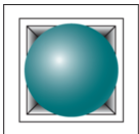


Youth and Young Adults with Disabilities Aging Out of Public Program Services: *Barriers, Inequities, and Recommendations*

May 22, 2024

Peggy McManus, MHS

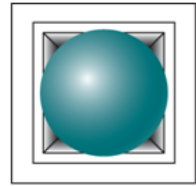
The National Alliance to Advance Adolescent Health/Got Transition



THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH



NAAAH/Got Transition



*THE NATIONAL ALLIANCE
TO ADVANCE ADOLESCENT HEALTH*

The National Alliance to Advance Adolescent Health is a nonprofit organization, based in Washington, DC, whose mission is to promote long-term, systemic improvements in comprehensive health care and insurance coverage for adolescents and young adults, with focused attention on those with low-incomes, from racially and ethnically diverse families, and with chronic and disabling conditions.

For more information about The National Alliance, please visit TheNationalAlliance.org.

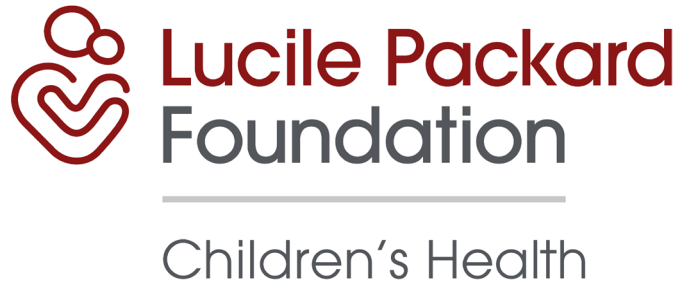


The National Alliance operates **Got Transition**, a national resource center on health care transition. For the past 10 years, we have developed a widely used set of clinical resources (called the Six Core Elements of Health Care Transition) as well as tools for youth and families, led the authoring group for the AAP/AAFP/ACP Clinical Report on Transition, conducted several systematic reviews on transition, supported numerous QI initiatives and Project ECHO series, and worked with state Title V public health programs and many health care systems to encourage the use of evidence driven approaches for transition planning, transfer of care, and integration into adult care.

For more information about Got Transition, please visit GotTransition.org.

Acknowledgments

*This webinar is supported by
The Lucile Packard Foundation for Children's Health
and the WITH Foundation*



Ryan Easterly, WITH Foundation

Ryan Easterly lives and works at the intersections of race, class, disability, and sexual orientation. Ryan serves as Executive Director of WITH Foundation. WITH promotes comprehensive healthcare for adults with developmental disabilities in the United States.

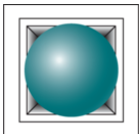
He currently serves as the co-chair of the Presidents' Council on Disability Inclusion in Philanthropy (along with Dr. Rich Besser of RWJF) as well as a member of the Disability & Philanthropy Forum Governance Committee. Ryan is a member of Grantmakers for Effective Organizations Board of Directors and co-chairs Exponent Philanthropy's Disability Funders Peer Circle. He was also recently appointed by President Biden to the White House Commission on Presidential Scholars.

Ryan hails from Alabama and often wonders when he will find his next glass of sweet tea. He currently resides in San Francisco, California



Today's Agenda

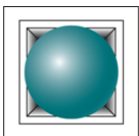
- 1. Background and Methods**
- 2. Self-Advocate Spotlight: André Marcel Harris**
- 3. Findings:**
 - National Study:
 - Data from the American Community Survey
 - Age cut-offs for Medicaid, CHIP, SSI, and Title V
 - Challenges and impacts, by program
 - Five State Case Study:
 - Inequities, at-risk populations, unmet health service needs
- 4. Recommendations:**
 - Medicaid and CHIP
 - SSI
 - Title V
- 5. Conclusions and Next Steps**
- 6. Evaluation Survey**



Background

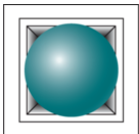
This study aimed to:

- 1) Bring new attention to the shift that low-income youth and young adults with disabilities face as they age into adulthood under Medicaid, CHIP, SSI, and Title V for CYSHCN
- 2) Uncover eligibility and enrollment challenges, inequities, and impacts
- 3) Identify challenges faced by Black young adults with disabilities, including those with intellectual and/or developmental disabilities (ID/DD), in five states that did not expand Medicaid
- 4) Recommend policy and program strategies to reduce disruptions and disparities in access to adult public program services



