹⁻⁴⁴

Cumulative rates of disenrollment were high between the ages of 19 and 22 years. Within these 3 years, nearly three-fourths of individuals without a CMC and 40% of those with a CMC experienced a disruption of at least 2 months in their insurance coverage. These findings may be somewhat sensitive to the time period of our study. The first year of disenrollment risk coincides with the beginning of the first Trump administration. Studies comparing gaps in insurance coverage during this time period to earlier years found few if any impacts on disenrollment in Medicaid population.^{45,46} Yet, even if incremental policy changes move estimates slightly year to year, the risk of disenrollment in this age group will likely remain high absent significant structural changes in how Medicaid handles transition from pediatric to adult eligibility.

The implications of our findings are particularly salient in the context of supports and services needed for care as adolescents with CMCs transition into adulthood and the barriers to receiving this care without insurance. Differences in disenrollment risk across states and conditions may drive health disparities, increasing risks of morbidity and mortality in states with higher rates of disenrollment.⁴⁷⁻⁴⁹ These states may see short-term savings with fewer beneficiaries, which may be attenuated by longer-term declines in population health or increases in uncompensated care.^{50,51} Future work may wish

to connect differential rates of disenrollment to state- or condition-specific risks and spending.

Limitations

While we had very detailed and granular information on Medicaid enrollment, a key limitation is that we were unable to observe why people disenroll or what happens to our population when they are not in Medicaid. The high rate of reenrollment within a year suggests that many do not lose all eligibility and do not have another source of insurance. Previous work has also shown losing Medicaid results in uninsurance for many, and in some cases most, individuals.^{2,4,46,52} A second limitation of this work is that estimates of state policy or individual characteristic correlations with enrollment are associational—they are not meant to imply causality. Finally, other years may show different magnitudes of disenrollment. Our study examined the most recent data available at study initiation not subject to continuous coverage provisions during the COVID-19 public health emergency.

Conclusions

This cohort study found a high level of Medicaid disenrollment at age 19 years among all enrollees and specifically among those with medical complexity and highlights this age as a particular risk factor for insurance disruptions. The findings show considerable variation in risk of losing Medicaid by both geography and, for those with CMC, by diagnosis. This description provides an example of the patchwork and somewhat arbitrary nature of health insurance that is a key feature of the US health system. This work adds to evidence that the myriad policies that govern Medicaid coverage result in differential risks of disenrollment by condition and geography, which can lead to disparities in health care access and health.

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REFERENCES

- Wallace J, Sommers BD. Health insurance effects on preventive care and health: a methodologic review. *Am J Prev Med*. 2016;50(5)(suppl 1):S27-S33. doi:10.1016/j.amepre.2016.01.003
- Sommers BD. From Medicaid to uninsured: drop-out among children in public insurance programs. *Health Serv Res*. 2005;40(1):59-78. doi:10.1111/j.1475-6773.2005.00342.x
- Tello-Trillo DS. Effects of losing public health insurance on preventative care, health, and emergency department use: evidence from the TennCare disenrollment. *South Econ J*. 2021;88(1):322-366. doi:10.1002/soej.12504

