



March 23, 2020

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

Re: Coordinating Care from Out-of-State Providers for Medicaid Eligible Children with Medically Complex Conditions CMS-2324-NC, Docket ID: CMS-2020-0006

Dear Administrator Verma:

On behalf of the 25 to 30 million Americans with one of the over 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks the Centers for Medicare & Medicaid Services (CMS or Agency) for the opportunity to provide these comments on CMS' request for information on "Coordinating Care from Out-of-State Providers for Medicaid Eligible Children with Medically Complex Conditions."

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

It is estimated that there are over 7,000 rare diseases, which are defined in the United States as diseases affecting 200,000 or fewer people. Today, over 90 percent of rare diseases still do not have a treatment indicated to treat the disease that has been approved by the Food and Drug Administration. Rare disease patients often require extensive, life-long medical care. Upon diagnosis, rare disease patients often find there are few medical experts, if any, who are available to treat their rare disease and health complexities. Moreover, they find that, many times, these experts practice in a different state than the one in which they reside.

NORD appreciates that CMS is soliciting information on coordinating care from out-of-state providers for Medicaid eligible children with medically complex conditions. We have heard from dozens of families in the rare disease community throughout the country that there are serious challenges to obtaining out-of-state care for their Medicaid eligible children under the current system. We appreciate the opportunity to share these experiences and policy recommendations as CMS works to provide guidance to state Medicaid directors.

As stated before, a rare disease is defined as one affecting fewer than 200,000 people in the United States. Many rare diseases affect far fewer 200,000 people. Therefore, it is not surprising that states might only have a handful of patients with a particular rare disease and no specialists

to treat that disease. It is not unheard of to have just one or two clinical centers in the entire United States with a specialist who is knowledgeable of, and can treat, a specific rare disease.

To help illustrate this point, the following stories represent a sample of some of the scenarios rare disease patients and their families encounter.

- One family lives in Arizona with a child that has a rare disease that causes gastrointestinal issues. They have private insurance, with Arizona Medicaid as a secondary insurance for their child. The child sees a gastroenterologist in Arizona, but the doctor and the parents felt the child needed to have surgical intervention by a specialist in Nebraska. Arizona's Medicaid refused to cover the procedure because it was out-of-state, despite the fact that a similar specialist could not be found in Arizona. Consequently, the family was forced to rely solely on their private insurance coverage. Before the surgery, the child had IV nutrition and tube feeds only. After the surgery, the child could eat all calories by mouth.
- Another family lives in a rural state in the northwest United States. Given the rural nature of the state, they face challenges finding physicians to provide care to their child and have had to wait for over a year for appointments. The only care center in the United States for their child's rare disease is located across the country in Massachusetts. At one point, the family tried traveling to Washington state to see some specialists familiar with the symptoms of their child's disease. Their Medicaid program required them to do a return trip on the same day as their appointments. This proved too taxing on the health of their child. Their state's Medicaid program has refused to pay for their child to receive care at the Massachusetts-based clinic, despite the fact that there are no specialists in state that are able to provide care.
- A family in New York was told by their child's physicians that they were incapable of providing the care that the child needed. In fact, the specialists even wrote a letter to New York's Medicaid program stating that the child needed to be referred to a children's hospital in Massachusetts. Despite this, New York's Medicaid program denied coverage and told the family to continue seeking care in state. The family appealed. After advocating for three years for their child, the Medicaid program finally approved a one-time only visit to the Massachusetts hospital.

If a patient is not lucky enough to live in a state with a clinical care center or specialists knowledgeable about a rare disease, they should be allowed to seek that care out of state, regardless of whether they are on Medicaid or another type of health care insurance. We are pleased that Congress acknowledged this as well by enacting the Advancing Care for Exceptional Kids (ACE Kids) Act (P.L. 116-16)¹, which requires guidance as well as this request for information and should allow children with rare diseases who are on Medicaid to obtain out-of-state care more readily, when necessary. As CMS prepares this guidance, we encourage the Agency to consider the following patterns that emerged through the process of seeking input from the rare disease community.

¹ <https://www.congress.gov/116/plaws/publ16/PLAW-116publ16.pdf>

Border State Flexibility

Patient testimonials indicate that it is often easier to obtain coverage of out-of-state care if the state in question borders the state that the patient lives in.

- One family lived in Illinois and had a child that needed care in neighboring Missouri. Illinois Medicaid already had a contract with the particular Missouri hospital, and the family was able to access the needed care.
- Another family, from Kentucky, is able to get care for their child in Ohio because Kentucky Medicaid has existing contracts with the relevant physicians in Ohio. The family does not have to get prior authorization and can see specialists in Ohio as needed. However, Kentucky Medicaid would not cover the cost for the same family to see a different specialist in Texas. Consequently, the child is not able to see their specialist in Texas as frequently as recommended because the family must pay for this care out of pocket.
- Access to specialists in Washington state has been allowed for a family living in Idaho. Idaho Medicaid has covered out-of-state care in Washington for their child since birth. In fact, Medicaid covered a \$90,000 life-flight bill with no issues at all.