Methods

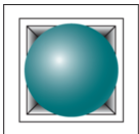
- **Two-year study**, from June 2022 to April 2024
- Guidance and expertise from a **National Advisory Committee** representing Medicaid, SSI, and Title V programs, researchers, and advocates
- **Data analysis** of the 2017–2021 American Community Survey, by Minnesota’s State Health Access Data Assistance Center
- **Literature review** of published articles, grey and white papers, and public program documents
- **Online surveys** with separate CHIP and Title V CYSHCN programs
- **Analysis of Medicaid MCO contracts** (40 general contracts, 3 specialty contracts)
- **Key informant interviews** with 55 officials from national organizations and state and federal agencies that represent Medicaid, CHIP, SSI, and Title V, along with family/disability advocates, legal advocates, and researchers
- **A case study** on challenges faced by Black young adults with disabilities when they lose their childhood eligibility for public programs in Alabama, Florida, Georgia, Mississippi, and Texas



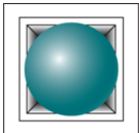
Self-Advocate Spotlight:

André Marcel Harris, MSW

André is a third-year PhD candidate studying Social Work at the University of Houston's Graduate College of Social Work. He is the Immediate Past President of the Association of Black Social Workers (NABSW) University of Houston Graduate College of Social Work chapter. André also serves on the Executive Board of the Sickle Cell Association of Houston and holds positions on several other advisory boards for sickle cell and rare disease stakeholders. He is a proud member of Phi Beta Sigma Fraternity, Inc. and serves as the National Sickle Cell Liaison Director, a position that allows him to strengthen the social action interests the fraternity has in supporting the sickle cell community.



Findings

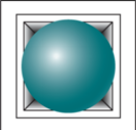


Racial Differences Among Youth and Young Adults by Disability Prevalence, Poverty Status, and Uninsurance Rates in the US, 2017-2021

	Youth (12-18)			Young Adults (19-25)		
	All	Black	White	All	Black	White
% with a disability	6.4%	7.7%	6.3%	7.0%	7.7%	7.4%
% with a disability and incomes below 100% of poverty	26.2%	39.5%	20.0%	65.9%	74.3%	63.5%
% with a disability and without health insurance	4.6%	4.0%	3.6%	12.9%	15.4%	10.5%

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

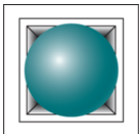
Source: University of Minnesota’s State Health Access Data Assistance Center (SHADAC) analysis of the 2017–2021 American Community Survey 5-Year PUMS files



Age Cut-Offs

- **Medicaid:** 19 to 21
- **CHIP:** 19
- **SSI:** 18
- **Title V:** Most often 21

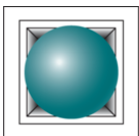
Currently, there are no publicly available estimates on the number of young adults with disabilities aging out of these programs.



National Study: Challenges, Medicaid and CHIP

- **Most common challenges:**
 - Lower income standards for adult eligibility
 - Residing in a Medicaid non-expansion state
 - Long waitlists for waivers
- **Other challenges mentioned:**
 - Lack of sufficient and accessible notice when eligibility ends
 - Lack of education about insurance changes and different options among youth/young adults and families
 - Limited availability of navigators to help enrollees remain insured
 - Problematic communication between Medicaid and marketplace

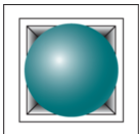
Note: Additional barriers are summarized in the national report.



National Study: Challenges, SSI

- **Most common challenges:**
 - More restrictive adult eligibility disability criteria
 - Complex and burdensome application process and documentation requirements
- **Other challenges mentioned:**
 - Difficulties navigating the system without a knowledgeable case worker
 - Accessing providers to obtain updated documentation
 - Outdated adult disability job standards that do not reflect the current economy and job market

Note: Additional barriers are summarized in the national report.

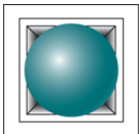


National Study: Challenges, Title V

Certain populations of CYSHCN face greater difficulties with aging out:

- Minoritized racial and ethnic populations
- Non-US citizens
- Those without insurance
- Those residing in rural areas
- Those with medically complex conditions
- Those who cannot find adult providers
- Those with significant intellectual and/or developmental disabilities

Note: Additional barriers are summarized in the national report.

