



March 23, 2020

The Honorable Seema Verma
Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Comments on CMS's Request for Information on Coordinating Care from Out-of-State Providers for Medicaid-Eligible Children with Medically Complex Conditions, CMS-2324-NC

Dear Administrator Verma:

The Cystic Fibrosis Foundation is a national organization dedicated to curing cystic fibrosis (CF). We invest in research and development of new CF therapies, advocate for access to care for people with CF, and fund and accredit a network of specialized CF care centers.

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 children and adults in the United States. It is a complex, multi-system disease that requires targeted, specialized care to preserve health and well-being. Development of the CF care model, paired with genetically-targeted therapies that address the underlying cause of the CF, have contributed to dramatic improvements in life expectancy over the last few decades. This milestone reflects over 50 years of hard work to improve CF treatments, develop evidence-based standards of care, and encourage adherence to a lifetime of chronic care. However, this system of comprehensive, multi-disciplinary care and the improvements in length and quality of life can only be realized if patients have access to CF care centers.

The CF Foundation appreciates the opportunity to provide feedback on CMS's request for information regarding the coordination of out-of-state care for medically complex children on Medicaid. Drawing on the experience of providers in the CF community, our comments highlight the challenges patients face when seeking care across state lines. We hope you bear our comments in mind as you work on forthcoming guidance to state Medicaid directors regarding such care.

Cystic fibrosis care model

The CF Foundation funds and accredits a nationwide network of more than 130 care centers located in hospitals across the country. These centers provide multidisciplinary, patient-centered care in accordance with systematically reviewed, data-driven clinical practice guidelines.

Each center employs a team of dedicated health care professionals, including pulmonologists, respiratory therapists, dieticians, social workers, mental health specialists, and program coordinators, among others. Together, the care teams apply the latest medical evidence and guidelines, resulting in comprehensive, coordinated, and personalized care. To maintain accreditation by the CF Foundation, each center undergoes an annual review and periodic re-accreditation peer site visits to ensure each center provides a consistently high standard of care.

The CF care model is at the vanguard of delivering coordinated care for patients with a chronic disease and our care center network has been widely recognized as a national model for care of other chronic diseases. Nearly 90 percent of people with the disease get care at a CF care center and this system of comprehensive, high-quality care has yielded amazing progress in improved health outcomes and longer, more fulfilling lives for people with CF.

These care centers, developed and refined over a number of years through a continuous improvement effort, clearly meet the standards established for health homes by the Act; standards for comprehensive and timely high-quality services, including care management, care coordination and health promotions, comprehensive transitional care, patient and family support, and referrals to community and social support services. In fact, we believe that these centers may serve as a model for health homes, and that the lessons of the CF Foundation in developing the network may be instructive for the agency as it moves forward with implementation of the health home option for states.

Out-of-state care for cystic fibrosis patients

According to the 2018 Cystic Fibrosis Patient Registry¹, 11.5 percent of people with CF and 8.9 percent of people with CF on Medicaid receive care at a care center located outside of their state of residence. To better understand how patients access care across state lines, we spoke with six CF care teams from five states, including those in Tucson, AZ; Denver, CO; St. Louis, MO; Cincinnati, OH; and Nashville, TN. These centers reported as many as 20-30 percent of their patients come from out-of-state, traveling anywhere from one to four hours to get there.

We hope the experience of our patient population can inform efforts to create comprehensive, coordinated care systems for other chronic conditions.

Care in neighboring states is generally accessible

In general, we found that Medicaid patients have a relatively easy time receiving care from centers in neighboring states. This is especially true when hospitals are located near state borders and therefore see a large number of patients from a neighboring state. For example, many patients enrolled in Kentucky Medicaid go to CF centers in Cincinnati, which may be the closest care center for them. In this case, Kentucky Medicaid contracts with hospitals in Ohio and allow patients seamless access to care in Cincinnati.

