



THE NATIONAL ALLIANCE
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A Five State Case Study: Black Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs

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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

CHIP: Children's Health Insurance Program

CYSHCN: Children and Youth with Special Health Care Needs

DD: Developmental Disability

DDS: Departments on Disability Services

ID/DD: Intellectual and/or Developmental Disabilities

LEND: Leadership Education in Neurodevelopmental and Related Disabilities

P&A: Protection and Advocacy

Rep: Representative

SHADAC: State Health Access Data Assistance Center

SSA: Social Security Administration

SSDI: Social Security Disability Insurance

SSI: Supplemental Security Income

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Executive Summary

Problem Statement. Black young adults with disabilities who reside in states that did not expand Medicaid for childless adults are at risk of losing coverage 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, including those with intellectual and/or developmental disabilities (ID/DD) 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).

Methods. The five states featured in this report are Alabama, Florida, Georgia, Mississippi, and Texas. They were selected based on lack of Medicaid expansion, high rates of uninsurance among Black young adults with disabilities, and having disproportionately large populations of Black young adults with low incomes. Guided by a National Advisory Committee, a series of key informant interviews were conducted with public program officials and disability and legal advocates in each state. Six self-advocates were also interviewed about their personal experience with aging out. In addition to this five state case study, the authors produced a national report and three separate briefs on Medicaid and CHIP, SSI, and Title V.

Challenges and Inequities. The most common difficulties reported during interviews with state agencies and advocacy organizations were inadequate and complex information about applying for adult services, siloed public service systems, lack of access to providers and services in rural areas, racism, prejudice, and unconscious bias, made even worse for those with an ID/DD. Self-advocates and their families also reported lack of awareness of the changes that occur at age 18, long wait lists, outdated medical documentation and more.

Populations Most Affected by Aging Out Challenges. This case study found that populations facing greatest challenges include Black young adults with co-occurring ID/DD and mental health conditions, living in rural areas, with limited education, who are male, and who are involved with law enforcement. Other Black populations cited during interviews as having greater challenges are those with invisible disabilities, those who fall outside the state's developmental disability definition, immigrants, those who are non-binary, those who are uninsured, and those who become pregnant.

Recommended Approaches. The most common recommendations were Medicaid expansion, less restrictive adult public program criteria, more accessible education and early outreach, education to clinicians about how to provide care to those with ID/DD, and increased navigation supports for transition to adult care. Additional recommendations can be found in the national report and three separate briefs on Medicaid and CHIP, SSI, and Title V.

Conclusion. Black youth and young adults with disabilities, particularly those with ID/DD, are disproportionately confronted with major challenges when they lose their childhood eligibility status under public programs. It is critical for policymakers to focus new attention on this population to ensure safe and continuous coverage and care.

Introduction

The purpose of this five state case study was to 1) gain insight about the barriers and inequities faced by Black young adults with disabilities, including ID/DD, who lose their childhood eligibility status under Medicaid, CHIP, SSI, and Title V Program for CYSHCN; 2) identify specific populations who face greater disadvantages when it comes to aging out; and 3) develop policy and program improvement recommendations that would reduce disruptions in coverage and ensure support is provided during the aging out process. The five states studied were Alabama (AL), Florida (FL), Georgia (GA), Mississippi (MS), and Texas (TX). They were selected based on lack of Medicaid expansion, having high rates of uninsured Black young adults with disabilities, and having large populations of Black young adults with low incomes. In addition, a corresponding report, *A National Report: Youth and Young Adults with Disabilities Aging Out of Medicaid, CHIP, SSI, and Title V Programs – Barriers, Inequities, and Recommendations*, brings new attention to the shift that low-income youth and young adults with disabilities face as they age into adulthood; uncovers eligibility and enrollment challenges, inequities, and impacts; describes challenges faced by Black young adults with disabilities; and recommends policy and program strategies to reduce disruptions and disparities in access to adult public program services. Click [here](#) to learn more.

Methods

Public program officials and advocates in the five states were contacted to request virtual key informant interviews. Interviews were requested with Medicaid agencies, CHIP programs, Social Security Administration (SSA) Regional Offices, Title V CYSHCN Programs, Protection & Advocacy (P&A) Organizations, and Family Voices chapters, that represented each of the five states. Eighteen Zoom interviews were completed between March and November 2023 (Table 1).

