

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

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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 Supplemental Security Income (SSI) following the age 18 redetermination process. It is part of a [larger national study](#) on aging out of public programs, including SSI, Medicaid, CHIP, and Title V Programs for Children and Youth with Special Health Care Needs (CYSHCN).¹ SSI defines eligibility criteria for adults more restrictively than for children. Consequently, many young adults with disabilities lose access to SSI benefits, which also includes loss of automatic Medicaid eligibility in most states.

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 study 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:

- **Literature review** of published articles, grey and white papers, and public program documents.
- **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.

Findings

Background

In 2022, the SSI program, which provides cash assistance and access to Medicaid, served 379,125 youth, ages 13-17, and 290,456 young adults, ages 18-21.² SSA does not publish these estimates by race and ethnicity. 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.³ 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.³

Age 18 Redetermination

At age 18, SSI eligibility is redetermined based on a more restrictive adult disability standard. In 2022, 69,134 age 18 redetermination reviews were conducted, and 51.3% received a cessation decision, meaning all SSA benefits were terminated.⁴ Information was not available on what proportion of these denials have been overturned in appeals. However, according to a 2018 study, roughly half of appeals were denied.⁵

No current published data are available on state variation in young adults losing their eligibility during the age 18 redeterminations. Though dated, an analysis of SSI data from 1998-2006 revealed a large variation of age 18 cessation rates across states, ranging from 20-47%.⁶ 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 the 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.⁶

Termination rates during age 18 redeterminations 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.⁷ 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%).⁸ Former child SSI recipients have high drop-out rates, low employment rates, and greater income volatility.^{9,10} 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. 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.¹¹

Challenges and Inequities

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

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*

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)
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)

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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)

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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)

* Responsible agencies are listed in parentheses

Conclusions

SSI benefits confer not only vital income support but also an automatic way into Medicaid in most states. Nearly half of all SSI child beneficiaries fail to qualify for SSI as an adult, resulting in substantial disruptions affecting their livelihood and health care access. New efforts are needed to simplify and streamline SSI's eligibility process, re-examine the age cut-off for childhood eligibility, understand state variation in program eligibility by race and diagnostic category, and collaborate with family and disability organizations in strengthening outreach, navigation, and communication programs for transition-aged populations. For more information, please contact Peggy McManus at MMcManus@TheNationalAlliance.org.

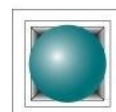
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