September 26, 2018

Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments on the South Dakota Career Connector Section 1115 Waiver Application

To Whom It May Concern:

On behalf of the Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, we appreciate the opportunity to provide comments on the Section 1115 Demonstration Waiver request for the South Dakota Career Connector program. Our comments address our concerns with the proposed work requirement policy that will ultimately limit access to care for low-income individuals in South Dakota living with cancer. For the reasons outlined in this letter, we are opposed to South Dakota’s 1115 waiver request and urge the Centers for Medicare and Medicaid Services (CMS) to reject it.

As the largest direct provider of social and emotional support services for people impacted by cancer, and the largest nonprofit employer of psychosocial oncology professionals in the United States, CSC has a unique understanding of the cancer patient experience. Overall, we deliver more than $40 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. Additionally, CSC is home to the Research and Training Institute—the only entity of its kind focused solely on the experiences of cancer patients and their loved ones. The Research and Training Institute has contributed to the evidence base regarding the cancer patient experience through its Cancer Experience Registry, various publications and peer-reviewed studies on distress screening, and the psychosocial impact of cancer and cancer survivorship.

Cancer patients face a wide variety of barriers in access to quality and comprehensive care. Almost all patients report experiencing barriers in accessing care, regardless of their income-level, location, and health plan. Low-income cancer patients however are particularly at risk as they face obstacles in qualifying for, accessing, and maintaining health care coverage for essential services. Of the patients surveyed in the Access to Care in Cancer 2016 study conducted by CSC, only 4.8% had gained access to coverage through Medicaid. Of the patients who reported being uninsured, 43% said they could not afford health insurance, and 31% said they were not eligible for Medicaid. According to the Kaiser Family Foundation, approximately fifteen percent of South Dakota’s population currently depends on Medicaid for their healthcare.
needs. The state has not expanded its Medicaid program, leaving an estimated 15,000 South Dakotans in the coverage gap between Medicaid and marketplace subsidies according to a 2018 Kaiser Family Foundation report on eligibility for ACA coverage among the uninsured. Any additional barriers in access to care for cancer patients will set back progress and harm cancer patients and their families already facing significant difficulty in securing and maintaining coverage while undergoing difficult, life threatening, and time consuming treatment regimens.

I. Work Requirements do not meet the requirements for a Section 1115 Waiver

Federal law does not permit the implementation of work requirements in the Medicaid program, as the core mission of the Medicaid program is to provide comprehensive health coverage to people whose income and resources are “insufficient to meet the costs of necessary medical services.” Section 1115(a) of the Social Security Act was created to allow the Secretary of the Department of Health and Human Services to waive certain provisions of the Medicaid program as long as the initiative is “likely to assist in promoting the objectives of the program”. The South Dakota proposal does not fulfill the requirement as it will create significant access barriers for low-income South Dakotans.

The state is seeking to implement work requirements to “improve participant’s health, encourage the development of healthy habits, and empower participants to be successful in today’s work force.” However, according to a 2017 study by the Kaiser Family Foundation, 8 in 10 Medicaid recipients already live in working families and a majority are working themselves. The Medicaid program is designed to provide coverage for those that are unable for a variety of reasons, to find or maintain employment that can provide for their health care needs. Medicaid enrollees who are not working most often reported that the major impediments to their ability to work included illness, disability, or caregiving responsibilities. In a study done by The Ohio Department of Medicaid, it was reported that three-quarters of Medicaid beneficiaries who were looking for work said that Medicaid made it easier for them to do so. For those who were currently working, more than half said that Medicaid made it easier to keep their jobs.

Health care and the ability to maintain good health is itself critical to an individual’s ability to retain employment. A 2018 Kaiser Family Foundation study concluded that, “access to affordable health insurance has a positive effect on people’s ability to obtain and maintain employment, while lack of access to needed care, especially mental health care and substance abuse treatment, impedes employment.” It goes on to explain that low-income adult Medicaid enrollees have high rates of chronic conditions, and that these individuals are better able to hold a steady job if these conditions are treated or controlled, but work may become impossible if these conditions go untreated. Health setbacks often lead to job loss, which would lead to loss of access to health care and treatment, which would in turn make it more difficult for individuals to retain employment. The South Dakota Career Connector proposal suggests that work requirements are necessary because unemployment is associated with poorer general health and higher rates of depression. The state proposal operates under the assumption that steady employment will lead to improved health, but in reality, South Dakotans, particularly those impacted by cancer, absolutely need access to health care to maintain good health, and ultimately employment.
II. Administrative burden and lack of adequate resources will restrict patient access

