

Policy Brief on Medicaid & CHIP: Recommendations to Assist Youth and Young Adults with Disabilities Aging Out of Medicaid & CHIP

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Introduction

This policy brief examines the change when low-income youth and young adults with disabilities lose their childhood eligibility status under Medicaid and the Children's Health Insurance Program (CHIP). It is part of a [larger national study](#) on aging out of public programs, including Medicaid, CHIP, Supplemental Security Income (SSI), and Title V Programs for Children and Youth with Special Health Care Needs (CYSHCN).¹ Public insurance and disability programs define eligibility criteria for adults more restrictively than for children, and in the case of CHIP, the program ends at age 19. Consequently, many young adults with disabilities lose access to public program benefits that they have relied on for years, despite their continued need for support.

Over the past several decades, little attention has been paid to this vulnerable transition-aged population by federal and state policymakers, public programs, and advocacy groups. This research aims to bring new awareness to the changes that low-income youth with disabilities face as they age into adulthood; uncover eligibility and enrollment challenges, inequities, and impacts; and provide policy and program strategies to reduce disruptions and disparities in access to adult public program services.

Methods

This research was conducted from July 2022 to April 2024 and funded by the Lucile Packard Foundation for Children's Health and the WITH Foundation. Methods included:

- **Analysis of the 2017–2021 American Community Survey** to learn about disability prevalence as well as insurance status, income level, and racial disparities among youth and young adults with disabilities.
- **Literature review** of published articles, grey and white papers, and public program documents.
- **Online survey** of separate CHIP program representatives in the 33 states with separate programs.
- **Key informant interviews** with 25 officials from national organizations and federal agencies that represent Medicaid, CHIP, SSI, and Title V, along with family/disability advocates, legal advocates, and researchers; ten national disability advocacy organizations to elicit information about aging out challenges experienced by Black youth and young adults with intellectual and/or developmental disabilities; and six young adult self-advocates to hear about their lived experience.
- **Analysis of Medicaid managed care organization (MCO) contracts.** This included a review of 40 standard MCO contracts, in effect as of July 2023, along with three specialty MCO contracts.

Findings

Background

Thirty percent of youth, ages 12-18, were publicly insured, between 2017 and 2021; among those 19-25 with a disability, the percentage dropped in half to 15%.² This decline in public insurance coincides with the ending of CHIP eligibility at age 19 and the ending of childhood Medicaid eligibility between 19 and 21, depending on the state. For a sizeable population of young adults with disabilities (13%), this shift all too often results in loss of insurance. Black young adults with disabilities experience higher rates of uninsurance than White young adults with disabilities (15.4% vs 10.5%).

Using the broader definition of CYSHCN, an even greater proportion are publicly insured. In 2017, Medicaid and CHIP covered almost half of CYSHCN under age 18 (47%).³ Most of these CYSHCN were poor or near poor, 27% were Black, and 41% were ages 12-17. No current literature was found on the characteristics and impacts of young adults with disabilities aging out of Medicaid or CHIP.

Age and Income Cut-Offs

State Medicaid agencies set their age cut-offs for children between 19 and 21 years of age. For those over the age limit, options for remaining on Medicaid differ by state, income, and disability eligibility pathways. It is estimated that less than 15% of Medicaid-insured children with disabilities receive SSI.³ Thus, the vast majority of those with disabilities qualify on the basis of their family's low income, not via disability-related pathways.³ As of April 2024, ten states have not expanded Medicaid (AL, GA, FL, KS, MS, SC, TN, TX, WI, WY). In these states, adults can only qualify via a disability, pregnancy/parenting, foster care pathway, or, in GA, meet a work requirement through their Pathway to Coverage program. In several states, including one non-expansion state (FL), the income level to qualify is higher for low-income adults ages 19 and 20. In FL, they can qualify if their income is at or below 24% of poverty; those 21 and over do not qualify.⁴ Young adults with disabilities living in expansion states were 11% more likely to have insurance coverage compared to those living in non-expansion states. They were also less likely to experience delayed health care and more likely to receive needed care.⁵ States have established more generous income eligibility levels under Medicaid for children under 18 than for adults. States have established more generous income eligibility levels under Medicaid for children than for adults. Starting January 2024, Congress passed the continuous eligibility requirement which requires all states to provide children enrolled in Medicaid and CHIP with a full year of eligibility, regardless of changes in family circumstances. This policy change helps ensure that children do not experience disruptions in their health care coverage over the span of the year or face unnecessary administrative barriers to stay enrolled in the program.

