March 23, 2020

Seema Verma
Administrator, Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, D.C. 20201
Submitted electronically to http://www.regulations.gov

RE: CMS-2324-NC, Request for Information on Coordinating Care from Out-of-State Providers

Dear Administrator Verma:

Thank you for the opportunity to provide comments on the Centers for Medicare & Medicaid Services’ (CMS) “Request for Information: Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions.” We appreciate CMS’ efforts to collect additional information and your ongoing dialogue on this important issue. As you know, children with medically complex conditions often require out-of-state care and this care is often provided by children’s hospitals. We look forward to working with you to implement solutions addressing current challenges in the system and improve the care provided to children with medically complex conditions.

The Complexity of Out-of-state Care

To put our comments in context, we wanted to share some examples of the children who often require care outside their state:

• One young man, who lived in a rural area near the Canadian border over 600 miles from a children’s hospital, required recurrent hospitalizations for fractures due to a complex condition. Special care and consideration in a children’s hospital gave him the best opportunity possible at a full life. In addition to supporting him while he was in the hospital, the hospital team developed a partnership with his nurse practitioner in his home community. This provider was a solo practitioner in an isolated community, but the team made sure she was never alone in providing him the best care possible. This support helped keep him in his community and out of the hospital several times. In the end, it also allowed him to have excellent end-of-life care close to home.

• At birth, Maddox was diagnosed with Down syndrome and an atrioventricular canal defect—his heart had several holes and only one valve. The nearest children’s hospital with the capability to care for him—cardiac surgical care—was in an adjacent state. His family acted quickly to get the best care for Maddox, and this required they travel across state lines. A few days later, Maddox was flown by air ambulance to the children’s hospital and transferred to the cardiac intensive care unit. At only seven weeks old and weighing barely five pounds, Maddox had open-heart surgery. Though the children’s hospital with the specialized care Maddox needs is far from home, he still gets his yearly blood work done there. The hospital has the necessary specialized expertise in Maddox’s condition. He also visits the Down syndrome clinic twice a year and the cardiology department annually for check-ups. Despite his condition, Maddox is a happy boy with a bright future ahead of him. He loves to dance and can even follow along with dance movements. He also loves to fold laundry and gets excited when it comes out of the dryer!

Champions for Children’s Health
In both of these examples, the families and the children’s hospitals had to follow a lot of administrative processes and spend significant time and resources to enable this care and the best outcomes for these kids. These two examples also show that when out-of-state care is done well it can make all the difference in a child’s life.

There are more children like the young man who lived in a rural area and Maddox, children who often need to travel outside their state for specialized care. Often there are not necessary pediatric specialists and other specialized services located in a child’s home state to address the unique needs the child may require. What’s more, the care the child requires for their very specialized condition—which may only affect a small number of children—is often only available in one or two locations in the entire country. A recent Medicaid and CHIP Payment and Access Commission (MACPAC) report finds that, “Children who qualify for Medicaid on the basis of a disability have a higher share of out-of-state inpatient hospital stays than other eligibility groups. These children are also more likely to access care outside of the hospital-referral region where they reside.”

The care these special children need is often provided by children’s hospitals. In FY 2013, “86.4% of children’s hospitals serviced out of state patients, a higher share than other hospitals,” according to MACPAC. In general, hospitals with out-of-state patients received payment from an average of three states, however, “children’s hospitals received Medicaid payment from more than six states.” Some children’s hospitals received payments from 25 state Medicaid programs. This data demonstrates that children’s hospitals are serving much larger geographic regions due to the unique and specialized services they provide. The map below is just one example of a children’s hospital—Children’s Hospital Colorado—treating children with medically complex conditions on Medicaid from more than 20 states.

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1 Medicaid Payment Policy for Out-of-State Hospital Services, MACPAC, January 2020, page 2.
2 Medicaid Payment Policy for Out-of-State Hospital Services, MACPAC, January 2020, page 3.
Specific Issues
For these children and families, care needed on a regular basis is significant, varied and complex—layering on out-of-state care challenges adds significantly and unnecessarily to this complexity. We, as a community of children’s hospitals, have identified the following major challenges and barriers to receiving and coordinating out-of-state care for children with medically complex conditions.

