

August 17, 2018

The Honorable Alex Azar, Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

**Re: Kentucky HEALTH Section 1115 Demonstration**

The National Consumer Voice for Quality Long-Term Care (“Consumer Voice”) appreciates the opportunity to comment on Kentucky’s proposal for Kentucky HEALTH, a demonstration project under section 1115 of the Social Security Act. Formed in 1975, Consumer Voice is the leading national voice representing consumers in issues related to long-term care, helping to ensure that consumers are empowered to advocate for themselves. We are a primary source of information and tools for consumers, families, caregivers, advocates and ombudsmen to help ensure quality care for long-term care consumers across the country. We advocate for public policies that support quality care and quality of life responsive to consumers’ needs in all long-term care settings; empower and educate consumers and families with the knowledge and tools they need to advocate for themselves; train and support individuals and groups that empower and advocate for consumers of long-term care; and promote the critical role of direct-care workers and best practices in quality-care delivery.

We urge the United States Department of Health and Human Services to reject the Kentucky HEALTH proposal. As more fully explained below, the state’s proposals to require low-income Kentuckians to work and to eliminate retroactive coverage will greatly harm family caregivers and in turn, long-term care consumers.

**A. Work Requirements Will Cause Many Family Caregivers to Lose Health Coverage**

Work requirements would greatly harm the health of many family caregivers who receive Medicaid, and in turn the long-term care consumers and other family members whom they care for. Many family caregivers leave the workforce or reduce their hours to provide informal care to family members. Therefore, these caregivers are likely to be low-income and unlikely to have access to health insurance through a job or spouse. While Kentucky’s proposal has a narrow exception for “adults who are the primary caregiver of a dependent, including a minor child or a disabled adult,” many caregiving responsibilities fall outside of these tightly drawn lines. Furthermore, even though Kentucky states it will count caregiving hours for “a non-

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*The National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a 501(c)(3) nonprofit membership organization founded in 1975 by Elma L. Holder that advocates for quality care and quality of life for consumers in all long-term-care settings.*

dependent relative or other person with a chronic, disabling health condition” towards meeting the work requirement, imposing a work requirement puts an enormous and unnecessary burden on these caregivers to understand and comply with reporting requirements in the midst of their caregiving and other duties.<sup>1</sup> Given these realities, many caregivers would be forced to choose between providing care for their loved ones and maintaining their own health.

### **B. Eliminating Retroactive Coverage Will Deprive Family Caregivers of Needed Coverage**

Kentucky seeks to waive the important patient protection that allows Medicaid coverage to begin up to three months prior to a person’s application, as long as the person met the Medicaid eligibility standards during those months. Eliminating the retroactive coverage protection goes against Medicaid’s objectives by denying coverage to persons who cannot afford health care or private insurance coverage.

When the retroactive coverage guarantee was established in 1972, the Senate Finance Committee noted that the provision would “protect[] persons who are eligible for [M]edicaid but do not apply for assistance until after they have received care, either because they did not know about the [M]edicaid eligibility requirements or because the sudden nature of their illness prevented their applying.”<sup>2</sup> This statement is just as true now as it was 45 years ago, and Congress has continued to support such coverage by rejecting recent legislative efforts to eliminate this protection.

In many instances, a family caregiver in need of health care cannot be expected to apply for Medicaid coverage at the exact moment they become eligible. They may be hospitalized after an accident or unforeseen medical emergency. They may also be unfamiliar with Medicaid, or unsure about when their declining financial resources might fall within the Medicaid eligibility threshold. However, under the proposal, a family caregiver could suffer a major heart attack on the evening of April 29 and be liable for thousands of dollars of hospital expenses due to the “failure” to file a Medicaid application within 36 hours, when April becomes May. Faced with such staggering debt, many family caregivers would no longer have the resources to provide support and services to keep their loved ones at home. As a result, their loved ones would be at increased risk of nursing home admission costing \$7,148/month.<sup>3</sup>

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<sup>1</sup> Paperwork requirements have been shown to reduce Medicaid enrollment across populations. Margot Sanger-Katz, “Hate Paperwork? Medicaid Recipients Will Be Drowning in It,” *The New York Times*, January 18, 2018, <https://www.nytimes.com/2018/01/18/upshot/medicaid-enrollment-obstacles-kentucky-work-requirement.html>.

<sup>2</sup> S. Rep. No. 92-1230, at 209 (1972), in Amendments to the Social Security Act 1969–1972, vol. 3, p. 221 of 1273.

<sup>3</sup> Compare Long Term Care Costs Across the United States, Genworth, 2017, <https://www.genworth.com/aging-and-you/finances/cost-of-care.html>.

**C. Conclusion**

We urge HHS to reject Kentucky HEALTH given the harm it would cause to both family caregivers and long-term care consumers and its violation of the statutory standards for waiver under Section 1115.

Thank you for consideration of our comments.

Sincerely,

A handwritten signature in cursive script that reads "Lori Smetanka". The signature is written in black ink and is positioned below the word "Sincerely,".

Lori Smetanka, J.D.  
Executive Director