



THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH



A National Report:
**Youth and Young Adults with Disabilities Aging Out of
Medicaid, CHIP, SSI, and Title V Programs**
Barriers, Inequities, and Recommendations

May 2024

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The Lucile Packard Foundation for Children's Health raises funds for child and maternal health at Lucile Packard Children's Hospital Stanford and the Stanford School of Medicine. The Foundation also invests in and shapes programs for children with complex medical needs by playing a pivotal role in developing national care coordination standards and improving communication between county-level agencies, as well as identifying and overcoming adoption barriers at the state level, investing in best practices research, and helping states determine how to finance care-coordination services. For more information about the Lucile Packard Foundation for Children's Health, please visit lpfch.org.

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Established in 2002, the WITH Foundation is a private foundation whose mission is to promote the establishment of comprehensive health care for adults with developmental disabilities that is designed to address their unique and fundamental needs. The Foundation's initial grantmaking benefited the disability community. In 2011, the Foundation began to focus its support on organizations and projects that promote the establishment of comprehensive and accessible health care for adults with intellectual and developmental disabilities. For more information about the WITH Foundation, please visit WITHFoundation.org.

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The National Alliance to Advance Adolescent Health is a nonprofit organization whose mission is to achieve long-term, systemic improvements in comprehensive health care and insurance coverage for adolescents, with focused attention on those from low-income families, racially and ethnically diverse groups, and with special health care needs. Through policy analysis, technical assistance, quality improvement, and advocacy, The National Alliance works to promote effective transitions from pediatric to adult health care as part of its Got Transition program. In collaboration with others, The National Alliance also works to expand the availability of adolescent-centered care, access to mental and behavioral health services, and improvements in health insurance coverage for adolescents and young adults. For more information about The National Alliance, please visit TheNationalAlliance.org. For more information about Got Transition, please visit GotTransition.org.

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List of Acronyms

ACA: Affordable Care Act

ACF: Administration for Children and Families

ACL: Administration for Community Living

ACS: American Community Survey

ADA: Americans with Disabilities Act

ADHD: Attention-Deficit/Hyperactivity Disorder

CDR: Continued Disability Review

CHIP: Children's Health Insurance Program

CMS: Centers for Medicare and Medicaid Services

CYSHCN: Children and Youth with Special Health Care Needs

EMR: Electronic Medical Record

EPSDT: Early and Periodic Screening, Diagnostic, and Treatment

FMAP: Federal Medical Assistance Percentages

GAO: Government Accountability Office

HRSA: Health Resources and Services Administration

ID/DD: Intellectual and/or Developmental Disabilities

IT: Information Technology

LGBTQA+: Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Intersex, Asexual, and More

MCHB: Maternal and Child Health Bureau

MCO: Managed Care Organization

NH: Non-Hispanic

PHE: Public Health Emergency

SAMHSA: Substance Abuse and Mental Health Services Administration

SHADAC: State Health Access Data Assistance Center

SHCN: Special Health Care Needs

SNAP: Supplemental Nutrition Assistance Program

SOAR: SSI/SSDI Outreach, Access, and Recovery

SSA: Social Security Administration

SSI: Supplemental Security Income

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Executive Summary

Problem Statement. Low-income youth with disabilities are at risk of losing coverage, disability income supports, and continuity of care when they transition into adulthood. To bring new attention to the challenges faced by this population, The National Alliance to Advance Adolescent Health undertook a two-year effort to examine the experience when youth and young adults with disabilities age out of Medicaid, the Children's Health Insurance Program (CHIP), the Supplemental Security Income (SSI) program, and Title V Programs for Children and Youth with Special Health Care Needs (CYSHCN). Guided by a National Advisory Committee, this report presents recommendations to address gaps, complexities, and disparities for each of the public programs studied. The recommendations were drawn from the findings from key informant and self-advocate interviews, literature and program document reviews, online surveys, analysis of national survey data, and a five-state case study. The following products were produced: a national report; three separate policy briefs for Medicaid and CHIP, SSI, and Title V; and a case study examining five non-Medicaid expansion states to obtain a deeper understanding of the aging out experience among Black young adults with disabilities.

Medicaid and CHIP. The decline in public coverage between youth and young adults with disabilities is precipitous (30% to 15%, respectively). Lower adult income criteria and lack of Medicaid expansion in selected states pose as roadblocks to continuous coverage and care, along with insufficient notification and lack of navigation assistance when childhood eligibility ends. Recommendations call for optional and mandatory eligibility expansions, proactive state and managed care organization (MCO) aging out preparation practices, and cross-agency demonstrations to facilitate coordinated access to coverage during this transition.

SSI. At age 18, when SSI is redetermined based on more restrictive adult disability standards, about 48% of those enrollees lose all their SSI benefits. Complex and burdensome application and documentation requirements and more restrictive adult disability criteria were commonly reported challenges. Recommendations call for delaying the age for adult eligibility redetermination, creating a simplified application process, improving the Continued Disability Review (CDR) communication, and examining state variation in applications and redeterminations by age, race, and disability criteria.