Delays, Unclear Processes and Administrative Burdens for Out-of-state Care

Home State Medicaid Plans: The first and most important step to getting out-of-state care is getting approval from the child’s home state Medicaid program. This is a clinical decision to determine if the care needed is not available in the state. Of course, if appropriate care can be provided within the child’s home state, that is the best option. However, for this group of children, often their needed specialized services/procedures are simply not available in their state. Sometimes the approval process for care goes smoothly, but often there are delays as paperwork is completed, reviewed, sometimes denied and appealed, and eventually approved. In some states it is harder to get out-of-state care approved than in others. For example, one state requires a monumental 20 denials before approving care in another state.

Individual Health Plans: There are also challenges working with individual health plans to get approval for care. There is no standardization for these decisions across health plans—even health plans in the same state. Prior authorization can delay care and create additional stress on families and children needing treatment. We have heard of families that needed to travel back home, covering many miles, to wait for prior authorization to leave again for care once approval was provided. Additionally, delays in approvals can create extra work while the providers who expect to care for the child go through the enrollment and screenings requirements, only to be told later whether the care is approved or not. More timely decisions and clearer processes to get out-of-state care approved are critical to improving coordination of care across state lines for children and families.

One children’s hospital noted, “Often the hospital works with families to explore whether authorization is needed and works with plans to see if they will enter into an agreement with the provider. A high number will not authorize care or enter into an agreement with the provider. While our hospital informs the family and asks them to advocate with their plans, very few families are able to subsequently obtain authorization or get provider agreements in place to cover that care. Most plans aren’t even sure they have a contracting department to assist with these questions.” Unfortunately, successful approval decisions can often be extremely dependent on facility. If the hospital/provider has experience with out-of-state care, they are usually more successful. Facilities without this experience are usually less successful. There should be more consistency across providers, states and health plans so children and families know the process and criteria for these decisions to help ensure the child can get the right care as close to home as possible.

Delays in the ability to access care add stress on families already facing many challenges in their daily lives. This stress is further exacerbated when risk to health status is escalated due to access delays.

Out-of-state Medicaid Provider and Screening Requirements: Some states continue to use onerous requirements to screen and enroll providers in another state who will be caring for children from their state. These include requirements for documentation—like original social security cards or other identification—and sometimes requirements to re-enroll every six months if an out-of-state provider does not care for a child from the state. Encouragingly, however, some states have accepted the providers’ home state enrollment or enrollment in Medicare as an acceptable process. In these cases, care is significantly more streamlined and less likely to result in delays in care for the child.

“The cost, time and administrative burden of credentialing providers for surrounding states’ Medicaid programs is sometimes more costly than actually providing the critical care a relatively small number of out-of-state children need,” a children’s hospital.
Out-of-pocket Costs and Lack of Other Non-financial Supports: Families face many out-of-pocket costs when traveling outside their home state for care—including lodging and other travel costs, day care expenses for children who remain at home, lost wages for missed work, and more. Families far from home are also separated from their typical community support systems. These issues can be financially taxing for families and add to the significant stress caring for a child with specialized care needs creates.

Access and Referral Issues When Children Return Home: Within Medicaid, there are general challenges with accessing some specialized services and supports, but this is exacerbated when needed care is not available at all in your home state. This often requires care across state lines, but also creates challenges when a child is discharged from the out-of-state provider and needed services and supports are either not available back home or very difficult for an out-of-state provider to order for the child. The most likely service challenges arise around getting needed durable medical equipment (in one state, there is no ventilator provider), ordering prescriptions from outside the state, obtaining needed respite care for families, or securing private duty nursing or other home care. Coordinating these services across providers in different states is challenging—sometimes due to communication and coordination challenges, but often because the services are just not available in the home state. These problems are particularly prevalent in rural areas. Some states require in-state providers to order prescriptions or durable medical equipment, but the in-state provider is not the provider most familiar with the child’s condition or care. Pediatric long-term care is riddled with similar issues. It is difficult to get approval for care outside the state—even when the needed care is not provided in the home state. In these instances, the child remains in the out-of-state hospital, unnecessarily waiting for approval for out-of-state care.