	AL	FL	GA	MS	TX
Medicaid/CHIP	X		X		X
SSA Regional Offices		X			X
Title V CYSHCN Programs	X		X	X	X
Protection & Advocacy/Legal Advocates	X	X	X	X	X
Family Voices	X		X	X	X

Gray = interviews were not completed because contacts could not be reached or contacts declined to participate.

Additional interviews were conducted with a targeted focus on Black young adults with ID/DD. Interviews were requested with Departments on Disability Services (DDS), Developmental Disability (DD) Councils, Legal Aid Programs, Leadership Education in

Neurodevelopmental and Related Disabilities (LEND) Programs, The Arc chapters, and self-advocates. Nineteen Zoom interviews were completed between August 2023 and March 2024 (Table 2).

Table 2. Interviews Conducted about Black Young Adults with ID/DD					
	AL	FL	GA	MS	TX
Developmental Disability Councils		X			X
Departments on Disability Services	X	X	X		
Legal Aid Programs		X	X		
LEND Programs	X		X	X	X
The Arc Chapters	X		X		
Self-Advocates	X	X (2)	X (3)		

Gray = interviews were not completed because contacts could not be reached or contacts declined to participate.

All key informant interview questions addressed three topics: 1) major challenges faced by Black young adults with disabilities, including those with ID/DD, 2) populations that face greater disadvantages when aging out of public programs, and 3) suggestions for reducing disruptions in coverage and care. The suggestions informed the development of policy and program strategies for Medicaid and CHIP, SSI, and Title V (policy brief links to be added for each). Notes from each structured interview were coded, and themes were generated and organized from the most to least common in a spreadsheet.

An analysis of 2017-2021 American Community Survey was conducted by the University of Minnesota’s State Health Data Access Center (SHADAC) to compare youth, ages 12-18, and young adults, ages 19-25, by race, disability, poverty, and insurance status in the US and the five states in this study. The findings from this report begin with selected results from the analysis, followed by summaries of the main themes from the key informant interviews.

Findings

Five State Data Analysis

As shown in Table 3, 13% of youth and 14% of young adults in the US are Black. In the five states studied, Black youth make up 12%-42% of the population and Black young adults make up 13%-43%. Black youth in the US and TX are statistically significantly more likely than White youth to have a disability diagnosis, as are Black young adults in the US compared to White young adults. Black youth and young adults with disabilities in the US as well as FL, GA, MS, and TX are significantly more likely to live in poverty compared to their White counterparts. In the US and TX, Black young adults with a disability are statistically significantly more likely to be uninsured compared to White young adults.

Table 3. Disability*, Insurance, and Income Status Among Youth and Young Adults by Race in the Five States						
	US	AL	FL	GA	MS	TX
% by race						
12-18 year olds						
Black, NH	13.3%	28.9%	19.0%	33.1%	41.5%	11.6%
White, NH	50.8%	58.7%	41.6%	44.4%	49.7%	31.5%
19-25 year olds						
Black, NH	14.0%	30.8%	19.4%	34.3%	42.5%	12.8%
White, NH	52.8%	59.0%	43.5%	46.0%	50.0%	33.7%
% with a disability						
12-18 year olds						
All	6.4%	6.4%	6.6%	6.2%	7.5%	6.2%
Black, NH	7.7%	7.2%	6.9%	7.0%	7.9%	7.7%
White, NH	6.3%	6.1%	6.6%	6.4%	7.1%	6.1%
19-25 year olds						
All	7.0%	8.0%	6.4%	6.8%	8.1%	6.6%
Black, NH	7.7%	8.0%	6.5%	6.9%	7.7%	7.5%
White, NH	7.4%	8.0%	7.1%	7.1%	8.5%	7.4%
% with a disability at or below 100% FPL						
12-18 year olds						
All	26.2%	30.0%	26.0%	29.1%	34.8%	28.1%
Black, NH	39.5%	33.8%	41.3%	39.3%	47.6%	34.0%
White, NH	20.0%	26.3%	19.6%	20.8%	23.0%	16.5%
19-25 year olds						
All	65.9%	69.4%	69.7%	69.0%	72.9%	65.3%
Black, NH	74.3%	74.9%	78.1%	73.8%	80.8%	71.0%
White, NH	63.5%	67.5%	66.2%	66.4%	68.6%	62.3%
% with a disability with no health insurance						
12-18 year olds						
All	4.6%	2.9%	7.6%	6.3%	5.1%	9.2%
Black, NH	4.0%	3.1%	9.1%	5.1%	5.6%	5.2%
White, NH	3.6%	2.7%	6.4%	5.0%	3.1%	6.9%
19-25 year olds						
All	12.9%	20.1%	19.4%	22.5%	21.4%	26.0%
Black, NH	15.4%	20.6%	20.6%	24.1%	23.0%	25.6%
White, NH	10.5%	18.7%	17.3%	19.2%	19.1%	19.3%