Title V. There is no adult public health counterpart for the Title V Maternal and Child Health Block Grant Program, which typically uses an age cut-off of 21 for its CYSHCN Program. Populations reported to face greater risks in accessing adult services were from racial and ethnic minoritized groups, immigrants, those in rural areas, those with complex conditions, and those with significant intellectual and/or developmental disabilities (ID/DD). Recommendations call for extending the childhood eligibility age with increased funding, establishing consistent processes for informing families and tracking the number who age out, and increasing family and interagency partnerships to implement coordinated transitions into adult programs.

Black Young Adults with ID/DD. The most common challenge mentioned during interviews was systemic disparities, stemming from delayed or limited diagnostic evaluations, bias in schools and public programs, disproportionate rates of school suspensions, and involvement in child welfare and criminal justice systems, each of which results in distrust of public systems. Populations of Black young adults with ID/DD facing greatest challenges with aging out include those with behavioral health conditions, those whose parents have ID/DD or reside in a multi-disabled household, those who are pregnant, those who are non-verbal, and those with unstable housing.

Conclusions. To ensure safe and continuous coverage, income stability, and care for youth and young adults with disabilities aging out of public program services, this report calls on Congress; federal and state agencies; national, state, and community-based organizations and advocates; and health professional organizations to focus new attention on the wide-ranging recommendations called for in this report.

Introduction

This report examines the shift experienced by low-income youth and young adults with disabilities when they lose their childhood eligibility status under Medicaid, CHIP, SSI Program, and the state Title V Program for CYSHCN. Public programs define eligibility criteria for adults more restrictively than for children, and in the case of CHIP and Title V, the programs end. Consequently, many low-income youth and young adults with disabilities lose access to public program benefits that they relied on for years, despite their continued need for supports.

Medicaid, CHIP, SSI, and Title V play important and distinct roles in supporting low-income children, youth, and young adults with disabilities and special health care needs (SHCN). Medicaid and CHIP extend comprehensive health insurance coverage to millions of children; SSI provides income supports to children and adults with disabilities and vital connections to Medicaid; and Title V helps to improve coordinated systems of services for CYSHCN. What happens during this shift from child to adult serving systems for youth and young adults with disabilities can have major impacts on their health and well-being.

Over the past several decades, there has been little attention paid by federal and state policymakers, public programs, and advocacy groups to this vulnerable transition-aged population. This report aims to 1) bring new attention to the shift that low-income youth and young adults with disabilities face as they age into adulthood; 2) uncover eligibility and enrollment challenges, inequities, and impacts; 3) identify challenges faced by Black young adults with disabilities, including those with ID/DD, in five states that did not expand Medicaid; and 4) recommend policy and program strategies to reduce disruptions and disparities in access to adult public program services. In addition, a corresponding report, *A Five State Case Study: Black Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs*, describes access issues and challenges faced by Black young adults with disabilities, including those with ID/DD, when they lose their childhood eligibility for public programs in Alabama, Florida, Georgia, Mississippi, and Texas. Click [here](#) to learn more.

Methods

This research was conducted from July 2022 to April 2024 and funded by the Lucile Packard Foundation for Children's Health. Supplemental funding was provided by the WITH Foundation to examine the experience of Black young adults with ID/DD. This effort was guided by a National Advisory Committee (Appendix A) that represented Medicaid, SSI, and Title V programs, researchers, and advocates. The Committee met virtually five times over the course of two years and participated between meetings in providing review and feedback on drafts. A combination of quantitative and qualitative methods, summarized below, was used to better understand the change from child to adult public programs, including a national survey data analysis, literature reviews, Medicaid MCO contract analysis, key informant interviews, online surveys, and a five-state case study.

1. **Analysis of the 2017–2021 American Community Survey (ACS)** was completed by the University of Minnesota’s State Health Access Data Assistance Center (SHADAC), using the Public Use Microdata Sample Files. Special tabulations were prepared for the US and for the five-state analysis for youth (12-18) and young adults (19-25) to learn about disability prevalence as well as insurance status, income level, and Black/White disparities among those with disabilities.
2. **Literature review of published articles, grey and white papers, and public program documents.** The purpose was to obtain program enrollment information, estimates of young adults losing eligibility, aging out challenges and risk factors, disparities, and strategies and recommendations (Appendix B).
3. **Online surveys with separate CHIP and Title V CYSHCN programs.** For CHIP programs, a survey was sent to program directors in the 33 states with separate CHIP programs to elicit information about the estimated size of those aging out and outreach and referral strategies used to inform youth and families when CHIP ends. For state Title V CYSHCN programs, a survey was sent to all 51 state directors about their outreach and referral efforts as well as their age cut-offs and estimates of the population aging out.
4. **Analysis of Medicaid MCO contracts.** A review of 40 general MCO contracts and three specialty MCO contracts, in effect as of July 2023, was conducted to understand the roles MCOs play with respect to eligibility renewal/redetermination, outreach and informing about changes in Medicaid eligibility, and interagency efforts for coordinating transitions.