The age cut-off for CHIP is 19. Estimates of the number of young adults aging out of CHIP are not publicly available. As a result of this gap in published information, the authors conducted a survey of separate CHIP program representatives and obtained a 45% response rate. When asked about estimates of those aging out (irrespective of disability status), states reported varying estimates: < 1,000 (KY, MT, NV, UT), 1,000-5,000 (AL, KS, MO), and 5,001-10,000 (CA, NJ, VA, WA). The remaining states (ID, IN, MA, PA) were unsure how many young adults age out.

Medicaid MCO Aging Out Provisions

Authority for determining eligibility ultimately rests with the state Medicaid agency, not the MCO. Sixteen (out of 40) general MCO contracts and two (out of three) specialty MCO contracts reviewed specified a role for MCOs in assisting with eligibility renewals/redeterminations, ranging from having staff available to answer questions, assistance with completing forms, and help with obtaining required documentation to process the application. Few states included anything in their EPSDT program requirements about outreach and informing youth and families about aging out of this expansive child benefit. Four general MCO contracts mentioned aging out of EPSDT but did not include details about what support MCOs should provide. Two specialty MCO contracts included requirements to provide guidance about transition planning in advance of those with disabilities aging out (DC, TX).

CHIP Aging Out Strategies

All state CHIP survey respondents (15) reported that they notify youth and their families when CHIP eligibility ends, but there is variation in the timing of the notification (ten days to four months prior). States described additional information that is included with the notices, including applications for Medicaid or marketplace coverage or a request for information needed to complete a review to determine eligibility for other programs. Almost three-quarters of CHIP survey respondents (11 out of 15) said they provide referral assistance to help young adults enroll in health insurance coverage. About half (7) have policy or administrative requirements to document whether referrals were made. Also, in about half (7), youth with SHCN or disabilities were evaluated for eligibility for waiver programs, and if found to be eligible, a referral was made.

Challenges and Inequities

The literature and key informant interviews identified two common structural barriers facing young adults with disabilities seeking to remain on Medicaid: 1) the lower income eligibility standards for adults versus children, and 2) the number of states that have not expanded Medicaid. Since many youth with disabilities become eligible for Medicaid via income and not disability pathways, the lower income eligibility cut-off represents a major impediment to remaining insured. Long waitlists for waivers were also repeatedly mentioned. Other barriers reported include:

- Lack of sufficient and accessible notice when eligibility ends.
- Not all Medicaid online applications are mobile phone friendly.
- Some state Medicaid computer systems have not been programmed to make an ex parte determination for those with a disability.
- Communication between Medicaid and marketplace coverage is often problematic – applications get lost, there are different ways of looking at income, and people can get referred back and forth between programs.
- Limited availability of navigators or people to help enrollees remain insured. “Case managers and navigators are few and far between.”)
- Lack of awareness among youth and youth adults with and without disabilities and their families/caregivers of insurance changes and different options, as well as the documentation requirements that are called for. “Young adults may never have had to look for insurance before, understand what their options are, and what certain terms mean.” “There are misconceptions that things seamlessly happen and that different systems are communicating, when that is not the case.” “Everything is last minute, and there is panic to try and figure out what to do next.”

