February 27, 2025

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

Draft Policy Recommendations

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MACPAC

Medicaid and CHIP Payment and Access Commission

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Overview

- Summary of challenges
- Additional factors affecting transitions
- Draft recommendations
- Next steps

Summary of Challenges with Transitions of Care

- 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

Additional Factors Affecting Transitions

- Aging out of the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit and Title V program eligibility
- Multiple simultaneous transitions as individuals approach adulthood can lead to loss of supports (e.g., education and career counseling, workplace readiness training, individualized education plan)
- Receive supports from multiple agencies that may or may not collaborate on the transition process (e.g., departments of developmental services, social services or child welfare)

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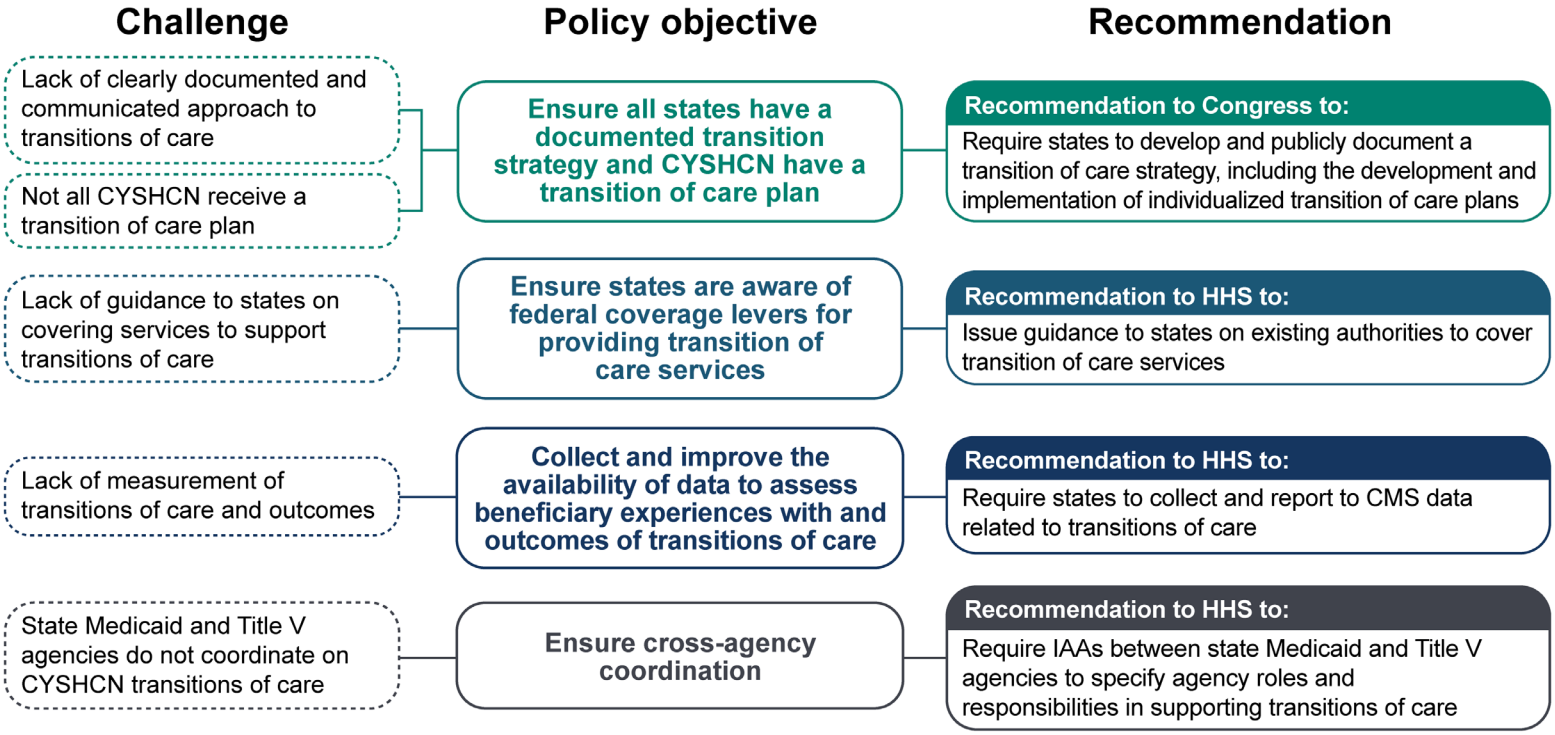

Notes. IAA is inter-agency agreement

Draft Recommendation 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 those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, Katie Beckett authorities, 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.

Rationale

- Evidence supports having a structured transition strategy that includes an individualized care plan to improve transition outcomes for CYSHCN
  - Few states have a documented transition of care strategy or develop transition of care plans for their CYSHCN beneficiaries
- Under this recommendation, states retain flexibility to determine a transition strategy that works best for their CYSHCN, delivery system, and program design
  - The CYSHCN population and the inclusion of additional vulnerable groups (e.g., children involved in the child welfare system)
  - Leveraging existing transition frameworks
  - Soliciting feedback from relevant stakeholders, including other state agencies that service these same populations
  - Engaging adult providers in the development of the transition strategy and care plans

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 individualized 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
  - If they are delegated this responsibility, potential administrative effort to develop individualized transition plans
- **Providers**: May be involved developing individualized transition plans

Draft Recommendation 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 those eligible for Medicaid under The Tax Equity and Fiscal Responsibility Act, Katie Beckett authorities, and children who qualify to receive an institutional level of care.

Rationale

- States need guidance on the use of existing authorities to pay for transition related services (e.g., targeted case management (TCM), capitation rate setting, EPSDT, interprofessional consultation)
- In the development of the guidance, 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, and covering ongoing care with two (a pediatric and adult) primary care providers
  - Payment for longer transition planning visits, which are important for ensuring the beneficiary and family are prepared for the transition

Implications

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

Draft Recommendation 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.

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 data to establish a baseline
  - Number of CYSHCN receiving transition-related services
  - Services received
  - Receipt of an individualized transition of care plan
- Considerations for CMS in the development of these collection and reporting requirements
  - Solicit input from beneficiaries, their families, caregivers, and other stakeholders
  - Leverage existing data collection efforts to prevent duplicative efforts
  - Develop post-transition measures to evaluate health outcomes and experiences with adult care

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 provide insight into beneficiary transition experience and aid state assessment of effectiveness of transition strategy
- **Enrollees**: Improved understanding 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 provide insight into beneficiary experience with individualized transition of care plan
- **Providers**: May have new reporting requirements and gain understanding of their patients and their transition experiences

Draft Recommendation 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.

Rationale

- Few state Medicaid and Title V agencies coordinate with each other on agency roles and responsibilities related to CYSHCN transitions of care
- Considerations for CMS when amending requirements for IAAs between state Medicaid and Title V agencies
  - Specify 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
  - Engage with other state agencies that serve CYSHCN to increase awareness of the multiple, simultaneous transitions that may affect health care transitions and identify opportunities for reducing beneficiary burden

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**: No anticipated implications for plans
- **Providers**: Potential changes to their role in supporting patient transitions of care

Next Steps

Next Steps

- Staff welcome feedback on the draft policy recommendations, rationale, and implications
- Staff will return in April with the draft chapter and a vote on the recommendations

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FEBRUARY MEETING

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