5. **Key informant interviews.** 25 key informant interviews were conducted with officials from national organizations and federal agencies that represent Medicaid, CHIP, SSI, and Title V, along with family/disability advocates, legal advocates, and researchers (Appendix C). These virtual interviews elicited perspectives on challenges faced by youth and young adults with disabilities, particular barriers affecting Black young adults, and current strategies underway to address these challenges. In addition, ten key informant interviews were conducted with national disability advocacy organizations to elicit information about aging out challenges experienced by Black youth and young adults with ID/DD and their families/caregivers as well as recommendations to help Black young adults with developmental disabilities.
6. **A five-state case study** examines access issues and challenges faced by Black young adults with disabilities, including those with ID/DD, when they lose their childhood eligibility for public programs in Alabama, Florida, Georgia, Mississippi, and Texas. These states were studied because they have not expanded Medicaid for childless adults, and they have a sizeable population of low-income Black youth and young adults. Click [here](#) for complete methods and findings from the five-state case study.

Scope of Research

There are several important related areas to explore that were outside of the scope of this work. First, the authors acknowledge that there are other public programs this population relies on and there are other racial and ethnic groups who face disparities. Second, a comprehensive review of all potentially relevant research and demonstration programs related to this population was not feasible. Finally, the public health emergency (PHE) extension was still in effect at the start of this effort, and toward the end, the Medicaid/CHIP continuous enrollment unwinding took place. These policy shifts were not the subject of this work.

Findings

American Community Survey Data Analysis

The analysis of the 2017-2021 ACS¹ data found that 1,952,399 (6.4%) youth, ages 12-18, and 2,124,272 (7%) young adults, ages 19-25, have a disability (Table 1). Young adults with a disability are far more likely than youth with a disability to have incomes below 100% of poverty (65.9% vs 26.2%) and to be uninsured (12.9% vs 4.6%). Compared to their White counterparts, Black young adults with disabilities experience higher rates of poverty and uninsurance (74.3% vs 63.6%; 15.4% vs 10.5%, respectively). These findings reveal just how significant the change is from childhood to adulthood, which many with lived experience describe as a “cliff.”

| Table 1. Racial Differences Among Youth and Young Adults by Disability Prevalence, Poverty Status and Uninsurance Rates in the US, 2017-2021 | | | | | |
|---|------|--|-------|--|-------|
| % of youth/young adults with a disability | | % at or below 100% FPL, among youth/young adults with a disability | | % with no health insurance, among youth/young adults with a disability | |
| 12-18 year olds | | 12-18 year olds | | 12-18 year olds | |
| All | 6.4% | All | 26.2% | All | 4.6% |
| Black, NH | 7.7% | Black, NH | 39.5% | Black, NH | 4.0% |
| White, NH | 6.3% | White, NH | 20.0% | White, NH | 3.6% |
| 19-25 year olds | | 19-25 year olds | | 19-25 year olds | |
| All | 7.0% | All | 65.9% | All | 12.9% |
| Black, NH | 7.7% | Black, NH | 74.3% | Black, NH | 15.4% |
| White, NH | 7.4% | White, NH | 63.5% | White, NH | 10.5% |

Source: American Community Survey (ACS), 2017-2021

Note: The ACS defines disability to include hearing disability, visual disability, cognitive disability, ambulatory disability, self-care disability, and independent living disability.

NH: Non-Hispanic

Aging Out of Medicaid and CHIP, SSI, and Title V

The following sections on Medicaid and CHIP, SSI, and Title V present 1) a background of the program for youth and young adults with disabilities, 2) a summary of challenges and inequities in the aging out process, and 3) program recommendations for improvement.

Medicaid and CHIP

Background

Between 2017 and 2021, 30% of youth were publicly insured. For young adults, the percentage dropped to 15%.¹ 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, this shift all too often results in loss of insurance (13%) (Table 1). Using the broader definition of CYSHCN, an even greater proportion are publicly insured. Medicaid and CHIP covered 47% of CYSHCN under age 18 in 2017. Most of these CYSHCN were poor or near poor, 27% were Black, and 41% were ages 12-17.² 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.² Thus, the vast majority of those with disabilities qualify on the basis of their family's low income, not via disability-related pathways.² 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.³ 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.⁴

States have established more generous income eligibility levels under CHIP for children under 18 than for adults covered by Medicaid. In AL, for example, children are eligible for the separate CHIP program up to 312% of poverty, while childless adults are not eligible for Medicaid because AL has not expanded Medicaid.³ 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.

Findings: Medicaid and CHIP

The cut-off for CHIP is age 19.^a Estimates of the number of young adults – with or without disabilities – 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. Through an analysis of MCO contracts, the authors found 16 (out of 40) general MCO contracts and two (out of three) specialty MCO contracts 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, such as explaining what services would likely no longer be covered under Medicaid for adults, marketplace insurance, or commercial insurance. Four general MCO contracts mentioned aging out of EPSDT but did not include details about what support MCOs should provide. Two of the three 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.

