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June 3, 2020

Seema Verma, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS–2324–NC
P.O. Box 8016
Baltimore, MD 21244–8010

RE: CMS–2324–NC– Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions; published in Vol. 85, No. 13 Federal Register 3330-3334 on January 21, 2020.

Submitted electronically via www.regulations.gov

Dear Administrator Verma:

UnityPoint Health ("UPH") and Blank Children's Hospital appreciate the opportunity to provide comments in response to the request for information related to the coordination of care from out-of-state providers for Medicaid-eligible children with medically complex conditions. Blank Children's Hospital was opened in 1944 to help meet the unique health care needs of children during the polio epidemic. Today, Blank Children's is a 108-bed environment that embraces and encourages families to be a part of their child's healing and recovery. Everything from equipment to decor is designed specifically for children. An additional 66 beds and Blank Children's newborn nurseries are available at the Maternity Centers at Iowa Methodist Medical Center, Iowa Lutheran Hospital and Methodist West Hospital. With more than 90 medical specialists and hundreds of doctors, nurses and staff who care for patients from before birth through adolescence, Blank Children's is a hospital unlike any other in Iowa. Programs and services, both within our hospital and clinics and through our community outreach efforts, are designed to improve care for children and meet the changing health needs of children and families. In 2019, Blank Children's made an impact for children and adults in nearly all 99 Iowa countries through a combination of more than 195,000 clinic visits, deliveries, admissions, outpatient services and outreach programs.

We appreciate CMS' efforts to collect additional information and your ongoing dialogue on this important issue. Blank Children's Hospital and UPH respectfully offer the following comments to this request for information.

COMPLEXITY OF OUT-OF-STATE CARE - ONE FAMILY'S STORY

For context on this important issue, Alicia Karwal, a member of our Family Advisory Council, shared how her daughter often requires care outside of Iowa:

> Sophia Grace was born on December 1, 2010 weighing 4 pounds, 15 ounces. Sophia initially struggled with her blood sugar levels and was gavage fed within the first moments of life. Miraculously, she was

discharged after only three days. Armed with a baby scale and a specialty car seat, we took our beautiful baby girl home.

Throughout the first few months of Sophia's life, we had concerns about her development. At 8 months Sophia still was not rolling over consistently and showed clear evidence of using only her left side. I called our pediatrician on a Friday, expecting her to say that I shouldn't worry. Instead, she asked to see Sophia that day and referred us for a brain MRI for the following Monday. This was the first time we would hear the term cerebral palsy mentioned for Sophia. In the weeks to come, we heard some of the scariest scenarios a parent can hear. It was unknown if her condition was life threatening, or if our baby girl would ever walk, talk, or meet other developmental and cognitive milestones. We suddenly had a team of specialists from neurology to hematology, physical, occupational, and speech therapists, gastroenterologists, ophthalmologists, audiologists, and physiatrists. To say the least, we were overwhelmed, but never lost hope for our baby girl. Appointment after appointment brought new diagnoses which were added to Sophia's medical records.

Sophia has received care locally at MercyOne Clinics, Blank Children's Hospital, and in Minnesota at Mayo Clinic and Gillette Children's Specialty Hospital. Testing at Mayo Clinic was necessary to rule out certain degenerative conditions, and we traveled to Gillette Children's Hospital to access a pediatric physiatrist. Our care is now centered at Blank Children's and we are thankful for their role in our daughter's health care and care coordination. However, the pediatric specialists that Sophia needs are not always available in Iowa. Currently, Sophia must travel out of state to see a pediatric physiatrist, neurologist, and surgeon. Additionally, Sophia receives pediatric gastroenterology, primary care, and most of the other therapies she requires locally at Blank Children's Hospital.

Sophia has far exceeded her early prognoses and quality of life. Sophia's potential would not have been realized without early intervention and regular access to intense pediatric therapies and ongoing specialty care. Through years of hard work and determination, Sophia is now able to walk independently and though she has articulation issues with her speech, she talks… a lot! She is now in school and with the support of special educators, she continues to amaze all of her doctors, therapists, friends, and family with all that she can do. She continues to defy the odds!