Issues Securing Payment

Securing Agreement for Payment and Fulfillment of Agreement for Out-of-state Care: There is no consistency across states—or sometimes even within states—dealing with different health plans on payment for out-of-state care. As noted above, children traveling for care typically have very complex, specialized medical needs. Every time a child travels for care, providers feel they are reinventing the wheel in terms of the process of securing payment for this care.

Often children’s hospitals enter into single case agreements to secure payment for the care provided to children from other states. Each time a child comes, they need to renegotiate and develop an agreement. Each health plan and state have different processes for this and often there is no single contact person knowledgeable on the case and process for out-of-state care. Even when agreements are in place, providers must often chase payment after the care is provided. There are cases where a children’s hospital is listed in a child’s care plan with instructions to go to the hospital under certain circumstances, yet the children’s hospitals is not aware of this, not included in the provider network, and without a standing payment agreement. A more standardized process and approach to payment would improve this process and ensure care is provided in the right setting, at the right time, and with the right provider.

Addressing These Issues

There are opportunities to address these challenges through more policy consistency and support across states. We believe implementation of the Advancing Care for Exceptional (ACE) Kids Act is one important opportunity to begin addressing challenges and creating a more seamless system of care for this population of children. Beyond the ACE Kids Act, there is more CMS and federal policymakers can do to better coordinate needed care across states for this population of children enrolled in Medicaid.
Support and Strengthen Foundational Medicaid Policies Critical for All Children: The critical national Medicaid policies that nearly 40 million children covered by the program rely on are even more critical to children with medically complex conditions. For children with medically complex conditions, continuity of coverage, access to the full array of medically necessary benefits that reflect the child’s unique needs, and limitations on out-of-pocket costs and other cost sharing are crucial to their ability to thrive and live their best quality of life. We ask CMS to uphold these important protections and ensure they are not inadvertently diminished as new policies are proposed or implemented; additional eligibility processes and procedures that could result in children inadvertently dropping off the program and losing coverage or policy changes that could result in reduced Medicaid program funding could be extremely detrimental to their health and ability to receive needed health care services outside their home state.

Implement the ACE Kids Act: Another opportunity to better coordinate out-of-state care for children with medically complex conditions is implementation of the ACE Kids Act. As you know, ACE Kids—enacted last year—establishes more consistency across states for this small group of children with very complex medical needs to begin to address the challenges they face accessing care outside their home states. For states that opt in, we expect the health homes tailored to this population will provide better coordinated care across state lines, better supporting families as they deal with administrative and other burdens associated with traveling for care. In addition, having a consistent framework for implementation to support states, providers and children who participate in ACE Kids—including guidance on how best to operationalize the ACE Kid eligible child definition and consistent quality metrics tailored to this population—will be important to delivering on the legislative intent to streamline and better support care across state lines. A consistent way of operationalizing across states will also enable better national data to identify care patterns, gaps, costs and quality improvement opportunities for this population of children. More consistency for accessing and coordinating care across state lines and better data on children’s needs will best enable states and providers in their provision of the best quality care for children with complex medical conditions, no matter where needed care is provided.

Encourage consistent approaches that work across states: We recognize that Medicaid is a joint federal/state program, and there are good reasons differences exist between Medicaid programs in different states. However, it would dramatically reduce the regulatory compliance burden and put patients ahead of paperwork if there could be standardization for this small, but very complex (and therefore very expensive) population that must cross state lines for care. More consistency in policies like credentialing, payment and telehealth rules would greatly help both in Medicaid managed care and in fee-for-service Medicaid.

Specific Recommendations

Building on the foundational policies outlined above, we recommend the following specific policies that CMS could implement to increase consistency between states and reduce challenges for children requiring out-of-state care:

- **Undertake an examination of this population of children, their care patterns, reimbursement and quality of care to do a better job of supporting care across states and fast tracking patient access to out-of-state care when needed**: This is a known population of children and through such an examination we should be able to identify where we can do a better job of supporting this care and streamlining policies and procedures. There should be clear guidelines and processes across states to better support care for this very medically vulnerable population of children.