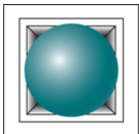


Five Case State Study:

ACS Data Findings on Youth and Young Adults with Disabilities

Source: University of Minnesota's State Health Access Data Assistance Center (SHADAC) analysis of the 2017–2021 American Community Survey 5-Year PUMS files

	US	AL	FL	GA	MS	TX
% at or below 100% FPL						
Black youth	39.5%	33.8%	41.3%	39.3%	47.6%	34.0%
White youth	20.0%	26.3%	19.6%	20.8%	23.0%	16.5%
Black young adults	74.3%	74.9%	78.1%	73.8%	80.8%	71.0%
White young adults	63.5%	67.5%	66.2%	66.4%	68.6%	62.3%
% without insurance						
Black youth	4.0%	3.1%	9.1%	5.1%	5.6%	5.2%
White youth	3.6%	2.7%	6.4%	5.0%	3.1%	6.9%
Black young adults	15.4%	20.6%	20.6%	24.1%	23.0%	25.6%
White young adults	10.5%	18.7%	17.3%	19.2%	19.1%	19.3%

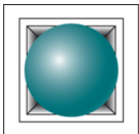


Five State Case Study: Black Young Adults with Disabilities

The most common challenges were:

- 1) Inadequate and complex information about obtaining/applying for services
- 2) Lack of access to providers and services due to living in rural areas or no transportation or Wi-Fi
- 3) Racism, prejudice, and unconscious bias against people of color

Source: Reported through key informant interviews with state agency officials and advocates

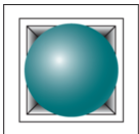


Five State Case Study: Black Young Adults with Disabilities

Populations facing greater disadvantages:

- Those with mental health, developmental disabilities, and other co-occurring conditions
- Who have invisible disabilities
- Who lack education
- Who are male
- Who fall outside the states developmental disability system
- Who identify as non-binary
- Who become pregnant

Source: Reported through key informant interviews with state agency officials and advocates

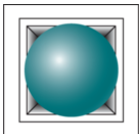


Five State Case Study: Black Young Adults with ID/DD

Unmet Health Services Needs:

- Providers who are trained to work with those with developmental disabilities
- Finding providers who accept Medicaid
- Mental and behavioral health services
- Dental care
- Specialty care

Source: Reported through key informant interviews with state agency officials and advocates



Five State Case Study: Black Young Adults with ID/DD

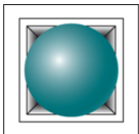
Examples of racism, prejudice, and bias were commonly cited for Black young adults in general and for those with ID/DD in particular.

Black students have not had their disability addressed correctly.

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.

As a Black mom, when I advocate for my son, I am perceived as aggressive, and I get told I am angry.

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.



Aging Out Recommendations

Medicaid and CHIP

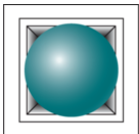
- Program and policy reform
- Transition supports
- Outreach, education, and collaboration
- Evaluation, review, and data-driven actions

SSI

- Program and policy reform
- Streamlined application and transition support
- Outreach, education, and interagency collaboration
- Analysis, review, and data-driven actions

Title V

- Program and policy reform
- Training and referral
- Tracking and feedback
- Partnership and interagency collaboration



Aging Out Recommendations

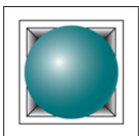
Medicaid/CHIP: Program and Policy Reform

Recommendation: Establish a national uniform definition of childhood eligibility for Medicaid and CHIP at either under 21 (consistent with EPSDT) or under 26 (consistent with ACA dependent child provision). (Congress)

Recommendation: Allow all SSI recipients automatic qualification for Medicaid without having to submit a separate Medicaid application. (Congress)

Recommendation: 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)

Responsible agencies are listed in parentheses next to each recommendation

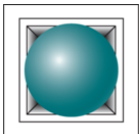


Aging Out Recommendations

Medicaid/CHIP: Transition Supports

“Everything is last minute, and there is panic to try and figure out what to do next.”

Recommendation: 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)

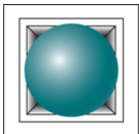


Aging Out Recommendations

Medicaid/CHIP: Outreach, Education, Collaboration

“Young adults may never have had to look for insurance before, understand what their options are, and what certain terms mean.”

