



March 23, 2020

Mr. Alex M. Azar II
Secretary, U.S. Department of Health and Human Services

Ms. Seema Verma, MPH
Administrator, Centers for Medicare & Medicaid Services

Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-2324-NC
Mail Stop C4-26-05,
7500 Security Boulevard
Baltimore, MD 21244-1850

Submitted electronically via email to <http://www.regulations.gov>

Re: RIN 0938-ZB57 – Request for Information - Coordinating Care From Out-of-State Providers for Medicaid-Eligible Children With Medically Complex Conditions [CMS-2324-NC]

Dear Secretary Azar and Administrator Verma:

Thank you for your leadership of the Department of Health and Human Services (HHS) and the Centers for Medicare & Medicaid Services (CMS), respectively. We value your commitment to ensuring that children with medically complex needs have prompt and timely access to appropriate care and supports that can include access to out-of-state providers.

The Medicaid Health Plans of America (MHPA) is the national trade association representing 90 member health plans that contract with state Medicaid agencies in 36 states to provide comprehensive, high-quality health care to more than 23 million Medicaid beneficiaries in a coordinated and cost effective way. We appreciate the opportunity to respond to the CMS Request for Information (RFI) - **“Coordinating Care From Out-of-State Providers for Medicaid-Eligible Children With Medically Complex Conditions.”**

Approximately two-thirds of the 3 million children with medically complex conditions are enrolled in the Medicaid program. Historically, many states exempted medically complex kids from Medicaid managed care; however, all states with managed care delivery systems today enroll at least some of this population into a managed care program. Our member plans understand the challenges related to coordinating care with out-of-state providers and appreciate the opportunity to share our perspective on best practices and to help identify barriers to

connecting Medicaid-eligible medically complex children with the care, supports, and services that best meet the specific and complex needs of each individual child and his or her family.

We have responded to nine topic areas in the RFI. Please note that unless otherwise stated, our responses draw from the experiences of our member plans related to the coordination of care of out-of-state providers for Medicaid eligible children with complex conditions through Medicaid managed care arrangements.

1) Best practices for using out-of-state providers to provide care to children with medically complex conditions including specific examples of what has and has not worked.

Drawing from our experience and expertise in health care delivery for vulnerable populations, we believe that Medicaid managed care organizations are uniquely positioned to provide assistance to children with medically complex conditions and their families and are pleased to share the following best practices:

- ***Care Management and Care Coordination***

Our member plans have found that children with medically complex needs benefit from a consistent care management and coordination team that can help the child and family navigate multiple health care systems and providers to ensure timely and appropriate care.

Care Management

The Agency for Healthcare Research and Quality (AHRQ) describes “care management” as: “*a team-based, patient-centered approach designed to assist patients and their support systems in managing medical conditions.*”¹ At the highest level, we believe that best practices for a successful care management program for children with medical complexities should include:

- 1) ***A Population Identification Process***- a process for identifying children with medical complexity who have health problems, social and family circumstances, or other issues; and
- 2) ***An Engagement Inventory*** - the availability of multiple options for engagement (e.g., multi-lingual, culturally appropriate, reflective of variations in health literacy, written, digital) tailored to meet the specific needs of a child with medical complexities and their families/caregivers that provide assistance and support in a timely manner to help manage the medical condition, facilitate access to providers, improve outcomes, support a better patient/family/caregiver experience, and reduce health care expenditures.

¹ <https://www.ahrq.gov/sites/default/files/publications/files/caremgmt-brief.pdf>

An individualized nurse-assisted health care planning and management program is an example of a best practice for care management services to patients with rare and chronic conditions. Through this program, each enrolled patient is assigned to a primary care nurse who remains the primary point of contact for the duration of the patient's participation in the program. The primary care nurse regularly assesses knowledge gaps in self-management skills and works to fill in those gaps to facilitate appropriate and timely care from providers, thus avoiding the need for costly emergency room or inpatient care visits.

Care Coordination

We believe that effective coordination of care for children with complex needs starts with a *dedicated care coordination team*. AHRQ describes care coordination as: “*deliberately organizing patient care activities and sharing information among all of the participants concerned with a patient's care to achieve safer and more effective care.*”² AHRQ emphasizes that care coordination necessitates communicating the patient's needs and preferences at “the right time to the right people” and that the information must be shared and used in a secure manner and in a way that provides “effective care to the patient.”