^aExceptions to the CHIP age cut-off exist. Some states cover pregnant individuals regardless of age.

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: Medicaid and CHIP^b

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)
-

^b Responsible agencies are listed in parentheses.

Findings: Supplemental Security Income

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)

Supplemental Security Income

Background

The SSI program provides cash assistance and access to Medicaid for eligible individuals. Recipients may qualify for SSI under the child or the adult program, depending on age. Children under age 18 may be eligible for SSI if they have a medically determinable physical or mental impairment, including an emotional or learning problem that results in marked and severe functional limitations; can be expected to result in death; or has lasted or can be expected to last for a continuous period of not less than 12 months.⁵ Adults ages 18 or older may be eligible for SSI if they have a medically determinable physical or mental impairment, including an emotional or learning problem, which results in the inability to do any substantial gainful activity.⁵

Findings: Supplemental Security Income

In 2022, the SSI program served 379,125 youth (ages 13-17) and 290,456 young adults (ages 18-21).⁶ SSA does not publish these estimates by race and ethnicity. By far, youth and young adults are disproportionately in the mental disorder diagnostic group (Table 2). This category includes the following diagnoses: autism spectrum disorder; developmental disorders; intellectual disorders; depressive, bipolar, and related disorders; neurocognitive disorders; schizophrenia spectrum and other psychotic disorders; anxiety and obsessive-compulsive disorders; somatic symptom and related disorders; personality and impulse-control disorders; neurodevelopmental disorders; eating disorders; developmental disorders in infants and toddlers; trauma- and stressor-related disorders; child/adolescent disorders not elsewhere classified.

Table 2. SSI Recipients by Diagnostic Group and Age, 2022

| | Ages 13-17 | Ages 18-21 |
|---|-------------------|-------------------|
| Total | 379,125 | 290,456 |
| Mental disorders | 313,388 (82.7%) | 228,949 (78.8%) |
| Diseases of the nervous system | 25,815 (6.8%) | 28,383 (9.8%) |
| Congenital anomalies | 13,826 (3.6%) | 14,703 (5.1%) |
| Other conditions | 4,693 (1.2%) | 2,682 (0.9%) |
| Unknown | 3,656 (1.0%) | 2,317 (0.8%) |
| Diseases of Blood and blood- forming organs | 2,793 (0.7%) | 1,818 (0.6%) |
| Diseases of Respiratory system | 2,734 (0.7%) | 1,377 (0.5%) |
| Musculoskeletal system and connective tissue diseases | 2,539 (0.7%) | 2,369 (0.8%) |
| Endocrine, nutritional, and metabolic diseases | 2,269 (0.6%) | 1,238 (0.4%) |
| Neoplasms | 2,138 (0.6%) | 1,772 (0.6%) |
| Injuries | 1,630 (0.4%) | 1,948 (0.7%) |
| Diseases of the digestive system | 1,416 (0.4%) | 750 (0.3%) |
| Diseases of the genitourinary system | 866 (0.2%) | 858 (0.3%) |
| Diseases of the circulatory system | 795 (0.2%) | 907 (0.3%) |
| Diseases of skin and subcutaneous tissue | 477 (0.1%) | 284 (0.1%) |
| Infectious and parasitic diseases | 90 (0.0%) | 101 (0.0%) |

Source: SSI Annual Statistical Report, 2022

Age 18 Redetermination

At age 18, a youth's SSI eligibility is redetermined during a CDR based on a more restrictive adult disability standard. In 2022, 69,134 age 18 redetermination reviews were conducted nationally and 51.3% of these received an initial cessation decision, meaning all SSI benefits were terminated.⁷ Current data were not available on what proportion of these initial denials have been overturned in appeals. However, according to a 2018 study, roughly half of appeals were denied.⁸ Termination rates during age 18 redetermination reviews also vary by diagnosis. Among those with neoplasms that undergo redetermination, 53.3% lose their SSI benefits, among those with "other mental disorders," 50.7% lose their SSI benefits; and among those with intellectual disabilities, 28.2% lose their benefits.⁹

There is some evidence of state variations in age 18 redetermination outcomes.¹⁰ An analysis of SSI data from 1998-2006 revealed a large variation of age 18 cessation rates across states, ranging from 20-47%. The South had the four states with the highest cessation rates: MS (47%), SC (44%), AR (42%), and LA (42%). Most of the other states in the South had cessation rates at or above the national average (34%). Factors that could influence state differences in SSI participation are variations in procedures and staffing of SSA-funded Disability Determination Service agencies, availability of advocacy and legal supports, extent of outreach, and/or differences in prevalence of disabilities.^{10,11} Current data on state variations in determinations are not available. However, given the continued differences in cross state participation, it is likely that variations in determinations persist since there has not been a change in policy to address this issue.