The state proposes to operate the Career Connector program as a pilot, applying to only Minnehaha and Pennington Counties, as they have been identified as the “best locations for access to employment and training resources.” The program will operate under the Department of Social Services (DSS), who will contract with the Department of Labor Regulation (DLR) to offer supports for individuals in the program throughout its five-year period. The proposal outlines an in-depth process through which individuals must meet with a DLR employment specialist to participate in an initial employment assessment and to create an individualized employment and training plan to meet the goals of the program. This plan may require that participants participate in a number of activities to retain coverage including health insurance and financial literacy courses, high-school or post-secondary education, un-paid volunteer work, and more, but does not provide for any financial support to meet these requirements. Cancer patients may have significant health problems, or lack access to transportation or technology necessary to complete these activities, all of which may make it difficult or impossible to attend an employment assessment or meet individual goals. Furthermore, the state’s proposal claims to impact approximately 1,300 individuals, but does not provide any additional funding to cover the costs of the additional administrative burden DLR and DSS will undertake to help individuals meet these requirements. This lack of detail and additional funding may make implementation within 90 days of approval as the state intends very difficult, likely leading to enrollees denial of benefits due to administrative burden or error.

III. Vague exemption categories will harm individuals living with cancer and their caregivers

The South Dakota waiver would be disproportionately detrimental to cancer patients and their families. The application outlines 11 categories of enrollees that would be exempt from the requirements. These exceptions are ill-defined and vague, likely leaving many patients unsure of whether they will qualify as exempt. Though the proposal includes exemptions for those classified as “medically frail” or those that are caregivers to family members or disabled/elderly individuals, there is no detail as to how participants must document or qualify for these exemptions. Many individuals living with cancer are not classified as “severe” enough by the Medicaid program to qualify for a disability exemption, but are facing significant health problems that would make it extremely difficult or impossible to fulfill these requirements. Treatment for cancer may not always produce “severe physical or mental impairments” that will easily and explicitly qualify patients for disability or medical frailty, but can greatly impede their health and ability to maintain steady employment. Patients often face symptoms of their disease as well as difficult side effects of medications such as extreme nausea, fatigue, diarrhea or constipation, nerve damage, heart problems, pain, etc.
Cancer patients also depend on caregivers for help coordinating medical care, traveling to and from appointments and treatment, managing finances, and continuing with daily life. The National Alliance for Caregiving estimates that during any given year more than 65 million people in the U.S. spend about 20 hours each week caring for an ill, disabled, or aged family member or friend. These individuals are absolutely vital to the wellbeing of people with cancer, but may face difficulty meeting exemption requirements on top of a commitment to unpaid caregiving. Cancer patients, caregivers, and their families should not be subject to fear, uncertainty, and delays in care while attempting to comply with and apply for an exemption from these requirements.

IV. Non-compliance lock-out periods will create further setbacks to enrollees health and independence

South Dakota’s proposal includes a non-compliance clause, with steps an enrollee must take at each month of non-compliance over the course of three months, before they ultimately lose eligibility and may face a lock-out period of 90 days, three more months. Cancer treatment duration can be a few weeks, months, or even years, depending on the individual patient, diagnosis, and treatment plan. Patients who do not qualify for an exemption and are also not able to meet program requirements may be locked out of coverage and unable to re-enroll before waiting three months, possibly interrupting lifesaving medical treatment. While the proposal suggests that an individual may apply to have the lockout reversed within 30 days for “good cause” there is little detail as to how a person may submit appropriate evidence to document this claim, again allowing for significant administrative burden on both the patient and the state.

V. Conclusion

We appreciate the opportunity to provide comments on the South Dakota Career Connector Section 1115 Waiver Demonstration Request. For the reasons above, we urge the rejection of this proposal, to ensure that vulnerable populations retain access to necessary and affordable healthcare. A program that was designed provide for the health care needs of low-income individuals without other options, should never be provisional based on unattainable goals or detrimental to the health of its citizens. Please reach out to me at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,

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Cancer Support Community
References


https://www.kff.org/medicaid/issue-brief/the-relationship-between-work-and-health-findings-from-a-literature-review/


The Ohio Department of Medicaid. (2015). *Ohio Medicaid Group VIII Assessment: A Report to*
the Ohio General Assembly. (2015). Retrieved from

http://medicaid.ohio.gov/portals/0/resources/reports/annual/group-viii-assessment.pdf