- **Streamline out-of-state Medicaid provider enrollment and screening**: CMS should strongly encourage states to streamline their enrollment and screening requirements for out-of-state Medicaid providers. Several states already accept the home state enrollment of the provider and/or providers’ Medicare enrollment. If more states used this approach, it would cut back significantly on the administrative burden on providers.
and result in more timely care for children. We support recent legislation introduced in the House—H.R. 5900—and expected legislation in the Senate that would allow a streamlined pathway to enrollment and screening similar to some states’ current policies to ensure this approach is adopted more consistently across states.

- **Provide support and guidance on telehealth**: We ask CMS to provide guidance on the use of telehealth, outlining current authority and rules around use and payment under Medicaid—particularly for this population of children. Robust telehealth networks with appropriate reimbursement for provider-to-provider (primary care to complex clinic) communication while a child is in an exam room or after a child returns to their home state would help significantly. Supporting this critical communication between the specialty provider and community providers will help ensure children stay as close to home as possible and only travel when necessary to specialty clinics or children’s hospitals.

- **Dedicated out-of-state point people at the state, health plan and federal level are needed to ensure we are efficiently and effectively serving this population**: When problems or issues arise in the process of out-of-state care, there are often no point people at these different levels to help families and providers navigate the systems and address problems along the way. In states where this process works the best, there have been point people to contact who are aware and knowledgeable about the different process steps and how best to support children, families and providers throughout the process. A point person at the federal level or an out-of-state care ombudsman is also needed to ensure best practices are shared across states and federal policies on out-of-state care are being implemented appropriately.

- **Support more consistency in the out-of-state care administrative processes, including the following**:
  - Develop a template for a single case agreement and encourage state/health plan use.
  - Provide guidance and best practices to states on approving out-of-state care to streamline the process, make the process more transparent for children and families and establish appropriate timelines/criteria for decisions.
  - Encourage states to have consistent policies on out-of-state care for all their Medicaid managed care plans, including consistent provisions in Medicaid managed care contracts on out-of-state care.
  - Encourage states to ensure that, if health plans include providers in children’s care plans, then the provider should be included in their provider network or have an agreement in place for that care.
  - Explore how best to identify the specific pediatric services children within a state will need to obtain out-of-state care in their Medicaid state plan amendments.

- **Additional support for families**: The sharing of best practices on how to support families requiring out-of-state care should be a key element of guidance to states. There is a need for additional support/training provided to family organizations to help support children and families as they access care outside the state and for identification of resources available to help with additional costs related to out-of-state travel for care. In addition, encouraging states to pay for family navigators to better support families who need to access care outside of their home state should be included in CMS’ guidance to states.

- **Explore and address the current state of Medicaid payment for out-of-state care**: We ask CMS to conduct a review of Medicaid out-of-state payment, related opportunities and related challenges, including the fact that out-of-state costs are often not reflected in in-state base rates or supplemental payments. We also ask CMS to explore a CMMI demonstration project to test new and creative approaches to payment, including allowing Medicaid funds to more clearly and seamlessly follow the child across state lines.

- **Use of non-face-to-face encounters and chronic condition management codes**: States that have reimbursed for non-face-to-face encounters and used chronic care management codes for payment have
more effectively supported out-of-state care. CMS should explore how best to share these best practices and encourage other states to adopt this approach.

- **Support additional sharing of information across care settings:** As interoperability is rolled out, CMS should keep front of mind the need for consistent, reliable flow of clinic notes to out-of-state primary care providers and secure e-communications between state agencies and interstate providers.

We thank you for your commitment to improving care for children with medical complexity. We look forward to partnering with you to address the current challenges in the system, so we can together better support children and their families who require care outside their home states. If you have question on our RFI response, please contact Aimee Ossman, Vice President for Policy Analysis, at aimee.ossman@childrenshospitals.org or 202-753-5333.

Sincerely,

Mark Wietecha  
President and CEO  
Children’s Hospital Association