Evidence has shown that adverse health impacts and income volatility result with the loss of SSI. Young adults exiting SSI after this redetermination are almost twice as likely to have health-related unmet needs after their exit as those who remain on SSI (58.9% vs. 31.9%).¹² Former child SSI recipients have high drop-out rates, low employment rates, and greater income volatility.^{13,14} They are also more likely to make up for that loss of disability income through criminal activities, not work. "In response to SSI removal, youth are twice as likely to be charged with an illicit income-generating offense than they are to maintain steady employment at \$15,000/year in the labor market," read one report on this issue. "As a result of these charges, the annual likelihood of incarceration increases by a statistically significant 60% in the two decades following SSI removal." Most of this crime is income generating (e.g., theft and prostitution, fraud and forgery, and drug distribution).¹⁵

Challenges and Inequities

The two most common structural problems with SSI mentioned during key informant interviews (Appendix C) were 1) the age cut-off for children at age 18 and the corresponding restrictive adult disability eligibility criteria and 2) the complex and burdensome application process and documentation requirements. Other challenges mentioned during key informant interviews are as follows:

Findings: Supplemental Security Income

Navigating the System

1. **Complexity of the System:** “The system is impossible to navigate unless you get the right social worker or case worker to help.” Also referred to as “bureaucratic disenfranchisement.” The SSI/SSDI Outreach, Access, and Recovery ([SOAR](#)) program, which is funded by SAMHSA, helps by training case managers, but it only applies to those experiencing or at risk of homelessness.
2. **Representation and Advocacy:** “A lot of youth who have been denied adult SSI benefits go through the process unrepresented.” This often coincides with them losing other supports, like special education.
3. **Evidence and Documentation Issues:** Often SSA receives incomplete evidence but may fail to actively secure needed information such as special education records, Medicaid records, mental health records, and vocational training program records.
4. **Invisible Disabilities:** Having an invisible disability, like a mental health condition, autism, and ADHD, makes qualifying for adult criteria difficult. “They may be considered able to work, but very few end up working at self-sufficiency levels.”
5. **Misunderstanding of Permanence:** “Parents often assume their child has SSI benefits for life.” Differences between child and adult eligibility criteria are not widely known. Language barriers further complicate access, as critical information is often presented at a high reading level.

Medical and Health Care Challenges

6. **Access to Providers:** Finding medical and behavioral health providers, especially during the COVID-19 pandemic, to obtain updated documentation is difficult given the low reimbursement rates and many behavioral health not accepting Medicaid. “Getting an assessment for developmental or mental health conditions can be in the thousands of dollars.”
7. **Health Disparities:** “There is a health disparity with access to genetic testing and mistrust about genetic testing,” testing that can aid in disability determination.
8. **Documenting Limitations:** “Often, people overstate what they are able to do to make it sound like they do a lot more. Many people don’t want to think and talk about their limitations, but that’s what SSA is looking for.” Medical records often lack sufficient documentation of functional status.

Policy and Practical Implications

9. **Outdated Job Standards:** Adult disability standards relate to jobs nationally and are very outdated. “The jobs do not match with what is available in economically depressed areas like Eastern Kentucky or Anacostia in DC.”
10. **Impact of Incarceration:** There is inconsistent and delayed receipt of SSI benefits following incarceration of less than 12 months.

Recommendations:^o SSI

Program and Policy Reform

1. Eliminate the requirement for justice-involved individuals who have been incarcerated for 12 consecutive months or longer to file a new application and again be approved for SSI. (SSA)
2. Create a new demonstration program to expand the use of Section 301 to make it more broadly accessible. The demonstration would require SSA to continue providing disability benefits even when recipients no longer meet the SSA adult disability criteria and up to age 26 for those enrolled in an appropriate program of vocational rehabilitation or special education. Additionally, the definition of “actively participating” would be modified to extend to those who are on waitlists or who have a pending application for vocational rehabilitation services. The demonstration would also provide training to field office workers about Section 301 benefits, including how 301 benefits work, how to process a request, and where to send it. (Congress)
3. Establish a subcommittee, with representation from those with lived experience, community-based organizations, and advocates, within the Social Security Advisory Board. This subcommittee will focus on issues affecting disability benefit access for children, youth, and young adults and could publish issue briefs and data reports to analyze disability access and equity for transition-aged populations. (Congress)
4. Delay application of the adult disability criteria until age 22, instead of age 18. This would extend childhood disability eligibility irrespective of attending school, college, or university, or vocational or technical training. Evaluation for continued benefits should occur within 12 months of an individual’s 22nd birthday based on adult eligibility criteria. (Congress)

Streamlined Application and Transition Support

5. Establish a simplified and streamlined application process and CDR process including requested information and need for in-person interviews, with input from family, disability, self-advocacy, legal, and Medicaid eligibility experts. The aim of these streamlined processes would be to reduce administrative hurdles and paperwork burdens, improve greater efficiencies across government agencies, and facilitate ongoing assessment of customer experience with the disability application and redetermination process. (SSA)
6. Provide free legal representation to those ages 18-26 with a continuing determination review that led to a termination of benefits and who need to appeal, but do not have the funds to hire a lawyer to pursue such an appeal and there are no back benefits to pay a lawyer’s fee. (ACL)

^o Responsible agencies are listed in parentheses.