*Disability status is determined if respondent has any one of the following: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, independent living difficulty. Further details can be found [here](#).

Note: Bold data are statistically significant; NH = Non-Hispanic

Black Young Adults with Disabilities: Challenges, Populations, and Recommendations

The following sections summarize themes from interviews with representatives listed in Table 1.

Challenges and Inequities

The most common challenges were 1) inadequate and complex information about obtaining services/applying for adult services; 2) lack of access to providers and services due to living in a rural area, limited or no transportation, or lack of wi-fi; and 3) racism, prejudice, and unconscious bias against people of color. The following paragraph is a snapshot of conversations with informants that demonstrate these themes.

As one P&A representative (rep) said, “families are given both too little and too confusing information.” Another noted that in their state, “there are three human service departments and they operate in siloes, which leads to people being lost and confused.” Regarding limited transportation, an advocate from Family Voices shared a similar sentiment that came across in multiple interviews: “She has to travel two hours to get to her child’s specialty care and sometimes, she’s traveling to see all four of her child’s specialists in one day.” A Medicaid official commented that “even if you qualify for Medicaid and CHIP, being in a rural area makes it challenging to access any care.” Regarding racism, an advocate from Family Voices noted that unconscious biases and assumptions made about Black families are huge challenges, stating that “even if we have service providers, they might assume a parent isn’t knowledgeable about resources. And if some parents don’t want to receive school services, they might assume that all parents don’t.” Another a Family Voices rep stated that “Black young adults...transition into nothing. We have one of the stingiest plans in the country – eligibility criteria are restrictive, and the services we provide are among the paltriest.”

Other challenges mentioned during interviews included:

- Lack of access to services due to lack of awareness and long waitlists for waivers
- Outdated medical documentation
- Low education and literacy levels
- Uncoordinated service delivery, poor system infrastructure, and no alert systems
- Shortage of health care providers who are Black, who treat adults, or who are specialists
- Lack of knowledge of EPSDT requirements among health care professionals

Findings: Challenges, Populations, and Recommendations

Populations Facing Greater Disadvantages

The most common populations identified were Black young adults 1) with mental health, developmental disabilities, and/or other co-occurring conditions; 2) who live in rural/underserved areas; 3) who lack education; 4) who are male; and 5) who are involved with the justice system. The following paragraph is a snapshot of conversations with informants that demonstrate these themes.

A state P&A rep shared that one population facing challenges is kids with co-occurring conditions, since access to services is driven by one's "primary diagnosis" in the state. "This becomes very problematic. For example, if someone's primary diagnosis is autism and they are high-functioning, and they have a psychiatric disorder, they won't have access to mental health services through Medicaid. Exclusionary criteria leads to denials of needed services." Regarding rurality and lack of education, a Family Voices advocate noted that, "generally, youth that live in underserved/rural areas have a more difficult time. There are lower rates of mental health services available to them, and there is hesitancy to seek out mental health assistance due to cultural background and limited education." Multiple interviewees also commented that being Black and disabled puts one at a disadvantage from the start. "Even if there is an acute need, there is a huge disproportionality with how Black students with mental health conditions are treated and how White students are treated. For instance, the school resource officers and police get involved when they don't need to get involved and can accelerate their pathway to prison. Black students have not had their disability addressed correctly," remarked a Family Voices rep.

