April 10, 2025

Children and Youth with Special Health Care Needs (CYSHCN) Transitions of Care

Review of recommendations and draft chapter for the June 2025 Report to Congress

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Medicaid and CHIP Payment and Access Commission

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Overview

- Background
- Federal requirements and guidance
- State role
- Challenges
- Recommendations

Background

- Almost one in five children have special health care needs, and almost half of these children are covered by Medicaid
  - Most are covered by Medicaid on the basis of income, under the Supplemental Security Income (SSI) eligibility pathway, or a state optional disability pathway
- As youth reach adulthood, they need to transition from pediatric to adult health care
  - The transition is a multi-step process, and structured transitions have been shown to improve health outcomes
- Few data sources collect consistent and comparable data about CYSHCN, their experiences with the transition process, and their health outcomes and service use after transitioning to adult care

Federal Transition of Care Requirements

- Federal Medicaid requirements
  - States should describe transition planning procedures for beneficiaries enrolled in section 1915(c) home- and community-based services (HCBS) waivers with age limits
  - States and MCOs are required to ensure access to care and continuity of care during transitions for beneficiaries with special health care needs across life span (42 CFR 438.208)
- The Centers for Medicare & Medicaid Services (CMS) has published some guidance related to these transitions, including early and periodic screening, diagnostic and treatment (EPSDT); clinical consultation between multiple providers; identifying CYSHCN; and health home state plan option
- Medicaid and Title V requirements
  - State Medicaid agencies must describe Inter-Agency Agreements (IAA) with state Title V agencies (42 CFR 431.615)
  - IAAs must specify roles and responsibilities and outline coordination efforts for CYSHCN

State Role

Transition of care approach

- States and managed care organizations (MCOs) identify and notify beneficiaries approaching transition age and may specify who is responsible for facilitating their transition
- Most states with age-limited HCBS waivers include some transition planning information
  - Specificity varies, and few waivers require the development of a transition of care plan
- Many MCO contracts include some provisions related to CYSHCN, but few include ones specific to the transition to adult care, who is responsible for facilitating the transition, and the development of a transition of care plan

State Role, cont.

Coverage of services to support transitions of care

- States can provide these services through state plan (e.g., targeted case management (TCM)) and waiver authorities
- States may not always be aware of how to cover these services or which Current Procedural Terminology (CPT) codes apply

Data collection on transitions of care

- Some state agencies and MCOs collect quality data related to CYSHCN, but in general, states do not collect data or monitor CYSHCN transitions of care and their health outcomes

Collaboration with state Title V agencies

- State Medicaid IAAs address program coordination and collaboration efforts related to CYSHCN
- IAAs are not required to specify roles and responsibilities for supporting CYSHCN transitions of care, so few do

Challenges

- Lack of clearly documented and communicated state strategies to transitions of care
- Not all CYSHCN receive a transition of care plan
- Lack of guidance to states on coverage of services to support transitions of care
- Lack of data collection on CYSHCN and their transitions of care
- State Medicaid and Title V agencies do not coordinate on CYSHCN transitions of care

Recommendations

Rationale and Implications

Recommendation 1.1

Congress should require that all states develop and implement a strategy for transitions from pediatric to adult care for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care. The strategy should address the development of an individualized transition of care plan, and describe (1) the entity responsible for developing and implementing the individualized transition of care plan, (2) the transition of care timeframes, including the age when the individualized transition of care plan is developed, and (3) the process for making information about the state's strategy and beneficiary resources related to transitions of care publicly available.

Recommendation 1.1: Rationale

- Evidence supports having a structured transition strategy that includes an individualized care plan to improve transition outcomes
  - Few states have a documented transition of care strategy or develop transition of care plans for CYSHCN
- States retain flexibility to determine a transition strategy that works best for their CYSHCN, delivery system, and program design
- States should consider:
  - Additional CYSHCN and vulnerable groups (e.g., children involved in the child welfare system)
  - Leveraging existing transition frameworks
  - Soliciting feedback from relevant stakeholders (e.g., other state agencies, provider groups, and beneficiaries)
  - Engaging adult providers in the development of care plans
  - Reviewing and updating care plans routinely

