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Transitions of Coverage and Care for Children and Youth with Special Health Care Needs

Ava Williams and Linn Jennings



Medicaid and CHIP Payment and Access Commission

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Overview

- Children and youth with special health care needs (CYSHCN) population
- CYSHCN in Medicaid
 - Transitions of coverage and care
- Federal and state policy scan findings
 - Federal requirements
 - State policies
- Literature review findings on transition experiences
- Next steps



CYSHCN Population

- The CYSHCN population includes individuals with a wide range of physical, mental, and behavioral health conditions and levels of limitations
- One in five children have special health care needs

CYSHCN in Medicaid

- Most CYSHCN are covered by Medicaid on the basis of income, under the Supplemental Security Income (SSI) eligibility pathway, or a state optional disability pathway
- It is becoming more common to enroll CYSHCN in Medicaid managed care
- Medicaid-covered CYSHCN can also receive services and supports from Title V agencies
 - Title V and Medicaid agencies are required to have an Inter-Agency Agreement (IAA)

Transitions of Coverage and Care

Coverage

- When CYSHCN age out of child Medicaid eligibility pathways, they need to transition to adult coverage
 - Most age out of child Medicaid eligibility pathways between ages 18 and 22

Care

- As youth reach adulthood, they need to transition from pediatric to adult health care
 - The health care transition (HCT) is a multi-step process and often begins several years prior to the child aging out of pediatric care

Federal and State Policy Scan

Key findings

Federal and State Policy Scan

- The goal of the policy scan was to:
 - identify federal and state coverage and care transition policies
 - understand how Medicaid agencies, managed care organization (MCO) contracts, and Title V programs define and identify CYSHCN, and define, monitor, and assess the transition process
- Federal statutes and regulations related to transitions of coverage and care policies for Medicaid and Title V
- State Medicaid program and demonstration waivers, MCO contracts, and IAAs

Federal Findings

- There are no federal Medicaid definitions or requirements for transitions of coverage and care for CYSHCN, but the Centers for Medicare & Medicaid Services (CMS) has provided some guidance
- States must identify, assess, produce a treatment plan, and provide direct access to specialists for individuals with special health care needs
- There are no Title V requirements for CYSHCN transitions of coverage and care

State Findings: CYSHCN Definitions and Identification

- Variability across state Medicaid programs and MCO contracts
 - State Medicaid programs can define the populations they serve based on eligibility pathways, state plan options, and waiver authority
 - There is no requirement to identify CYSHCN in need of a transition from pediatric to adult care

State Findings: Coverage Transitions

- The notification of CYSHCN in need of transition is most often initiated by the state Medicaid agency, another state agency (e.g., partner agencies serving adults with special health care needs), or a state assigned case manager
- Five reviewed MCO contracts require coverage transition assistance, such as assigning a care coordinator or case manager to support individuals aging out and enrolling in adult Medicaid coverage and other coverage options
- The scan did not identify requirements for monitoring and oversight of coverage transitions for CYSHCN

State Findings: Care Transitions

Transition process

- Some state Medicaid waivers and MCO contracts include language related to care transition processes, and there is wide variation in these processes
- Some home- and community-based services (HCBS) waivers define transition of care services and transition plans
 - For example, the plans include the development of a continuity of care plan, identifying adult health care providers, and establishing a timeline for transition
- Few MCO contracts specify the transition process
 - For example, one contract permits the beneficiary to receive care from a pediatrician and adult provider at the same time to facilitate the transition of care

State Findings: Care Transitions, cont.

Monitoring and oversight

- Waivers do not require monitoring and oversight from child to adult care
- Few MCO contracts include monitoring requirements and information about processes for measuring these transitions
 - For example, one state Medicaid agency requires the MCO to designate a transition specialist to the care coordination team to monitor the effectiveness of the transition plan

State Findings: Care Transitions, cont.

State Medicaid and Title V agencies roles and responsibilities

- Few IAAs describe specific Title V or Medicaid agency responsibilities related to health care transitions
 - The Maine Title V and Medicaid agencies agree to create messaging focused on continuity of care for transitioning populations
 - The Massachusetts Title V agency is responsible for providing technical assistance to Medicaid providers on transition of care needs for CYSHCN and their families

CYSHCN Transition Experiences

- Literature indicates that outcomes (e.g., quality of life, health status, patient and family experience, etc.) are improved when CYSHCN receive structured HCT services
 - The majority of CYSHCN and their caregivers do not report receiving transition support during their transition from pediatric to adult care
- Barriers to successful transitions of care include:
 - CYSHCN and their caregivers: inadequate transition preparation, lack of care coordination, provider availability, and distance to travel to adult providers
 - Pediatric and adult providers: limited coordination and communication between pediatric and adult providers to facilitate transitions, few Current Procedural Terminology (CPT) codes related to transition services

Next Steps

- Spring and summer 2024: Conduct national and state stakeholder interviews and beneficiary focus groups
- Fall 2024: Present interview and focus group findings
- Commissioners:
 - Do you have feedback on the direction of this work?
 - Are there any additional considerations to include as we begin the next phase of work and plan for upcoming presentations?


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