December 12, 2024

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

Policy Considerations and Options

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Overview

- Project overview
- CYSHCN transitions of care findings
- Policy options
- Next steps and discussion questions

Project Overview

- Study objectives:
  - Examine how state Medicaid programs and managed care organizations (MCOs) operationalize their CYSHCN transition of care policies
  - Understand beneficiary and family experience
  - Identify barriers to transitions that can be addressed in federal Medicaid policy
- Approach:
  - Literature review
  - Federal policy review
  - State policy scan (e.g., 1915(c) waivers, MCO contracts, state Medicaid and Title V inter-agency agreements (IAAs))
  - Stakeholder interviews (e.g., federal and state officials, national research experts, and family advocates)
  - Beneficiary, family, and caregiver focus groups with participants who were currently transitioning or had transitioned to adult care
  - Analysis of the 2022 National Survey of Children's Health

Transitions of Care Findings

No Federal Requirement for States to Have a Transition of Care Approach for CYSHCN

- Lack of clearly documented and communicated state approaches to transitions of care
  - State approaches are often not publicly documented, so it is difficult to identify resources about the transition from pediatric to adult care
- Not all CYSHCN receive a transition of care plan
  - Plans are used to support the transition to adult care and describe the steps needed to transition (e.g., connecting with adult providers)
  - Many beneficiaries did not have a transition plan and if they did, it was not always useful because they did not address needed components

Coverage and Measurement of Transitions of Care

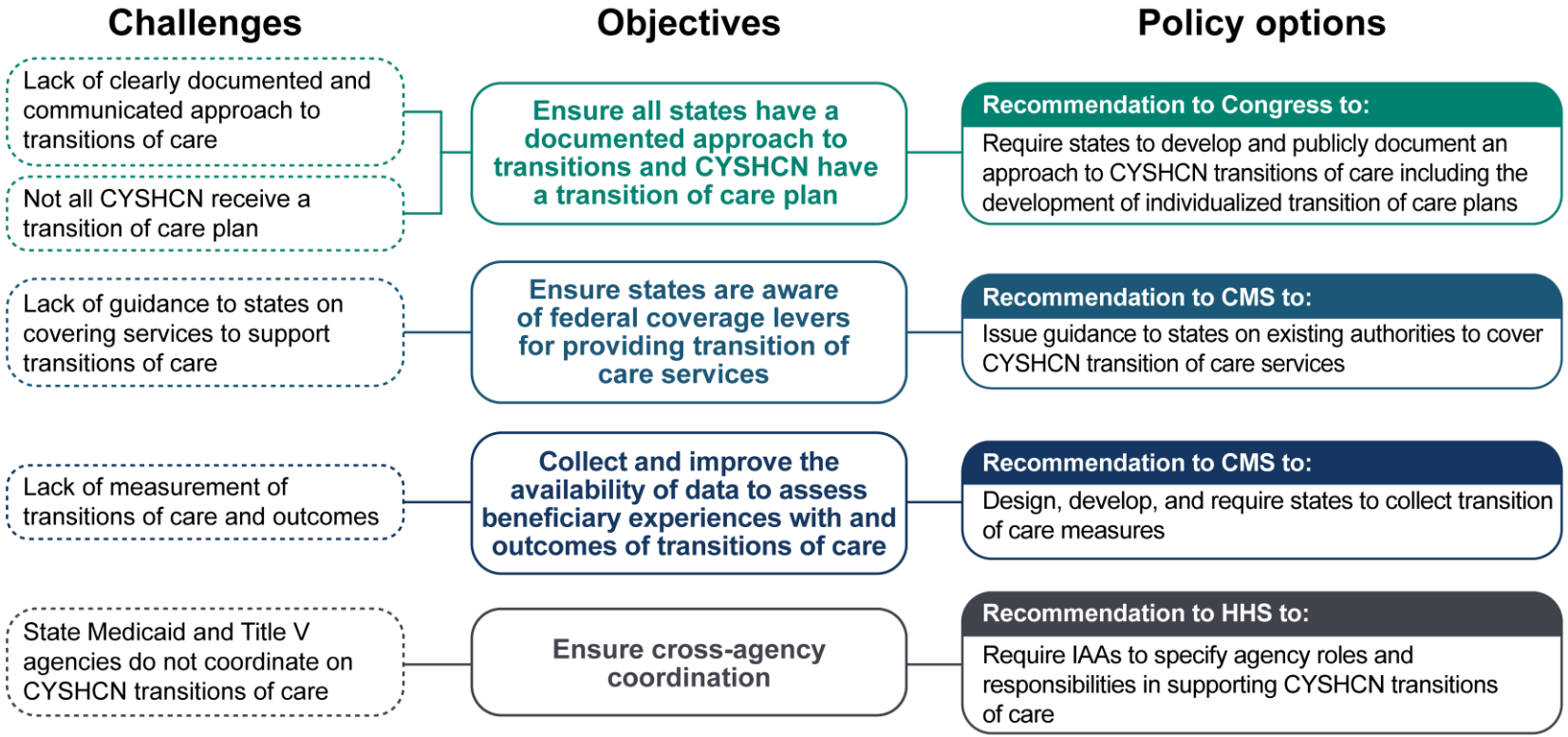
- Lack of guidance to states on coverage of services to support transitions of care
  - States may be unaware of how to cover services to support transitions of care through existing state plan or waiver authorities (e.g., targeted case management (TCM))
  - Existing CPT codes cover some but not all aspects of transition services
- Lack of measurement of transitions of care and outcomes
  - State Medicaid agencies often do not measure the experiences of CYSHCN with their transitions, or outcomes
  - Lack of commonly used measures results in few data sources
  - Lack of data collection limits stakeholder understanding of CYSHCN experiences and needs