4. Sugar S, Peters C, De Lew N, Sommers BD. Medicaid churning and continuity of care: evidence and policy considerations before and after the COVID-19 pandemic. Office of Health Policy, Assistant Secretary for Planning and Evaluation. Accessed January 8, 2026. <https://aspe.hhs.gov/sites/default/files/documents/5f6e4d78d867b6691df12d1512787470/medicaid-churning-ib.pdf>
5. Corallo B, Garfield R, Tolbert J, Rudowitz R. Medicaid enrollment churn and implications for continuous coverage policies. Kaiser Family Foundation. Accessed January 8, 2026. <https://www.kff.org/medicaid/medicaid-enrollment-churn-and-implications-for-continuous-coverage-policies/>
6. Cohen E, Kuo DZ, Agrawal R, et al. Children with medical complexity: an emerging population for clinical and research initiatives. *Pediatrics*. 2011;127(3):529-538. doi:10.1542/peds.2010-0910
7. Cohen E, Berry JG, Camacho X, Anderson G, Wodchis W, Guttman A. Patterns and costs of health care use of children with medical complexity. *Pediatrics*. 2012;130(6):e1463-e1470. doi:10.1542/peds.2012-0175
8. Yu JA, McKernan G, Hagerman T, Schenker Y, Houtrow A. Identifying children with medical complexity from the National Survey of Children's Health combined 2016-17 data set. *Hosp Pediatr*. 2021;11(2):192-197. doi:10.1542/hpeds.2020-0180
9. Coller RJ, Nelson BB, Sklansky DJ, et al. Preventing hospitalizations in children with medical complexity: a systematic review. *Pediatrics*. 2014;134(6):e1628-e1647. doi:10.1542/peds.2014-1956
10. McLellan SE, Mann MY, Scott JA, Brown TW. A blueprint for change: guiding principles for a system of services for children and youth with special health care needs and their families. *Pediatrics*. 2022;149(suppl 7):e2021056150C. doi:10.1542/peds.2021-056150C
11. Children and youth with special health care needs. Health Resources and Services Administration: Maternal & Child Health Bureau. Accessed January 8, 2026. <https://mchb.hrsa.gov/sites/default/files/mchb/programs-impact/nsch-data-brief-children-youth-special-health-care-needs.pdf>
12. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: results from the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2005;115(6):1562-1568. doi:10.1542/peds.2004-1262
13. Ilango S, Schmidt A, McManus M, White P. A five state case study: Black youth and young adults with disabilities aging out of Medicaid, CHIP, SSI, and Title V programs. The National Alliance to Advance Adolescent Health. Accessed January 8, 2026. <https://lpfch.org/wp-content/uploads/2024/05/Five-State-Case-Study.pdf>
14. Ellison JL, Brown RE, Ameringer S. Parents' experiences with health care transition of their adolescents and young adults with medically complex conditions: a scoping review. *J Pediatr Nurs*. 2022;66:70-78. doi:10.1016/j.pedn.2022.04.018
15. McManus M, Ilango S, White P, Schmidt A. A national report: youth and young adults with disabilities aging out of Medicaid, CHIP, SSI and Title V programs-barriers, inequities and recommendations. The National Alliance to Advance Adolescent Health. Accessed January 8, 2026. <https://lpfch.org/resource/a-national-report-aging-out/>
16. Hamideh D, Alvarez O. Sickle cell disease related mortality in the United States (1999-2009). *Pediatr Blood Cancer*. 2013;60(9):1482-1486. doi:10.1002/pbc.24557
17. Blinder MA, Duh MS, Sasane M, Trahey A, Paley C, Vekeman F. Age-related emergency department reliance in patients with sickle cell disease. *J Emerg Med*. 2015;49(4):513-522.e1. doi:10.1016/j.jemermed.2014.12.080
18. Ritchwood TD, Malo V, Jones C, et al. Healthcare retention and clinical outcomes among adolescents living with HIV after transition from pediatric to adult care: a systematic review. *BMC Public Health*. 2020;20(1):1195. doi:10.1186/s12889-020-09312-1
19. Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in spina bifida? a single center 7-year experience. *J Pediatr Urol*. 2017;13(1):40.e1-40.e6. doi:10.1016/j.jpurol.2016.09.020
20. Appleton R, Connell C, Fairclough E, Tuomainen H, Singh SP. Outcomes of young people who reach the transition boundary of child and adolescent mental health services: a systematic review. *Eur Child Adolesc Psychiatry*. 2019;28(11):1431-1446. doi:10.1007/s00787-019-01307-7
