November 1, 2024

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

Interview and Focus Group Findings

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Overview

- Background on children and youth with special health care needs (CYSHCN)
- Interview and focus group findings
  - Transition of care and process
  - Monitoring
  - Role of Title V
- Next steps
- Discussion questions

Background

- CYSHCN includes individuals with a wide range of physical, mental, and behavioral health conditions, and levels of limitations
- Most are covered by Medicaid on the basis of income, under the Supplemental Security Income (SSI) eligibility pathway, or a state optional disability pathway
- The majority of CYSHCN are enrolled in Medicaid managed care
- Medicaid-covered CYSHCN can also receive services and supports from Title V agencies

Current Landscape of Transitions of Care

Current federal and state policy

- No federal Medicaid requirement that states provide CYSHCN transitions of care services or document a process
- Some states specify transition policies in Medicaid home-and community-based services (HCBS) Section 1915(c) waivers and Managed Care Organization (MCO) contracts

Existing transition of care frameworks

- Several approaches are used to develop the steps needed to transition CYSHCN from pediatric to adult care
- Limited literature and insufficient evidence to support the use of a particular health care transition approach

Interview and Focus Group Findings

Interviews and Focus Groups

- Goal was to understand:
  - How state Medicaid programs and MCOs operationalize their CYSHCN transition of care policies
  - Beneficiary and family experience
  - Barriers to these transitions that can be addressed in federal Medicaid policy
- Stakeholder interviews included:
  - Federal and state officials
  - National research experts and family advocates
- Focus groups:
  - Two with parents and caregivers, and two with beneficiaries
  - Participants were currently transitioning or had transitioned to adult care

Identification and Notification

- Some states and MCOs use beneficiary demographic and health information to identify when CYSHCN are approaching transition age
  - Care coordinators, case managers, or other assigned staff may be responsible for identification
- There is variation in the timeline and processes, including who is responsible, for notifying beneficiaries and their families of the upcoming transition

How States Provide Transition Services

- Cover transition services through state plan and waiver authorities, often through targeted case management and care coordination
- Use a variety of clinical and non-clinical professionals (e.g., service coordinators and other providers) to support CYSHCN and provide transition services
- Some states develop or require MCOs to develop transition plans for pediatric to adult care transitions
- Providers can also be involved in the transition process

State Coverage Decisions

- Although state Medicaid programs can cover transition of care services, many do not
  - Some do not cover some transition related Current Procedural Terminology (CPT) codes (e.g., medical team conferences, interprofessional health record consultations)
  - Few cover warm handoffs between pediatric and adult providers, which has been shown to help facilitate smooth transitions
- One state managed care advisory committee has made recommendations to the state to reimburse for warm handoffs and transition-related CPT codes

Beneficiary and Family Experience with Transitions

- Few families reported receiving help and felt responsible for initiating the process and unprepared for the transition
  - Even when they received support, it was not as helpful as it could have been
  - Care coordinators were often insufficiently prepared to support them
- Frustration with the lack of clear information
- Mixed experiences with transition plans
  - Plans became unhelpful as the child aged or moved out of state

Barriers to Transitions for CYSHCN

Lack of clearly documented and communicated state policies for transitions of care

- Poorly defined roles and responsibilities for care coordinators, providers, caregivers, and beneficiaries
- Difficult to find and understand state resources on transitions

Lack of guidance to states on covering transitions of care services

- No federal restrictions on covering CPT codes related to transition services, but states may not cover them
- CMS has not issued guidance on how to reimburse for warm handoffs and same day visits by two providers in the context of transitions of care

Monitoring

- There are no federal Medicaid monitoring requirements or performance indicators for CYSHCN and transitions of care
- Very few states monitor transitions and collect data to measure or assess the process or health outcomes
- Advocates and researchers raised the need for data collection and monitoring to understand how CYSHCN are served by current policies and processes, and if there are gaps in access to services

Barriers to Measuring Transitions

- Few measures for monitoring the transition of care process or transition and health outcomes after the transition to adult care
- States are not required to monitor or measure transitions of care, so few actively track these types of transitions
  - No states reported having a process for tracking post-transition of care outcomes

Role of State Title V Programs

- State Medicaid agencies are required to develop an interagency agreement (IAA) with the state Title V agency (42 CFR §431.615(d))
  - The IAA should describe how they coordinate the benefits and services they provide to their overlapping CYSHCN population
  - There are no IAA requirements related to CYSHCN transitions of care or how these agencies should coordinate transition efforts
- Few IAAs describe specific Title V or Medicaid agency responsibilities related to CYSHCN transitions of care
- Limited cross-agency coordination, and some stakeholders expressed a need for more collaboration to address transitions and gaps in supports

Barriers to State Medicaid and Title V Agency Coordination

- Generally, state IAAs do not describe specific agency responsibilities related to CYSHCN health care transition
  - Few states have initiated cross-agency collaboration to provide services or educational resources to CYSHCN
  - Even in states with some collaboration, advocates shared that the beneficiaries are often not experiencing benefits from current efforts
- Several states shared that these agencies are based in separate divisions (e.g., Medicaid versus the public health department), and noted this as a challenge for facilitating collaboration

Next Steps and Questions

Next Steps

- Commissioner feedback on interview and focus group findings, in particular related to these primary barriers:
  - Lack of clearly documented and communicated state policies for transitions of care
  - Lack of guidance to states on covering transitions of care services
  - No state monitoring or measurement of transitions of care and health outcomes
  - Little coordination between state Medicaid and Title V agencies
- Return in December with potential policy options

Questions

- Are there outstanding questions about the findings that staff can answer?
- Does the evidence support the need for particular federal or state policy changes that MACPAC could consider?
- Aside from the information presented above, are there other factors that should be considered in developing policy options?

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