Other populations of Black young adults who face greater challenges that were mentioned during interviews include those who:

- Have invisible disabilities
- Fall outside of the state's developmental disability definition
- Are immigrants, people of color, and non-English speakers
- Identify as non-binary
- Are students with IEPs
- Are uninsured
- Become pregnant

Recommended Changes

The most common recommendations were related to 1) Medicaid expansion to childless adults under the Affordable Care Act; 2) changes to adult public program criteria; 3) clear, accessible, and early messaging about eligibility changes and available adult services; 4) better education for adult providers and incentives to care for people with disabilities; and 5) increased availability of transition supports in collaboration with family leaders and community-based organizations.

Findings: Spotlight on Black Young Adults with ID/DD

Additional suggestions mentioned by one or two organizations and agencies included:

- Regarding Medicaid, create organized outreach for transition-aged youth, provide transition case management, consider alternative means than work requirements to support economic mobility, eliminate long waitlists for waivers, create a uniform way to move children to adult coverage across states
- Regarding SSI, make application easier with less restrictive criteria, increase data collection to include information about the aging out population
- Recognize and elevate Black families as a particularly vulnerable group
- Create medical training programs to better serve young adults with disabilities
- Create a centralized information hub of aging out resources for families

Spotlight on Black Young Adults with ID/DD

The following sections summarize themes from interviews with representatives listed in Table 2.

Challenges: Aging Out of Child Program Services

The most common themes that related to challenges faced by Black young adults with ID/DD were 1) lack of awareness, resources, and family outreach around the aging out process; 2) siloed public service systems and system issues; and 3) lack of public transportation and rurality. The following paragraphs provide snapshots of conversations with informants that demonstrate these themes.

“Parents aren’t up to date on how to get their child re-enrolled for services after they end. There is no awareness across the board,” commented one state rep from The Arc. A DD Council rep shared that “the problem is that parent participation drops as youth get older. You can send a brochure home, but the lack of a personal relationship with a parent is an issue. This leads to a lack of awareness.” A LEND rep noted that “it’s assumed that everyone’s level of understanding is the same. And it’s not. Some people hire someone to help fill forms out and not everyone can. Families also don’t accurately report their child’s needs when filling out paperwork. Parents report their child is more able to participate in daily living activities than they really are.”

Regarding the system challenges, a LEND rep commented that “the systems are siloed and not interconnected. If you work and lose your SSI benefits because you received an income over [the eligibility] limit, the system does not tell you to apply under a different Medicaid option. The system is what makes it difficult.” To improve on this, an interviewee commented that “it would be helpful to having a cross-system approach since lack of consistent information being shared across every system is the problem.” A rep from LEND also noted that in their state, “there is an app to apply for services, which is great, but once you submit, it will tell you that your application is 50% of the way under review. And you don’t know what to do in the meantime. There is no direction.”

Findings: Spotlight on Black Young Adults with ID/DD

Regarding lack of public transportation and rurality, a Legal Aid rep shared that there is a lack of Medicaid funding for community clinics in rural areas. “These clinics are closing in the rural South and there is no alternative. Accessing documentation is a barrier for areas without these clinics.” To target rural communities, a Legal Aid rep explained that there needs to be direct public transportation to provide access to courts to people living in transportation deserts. “Most Southern states lack providers especially in rural areas whether you have Medicaid or not. It’s an issue for everyone,” noted a P&A rep.

Other challenges mentioned during interviews included:

- Issues with documentation, enrolling, and meeting criteria
- Long waitlists for waivers
- Health literacy and language barriers
- Low socioeconomic status
- Workforce shortage

Challenges: Particular Health Services

When the states were asked about particular health services that are challenging for Black young adults with ID/DD to access, most mentioned mental and behavioral health services, with one LEND rep even commenting that “community mental health centers don’t know how to care for people with ID/DD.” In general, “access to providers that live nearby, and that are trained to work with developmental disabilities, are limited.” Several interviewees also mentioned access to dental services as a challenge, specifically finding providers that accept Medicaid. Finally, three different state LEND reps identified long waitlists as a barrier to accessing particular health services, such as specialty care.