Care coordinators act as critical navigators for children and their families to help guide them through the care journey. This can include working to find a team of providers and specialists, whether in-state or out-of-state, that best meet the needs of the child. Care coordinators understand the individual needs of children with complex conditions and are best suited to support children and their families in finding the right care at the right time. Care coordinators are central to working with the child and family on assessments, collaborating on plans of care, and monitoring services to ensure a child does not have a gap in care. They can also identify potential duplications in care.

Without a consistent care coordinator, families must identify the right providers and how to access care on their own. This process may be challenging to navigate given the intensive needs of this population.

When the care of a child with medically complex needs is best served by access to an out-of-state provider, a care coordinator should be available to perform several key functions including:

- Helping connect families to needed provider who are out-of-state;
- Coordinating any approvals for the member (e.g., work to obtain any necessary referrals and authorizations);
- Assisting with transportation needs;
- Assisting with follow-up after the visit (e.g. set up appointments);
- Preparing the member with knowledge, pre-read, and organize questions and caregivers who come to the visit;
- Supporting collaboration with existing in-state providers caring for the child; and

² <https://www.ahrq.gov/ncepcr/care/coordination.html>

- Planning for any ongoing needs with an out-of-state provider such as whether ongoing follow-up is needed or if care continue in the local market.

It is critical that care coordinators work collaboratively across all support systems and providers to ensure that the “whole person needs” of medically complex children – and the support required for their families and caregivers - are met at the right time and at the right place and in the right manner.

- ***Facilitating Access to Out-of-State Providers***

Children with medically complex conditions and their families often face a multitude of needs (e.g., medical, occupational, physical therapies) requiring navigation of multiple health care and support systems and management of the services delivered. Due to the complexity of their condition, these children often require multiple specialty services and specialty providers may not be readily available in-state requiring families to travel out-of-state, sometimes over extended periods of time. Factors contributing to medically complex children having long-term relationships with out-of-state providers include specific disease-focused Centers of Excellence or particular providers who may have considerable expertise in treating a rare condition.

We believe it is important to recognize that the unique and complex needs of these children may, at times, be best met and supported through access to providers who are out-of-state. In other words, in-state options may not always be available or appropriate given the unique complexities of a child’s medical condition. Accordingly, we recommend the establishment of a process or processes for facilitating access to these providers as a best practice. While not intended to be exhaustive, the following examples illustrate the types of scenarios where processes should be in place to support access to an out-of-state provider given the specific needs of the child.

Example 1: *A child with a rare sub-type of leukemia is in a community where in-state providers lack experience.*

- Services are not available in-state or at a level of expertise that will drive markedly improved outcomes.
- There is a Center of Excellence out-of-state that has a higher volume of cases for that specific sub-type of leukemia and their protocols developed to manage the uniqueness of the sub-type would be in the best interests of the child.

Example 2: *A child with cerebral palsy has been cared for by an out-of-state provider since birth and has had multiple procedures over time performed by the same out-of-state provider.*

- The medically complex child has a long standing relationship with an out-of-state provider and has undergone multiple complex surgeries/procedures with the out-of-state provider and ongoing care is likely to result in a better outcome and experience.

- The out-of-state provider accepts Medicaid rates.
- The patient/family are comfortable and familiar with the out-of-state provider;
- The local pediatrician coordinates with the out-of-state provider to ensure the continuum of care including rehabilitation efficiently and effectively.

Example 3: *A foster child with a serious behavioral health issue is unable to be placed with a behavioral health community in-state (or if the child has been placed multiple times).*

- Placement in a new facility out-of-state is determined to be the most appropriate option after consideration of available and appropriate in-state options.
- Transition to the out-of-state placement and coordination of out-of-state care should be seamless to minimize disruptions to the child’s treatment and services.

2) Coordinating care from out-of-state providers for children with medically complex conditions including when care is provided in emergency and non-emergency situations.

- ***Provider Relationships and Out-of-State Referral Patterns***

Provider engagement across sites of care, both in-state and out-of-state, can help build critical relationships when determining if in-state providers are available and appropriate to meet the needs of a medically complex child.

With non-emergent care needs, we believe there are opportunities to build on relationships between local providers and state partners to provide families with the best and most actionable information as they look to meet the needs of their child. Specifically, engagement with the Chief Medical Officer and local health plan can provide insight into in-state provider options and help facilitate access to the best option, whether in-state or out-of-state.

