

# Policy Brief on Title V: Recommendations to Assist Youth and Young Adults with Special Health Care Needs Aging Out of Title V

May 2024 | The National Alliance to Advance Adolescent Health/Got Transition

## Introduction

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

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.
- **Online survey** of Title V CYSHCN program directors about their outreach and referral efforts, age cut-offs, and estimates of the population aging out.
- **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 (ID/DD); and six young adult self-advocates to hear about their lived experience.

## Findings

### Background

The Title V Maternal and Child Health (MCHB) Program is a block grant designed to support 59 states/jurisdictions in addressing the needs of mothers, infants, children – including CYSHCN – and their families.<sup>2</sup> Of the populations served by Title V in 2022, 29.6% were CYSHCN.<sup>3</sup> 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). Estimates of the number of young adults with special health care needs (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. Information below was obtained through an online survey administered to 51 state Title V CYSHCN directors (31 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 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\***

### **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)

### **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)

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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)
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\* Responsible agencies are listed in parentheses

## Conclusions

Title V Programs for CYSHCN play an important role helping to ensure access to a coordinated system of services for CYSHCN. Despite the absence of an adult public health program counterpart, state Title V Programs have the opportunity to facilitate expanded outreach, education, referral, and interagency collaboration to strengthen connections to adult-serving systems. This expanded work can be incorporated into MCHB's efforts to implement their Blueprint for Change<sup>4</sup> and into state Title V implementation of MCHB's national performance measure on transition, which has been prioritized by 36 states/jurisdictions.<sup>5</sup> For more information, please contact Peggy McManus at [MMcManus@TheNationalAlliance.org](mailto:MMcManus@TheNationalAlliance.org).

## References

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**Suggested Citation:** McManus M, Ilango S, White P, Schmidt A. *Policy Brief on Title V: Recommendations to Assist Youth and Young Adults with Disabilities Aging Out of Title V*. Washington, DC: The National Alliance to Advance Adolescent Health, May 2024.

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