

February 21, 2018

U.S. Department of Health and Human Services Center for Medicaid Services Director Seema Verma

Re: Wisconsin Badger Care Reform - Extension Application

Dear Director Verma:

Thank you for the opportunity to comment on the Wisconsin Department of Health Services's (DHS) proposed changes to the BadgerCare waiver.

People with disabilities are in BadgerCare

Although Wisconsin's BadgerCare participants are often referred to as the "able-bodied" Medicaid population, many people with disabilities access Medicaid health care and services through BadgerCare. People with disabilities in BadgerCare fall into four general categories:

- People with Intellectual/Developmental Disabilities (I/DD) who do not meet the functional screen criteria for Wisconsin's Family Care or IRIS long-term care Medicaid waiver programs
- People with disabilities who do not have or are in the waiting period for a disability determination
- People with intermittent disabilities (multiple sclerosis, for example) or disabilities that are
 progressive or may increase in severity and lead to functional limitations over time
- People with a primary diagnosis of mental health conditions

The Wisconsin Board for People with Developmental Disabilities (BPDD) is concerned that the proposed changes to the BadgerCare waiver will negatively and disproportionally impact BadgerCare participants who have disabilities.

BadgerCare is an important pathway for people with disabilities to access Medicaid health care and services that are not available at all or in the amount needed in private sector insurance plans. People with I/DD—including those with autism, epilepsy, and conditions that do not currently require a nursing home level of care—may require health care and supports that are only available through Medicaid. For these individuals, BadgerCare may be the only Medicaid program option.

For people with I/DD who have progressive conditions or disabilities that will eventually impact function, BadgerCare plays an important role in maintaining health coverage until the individual qualifies for long-term care programs. BadgerCare is critical for people with disabilities who are awaiting a disability determination from the Social Security Administration; it may take two years for an initial

determination, and many people with disabilities find it necessary to take additional time in an appeals process before receiving a formal recognition of their disability.

BadgerCare also provides a bridge for people with disabilities who lack formal documentation of their disability prior to age 18 or who were diagnosed after age 18. It is important to note that underserved populations, including those from culturally and linguistically diverse communities, are less likely to have a formal documented diagnosis of their disability prior to age 18 due to lower health care access and other barriers, which may impact their ability to obtain an adult disability determination.

Caregivers of People with Disabilities are in BadgerCare

Many people with disabilities—especially in the context of Wisconsin's growing caregiver crisis—rely on family members to provide some or a large proportion of the caregiving needed. Families often provide daily supports including personal care, supervision, service coordination, and medical and financial management. An estimated 40% of Wisconsin's overall community workforce includes family members.

Often, some combination of paid and unpaid caregiving is used, and multiple family members may contribute hours to meet all caregiving needs. We hear from families across the state that they have often had to rearrange schedules and even leave their jobs to fill in caregiving gaps. When caregivers work fewer hours or leave their jobs to do caregiving work, their reduced income may make them financially eligible for BadgerCare.

The Waiver proposal includes an exemption from work requirements and time limits to Medicaid eligibility for "primary" caregivers. We support exempting caregivers—who are already working within the home—from work requirements and time limits on their Medicaid eligibility, however we believe the qualifier "primary" is unnecessary and may fail to recognize and even discriminate against caregivers who make significant contributions towards an individual's care. Multiple caregivers often provide needed supports and contribute to the care of one or more individuals in a household.

Many caregivers are working within the home to provide supports and cares on a daily basis. The level and intensity of care needed can vary as people age and health conditions change, and caregiver roles may change depending on the individual's needs, especially in households where there may be multiple members needing care (children, person with a disability, and older adults).

It should be noted that many professional home health, personal care, direct care, and other community-based care workers who support people with disabilities and older adults in their homes are BadgerCare participants themselves. Wisconsin absolutely needs these caregivers—and more--to keep older adults and people with disabilities in their homes and out of expensive Medicaid-funded institutional settings.

Waiver provisions that will negatively impact people with disabilities and caregivers

Despite Wisconsin DHS's intent to exempt BadgerCare participants with disabilities from some of the new waiver requirements imposed on the childless adult population, BPDD believes many caregivers

and people with disabilities—including those with I/DD—may be subject to premiums, health risk assessments, financial penalties for Emergency Room use, work requirements, and potential loss of Medicaid eligibility based on the amount of time spent in the program, especially if they do not have or are in process of obtaining documentation of a disability or a disability determination.

Additionally, the drug screening provisions apply to all BadgerCare participants and BadgerCare applicants and would therefore by default impact people with disabilities and caregivers.

Drug Testing and Substance Abuse Treatment

The proposed waiver clearly requires drug screening to occur as a condition of eligibility. It is not clear what "drug screening" could entail, what screening results would trigger drug test requirements, what drug tests could be required, how frequently these screenings and tests could be required, and how much administering these screenings/tests will cost the Medicaid program.

