



Headquarters Office:
734 15th Street, NW, Suite 300, Washington DC 20005
202.659.9709 Phone 202.974.7999 Fax 888.793.9355 Toll Free

New York City Office:
165 West 46th Street, Suite 1002, New York, NY, 10036
917.305.1200 Phone 212.967-8717 Fax 888.445.3248 Toll Free

Research & Training Institute:
4100 Chamounix Drive, Fairmount Park, Philadelphia, PA 19131
267.295.3000 Phone 215.883.2580 Fax

March 18, 2018

Barbara Sears
Bureau of Health Plan Policy
Ohio Department of Medicaid
50 W. Town St; 5th Floor
Columbus, OH 43215

**Re: Ohio Group VIII Work Requirement and Community Engagement 1115
Demonstration Waiver**

Dear Director Sears,

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 Ohio Group VIII Work Requirement and Community Engagement 1115 Waiver. Our comments address our concerns with the proposed work requirement and community engagement program as well as the administrative burden that we believe will ultimately limit access to care for low-income Ohioans living with cancer. For the reasons outlined in this letter, we are opposed to the Ohio 1115 Demonstration Request and urge the Ohio Department of Medicaid to withdraw the application.

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. Each year, CSC serves more than one million people affected by cancer through its network of over 40 licensed affiliates, more than 120 satellite locations, and a dynamic online community of individuals receiving social support services. 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 (RTI)—the only entity of its kind focused solely on the experiences of cancer patients and their loved ones. The RTI 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. According to the *Access to Care in Cancer 2016* study from the Cancer Support Community, 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 study, 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. 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 implementation of a statewide work and community engagement requirement will create an unnecessary burden on all Group VIII Ohioans that will not assist in promoting the program objectives.

The state proposal states that a recent Ohio study showed a positive correlation between employment and healthcare coverage. It continues, “Group VIII survey respondents indicated that Medicaid coverage helped them maintain their employment, or if unemployed, helped them look for employment.” The interpretation of these results as justification for the implementation of work requirements is flawed. Where the state claims that employment is necessary for Medicaid coverage, these results actually demonstrate that Medicaid coverage is necessary for employment. Ohioans with access to quality health care are ultimately healthier and better able to seek and maintain employment. Requiring Ohioans to seek and maintain employment without access to quality health care will only leave more people out of work as they have to choose between their health and maintaining employment.

According to a study by the Kaiser Family Foundation (2017), 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 insurance needs. According to the same Kaiser study, 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 (2016), 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. Taking away health care coverage from those who struggle to or are unable to meet the work requirements will not improve health outcomes for residents of the state of Ohio.

II. Undefined exemption categories and an 80 hour/month work requirement will harm cancer patients



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The Ohio waiver application outlines 11 categories of enrollees that would be exempt from the requirements, none of which explicitly protect coverage for chronically ill patients or their caregivers. Exemption categories including “physically or mentally unfit for employment”, and “caring for a disabled/incapacitated household member” have no further definition or clarification, leaving the decision entirely up to the state appointed appraiser. Many individuals living with cancer are not classified as “severe” enough by the state to qualify for a disability exemption or Supplemental Security Income (SSI), but are facing significant health problems that would make it extremely difficult or impossible to fulfil the work requirement. Treatment for cancer may not always produce “severe physical or mental impairments” that will easily and explicitly qualify patients for disability, 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, depression, anxiety, diarrhea or constipation, nerve damage, heart problems, pain, etc. Cancer patients should not be subject to fear, uncertainty, and delays in care while attempting to comply with and apply for an exemption from these requirements that can be denied because of undefined requirements.

Furthermore, the waiver application includes exemptions that leave out a large portion of the population that Group VIII was created to serve. According the Ohio Medicaid Group VIII Assessment (2016), 55.7% of enrollees are male, 82.1% do not have a child in the home, and 48.6% are under the age of 45. These enrollees also had similar rates of employment as pre-expansion enrollees (43.2% versus 41.5%). The exemptions outlined in the waiver proposal will ultimately target this population for whom the Medicaid program was expanded. Approximately 27% of these patients were diagnosed with at least one chronic health condition after obtaining Medicaid coverage and now rely on that coverage to manage their health needs to remain a productive and employed Ohioan.

The Ohio proposal intends to use the existing work and community engagement requirements used within the Supplemental Nutrition Assistance Program (SNAP) and Able-Bodied Adults Without Dependents (ABAWD) programs, which requires 80 hours per month (20 hours per week) of work, community engagement, or a combination. As previously mentioned, cancer patients, survivors, and their family or caregivers often face significant barriers to maintaining steady employment. Many have to regularly take time off of work for treatment and appointments, often traveling hours or overnight, and spend days recuperating. These challenges, in addition to the physical burden and symptoms throughout cancer treatment and beyond, are unpredictable and timely. Cancer patients and their loved ones will face enormous challenges finding and maintaining steady employment that will meet the requirements as well as their own needs.

Furthermore, cancer is costly. According to our *Access to Care in Cancer* (2016) study, 48.7% of patients surveyed reported that the high out-of-pocket costs for services was their number one concern. Approximately 22% of respondents chose not to get the health care services

recommended by their doctor because of the high out-of-pocket costs. These challenges, already faced by cancer patients who have access to care, will pose an even greater risk to those who cannot maintain employment and are required to participate in 20 hours per week of uncompensated community engagement. Cancer patients deserve the time and supports necessary to focus on their treatment and recovery, and if possible, a healthy return to the workplace.

III. Implementation will create significant administrative burdens and delays in care

Ohio has suggested significant administrative changes that must be made to effectively implement these requirements, collect data from patients, declare eligibility, and administer care. Effective implementation of these requirements would be a significant burden and cost to Ohio's existing Medicaid and SNAP and Temporary Assistance for Needy Families (TANF) programs, requiring new procedures, system changes, and appeals processes, in addition to the need for additional time and staff to screen, verify, and track compliance. The proposed appraisal process, to be initiated within 30 days of initiation, will require significant administrative planning as well as increases in staffing to accommodate the lengthy appraisal process. Those administering appraisals will require training in eligibility protocol as they are given the power to decide whether to allow an exemption, assess barriers and offer reasonable modifications to the requirements, or provide additional supports. The state further suggests that any support services needed to find and maintain employment should be provided through the existing SNAP and TANF programs. All of these proposed changes require a considerable investment of time and funding to implement, especially within the 30 days. Lack of appropriate funds and resources in the implementation of this requirement will potentially cause serious delays in access to care and create a significant paperwork burden for both enrollees and the state as they work to satisfy the programs requirements.

The enormous changes required in a short timeline and without a guaranteed increase in funding are cause for concern in the efficacy and efficiency of the program as a whole. Our *Access to Care in Cancer* (2016) study found that 38.1% of people with Medicaid coverage reported delays in gaining access to cancer care, before the addition of proposed work or community engagement requirements. The Ohio Department of Medicaid itself estimates in the 1115 Demonstration Request that of the 36,036 individuals considered not exempt from these requirements, 50% or 18,018 will be unable to comply and will lose their Medicaid eligibility. Cancer patients in Ohio who rely on Medicaid for their life-saving treatment cannot afford these intensive barriers and delays in care due to lengthy administrative, exemption, or appeals processes for a program that they rely on for their health care.

In closing, we appreciate the opportunity to provide comments on the Ohio Section 1115 Waiver Demonstration Request. For the reasons above, we urge the withdrawal of this application. Please reach out at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,



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Elizabeth Franklin, LGSW, ACSW
Executive Director, Cancer Policy Institute
Cancer Support Community

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