January 24, 2025

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

Revised Policy Options

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Overview

- Project overview
- Background
- Transition of care findings
- Revised 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, all 50 state and DC's 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

Background

Transitions of Care in Medicaid

Transitions of care

- There is no standard transitions of care process; however there are recommended components (e.g., assessing transition readiness, developing a transition plan, facilitating transitions to adult providers and care)

Medicaid

- Some states document transition of care strategies but they vary in detail and components
- Few beneficiaries were aware of the state's strategy and few had an individualized transition of care plan

Other Agencies Supporting CYSHCN Transitions

- The Health Resources and Services Administration awards grants to states to increase the number of CYSHCN who receive comprehensive services and supports including for their transitions of care
- HRSA's Maternal and Child Health Bureau developed the Blueprint for Change for CYSHCN
  - Resources on how to improve transitions for CYSHCN (e.g., integrating systems that serve CYSHCN and care coordination)

State Title V Agencies

- Title V block grants are used to provide direct health, enabling (e.g., care coordination), and public health services
- Agencies are required to use 30 percent of their grant for primary and preventive care for CYSHCN
  - States have flexibility in how they support transitions (e.g., care coordination and case management services)
- IAAs are required to detail the mutual objectives, roles, and responsibilities for the Medicaid and Title V agencies
  - Required to coordinate on EPSDT services
  - No requirement to coordinate on transitions of care

Transition of Care Findings

Summary of Findings

- Locating information about state transition strategies is challenging, and beneficiaries do not feel supported when transitioning
- A structured transition approach, including an individualized care plan can improve transition outcomes for CYSHCN
- Some states may be unaware of the authorities by which transition related services can be covered
- States are not required to and do not collect data on transitions of care
- Few state Medicaid and Title V agencies coordinate on CYSHCN transitions of care

Revised Policy Options

Policy Options

Challenges	Objectives	Policy options
Lack of clearly documented and communicated strategy to transitions of care Not all CYSHCN receive a transition of care plan	Ensure all states have a documented strategy to transitions and CYSHCN have a transition of care plan	**Recommendation to Congress to:** Require states to develop and publicly document a strategy for CYSHCN transitions of care including the development of individualized transition of care plans
Lack of guidance to states on covering services to support transitions of care	Ensure states are aware of federal coverage levers for providing transition of care services	**Recommendation to HHS to:** Issue guidance to states on existing authorities to cover CYSHCN transition of care services
Lack of data collection on transitions of care and beneficiary experience	Collect and improve the availability of data to assess transition service utilization and beneficiary experiences with transitions of care	**Recommendation to HHS to:** Require states to collect and report data related to transitions of care for CYSHCN
State Medicaid and Title V agencies do not coordinate on CYSHCN transitions of care	Ensure cross-agency coordination	**Recommendation to HHS to:** Require IAAs to specify agency roles and responsibilities in supporting CYSHCN transitions of care

Policy Option 1

Recommendation to Congress to:

- 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 require 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) 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.

Clarifications

- The policy option requires states to document their transition strategy that includes an individualized transition of care plan
- States retain flexibility to determine their transition strategy that works best for their CYSHCN, delivery system, and program design
- CYSHCN who have an institutional level of care need are included in the option language

Policy Option 2

Recommendation to The Secretary of the U.S. Department of Health and Human Services (HHS) to:

- Direct the Centers for Medicare & Medicaid Services to issue guidance to states on existing authorities to cover transition of care services for CYSHCN, which includes and is 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 require an institutional level of care.

Policy Option 3

Recommendation to the Secretary of HHS to:

- 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 transitions from pediatric to adult care, (2) service utilization to 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.

Clarifications

- The policy option does not require states to collect or measure quality of care or outcomes related information
- States should collect and report data related to:
  - number of CYSHCN receiving transition related services,
  - what services CYSHCN are receiving,
  - and if they received an individualized transition of care plan
- States should also collect data related to beneficiary and caregiver experience

Policy Option 4

Recommendation to the Secretary of HHS to:

- Direct the Centers for Medicare & Medicaid Services to amend 42 CFR 431.615(d) to require that inter-agency agreements between state Medicaid and Title V agencies specify the roles and responsibilities of the agencies in supporting CYSHCN transitions from pediatric to adult care

Clarifications

- A few state IAAs describe Medicaid and Title V coordination on transitions, but with little detail, for example:
  - The agencies will “coordinate on endeavors” and “develop messaging” related to transitions of care
  - Title V will provide technical assistance to Medicaid providers related to transitions of care
  - The state Medicaid agency is responsible for “administering peer and social support for transition aged youth”

Questions and Next Steps

Next Steps

- Commissioner feedback on the policy options and which options 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?
  - Are there other factors for staff to consider while developing recommendation language and rationale?
- Staff will return with recommendation language and draft chapter

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