Recommendations*

Program and Policy Reform

1. Encourage state Medicaid agencies to develop MCO contract provisions related to transitions in coverage for youth and young adults with disabilities. (CMS, state Medicaid agencies)
2. Identify flexibilities from the PHE unwinding that can be made permanent and lessons learned from the unwinding experience to help keep transition-aged youth and young adults, especially those with disabilities, connected to Medicaid coverage. (CMS, state Medicaid agencies)
3. Encourage state 1115 demonstration waiver applications to address health-related social needs in life transitions by extending Medicaid childhood eligibility and benefits for those with SHCN up to the age of 26 to reduce disruptions in care and services, similar to Oregon’s 2022-2027 Medicaid Demonstration Waiver. Alternatively, create either a state Medicaid eligibility plan option or a waiver option to extend the childhood age limit to age 26, with corresponding childhood benefits. (CMS, Congress)
4. Ensure that states are making timely and legally required ex parte redeterminations for individuals with disabilities. Increase data transparency and incentivize states to improve ex parte rates. Address deficiencies identified through recent litigation in TN, NC, and FL that surface challenges with Medicaid redeterminations through disability pathways. (CMS and Congress)
5. Establish a national uniform definition of childhood eligibility for Medicaid and CHIP at either under 21 (which is consistent with EPSDT) or under 26 (which is consistent with the ACA dependent child definition). The federal match (FMAP) for this group, who would otherwise fall into the expansion group, would be 90%. (Congress)
6. Allow all SSI recipients automatic qualification for Medicaid without having to submit a separate Medicaid application. (Congress)

Transition Supports

7. Encourage documentation in patients' medical records of whether a youth or young adult receives Medicaid, CHIP, SSI, Title V, and/or special education services. Clinicians (e.g., physicians, nurses, social workers) should alert patients to eligibility changes before they turn 18 and ensure their medical summary is up to date. (State Medicaid agencies, IT vendors/EMR industry, clinicians)
8. Create an aging out assessment checklist for state Medicaid agencies to conduct with their MCOs to ensure soundness of their aging out policies and practices. Also, provide technical assistance/support to help states implement and enhance their processes around youth and young adults with disabilities and special needs who are aging out, like the previous Medicaid Innovation Accelerator [Program](#). (CMS)

Outreach, Education, and Collaboration

9. Develop state Medicaid guidance on outreach and informing of Medicaid-insured youth and their families/caregivers 12-24 months before they age out of Medicaid. Outreach should include informing the individuals of the benefit changes that will result when they no longer qualify for Medicaid as a child, along with case management to tie them to insurance and medical, social, and other supports in preparation of their aging out. Such guidance should encourage coordination between agencies to ensure that accommodations under the ADA and Section 504 are discussed and implemented prior to aging out and that care continuity following the loss of EPSDT is encouraged. (CMS)
10. Ensure Medicaid members receive materials/resources that clearly communicate the age cut-off, implications for transitioning out of the child Medicaid eligibility category, and availability of other Medicaid coverage pathways. (CMS)
11. Collaborate at national, regional, and state levels to facilitate disability and insurance application assistance, data sharing, simplified applications, targeted outreach, and coordinated benefits counseling for transition-aged youth and young adults with disabilities and their families/caregivers. (CMS)

Evaluation, Review, and Data-Driven Actions

12. Develop collaborative demonstration programs between Medicaid, CHIP, SSA, school special education transition programs, Title V CYSHCN programs, and community-based organizations to facilitate preparation for aging out of special education/504 plans, insurance, income support programs, and Title V in order to access continuous health care and coverage. (CMS, SSA, Dept of Education, MCHB)
13. Monitor and report on changes in retention in Medicaid, loss of coverage among young adults with disabilities who age out of Medicaid and CHIP and who should be eligible for Medicaid or marketplace coverage, and rates of transition to alternate Medicaid pathways or marketplace coverage, with particular attention to disparities by race, ethnicity, eligibility pathway, and state. (CMS)
14. Examine the availability of public system supports that promote clear pathways to disability benefits, public health insurance eligibility, adult health care, and other adult system supports. (GAO)

* Responsible agencies are listed in parentheses

Conclusions

Medicaid and CHIP represent two of the most important public programs for low-income youth with disabilities. The risk of losing insurance during the transition to adulthood among publicly insured young adults with disabilities is substantial. This population cannot afford to lose access to needed primary, specialty, behavioral, and ancillary health care services when they become adults. Despite numerous efforts by CMS and states to streamline and coordinate Medicaid, CHIP, and marketplace coverage options, additional focused efforts are needed to better inform, prepare, facilitate, and expand continuity of coverage and care for youth and young adults with disabilities and their families. For more information, please contact Peggy McManus at mmcmanus@TheNationalAlliance.org.

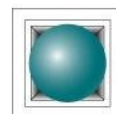
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