Prospective BadgerCare applicants should not have to submit a drug test as a pre-requisite for Medicaid eligibility; the current means testing criteria should continue to be used to assess eligibility. There is no evidence that BadgerCare participants are any more likely to use illegal drugs than those insured under private sector plans. Private sector plans do not require drug tests as a pre-requisite to accessing non-drug related health care.

BPDD wants assurances that any costs associated with drug screening and drug testing will be the responsibility of the state and will not be borne by the applicant or BadgerCare participant. It is unclear whether applicants/participants will be able to complete required drug screening questionnaires online or over the phone; BPDD wants assurances that this administrative step can be completed in many ways in order to accommodate people's work schedules, and transportation/literacy/access to technology barriers.

BPDD also wants assurances that retroactive Medicaid coverage is in effect the date of the initial application for BadgerCare coverage. As written, the waiver proposal requires completion of the drug screening questionnaire before the applicant can become eligible for BadgerCare coverage. BPDD foresees—especially if the application and drug screening are separate processes or require interactions with different professionals—that there could be significant time delays between application and coverage and/or participant confusion and assumption of coverage when an application has been completed, but the drug screening questionnaire has not.

It is not clear what criteria will be used to assess questionnaire answers and determine which applicants the Department will require to undergo a drug test. BPDD is concerned—because the screening questionnaire would prevent eligibility for BadgerCare until it is completed and answers to the questionnaire trigger additional steps (drug testing) that the applicant must do before they may become eligible for BadgerCare—that excessive scrutiny or overly broad interpretations of questionnaire answers may result in more people being required to do unnecessary drug tests and delay their eligibility for health care coverage.

For people who are required to undergo a drug test is unclear how they will complete the test, and many may have transportation, work schedule, or other barriers that impact where and how they can complete drug testing. The prospective BadgerCare population is by definition low-income—at or below 100% of the Federal Poverty Level—and does not have health care coverage. Without health insurance, lab and other costs associated with drug testing may be prohibitively expensive for low income applicants, and could become a financial barrier that would prevent access to BadgerCare.

For people required to undergo drug testing, eligibility appears to be restricted until test results have been reported. Lab delays and other administrative factors outside of the individual's control should not be used to delay access to health care. The time from initial application to lab results could potentially be a significant amount of time. BPDD wants assurances that retroactive Medicaid coverage is in effect the date of the initial application for BadgerCare coverage.

Many low income prospective BadgerCare participants face additional barriers including reliable/affordable transportation, non-regular work hours, caregiving responsibilities, low access to health care providers etc. Requiring a drug assessment and/or screening test significantly increases the burden on low income people to overcome multiple barriers in order to get the drug test.

Although evidence of a valid prescription exempts individuals from substance abuse treatment requirements, the waiver application does not exempt BadgerCare participants from initial or annual drug screenings or tests. It is not clear how Wisconsin DHS will handle false positive test results or what the process will be to confirm the validity of drug testing results. Many people with disabilities may have multiple prescriptions, which may result in positive drug screening results.

State investment in administrative oversight and management of drug test assessments and results for all participants is a considerable expense that will not result in improved health, access to care, or better services for the vast majority of BadgerCare participants.

Work Requirements

Health care needs and access are independent from an individual's work status; BPDD does not support the Department's addition of a work requirement to the demonstration waiver. This proposal may result in low income individuals who are unemployed, cannot work the number of hours required per month, or who have cyclical or a series of limited-term employment positions losing access to health care. Health status is a pre-requisite to being able to work; work should not be a pre-requisite to achieve health.

Despite the Department's intent to exempt people with disabilities and some caregivers from work requirements, BPDD believes many people with disabilities—including those with I/DD—could inadvertently be impacted without clarifying what is needed to demonstrate qualification for exemption. There are always people with disabilities who fall through the cracks, especially when they do not have a robust support system.

The addition of exempt populations will necessitate new administrative functions for the Department and new bureaucratic requirements for people with disabilities and caregivers to prove they are exempt. Having documentation acceptable to the agency's requirements, getting it signed by an acceptable source, and having that documentation accepted and processed by staff that can sometimes excessively scrutinize those verifications, can all be barriers for people with disabilities.

It is unclear in the waiver application what will be required of participants. BPDD supports the current practice of Income Maintenance workers accepting many forms of documentation of disability (a doctor's note, a therapist or social worker letter, a paper signed by an M.D. etc.). It is also unclear with what frequency participants will have to reaffirm their exempt status.

BPDD cautions that any changes to program requirements or administrative process will cause participant confusion—and potentially loss of eligibility should they, or the workers advising them, not understand how they can comply and the timeframe by which they must complete requirements to remain eligible.

This is especially true among populations—including people with intellectual and developmental disabilities—who may be non-readers, non-verbal, use adaptive or responsive technology (including touchpads), have large print needs, may not have access to the internet, etc. In addition, changes in housing location, lack of access to transportation, shortened hours at welfare offices, and other common barriers for people with disabilities make it imperative that any changes have a multi-pronged communications approach that makes every effort to locate and inform participants in plain language what they must do to maintain eligibility for needed programs.