With both non-emergent and emergent care needs, understanding referral patterns can present opportunities to assess whether care is being delivered in the most optimal manner. The scenario described in the example below illustrates the types of challenges that can arise and how a provider relationship can potentially drive a long-standing referral pattern:

Example 1: *A newborn is referred to care out-of-state. The referral is part of a long existing referral pattern from a provider in State A to the University of Another State (UAS) for NICU babies born with a rare heart condition³ who were flown to UAS for surgical intervention within a few days of birth bypassing multiple providers that were closer and had the ability to provide high quality care. In this example, it is considered emergent care because the facility that the child was born could not provide the care and UAS accepted State A’s Medicaid rates and were registered with State A’s Medicaid Enterprise.*

³ To ensure that children and their families cannot be identified, the nature of the clinical condition has been changed in this example.

The example also raises a number of questions about the broader impact of a long-standing referrals pattern, including:

- What is the impact of family separation? – The above scenario means that the parents had to be in Another State acutely, sometimes separated from each other, other siblings and their support system.
- What is the impact of required travel? - Follow-up visits require travel to UAS periodically.
- Is this the best option for ongoing care? - Redirecting ongoing care is challenging because of the complexity of the disease and the trust established with the provider and family.
- What does this mean for care transitions? - When transitioning the child back to State A, a transfer from the UAS NICU to the State A's NICU would allow for more effective discharge processes.
- What about reimbursement? What about scenarios when the out-of-state provider does not accept State A's Medicaid rates?

We believe that a better understanding of long-standing referral patterns would provide insight into how and where care is being delivered and set the groundwork for an evaluation of whether the care and services delivered out-of-state are most appropriate given the unique needs of medically complex children or whether local options are available and appropriate.

3) Barriers (administrative, fiscal, regulatory) that states, providers, beneficiaries, and their families experience that prevent care being provided in a timely fashion as well as identification of successful approaches for reducing those barriers.

- *Contracting with Out-of-State Providers*

Credentialing

States each have their own requirements, methods, and systems for credentialing providers and pharmacies. The 21st Century Cures Act requires all Medicaid providers and prescribers to enroll with state Medicaid agencies in addition to a managed care plan's network. This, however, can present challenges when a member is out of state or if the pharmacy or provider is not located in the member's state. For example, in the foster care system, a child with a behavioral health condition may need to be placed in an out-of-state facility; however, a state Medicaid program can run into a reimbursement hurdle if the out-of-state provider does not have a sending state's Medicaid Identification number. Another example is with limited distribution drugs or high dollar medications typically are only dispensed by specialty pharmacies. Oftentimes, those pharmacies are dispensing and mailing to members in another state. Requiring these pharmacies to enroll in each Medicaid agency can cause complications for all patients, but it is especially problematic for children with complex conditions who may need out-of-state care.

To address this barrier to care, we recommend establishing and enforcing standards that work to streamline the credentialing process. We understand and support the need for credentialing to ensure program integrity; however, we encourage a more streamlined approach that will ensure that there are no unnecessary delays to appropriate care for children with medically complex needs who need to access care or services from an out-of-state provider.

Single Case Agreements

Our member plans have also found that single-case agreements are an optimal way to contract with out-of-state providers. Single case agreements lay out the scope of the care authorized, timeframe, and payment arrangements. Clear agreement on expectations of care is extremely important for children who may have multiple co-occurring conditions. Single case agreements also emphasize the quality of care that is required of the provider and rates are often comparable between out-of-state providers and in-network providers.

One of the advantages of managed care organizations working with out-of-state providers on a regular basis is that we can work to bring out-of-state providers into our network whenever possible. Once these providers are part of our network, members can more easily obtain care from out-of-state providers when they need it.

- ***Prior Authorization***

Family and Caregiver Engagement

Prior authorization for out-of-state/out-of-network care is an administrative process intended to support access to appropriate care. However, the process can sometimes require time and be perceived as an unnecessary delay to patients, families, and caregivers. To address the perception of prior authorization as a barrier to care, we recommend engagement of a health services team to conduct outreach and help families and caregivers understand the situations when we cannot approve a request and work to help the family and provider identify appropriate, alternative options.

- ***Out-of-State Provider Rate-setting***

Greater Flexibility and Alignment

Reimbursement differentials can result in an uneven playing field between a sending state's Medicaid program and cost of services from an out-of-state provider. To level the playing field, we recommend that the sending state's Medicaid program have the flexibility and latitude to negotiate rates with out-of-state providers that are consistent with their own state Medicaid program's reimbursement methodologies; we believe this would allow for more constructive negotiations with out-of-state providers.