Recommendation 1.1: Implications

- **Federal Spending**: The Congressional Budget Office (CBO) does not estimate a direct effect on federal spending
- **States**: Would need to allocate resources to develop and publicly document their strategy for transitions of care and establish parameters for individualized transition of care plans. They may need to monitor the development of transition of care plans
- **Enrollees**: Improves understanding of their state's strategy, resources for transitions, and expectations for their own transitions
- **Plans**: Improves understanding of state's strategy and expectations for supporting transitions of care. Potential administrative effort to develop transition plans
- **Providers**: May be involved developing transition plans

Recommendation 1.2

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities for covering transition of care services for children and youth with special health care needs, including but not limited to, children enrolled in Medicaid through Supplemental Security Income-related eligibility pathways and the Katie Beckett pathway for children with disabilities, those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, and children who qualify to receive an institutional level of care.

Recommendation 1.2: Rationale

- States need guidance on the use of existing authorities to pay for transition-related services (e.g., TCM, capitation rate setting, EPSDT, and interprofessional consultation)
- CMS should consider addressing transition of care payment concerns:
  - Covering pediatric to adult provider consultations, (e.g., warm handoff, etc.)
  - Billing for same day visits
  - Covering ongoing care with two primary care providers (pediatric and adult)
  - Payment for longer transition planning visits

Recommendation 1.2: Implications

- **Federal Spending**: CBO does not estimate a direct effect on federal spending
- **States**: Improved understanding of authorities to pay for transition services and administrative effort to implement payment policy changes
- **Enrollees**: Increased access to transition-related services and supports
- **Plans**: May need to develop payment policy and guidance for providers
- **Providers**: May receive payment for transition-related services not previously reimbursed and engage with CYSHCN transitions sooner

Recommendation 1.3

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services (CMS) to require states to collect and report to CMS data to understand (1) which beneficiaries are receiving services to transition from pediatric to adult care, (2) utilization of services that support transitions of care, (3) and receipt of an individualized transition of care plan. Additionally, CMS should direct states to assess and report to CMS beneficiary and caregiver experience with transitions of care.

Recommendations 1.3: Rationale

- Lack of transition of care data limits CMS, state, and other stakeholder understanding of the extent to which CYSHCN receive transition of care services and areas for improvement
- States should collect and report on an ongoing basis:
  - Number of CYSHCN receiving transition-related services
  - Service utilization
  - Receipt of an individualized transition of care plan
- CMS should consider:
  - Soliciting input from beneficiaries, their families, caregivers, and other stakeholders
  - Leveraging existing data collection efforts
  - Collecting information related to adult care utilization
- Post-transition measures to evaluate health outcomes are important, but more work is needed to identify them

Recommendation 1.3: Implications

- **Federal Spending**: CBO does not estimate a direct effect on federal spending
- **States**: Depending on extent to which CMS leverages existing data collection, states may not have to make changes. Data will provide insight into beneficiary experience and aid assessment of effectiveness of transition strategy
- **Enrollees**: Improved understanding of beneficiary experience and how to improve transitions of care
- **Plans**: Depending on extent to which CMS leverages existing data collection, plans may not have to make changes. Data will provide insight into beneficiary experience
- **Providers**: May have new reporting requirements and gain understanding of their patients and their transition experiences

Recommendation 1.4

The Secretary of the U.S. Department of Health and Human Services should direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements (IAAs) between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care. The roles and responsibilities of the state Medicaid agency described in the IAA should reflect the agency's strategy for transitions of care.

Recommendation 1.4: Rationale

- Few state Medicaid and Title V agencies coordinate with each other on agency roles and responsibilities related to CYSHCN transitions of care
- CMS should consider:
  - Specifying agency roles and responsibilities for providing transition services, developing pertinent training and educational resources, and providing other supports to facilitate the transition from pediatric to adult care
  - Engaging with other state agencies that serve CYSHCN to increase awareness of the multiple, simultaneous transitions and identify opportunities for reducing beneficiary burden

Recommendation 1.4: Implications

- **Federal Spending**: CBO does not estimate a direct effect on federal spending
- **States**: May need to update IAAs to meet new requirements
- **Enrollees**: May experience more coordination and support from both agencies
- **Plans**: May need to collaborate and coordinate with state Title V agency on services and supports
- **Providers**: Potential changes to their role in supporting patient transitions of care

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