Limiting eligibility to no more than 48 months

The waiver application does not explicitly state that participants who are exempt from work requirements will not accrue time towards the 48-month limit; we recommend CMS explicitly instruct Wisconsin DHS to exempt these individuals from the time limit.

BPDD recommends that the time spent by people actively seeking a disability determination be exempted from the 48-month limit. The average time an applicant spends waiting for a disability determination from SDDI is two years, and that can extend longer as applicants move through an appeals process.

A similar exemption should be included for those with intermittent disabilities and those with multiple chronic health conditions; this would help address the population in BadgerCare who have acute health or mental health needs as well as those who do not yet have or have not been able to get a formal diagnosis.

BPDD objects to the six-month lockout period that occurs after 48 months has passed and before a participant can re-apply for health care coverage under BadgerCare. Abrupt loss of health care-especially for people with acute or multiple chronic conditions, intermittent disabilities, or people with

disabilities waiting for a determination can lead to rapid deterioration of health conditions—will be more costly when they are re-enrolled in BadgerCare or result in uncompensated care or even death.

The administration required for DHS to track how many months individuals have been on BadgerCare without being exempt from work requirements, working 80 hours per month, or participating in a qualified training program will be complex. The potential for recordkeeping mistakes that result in loss of health care is serious. It will be difficult for participants to track their remaining months of coverage and identify any mistakes that resulted in incorrect accounting of employment or exempt status. There must be an appeal process that enables participants to dispute the Department's accounting and CMS must require DHS to have a robust accounting system.

CMS should also require a notification process—we recommend annually for all participants with additional notifications 9, 6, 3, and 1 month before coverage is terminated—that states how many months of coverage an individual has left if work requirements are not met. Any notification process must recognize the diversity of BadgerCare participants and the barriers that low income people and people with disabilities often face—changes in housing location, lack of access to internet-based systems, literacy, etc.

Health risk assessment

People with chronic health conditions and disabilities may have conditions that fall into the categories of "Risky Behavior" that DHS has included as part of its waiver application (such as excess body weight). Some observable conditions categorized as Risky Behaviors can be the result of an individual's condition or side effects from medications used to manage their condition. Premium increases in these situations are punitive and do not serve to change health or behaviors.

Similar to our concerns with the annual drug testing requirement, requiring an annual Health Risk Assessment results in an extra administrative hurdle to maintain health coverage for populations that already face many barriers—including reliable/affordable transportation, non-regular work hours, caregiving responsibilities, low access to health care providers.

Premiums and penalties for Emergency Room Use

BPDD is not aware of BadgerCare participants using the Emergency Room as their vehicle for primary health care. BadgerCare participants are able to choose primary health care providers; if an ER is the only health care setting participants can access, a need for increased provider capacity in underserved geographical locations should not be penalized.

For people with chronic conditions or disabilities, transportation barriers may lead to ER use. Lack of access to preventative care or missed appointments due to lack of transportation may lead to worsening health conditions. Less expensive clinics and urgent care may be closed after business hours, requiring an ER visit for an acute issue. Participants may not have a choice on the destination if an ambulance is being used; if they are delivered to an ER as a default, we do not believe this merits an additional copay.

Similar to our concerns with a six month lockout on health care coverage after 48 months have been exceeded, BPDD opposes locking participants out of access to health care for six months due to unpaid premiums. Abrupt loss of health care, especially for people with acute or multiple chronic conditions, intermittent disabilities, or people with disabilities waiting for a determination can lead to rapid deterioration of health conditions—which will be more costly when they are re-enrolled in BadgerCare or result in uncompensated emergency room care—or even death.

People at less than 133% FPL do not have excessive disposable income; any additional bill puts participants at risk of being unable to cover their financial obligations (including housing, food, transportation) all of which may have a direct correlation to maintaining health. The amount of money gathered from premiums does not significantly offset the financial risks to the state should people lose health care coverage.

BPDD also questions the administrative expense associated with tracking relatively small premium amounts for each individual participant. The potential for recordkeeping mistakes that result in loss of health care is serious. Without clear communications, participants may not recognize small premiums as bills and what the consequences are should they not be paid.

Communication with members on how to maintain coverage

The proposed waiver creates many separate items that must be completed on a cyclical basis in order to maintain coverage: 1) annual drug assessment/testing, 2) annual health risk assessment 3) continual tracking of employment and number of hours worked 4) continual tracking of premium charges and payments. 5) potential additional co-pays or premium amounts based on ER use or health risks.

This creates complexity for participants and can cause confusion. At the minimum, any individual notifications and explanations to participants should cover each of these elements and detail any deadlines, steps that must be taken, documentation needed, appeal processes etc. for each requirement.

Changes in housing location, lack of access to internet-based systems, literacy and other barriers make it imperative that the Department have a multi-pronged communications approach that makes every effort to locate and inform participants in plain language what they must do to maintain BadgerCare.

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

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Beth Swedeen, Executive Director Wisconsin Board for People with Developmental Disabilities