7. Incentivize existing case management/navigator programs from agencies already working with SSA (such as Vocational Rehabilitation or Work Incentives Planning and Assistance) to help those ages 16-26 with the transition to adult disability, insurance coverage, and health care supports along with other needed transition supports. This could be a dedicated case worker who helps facilitate access to continuous supports/services during the transition from child to adult services, available to anyone who needs it. (Congress)
8. Create a centralized application and appeals center to help youth and young adults and their families/caregivers have their applications processed more efficiently. (Congress)

Outreach, Education, and Interagency Collaboration

9. Conduct targeted outreach, communication, and training on the disability determination process for those nearing the age 18 redetermination process and for those applying for adult disability status. Enhanced strategies should include comprehensive, plain language communication, outreach, and training for English and non-English speaking youth, young adults, and families/caregivers about eligibility requirements (e.g., differences between child and adult disability criteria, documentation requirements, appeals, benefit continuation during appeals) and steps in the process for transitioning to and obtaining adult SSI. It should also include more explanation of the information SSA would like to have as part of the CDR function report (e.g., an explanation of the importance of information related to daily limitations that affect ability to engage in work activity). (SSA)
10. Edit the CDR cover letter to clearly note the significance of the review and plainly disclose that responses to each question on the form will determine if a person continues to receive SSI. This cover letter should be a required component with the CDR form. This outreach method could be tested to see if there was a reduction in the number of technical problems with the application and whether recipients understand the meaning of the cover letter text. (SSA)
11. Offer enhanced outreach and communication training to local SSA field officers, persons involved in the disability determination services, school/special education programs, Title V programs, family/disability groups, and care coordination/case management/community work incentive coordinator programs about the importance of updated evaluation and treatment summaries and how to communicate with SSA. This could expand on SSA's vulnerable population [outreach](#) to target youth and young adults to address the cross-state and within state variations in SSI. (SSA)
12. Establish a joint demonstration project between SSA and CMS on strategies to facilitate more consistent cross-system data sharing implementation of ex parte provisions, streamlined applications, and coordinated outreach and informing. (SSA, CMS)

13. Identify a lead agency and establish interagency partnerships to facilitate coordinated child to adult program transitions and emergency supports (e.g., when a young adult loses SSI disability benefits, when a young adult loses insurance, when a young adult or parent loses their job, when SNAP runs out, when a young adult or family are justice-involved or are evicted), working with family and community-based organizations. (SSA, CMS, SAMHSA, ACL, ACF, HRSA)

Analysis, Review, and Data-Driven Actions

14. Conduct reviews of medical and functional criteria every three years by external pediatric and adult clinical experts to ensure consistency with current scientific evidence. This should include reviews of SSA changes in standards for conditions, such as sickle cell disease and asthma, that resulted in fewer meeting the disability criteria, as well as reviewing alternative functional and disability medical definitions. External medical experts should receive adequate reimbursement rates for participating in ongoing reviews of disability determinations where there are significant variations in determinations during the redetermination for adult disability standards. (SSA)
15. Conduct and publish a comprehensive analysis of youth and young adults with disabilities on SSI looking at differences in rates of applications, recipients, and age 18 cessations by state, race, age grouping (i.e., 14-17, 18-21, 22-25), condition type, and rural versus urban geographic area. This analysis should also examine barriers faced by youth and young adults with disabilities and their families that include, but are not limited to lack of access to timely medical/behavioral health care, outdated medical records, limited data on school system referrals, underdiagnosis of mental/behavioral/developmental conditions, higher rates of school dropouts, overcriminalization, lack of family supports, and lack of understanding of SSI eligibility process. In addition, data collection on racial disparities could be incorporated into one of SSA's upcoming survey of children. (SSA)

Title V Program for Children and Youth with Special Health Care Needs

Background

The Title V Maternal and Child Health Program is a block grant designed to support 59 states/jurisdictions to address the needs of mothers, infants, children, including CYSHCN, and their families.¹⁶ Of the populations served by Title V in 2022, 36% were CYSHCN.¹⁷ States have discretion in using their federal Title V funding to complement state-supported efforts related to the provision of direct health services (e.g., specialty clinics), enabling services (e.g., care coordination), and public health services and supports (e.g., education and training). Unlike Medicaid or SSI, there is no Title V counterpart program for adults. Estimates of the number of young adults with SHCN who age out of state Title V CYSHCN program services each year are unknown. No published literature or reports were available on aging out of Title V. The information below was obtained through an online survey administered to 51 state Title V CYSHCN directors. Thirty-one states responded for a 61% response rate.