Challenges: Racism, Bias, And Poverty

Central themes when talking to the interviewees about challenges included systemic racism, lack of representation, and bias against people of color. “Black and Brown families, especially immigrant families, are afraid to ask what services their young adult qualifies for. And a young adult with ID/DD may not be able to ask the questions themselves,” shared a LEND rep. Another noted that “it is unfortunately common among Black and Latino families to lack resources, not know how to navigate the system, and have literacy issues.” Another gave an example of one of the families they work with. “As a Black mom, when she advocates for her son, she is perceived as aggressive and gets told she is angry.” A DD Council rep shared that there is “a delayed diagnosis of autism among Black children, and then they have problems accessing services at an older age. They’re miscategorized and perceived as ‘bad’ as opposed to disabled.” Lack of representation was also identified as a significant challenge. “[There is] a lot of difficulty to get Black and Hispanic individuals to participate in stakeholder workgroups.”

Recommended Approaches

When asked about recommended targeted approaches to help Black young adults with ID/DD, the most common suggestions related to 1) education and outreach and 2) systems and services changes. The recommendations listed below informed the development of specific policy and program strategies for [Medicaid and CHIP](#), [SSI](#), and [Title V](#).

Education & Outreach

- Ensure information provided is in plain language and uncomplicated
- Create targeted, accessible materials relevant to those with different needs
- Educate families on how to fill out forms in a way to ensure they are able to access all of the services they need
- Require vocational rehabilitation offices to educate families about transition to adult services
- Require schools to provide resources and information at IEP meetings about aging out
- Utilize local faith-based and community based organizations to spread necessary information to families


Systems and Services Changes

- Create a coordinated, un-siloed system that is a one-stop shop and which provides information about available services
- Create statewide efforts for training and systems change initiatives to benefit youth and young adults with disabilities with the transition to adult services
- Rethink eligibility criteria to recognize populations that are more costly for the system if they do not receive adequate health care
- Establish a process to more easily identify patients who need insurance and assist them in obtaining it
- Eliminate waitlists and create easier application processes
- Create a central directory of all the available services for youth with disabilities in the state
- Ensure enough navigators or case managers are available to help with applications, and ensure everyone receives needed assistance


Stories from Black Self-Advocates with ID/DD

The following experiences shared by Black Self-Advocates with ID/DD exemplify the complex and often stark reality of navigating the transition to adult services. While several describe gaps in care and coverage, it is important to note that not all experiences shared were negative.

A is a 22-year-old with cerebral palsy living in Florida. He takes several expensive medications and therapies, and it is very difficult for him to move around since he is wheelchair bound. He went to the hospital and was told that his Medicaid would no longer cover his medical expenses since he had aged out, and that he would need to re-apply for Medicaid as an adult. “It was a very new experience and a very confusing experience. I had to get a lot of new documents. My parents are getting old, and I feel like have to take responsibility for myself.” It has been three months since A applied for Medicaid, and he is still waiting for approval. Apparently, notice of his expiring Medicaid was sent in advance to his dad, but A was not looking at that mail. “I should have been the one that got the information myself, not my dad. I should have gotten the information earlier. I wish they explained more to me when I was young. In my present condition I couldn’t do a lot, like walk. **The government should think about people with special complications and assist more if they have these conditions. Instead, we have to find a way for ourselves.**”



“The government should think about people with special complications and assist more if they have these conditions. Instead, we have to find a way for ourselves.”




“It started fine on the website but I didn’t have the documents needed for eligibility, so I went to the Medicaid office and that was the stressful part of it. The staff didn’t treat me well.