21. Jenkins AM, Berry JG, Perrin JM, et al. What types of hospitals do adolescents and young adults with complex chronic conditions use? *Acad Pediatr*. 2022;22(6):1033-1040. doi:10.1016/j.acap.2021.12.020
22. Butalia S, McGuire KA, Dyjur D, Mercer J, Pacaud D. Youth with diabetes and their parents' perspectives on transition care from pediatric to adult diabetes care services: a qualitative study. *Health Sci Rep*. 2020;3(3):e181. doi:10.1002/hsr.2181
23. Pullmann MD, Heflinger CA, Satterwhite Mayberry L. Patterns of medicare disenrollment for youth with mental health problems. *Med Care Res Rev*. 2010;67(6):657-675. doi:10.1177/1077558710369911
24. Carey ME, Tao S, Koffer Miller KH, et al. Association between Medicaid waivers and Medicaid disenrollment among autistic adolescents during the transition to adulthood. *JAMA Netw Open*. 2023;6(3):e232768-e232768. doi:10.1010/jamanetworkopen.2023.2768
25. Berry JG, Hall M, Neff J, et al. Children with medical complexity and Medicaid: spending and cost savings. *Health Aff (Millwood)*. 2014;33(12):2199-2206. doi:10.1377/hlthaff.2014.0828
26. Transitions between Medicaid, CHIP, and exchange coverage. Medicaid and CHIP Payment and Access Commission. Accessed January 8, 2026. <https://www.macpac.gov/publication/transitions-between-medicaid-chip-and-exchange-coverage/>
27. Cholera R, Anderson D, Raman SR, et al. Medicaid coverage disruptions among children enrolled in North Carolina Medicaid from 2016 to 2018. *JAMA Health Forum*. 2021;2(12):e214283. doi:10.1001/jamahealthforum.2021.4283
28. Shea LL, Field R, Xie M, Marcus S, Newschaffer C, Mandell D. Transition-age Medicaid coverage for adolescents with autism and adolescents with intellectual disability. *Am J Intellect Dev Disabil*. 2019;124(2):174-185. doi:10.1352/1944-7558-124.2.174
29. Wang G, Grembowski D, Watts C. Risk of losing insurance during the transition into adulthood among insured youth with disabilities. *Matern Child Health J*. 2010;14(1):67-74. doi:10.1007/s10995-009-0470-5
30. Shen Y, Sommers BD, Hatfield LA, Hayes C, Pandya A, Menzies NA. Insurance dynamics during childhood in the fragmented US health system. *JAMA*. 2025;334(17):1533-1540. doi:10.1001/jama.2025.15488
31. Transformed Medicaid statistical information system (T-MSIS) analytic files (TAF). US Centers for Medicare & Medicaid Services. Accessed January 8, 2026. <https://www.medicaid.gov/medicaid/data-systems/macbis/medicaid-chip-research-files/transformed-medicaid-statistical-information-system-t-msis-analytic-files-taf/index.html>
32. Schpiero WL, McConnell KJ, Bushnell G, et al. The T-MSIS analytic files (TAF) analysis reporting checklist: a guide for research using Medicaid claims data. *JAMA Health Forum*. 2025;6(10):e253622. doi:10.1001/jamahealthforum.2025.3622
33. Explore the quality and usability of the Medicaid and CHIP data in the T-MSIS analytic files. Medicaid and CHIP Business Information Solutions (MACBIS). Accessed September 18, 2024. <https://www.medicaid.gov/dq-atlas/welcome>
34. Simon TD, Cawthon ML, Stanford S, et al; Center of Excellence on Quality of Care Measures for Children with Complex Needs (COE4CCN) Medical Complexity Working Group. Pediatric medical complexity algorithm: a new method to stratify children by medical complexity. *Pediatrics*. 2014;133(6):e1647-e1654. doi:10.1542/peds.2013-3875
35. Simon TD, Haaland W, Hawley K, Lambka K, Mangione-Smith R. Development and validation of the Pediatric Medical Complexity Algorithm (PMCA) version 3.0. *Acad Pediatr*. 2018;18(5):577-580. doi:10.1016/j.acap.2018.02.010
36. Cliff BQ, Sinha S, Cross DA, et al. Prevalence of complex medical conditions among teens and young adults in Medicaid: national and state estimates. *J Adolesc Health*. 2025;77(2):308-315. doi:10.1016/j.jadohealth.2025.04.010
37. Leyenaar JK, Schaefer AP, Freyleue SD, et al. Prevalence of children with medical complexity and associations with health care utilization and in-hospital mortality. *JAMA Pediatr*. 2022;176(6):e220687-e220687. doi:10.1001/jamapediatrics.2022.0687
38. Cliff BQ, Miller S, Ayanian JZ, Kullgren JT, Hirth RA. Adverse selection in Medicaid: evidence from discontinuous program rules. *Am J Health Econ*. 2022;8(1). doi:10.1086/716464
39. Keim-Malpass J, Constantoulakis L, Letzkus LC. Variability in states' coverage of children with medical complexity through home and community-based services waivers. *Health Aff*.