The fact that Medicaid programs are willing to cover out-of-state care more readily in situations that involve a border state suggests that denials of out-of-state care are not so much a matter of policy as they are a matter of convenience. Given the close proximity of border states, it is easy to imagine that the Medicaid programs in these states would frequently receive requests to cover care in the bordering states. After time, it only makes sense that relationships would form, and it would become easier for those Medicaid programs to approve of care in these states. Under federal regulation, however, there are a number of conditions under which out-of-state care must be covered as it would be in state, and those conditions are not limited to border states.² In making out-of-state care determinations, it should not make a difference whether the state in question is 25 miles away or 2,500 miles away.

We understand that there are complexities in negotiating out-of-state contracts. However, rare disease patients should not be denied access to care because of where they live and the complexities of Medicaid. For rare disease patients to be able to access the specialists they need wherever they may be in the United States, CMS should explore ways to facilitate the process of covering out-of-state care, possibly by creating a standardized, nation-wide process, so that possible “inconveniences” can be mitigated.

Out-of-State Prescriptions

Another challenge experienced by many in our rare disease community is the failure of Medicaid to cover prescriptions and diagnostics when they are prescribed by an out-of-state physician. While in some instances, out-of-state specialists are able to coordinate with in-state physicians to order labs and prescriptions, in other instances, this is not the case. Delays in access to

² 42 CFR § 431.52

medication have costly implications for rare disease patients and families. CMS should consider ways to facilitate coverage of prescriptions placed by out-of-state physicians, particularly when care from the same out-of-state physician as already been approved.

Emergency Care

States should be encouraged to allow maximum flexibility in out-of-state emergency situations and discouraged from requiring repeat prior authorizations. Both of these practices can have serious implications for access to timely care. Per the same federal regulation mentioned above, state Medicaid programs are required to cover out-of-state care in an emergency.³ Despite this, patient testimonials indicate that is not always the reality on the ground.

- One state's Medicaid plan only covered emergency services within a 25-mile radius.
- Another family lived in Illinois but were vacationing in Florida when one of their children encountered a medical emergency and needed immediate surgery. Illinois Medicaid refused to pay the cost incurred, and the family had to pay \$40,000 in medical bills.

CMS should consider providing additional guidance to states regarding coverage of emergency out-of-state care. States should not only be providing coverage in these circumstances, but there should be additional transparency around the relevant processes. Families should not have to question their ability to receive emergency care when taking a temporary excursion.

Work Force

Navigating Medicaid can be incredibly difficult, particularly when dealing with an abnormal situation, such as having a child with a rare disease that requires care outside of the state. Case workers should be knowledgeable about specific state policies or held accountable to follow up with accurate information in a timely manner. Patient testimonials have shown the potential benefit of having skilled case workers available to help patients as well as the potential harm that can arise from having ill-informed case workers working with patients.

- A family living in Minnesota had their out-of-state care claim rejected because the case worker mistakenly thought the family lived in Illinois.
- New Jersey Medicaid greatly helped a family by providing early intervention efforts as well as a case worker who actually visited the family's home and walked them through the required processes.
- A family living in South Carolina found the Medicaid case workers to be ill-informed. They seemed to be reading from binders. Even after 18 months, the family still could not find anyone within their state's Medicaid program capable of answering their questions about out-of-state coverage.

³ 42 CFR § 431.52

When CMS provides guidance to states, we urge the Agency to increase transparency and accessibility for the sake of providers, patients, and caregivers. Contact information for case workers should be readily available to families. Families have had to spend countless hours and resources trying to navigate their Medicaid program, following up with Medicaid case workers, providers, hospitals, etc. For many rare diseases, caregivers spend much of their time caring for their loved one with the rare disease. It is not feasible for them to devote significant amounts of time toward navigating the intricacies of out-of-state Medicaid coverage, nor should it be expected.

Without consistency and uniformity among states about the parameters for providing out-of-state care for Medicaid eligible children, state Medicaid programs and CMS risk creating a discriminatory system wherein patient access to needed care is determined by zip-code. With most rare diseases, patients are unable to choose their providers. They need to see the one specialist who knows about their rare disease. In light of this and other reasons, current federal regulation permits Medicaid to cover out-of-state care for patients when necessary.⁴ State Medicaid programs across the country have fallen short of executing this regulation to the fullest extent, often putting families in difficult positions both medically and financially. We urge CMS to provide guidance to states that will call on them, and enable them, to ensure flexibility, transparency, functionality, and improved communication with regard to the coverage of out-of-state care within Medicaid.

NORD thanks CMS for the opportunity to comment and looks forward to working with the Agency to ensure that rare disease patients on Medicaid have access to essential, high-quality health care regardless of the state they live in. For questions regarding NORD or these comments, please contact me at rsheer@rarediseases.org, or 202-588-5700.

Sincerely,

A handwritten signature in black ink that reads "Rachel Sher". The signature is written in a cursive, flowing style.

Rachel Sher
Vice President, Policy and Regulatory Affairs

⁴ 42 CFR § 431.52