Age Cut-Offs

The Title V statute does not include any reference to when CYSHCN age out of Title V program services. Among the states that completed the survey, 61% reported their age cut-off was 21. Forty-eight percent reported that there are exceptions to their state's age limit based on need and selected chronic conditions, such as cystic fibrosis, phenylketonuria, and hemophilia. Seventy-five percent estimated that less than 200 CYSHCN age out of their state Title V program each year; 15% said between 200 and 500; 15% said between 501 and 1000; and 3% have between 1001-2000. Thirteen percent of states did not respond to this question.

Program Strategies

When states were asked about types of outreach strategies they offer to assist CYSHCN who are aging out of Title V services, more than half reported they offer referral assistance, most often to Medicaid and SSI. About half of responding states reported they participate in interagency efforts to facilitate transitions from child to adult-serving systems. Specifically, most noted that interagency efforts were with Medicaid. Four states reported none of the above strategies or they responded not applicable.

Challenges and Inequities

About half of respondents shared that certain populations of CYSHCN experience more difficulties in accessing adult public program benefits. These populations include those who are from minoritized racial/ethnic groups, those who are non-US citizens, those without insurance, those living in rural areas, those who cannot find adult health care providers, those with medically complex conditions, and those with significant ID/DD.

Recommendations:^d Title V

Program and Policy Reform

1. Increase the childhood eligibility age cut-off for state Title CYSHCN to age 26 with corresponding increases in Title V Block Grant funding. (Congress)
2. Establish a consistent process for informing youth, young adults, and families about the ending of Title V CYSHCN program eligibility and options for ensuring continuity of care and coverage. (Title V agencies)
3. At least one year prior to aging out of direct or enabling Title V CYSHCN services, ensure that each youth/young adult has an updated plan of care, medical summary, and other documents needed to transition to adult care, insurance coverage, and adult public program services. (Title V agencies)

^d Responsible agencies are listed in parentheses.

Training and Referral

4. Develop training for Title V-supported care coordinators and Family Voices chapters in benefits counseling related to the transition from child to adult serving systems. This training could be expanded as an interagency effort to include special education transition coordinators and other care coordination programs in the state. (MCHB and Title V agencies)
5. Take advantage of the Title V toll-free hotline to assist transition-aged youth and young adults and families with information and referral to adult services. (Title V agencies)

Tracking and Feedback

6. Establish mechanisms to identify and track the number of young adults with SHCN who age out of Title V CYSHCN services. This tracking system should also include which services/ programs that the young adult was referred to and additional information, such as race, ethnicity, and insurance status of the young adult. (Title V agencies)
7. Elicit feedback from young adults and families/caregivers who have already aged out of Title V CYSHCN services to understand their experience and identify solutions and strategies to improve transition to adult programs and services. (Title V agencies)

Partnership and Interagency Collaboration

8. Partner with Family Voices, Family-to-Family Information Centers, and Title V-supported care coordinators to implement a planned approach to inform and prepare young adults and families/caregivers for the ending of Title V CYSHCN services before they age out. This preparation could include referrals to adult public programs, including but not limited to Medicaid, SSI, vocational rehabilitation, safety net sources for medical, behavioral, reproductive, and oral health care as well as state and community hotlines for help with health-related social needs (e.g., food, housing assistance). (Title V agencies)
9. Participate in interagency efforts to simplify and coordinate transition processes moving from child to adult-serving systems. This could include, but is not limited to, state disability determination service agencies, Medicaid and departments of special education, vocational rehabilitation, behavioral health, developmental disabilities, and child welfare. (Title V agencies)
10. Partner with the state Medicaid agency's EPSDT program to implement outreach and communication strategies for publicly insured youth and young adults with special needs and their families, informing them of the changes in Medicaid benefits that will take place when they are no longer eligible as a child. This could be implemented through an interagency memorandum of agreement. (Title V agencies, state Medicaid agencies)

Spotlight on Black Young Adults with ID/DD

The findings from key informant interviews with national disability and advocacy organizations (Appendix C) about specific challenges faced by Black young adults with ID/DD are summarized below. Many of the interviewees mentioned challenges that overlapped with the findings discussed previously under Medicaid and CHIP, SSI, and Title V. The challenges, populations, and service needs described below are additional.

Challenges and Inequities

By far, the most common challenge reported was visible and invisible systemic racism against Black young adults in general, and those with ID/DD in particular. This critical problem has harmful impacts on health and well-being. “We abandon people, and point them in no direction. There’s no other way to put it,” one interviewee expressed. Other specific challenges and inequities mentioned during interviews include:

- **Maintaining benefits** when Black children are disproportionately suspended in school, faced with criminal justice and child welfare systems, and experience racism. They face racism among people who make decisions that impact eligibility and termination of certain services and supports.
- **The benefits funnel.** There is a tendency to filter Black young adults with ID/DD into more restrictive services, and that tends to be race-based, leading to involvement in criminal justice, hospitalization, and institutionalization.
- **Racial bias.** Within the law enforcement system, there is bias particularly affecting Black young adults with ID/DD with behavioral health issues. Within vocational rehabilitation, insufficient support is provided to Black young adults with ID/DD, including lack of assistance in helping to deal with racism in the workplace. “There is a distrust of public systems by Black people, and that is important to understand.”
- **Fear and anxiety.** The whole idea of navigating through a bundle of systems can be very complicated and overwhelming.
- **Lack of cultural and linguistically sensitive systems.**
- **Stagnant SSA asset limit** and standards for work requirements. “This hasn’t been updated since 1989.”