(*Millwood*). 2019;38(9):1484-1490. doi:[10.1377/hlthaff.2018.05413](https://doi.org/10.1377/hlthaff.2018.05413)

40. Sommers BD, Kenney GM, Epstein AM. New evidence on the Affordable Care Act: coverage impacts of early Medicaid expansions. *Health Aff (Millwood)*. 2014;33(1):78-87. doi:[10.1377/hlthaff.2013.1087](https://doi.org/10.1377/hlthaff.2013.1087)

41. Dass D, Price M, Fung V. Expanding Medicaid eligibility for young adults: impact on coverage in Massachusetts. *Health Serv Res*. 2021;56:25-26. doi:[10.1111/1475-6773.13753](https://doi.org/10.1111/1475-6773.13753)

42. Medicaid eligibility. NC Medicaid Division of Health Benefits. Accessed November 15, 2025. <https://medicaid.ncdhhhs.gov/documents/files/basic-medicaid-eligibility-chart-2016-09-19/download>

43. Income eligibility chart: New York state marketplace coverage. City of New York. Accessed November 20, 2025. https://www.nyc.gov/assets/ochia/downloads/pdf/fpl_for_2017_open_enrollment_thru_103117_wkshp.pdf

44. Determining your income limit. Florida Department of Children and Families. Accessed November 20, 2025. <https://www.myflfamilies.com/medicaid/determining-your-income-limit>

45. Sommers BD, Clark KL, Epstein AM. Early changes in health insurance coverage under the Trump administration. *N Engl J Med*. 2018;378(11):1061-1063. doi:[10.1056/NEJMcl1800106](https://doi.org/10.1056/NEJMcl1800106)

46. Einav L, Finkelstein A. The risk of losing health insurance in the United States is large, and remained so after the Affordable Care Act. *Proc Natl Acad Sci U S A*. 2023;120(18):e2222100120. doi:[10.1073/pnas.2222100120](https://doi.org/10.1073/pnas.2222100120)

47. Levy H, Buchmueller TC. The impact of health insurance on mortality. *Annu Rev Public Health*. 2025;46(1):541-550. doi:[10.1146/annurev-publhealth-061022-042335](https://doi.org/10.1146/annurev-publhealth-061022-042335)

48. Wyse A, Meyer BD. Saved by Medicaid: new evidence on health insurance and mortality from the universe of low-income adults. US National Bureau of Economic Research. Accessed January 8, 2026. <https://www.nber.org/papers/w33719>

49. Miller S, Johnson N, Wherry LR. Medicaid and mortality: new evidence from linked survey and administrative data. *Q J Econ*. 2021;136(3):1783-1829. doi:[10.1093/qje/qjab004](https://doi.org/10.1093/qje/qjab004)

50. Buchmueller T, Levy H, Nikpay S, Rhodes J. The Healthy Michigan Plan PA 107 §105(d)(8-9) 2018 report on uncompensated care. State of Michigan. Accessed January 8, 2026. https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder4/Folder17/Folder3/Folder117/Folder2/Folder217/Folder1/Folder317/Report_on_Uncompensated_Care_December_31_2019.pdf?rev=89430f61a41746b28c468f08e7a6ff2d

51. Dranove D, Garthwaite C, Ody C. Uncompensated care decreased at hospitals in Medicaid expansion states but not at hospitals in nonexpansion states. *Health Aff (Millwood)*. 2016;35(8):1471-1479. doi:[10.1377/hlthaff.2015.1344](https://doi.org/10.1377/hlthaff.2015.1344)

52. Frenier C, McIntyre A. Insurance coverage transitions after disenrollment from Medicaid in Minnesota. *JAMA Netw Open*. 2023;6(4):e239379-e239379. doi:[10.1001/jamanetworkopen.2023.9379](https://doi.org/10.1001/jamanetworkopen.2023.9379)