Cross-Agency Coordination

- State Medicaid and Title V agencies are not required to and many do not coordinate on CYSHCN transitions of care
  - Both agencies are required to coordinate with each other on CYSHCN but not on their transitions
  - Lost opportunity for sharing of CYSHCN needs

Policy Options

Policy Options



Policy Option 1: State Approaches to Transitions and Individualized Transition Plans

Recommendation for Congress to direct states to:

- Develop an approach for transitions of care for CYSHCN, 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 and Katie Beckett authorities
- Provide an individualized transition of care plan for eligible beneficiaries, and at a minimum must describe (1) who is responsible for developing the individualized transition of care plan, (2) the timeframes for the transition of care, and (3) the process for making information about the state's approach publicly available to beneficiaries and other stakeholders

Policy Option 1, cont.

- Beneficiaries and stakeholders indicate that finding information about transitions is challenging, and beneficiaries did not feel supported in their transition
- Research and literature indicates that a structured transition approach, including an individualized care plan, can improve transition outcomes for CYSHCN
  - Those with individualized plans experienced improved transition readiness, decreased hospital visits, and increased satisfaction with health-related goals
  - Beneficiaries and their families noted that a structured plan that address key components would be helpful (e.g., readiness assessments)

Policy Option 2: Covering Services that Support Transitions of Care

Recommendation to the Centers for Medicare and Medicaid Services (CMS) to:

- Issue guidance to states on authorities to cover transition of care services for CYSHCN, 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 and Katie Beckett authorities

Policy Option 2, cont.

- States may be unaware of the authorities by which these services can be covered
  - CMS has not issued guidance on how to use existing authorities to cover these services
- States need clarity on the use of existing authorities for paying for services that support transitions of care and on the use of:
  - Targeted case management
  - State Medicaid payment for transitions of care services in managed care and fee for service
  - Payment for interprofessional consultation
  - Payment for transitions of care covered through the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit

Policy Option 3: Measure Transitions of Care Process for CYSHCN

Recommendation to CMS to:

- Design, develop, and require states to collect transition of care measures to assess access to transition of care services and beneficiary experience with the development of and execution of their transition of care plan. These measures should be developed with the input of beneficiaries, their families, and caregivers.

Policy Option 3, cont.

- States are not required to and do not measure CYSHCN transitions from pediatric to adult care
- Some existing process measures for assessing transitions of care in survey data
- Challenges with designing health outcome measures
- There are few data sources to understand CYSHCN access to and experience with transition services

Policy Option 4: Improved Coordination Between State Medicaid and Title V Agencies

Recommendation to the U.S. Department of Health and Human Services to:

- Require that state Medicaid agency IAAs with state Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transition from pediatric to adult care

Policy Option 4, cont.