Providers described similar contracts between centers in St. Louis and Arkansas Medicaid and Illinois Medicaid, Nashville and Kentucky Medicaid, and Denver and Wyoming Medicaid. Care centers reported

¹ <https://www.cff.org/Research/Researcher-Resources/Patient-Registry/2018-Patient-Registry-Annual-Data-Report.pdf>

few issues with billing and reimbursement as long as the patient is referred to the center. Providers said their hospitals contract with fee-for-service Medicaid and managed care plans out-of-state.

Care further away is more challenging

When Medicaid patients seek care further away from their state of residence, there are often more challenges. CF patients often have to travel further for organ transplantation or other highly-specialized care needs, as many care centers do not have transplant teams onsite, forcing patients to cross state lines. Patients may also travel to out-of-state care centers to be closer to their support system, since transplant is a physically and emotionally demanding process and most transplant centers require patients to have social support nearby. Additionally, patients may be referred to out-of-state transplant centers that have certain clinical expertise (e.g., transplanting patients with particular bacteria colonization). Yet despite current Medicaid regulations requiring states to provide out-of-state coverage when “the needed medical services, or necessary supplementary resources, are more readily available in another state,” coverage for out-of-state transplants is inadequate.²

Arranging care in the absence of statewide coverage arrangements between Medicaid programs and neighboring states’ facilities is challenging for care teams and patients, and often unsuccessful. Centers appeal to state Medicaid programs on a case-by-case basis for out-of-network coverage and this process can be administratively demanding for providers who spend a considerable amount of time trying to resolve these cases. One center described the process of coordinating out-of-state transplants for their patients as a “nightmare.” Another center said they have not been able to successfully refer a single patient out-of-state for transplantation. Moreover, these appeals can take weeks or months to reach a conclusion, leading to delays in critical patient care.

Hospitals and patients bear the full cost without out-of-state coverage

When Medicaid patients are not able to obtain needed out-of-state coverage, hospitals and patients must cover the costs. The care center in St. Louis, MO reported one patient who received a transplant at an out-of-state facility with no insurance coverage. Their insurer denied coverage for pre-transplant care, the procedure itself, and post-procedure recovery care and the institution absorbed the full cost. While the institution can cover the costs using uncompensated care funds, this is extremely expensive for hospitals—especially in the case of costly procedures such as lung transplantation—and widely unsustainable.

Still, in other cases, patients must decide between paying out-of-pocket or forgoing care altogether. Unfortunately, this is a dilemma we see all too often in CF – over a 12-month period, 58 percent of people with cystic fibrosis reported delaying or forgoing care due to cost. Because CF is a progressive disease, patients who delay or forgo care face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Transportation and lodging present additional barriers

Even when centers are successful in arranging Medicaid coverage for out-of-state services, traveling to and from these facilities can be expensive. As previously noted, centers described seeing patients that

² 42 CFR § 431.52 – Payments for services furnished out of State

travel as many as 3 to 4 hours to get to their clinic. Together, the cost of gas, food, and lodging can pose a major access barrier for CF patients who are encouraged to visit their care centers at least four times a year. These costs are exacerbated when patients spend an extended amount of time away from their home and away from work, as is the case for many transplant patients.

Unfortunately, many people with CF require additional financial assistance beyond what Medicaid programs reimburse for transportation and lodging to doctors' visits. Medicaid coverage of, and reimbursement for, transportation varies state-by-state and plan-by-plan. For example, the care center from Cincinnati, OH reported that one of their neighboring state's Medicaid program will only reimburse travel expenses for services 125 miles away and further, leaving those who live 100 or even 115 miles away to pay out-of-pocket. These travel costs only add to the financial stress of patients who are already struggling to afford their care. In order to make ends meet, 78 percent of people with CF receive some form of financial assistance. As a result, patients are forced to make difficult tradeoffs in everyday spending to afford the care they need to stay healthy.

Thank you for the opportunity to weigh in on this issue.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', written in a cursive style.

Mary B. Dwight
Chief Policy & Advocacy Officer
Senior Vice President of Policy & Advocacy
Cystic Fibrosis Foundation