B is a 24-year-old with ADHD living in Florida. He describes his experience registering for Medicaid as both “good and bad.” “It started fine on the website but I didn’t have the documents needed for eligibility, so I went to the Medicaid office and that was the stressful part of it. The staff didn’t treat me well. But at the end of the day, I got it.” When asked about how he was treated by the staff, B said he was left at the reception desk for hours, even though the staff representative said they would be back in ten minutes. He had to wait an hour before he found another person to talk to. “I think that’s very wrong. It really messed up my day. I think they did not care about me because of my identity. The person at the desk was White and I wish it was someone that was the same race as me [Black]. I was emotional

because I felt neglected and I am Black and I felt not important.” B explains that it would have been helpful to have a guide that really understood his problems and someone

explains that it would have been helpful to have a guide that really understood his problems and someone to help him through these kinds of services. Prior to applying, B did not get a lot of information from Medicaid outside of his own online research. **“It came like a shock! A friend told me that services end and you age out. It was all because of a friend that I knew.”**



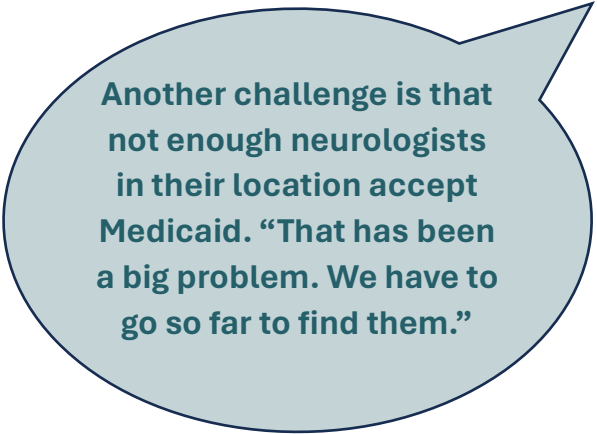
“I had to look for other means after I aged out. So, I did research and asked people who had the exact situations. It was hectic. I had to start a new journey.”

.....

C is a 22-year-old with autism living in Alabama. His experience with Medicaid has had lots of ups and downs. He applied for Medicaid as an adult and his application has been pending for eight months. In the interim C had to rely on friends to connect him with opportunities and to make a plan. **“I had to look for other means after I aged out. So, I did research and asked people who had the exact situations. It was hectic. I had to start a new journey.”** C wishes that there would have been better communication with Medicaid during this process. He didn’t feel like he was being understood, and he didn’t understand them. **“Maybe I am not getting care because I am Black. I lost my Medicaid, and I don’t know if I will get it back.”**

.....

D is a 19-year-old with epilepsy and cerebral palsy living in Georgia. He has been on Medicaid since birth and his coverage has never changed. He was on SSI as a child, and when he turned 18, he transitioned to adult SSI. That transition was smooth, with no issues or lapses in coverage. D and his mother noted that their main issue with Medicaid is that it no longer covers some of the costly prescriptions D was originally on, so they have to pay out of pocket or have doctors write a different prescription for a covered option. Another challenge is that not enough neurologists in their location accept Medicaid. **“That has been a big problem. We have to go so far to find them.”**



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E is a 20-year-old with Bainbridge-Roper syndrome living in Georgia. He is on Medicaid and Social Security Disability Insurance (SSDI). There has never been a time when they experienced a gap in benefits, with E’s mother describing it as “smoother sailing.” E’s mother explained that the only thing that they had to do was re-do some of the bank accounts to

keep the limits within the eligibility amounts. Every six months she does an interview with Children’s Medical Services who talks through all the benefits available to them.

Conclusions

F is a 20-year-old with cerebral palsy living in Georgia. She has been on Medicaid and SSI her whole life. F has never experienced gaps in coverage or interruptions in services. F is a part of a special school that provides lots of information on transition. F's mother shared that **“before her graduation, her teacher provided a packet about transitioning from high school to adulthood and it had different brochures about her as an adult, including guardianship paperwork. Most of the information has always been from school, even information on SSI and Medicaid.** The school has a website about all the resources offered to people with chronic conditions in the state of GA and this is to help kids with special needs.”

Conclusions

This five-state case study would not have been possible without the perspectives and stories from each key informant and self-advocate. This study reveals that Black youth and young adults, particularly those with ID/DD, in these five non-expansion Medicaid states are confronted with major challenges when they lose their childhood eligibility status under public programs. Options for their continued insurance coverage, income support, and ongoing care are disrupted, resulting in worsening disparities. Suggestions offered by these representatives and advocates informed a set of policy and program recommendations that can be found [here](#).

The National Alliance to Advance Adolescent Health/
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