Recommendation: Develop state Medicaid guidance on outreach and informing of Medicaid insured youth and families that would be given 12-24 month before aging out of Medicaid. This should include informing about benefit changes with loss of childhood eligibility and case management to tie them to insurance and medical, social and other supports in advance of aging out. (CMS)

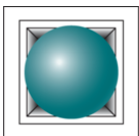


Aging Out Recommendations

Medicaid/CHIP: Evaluation, Review, Data-Driven Actions

“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.”

Recommendation: 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)



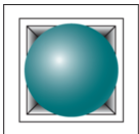
Aging Out Recommendations

SSI: Program and Policy Reform

Recommendation: Delay application of the adult disability criteria until age 22, instead of age 18.

“A lot of youth who have been denied adult SSI benefits go through the process unrepresented.”

Recommendation: 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)



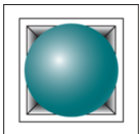
Aging Out Recommendations

SSI: Streamlines Application and Transition Support

“The system is impossible to navigate unless you get the right social worker or case worker to help.”

Recommendation: Establish a simplified and streamlined application process and continuing disability review process with input from family, disability, self-advocacy, legal, and Medicaid eligibility experts. (SSA)

Recommendation: Create a centralized application and appeals center to help youth and young adults and their families have their applications processed more efficiently. (Congress)

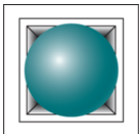


Aging Out Recommendations

SSI: Outreach, Education, Interagency Collaboration

“Parents often assume their child has SSI benefits for life. Differences between child and adult eligibility criteria are not widely known.”

Recommendation: 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 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 Continuing Disability Review (CDR) function report. (SSA)

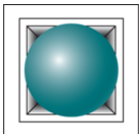


Aging Out Recommendations

SSI: Analysis, Review, Data-Driven Actions

“Without more robust reporting on data on race and ethnicity from SSA, it is very difficult to review anything from individual case decisions to widespread policy changes to see if they have a racially disparate impact.”

Recommendation: 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 group (14-17, 18-21, 22-25), condition type, and rural versus urban geographic area. (SSA)



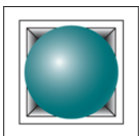
Aging Out Recommendations

Title V: Program and Policy Reform

“We have, as a country, improved the life expectancy for children with certain conditions, however, in many ways we have failed them. The reason is because they age out often without any place to transition too. We must do better.”

Recommendation: Increase the childhood eligibility age cut-off for state Title V CYSHCN programs to age 26, with corresponding funding increases in Title V Block Grant funding. (Congress)

Recommendation: 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. (State Title V agencies)

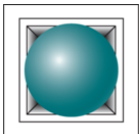


Aging Out Recommendations

Title V: Tracking and Feedback

“There is no system to track or monitor youth after they left the system. It is a hole in the system.”

Recommendation: 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. (State Title V agencies)

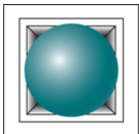


Aging Out Recommendations

Title V: Partnership and Interagency Collaboration

“We need a supported workforce to prepare youth and parents before they age out, especially in rural areas, where there is a lack of providers to connect young adults to.”

Recommendation: 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. (State Title V agencies)

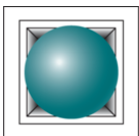


Conclusions

- Far too many low-income and Black young adults with disabilities do not receive necessary education, preparation, and support for making the shift to health insurance coverage and disability benefits as an adult.
- The authors call on federal and state agency officials and Congress to bring attention to this transition-aged population and consider these recommendations for improvement.

“Policies need to be challenged in a significant, legislative way. They are unjust and punitive to people with disabilities”

— national disability organization representative



Next Steps

- We plan to share these findings with advocacy and disability organizations, government agency representatives, community-based organizations, and family and youth leaders in the months ahead.
- Please share these findings with your networks.

**National
Report**



**Policy Brief
on Medicaid
& CHIP**



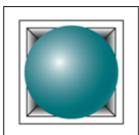
**Policy Brief
on SSI**



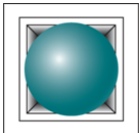
**Policy Brief
on Title V**



**Five State
Case Study**



Evaluation Survey



Thank you!

For any comments or questions, please email Peggy McManus:

MMcManus@TheNationalAlliance.org