4) Barriers that impact caregivers from accessing or navigating care in a timely fashion as well as examples of successful approaches to reducing those barriers.

- ***Impact of Time and Distance***

Case Management

Referrals to out-of-state providers for children with medically complex needs can separate families from their support systems and result in significant emotional and financial strain. It can also mean short-term (and potentially long-term) transportation and housing needs, lost income, and present other socio-economic challenges.

Case management can be an important resource for families that provides assistance with housing and transportation when the benefit is included by the state. A critical attribute of successful case management approaches that optimize family and caregiver engagement is ensuring that all communications with the family and caregivers are transparent, clear, consistent, culturally appropriate, and take into consideration the issue of health literacy. In addition, efforts to engage with parents, siblings, and caregivers should be made in a trauma-informed manner, especially when looking at care plans and the impact travel and out-of-state care will have on the family (e.g., employment issues, loss of care, lack of a local care support network, impact to family income).

5) Barriers related to individual financial barriers as well as examples of successful approaches to reducing those barriers.

- ***Travel and Transportation***

Traveling out-of-state to receive care can be extremely expensive for families. For children with complex needs, families may have to travel long distances and stay for long periods of time. Many of our member plans provide assistance to members and their families who need to travel out-of-state for care.

6) Successful methods to inform caregivers of children with medically complex conditions about ways to access care from out-of-state providers.

All communications with the family and caregivers, in writing and in-person, should be clear, consistent, culturally appropriate, and take into consideration the issue of health literacy. In addition, efforts to engage with parents, siblings, and caregivers should be made in a trauma-informed manner.

7) State processes that could be employed for screening and enrolling out-of-state Medicaid providers that streamline processes or address burden.

As referenced earlier, the credentialing requirement of each state can act as a barrier for accessing care. We believe a partnership for rapid enrollment of out-of-state providers is critical given that the ability to pay them is dependent on their enrollment with their respective state.

We recommend a pathway for escalation the enrollment of a provider or providers when there is a more urgent need to access their services.

8) Challenges related to referrals to out-of-state providers.

- *Credentialing*

Please see our earlier discussion of the challenges related to credentialing requirements for out-of-state providers in our response to #3 above, **“Barriers (administrative, fiscal, regulatory) that states, providers, beneficiaries, and their families experience that prevent care being provided in a timely fashion as well as identification of successful approaches for reducing those barriers.”** We recommend establishing and enforcing standards that work to streamline the out-of-state provider credentialing process.

- *Long-Standing Referral Patterns*

Another challenge related to referrals to out-of-state providers is the impact of long-standing referral patterns between providers based on personal relationships or habit rather than on medical appropriateness or the best interests of the patient. Please see our response above to #2 **“Coordinating care from out-of-state providers for children with medically complex conditions including when care is provided in emergency and non-emergency situations”**. To address this issue, we recommend that CMS consider tracking the providers that have the highest rates of referral over time (in-state and out-of-state) to determine large scale patterns across state Medicaid programs including care delivered through both fee-for-service and managed care. As data is collected on referral patterns across fee-for-service and managed care to out-of-state providers, we would recommend an ongoing evaluation of the ability of in-state providers to meet the specialty care needs of children. And, as gaps in care for specialty services are closed, the state fee-for-service program and managed care partners can collaborate to align care and referral patterns to provide parents and caregivers with local options to meet their children’s needs.

9) Appropriate and reasonable contractual terms and rates for out-of-state providers for both Medicaid fee-for-service and Medicaid managed care.

As referenced in an earlier response, we recommend that the sending state’s Medicaid program have the flexibility and latitude to negotiate rates with out-of-state providers that are consistent with their own state Medicaid program’s reimbursement methodologies; we believe this would allow for more constructive negotiations with out-of-state providers.

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Thank you for your consideration of our comments in response to this RFI. We recognize the importance of working collaboratively to meet the needs of children with medically complex conditions and their families and caregivers to ensure that these particularly vulnerable individuals receive the right care at the right time and at the right place. Please feel free to reach out to me directly at sattanasio@mhpa.org with any questions or should you need any additional information.

Sincerely,

Shannon Attanasio

Shannon Attanasio
Vice President, Government Relations and Advocacy