



January 12, 2015

Ms. Jolie Matthews
NAIC Senior Health and Life Policy Counsel
c/o National Association of Insurance Commissioners (NAIC)
Suite 701 Hall of the States Building
444 North Capitol Street, NW
Washington, DC 20001

Re: Health Benefit Plan Network Access and Adequacy Model Act

Sent via email: jmatthews@naic.org

Dear Ms. Matthews:

The Cystic Fibrosis Foundation appreciates the opportunity to comment on the Health Benefit Plan Network Access and Adequacy Model Act and we commend the work of the National Association of Insurance Commissioners (NAIC) Regulatory Framework (B) Task Force in updating the managed care network adequacy act. We believe the evidence-based, multidisciplinary approach to high-quality, coordinated care provided within the cystic fibrosis (CF) care center network can serve as a model of effective, quality care delivery and should be an in-network option for individuals with CF. We have recommended some modifications to the draft that reflect the needs of individuals with cystic fibrosis (CF) and others with serious and life-threatening illnesses.

The CF Foundation supports an aggressive research and development program that has produced a number of therapies for the symptoms of CF and also drugs that address the underlying cause of the disease. The Foundation also coordinates a network of clinical care centers that provide quality care to children and adults with CF and that participate in an ongoing program for quality improvement. Through our research, clinical care, and quality enhancement efforts, we have contributed to a dramatic improvement in life expectancy for those with CF. In the last 60 years, the average life expectancy of those with CF has increased from five years to 41 years. However, longer lives and high quality of life for those with CF can only be achieved if patients have access to a lifetime of care that must be administered on a daily basis and that must also include access to new drugs and inpatient care to address serious lung infections that still remain the primary cause of death for those with CF.

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Process for Obtaining Care Out-of-Network (Section 5(C))

The model act would require a health carrier to have a “process to assure that a covered person obtains a covered benefit at in-network level of benefits from a non-participating provider” if the covered person is diagnosed with a condition or disease that requires specialized health care services or medical services and the health carrier does not have a network provider of the required specialty with the professional training and expertise to treat or provide health care services for the condition or disease or cannot provide access to an appropriate in-network provider without unreasonable delay. We recommend that the model act be revised to set more specific standards for this process so that a covered person with an urgent or acute medical condition could be assured access to an out-of-network provider within 48 hours. We also recommend that the access plan filed by the carrier provide specific information about the exceptions process for obtaining out-of-network care. Individuals with CF may present with urgent medical problems that do not meet the model act’s definition of an emergency medical condition, but nonetheless they may need care from an out-of-network provider without delay. For example, a newly diagnosed infant or child should be provided access to an appropriate specialist without delay. As a progressive disease, early diagnosis of CF through newborn screening allows individuals to begin treatment earlier thereby supporting normal growth and development as well as minimizing or delaying complications. Early diagnosis and intervention is critical to setting the course of the disease for the remainder of an individual’s life.

We also recommend that a determination that a covered person should be provided access to care out-of-network should be applicable for the remainder of the plan year. Individuals with CF require a lifetime of daily care, and it would be an unreasonable burden for them and carriers to revisit the out-of-network access determination on a frequent basis. If a CF patient is referred to a CF care center that is out-of-network, the patient will require ongoing access to that medical home.

In addition to a more precise definition of the process for obtaining out-of-network care, we recommend additional language to identify situations where out-of-network care might be necessary. We recommend that the language of Section 5(c)(2)(b)(I) be amended to read, “Does not have a network provider of the required specialty with the professional training and expertise or knowledge of relevant treatment guidelines or standards of care to treat or provide health care services for the condition or disease.” To provide up-to-date and appropriate care to individuals with CF, health care providers must not only have program training and expertise but must also be well-versed the in standards for multi-disciplinary CF care. Accredited cystic fibrosis care centers provide multidisciplinary treatment for individuals living with this disease. Providers are held to high standards of continuously updated evidence-based care and centers are regularly peer-reviewed to ensure high-quality, specialized care. The coordinated care provided by CF experts at accredited care centers is unparalleled and vital for individuals with the disease. This qualification would be necessary for specialists treating others with serious chronic diseases.

Requirements for Health Carriers and Participating Providers (Section 6)

We are pleased that the criteria that carriers must use to select participating providers would not permit carriers to exclude providers “because they treat or specialize in treating populations presenting a risk of

higher than average claims, losses, or health care services utilization.” The inclusion of this protection against discriminatory benefit design is important as a protection for individuals with CF and other serious chronic diseases who are above average health care services utilizers. The multi-disciplinary medical groups that manage the chronic and acute care required by CF patients can be easily identified, and they and their parent health care systems are at risk of network exclusion. The model act properly addresses this issue, and enforcement of the non-discrimination provisions will be critical to ensuring that the model act in fact protects access to care for those who are above average utilizers.

Provider Directories (Section 8)

We support the standards of the model act that require online posting of the carrier’s provider directories with search functions that will provide covered individuals information about hospital affiliation, medical group affiliations, board certifications, and certain other data. Monthly updating, as required by the model act, is also important.

For consumers to be able to make informed decisions about their ability to obtain quality care, the online information must also include information about the plan’s processing of requests for out-of-network care, including the average length of the exceptions process, the percentage of requests granted, and the reasons that requests were denied. The model act might also be amended to require carriers to carefully monitor consumer complaints regarding access to out-of-network care.

Disclosure and Notice Requirements (Section 7)

The model act includes provisions requiring disclosure and notification to covered individuals that they might receive care from an out-of-network provider while receiving care in an in-network hospital. These provisions of the model act are inadequate and should be modified to require that out-of-network care that is provided to a covered individual in an in-network facility should be reimbursed as if it were in-network care. The required disclosure to the patient about possible financial liability is inadequate to permit the patient to make an informed decision about his or her care. At the time that they are provided out-of-network care, these patients might be in no position to decline the care and are unlikely to be able to request and receive in-network care as a substitute for the out-of-network care.

We appreciate the opportunity to comment on the network adequacy model act and look forward to seeing revisions that will strengthen the model act and its protections of covered individuals.

Cc:

Monica J. Lindeen, President, NAIC; Montana Commissioner of Securities and Insurance
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