Blanks Children's Hospital is proud of the outstanding care we offer to children with medically complexity within Iowa. That said, as a rural state, Iowa does not always have instate access to specialty care required by these children. Access to quality pediatric specialty care should not be dependent upon where you live.

ISSUES WITH COORDINATING CARE FOR MEDICAID-ELIGIBLE CHILDREN WITH MEDICALLY COMPLEX CONDITIONS

Delays, Unclear Processes and Administrative Burdens for Out-Of-State Care

Home State Medicaid Plans: The 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. As a rural state, Iowa lacks some of the specific pediatric specialties essential to meeting the needs of children with complex medical conditions. ***Delays in the out-of-state approval process in Iowa can take 4 to 6 months in which time the child's condition can significantly worsen***.

Logistical Issues and Barriers for Families When Traveling Across State Lines for Care

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. ***As a result, Blank Children's Hospital has engaged in philanthropy efforts to assist these families. In 2019, Blank Children's Hospital provided compassion funding to over 1,000 families totaling $101,000.*** Many of those funds are used to offset the financial and travel burdens families face in seeking out-of-state care for their child's complex medical condition.

Issues Securing Payment

Securing Agreement for Payment and Fulfillment of Agreement 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. Difficulties in receiving accurate and timely payment of the single case contracts has made some hospitals hesitant in engaging in future single case contracts. ***Blank Children's Hospital has had other Midwest out-of-state pediatric specialty hospitals refuse to accept our pediatric patients for care simply because they have had such a difficult time previously receiving timely and accurate payment from Iowa Managed Care Organizations. A more standardized process and approach to payment would alleviate these issues and ensure care is provided in the right setting, at the right time, and with the right provider.***

ADDRESSING ISSUES FOR COORDINATING OUT-OF-STATE CARE

Broad Areas of Opportunity

Support and Strengthen Foundational Medicaid Policies Critical for All Children: 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.*** We caution that additional eligibility processes and procedures may result in children inadvertently dropping off the program and losing coverage. Likewise, policy changes may inadvertently result in reduced Medicaid program funding and may be extremely detrimental to children's health and their ability to receive needed health care services outside their home state.

Implement the Advancing Care for Exceptional (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. Senator Grassley has been a champion on this issue and recognizes the importance for coordinated care for children enrolled in Medicaid. As you know, the ACE Kids Act establishes more consistency across states for this small group of children with very complex medical needs who require out-of-state care. 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

Data-driven Approach to Future Recommendations: *We would encourage that CMS undertake an examination of this population of children, their care patterns, reimbursement and quality of care to identify how to improve care across states and to fast track patient access to out-of-state care when needed*. For instance, all of Blank Children's Hospital's pediatric bone marrow transplant referrals go to a single out-of-state provider. Processes should be streamlined when we know there are no in-state options for care to provide fewer delays for the next patient referred for the same out-of-state care. We are confident that this analysis would assist CMS to develop clear guidelines and processes across states to better support care for medically vulnerable children.

Provide Support and Guidance on Telehealth: We would 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. ***We cannot emphasize enough that robust telehealth and payment parity are essential for the future evolution of healthcare in the United States***.

Support More Consistency in Out-Of-State Care Administrative Processes: Suggestions include:

- 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.

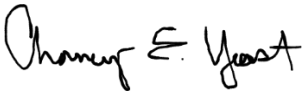
A template and consistent process guidance would greatly expedite the administrative process and reduce delays in patient care. It is not uncommon that Blank Children's Hospital provides additional, less effective care for the patient during the interim while we wait upwards to 4 to 6 months for the single case agreement to be finalized. That is not a cost-efficient process and merely increases costs to Medicaid over the long run.

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. ***The Enhanced Pediatric Health Home (EPHH) model outlined in the ACE Kids Act is a model and would allow for greater care coordination across state lines and ease the burden on families***. 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.

We are pleased to provide comments to the request for information. To discuss our comments or for additional information on any of the addressed topics, please contact Chaney Yeast, Director of Government Relations & Family Services at chaney.yeast@unitypoint.org or 515-241-4312.

Sincerely,

Stephen R. Stephenson, MD
President/COO, Blank Children's & Women's Services
Executive Vice President, UnityPoint Health – Des Moines



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