Populations of Black Young Adults with ID/DD Facing Greater Challenges

Several subpopulations of Black young adults with ID/DD were identified as experiencing greater challenges regarding aging out of public programs. Interviewees mentioned:

- Young parents (ages 18-25) or pregnant individuals
- Individuals who identify as LGBTQA+
- Those in the foster care system or involved with the justice system

Findings: Spotlight on Black Young Adults with ID/DD

- Those who are at or below or minimally above the poverty level
 - “These folks are already at-risk for many other things like food insecurity.”
 - “Losing these supports affects lifelong decreased life outcomes.”
- Young people without stable housing
 - “There is a lot of moving around within the state due to housing issues. That can create a disconnect from resources and transition pathways. Especially the disconnect from paperwork.”
- Those living in multi-disabled households, which can impact benefits.
 - “My mother and I are both disabled and were living in Section 8 housing. As soon as I became employed, I had to move out, forcing me into a less stable living situation.”
- Youth who are non-verbal
- Those with behavioral health conditions.
 - “There has been a history of not treating people with ID/DD as having mental health issues. Young adults with ID/DD often have difficulty engaging with the mental health care system, including getting appointments and seeing providers with cultural and disability competency.”

Service Needs

When interviewees were asked about the types of services that are lacking among Black young adults with ID/DD, many reported dentistry, primary care, and preventive care, such as nutrition and exercise. One interview remarked that “Relatively bad health outcomes in these populations are preventable. Those types of services are really lacking, and this leads to other delayed and mismanaged care.” Additional service needs mentioned for Black young adults with ID/DD include:

- Health care systems with clinicians that have been trained to provide for young people with ID/DD
- Service and payment adjustment based on patient complexity
- Family planning services
- Treatment for pain among Black females
- Genetic testing, to help with documentation and access to benefits
- Continuum of services young adults with ID/DD can qualify for, instead of “all-or-nothing”
- Adult counterpart programs for all child serving programs

Conclusions

Low-income youth and young adults with disabilities and their families, especially Black youth and young adults with ID/DD, experience substantial challenges when they are no longer eligible for Medicaid, CHIP, SSI, and Title V. Many become uninsured, face worsening poverty levels, experience disruptions in their care, and report extraordinary worries and pressures. This two-year national effort underscores that far too many do not receive necessary education, preparation, and support for making the shift to health insurance coverage and disability benefits as an adult. Navigating more restrictive adult program application processes and complex documentation requirements for this transition-aged population is daunting and out of reach for many. This report offers recommendations to address the challenges and inequities uncovered. The authors call on program agency officials and Congress to bring attention to this transition-aged population and consider these strategies for improvement.

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Appendix A. National Advisory Committee Members*

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** The views, thoughts, and recommendations expressed in this report belong to The National Alliance to Advance Adolescent Health and not necessarily to the advisory committee members or organizations they represent.*

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Appendix C. List of Key Informant Organizations and Agencies

SSI

Center on Budget and Policy Priorities
Community Legal Services in Philadelphia
Cystic Fibrosis Social Security Project
Justice in Aging
Mathematica
Social Security Administration
SSI/SSDI Outreach, Access, and Recovery
University of Chicago

Medicaid/CHIP

American Association on Health and Disability
Benefits Tech Advocacy Hub
Centers for Medicare and Medicaid Services, Office of Minority Health
Georgetown University Center for Children and Families
Kaiser Family Foundation
Medicaid and CHIP Payment and Access Commission
National Health Law Program
Office of the Assistant Secretary for Planning & Evaluation
US Department of Health and Human Services, Office of the Secretary
Young Invincibles

Title V

Health Resources and Services Administration, Maternal and Child Health Bureau

Family Advocates

Family Voices
PATH Connecticut
TX Parent to Parent

National Disability and Advocacy Organizations

American Academy of Developmental Medicine & Dentistry
American Association on Intellectual and Developmental Disabilities
Autistic Self Advocacy Network
Center for Dignity in Healthcare for People with Disabilities
Center on Youth Voice, Youth Choice/Institute for Community Inclusion
Community Catalyst
Georgetown National Center for Cultural Competence
Kennedy Krieger Institute
National Association of State Directors of Developmental Disabilities Services
The Arc

The National Alliance to Advance Adolescent Health/
Got Transition

Find us at GotTransition.org, TheNationalAlliance.org