- Few state Medicaid and Title V agencies coordinate with each other on CYSHCN transitions of care
  - This can be a barrier to beneficiaries, families, and the care team understanding the state approach to the transition and who is responsible for ensuring the beneficiary transitions to adult care
- State Medicaid and Title V agencies need IAAs that specify the roles and responsibilities of the agencies in providing:
  - Direct services to CYSHCN
  - Training and educational resources to plans, providers, and CYSHCN and their families and caregivers on the state approach to transition of care planning
  - Other supports to facilitate the transition from pediatric to adult care for this population

Next Steps and Questions

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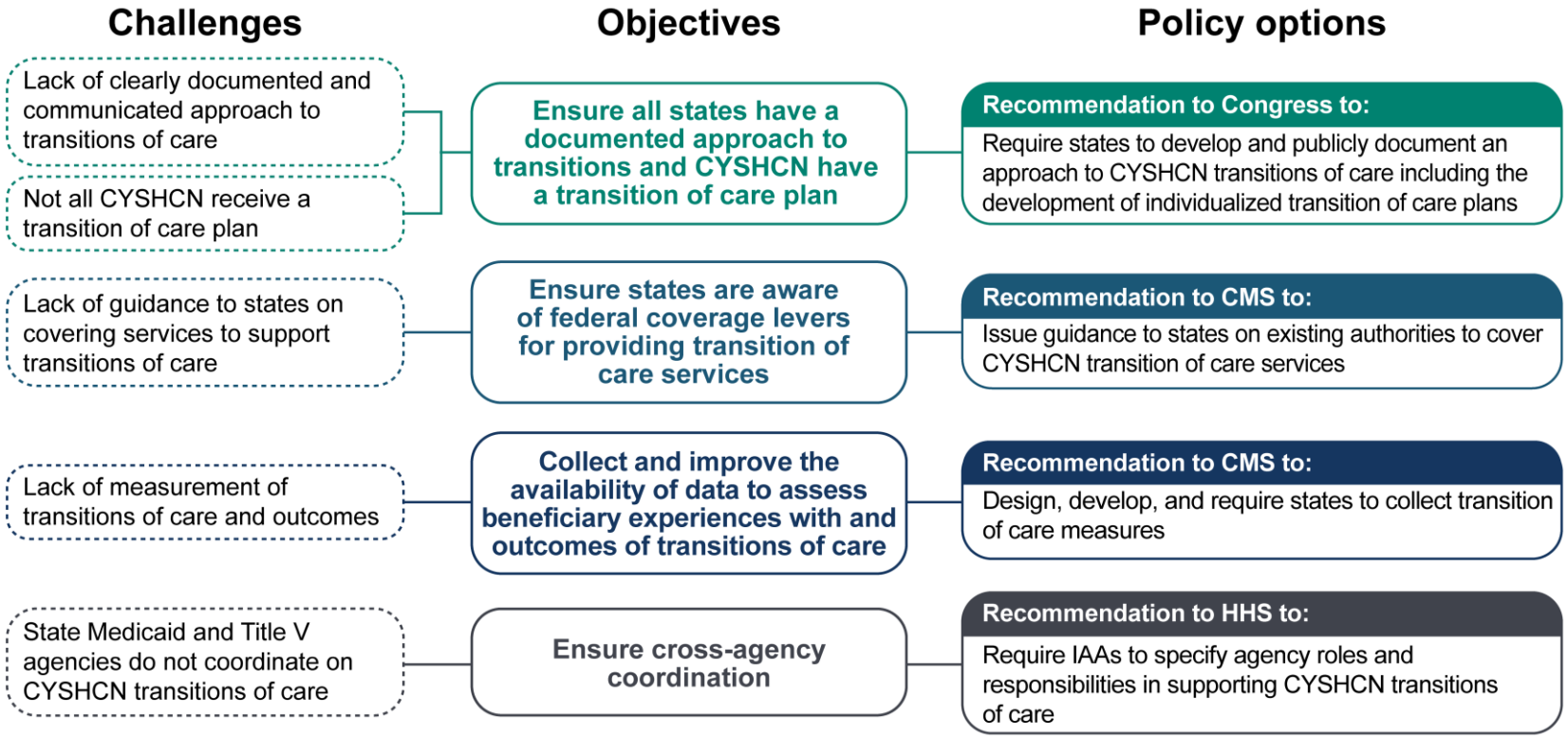
- Commissioner feedback on the policy options and which options you would like to advance for the June Report to Congress
  - Are there outstanding questions about the policy options that staff can answer?
  - Do the policy options address the identified challenges and does the evidence support the policy options?
  - Are there other factors for staff to consider while developing recommendation language and the rationale?
- Return in January with refined policy options

Policy Options



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