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

RE: CMS-2454-IFC
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To Whom it May Concern:

The Survival Coalition of Wisconsin is comprised of more than 20 statewide disability organizations that advocate and support policies and practices that lead to the full inclusion, participation, and contribution of people living with disability. Member organizations represent concerns of people with disabilities and complex medical conditions across the lifespan and family caregivers.

In Wisconsin, it is estimated 180,000 people in the BadgerCare program will be subject to the CMS Community Engagement rule. Many people with disabilities and caregivers are in the BadgerCare program, and that many of these individuals will fall through gaps in the medical frailty exemption and will also not be able to meet the community engagement requirements. We appreciate this opportunity to outline our concerns with the Community Engagement Rule and recommendations to reduce negative impact on caregivers and people with disabilities.

Gaps in Medical Frailty Exemption

Wisconsin's Department of Health Services (DHS) estimates 63,000 people are at high risk for losing BadgerCare coverage. Survival Coalition believes many of these will be people with disabilities or serious medical conditions who fall through gaps in the medical frailty exemption.

People with physical, Intellectual or Developmental Disabilities with ADL limitations

To qualify for this exemption, people must meet three separate criteria:

- They must have a disability that meets the definition in the Americans with Disabilities Act (ADA)
- They must have their ability to perform one or more Activities of Daily Living (ADL) (need help with eating, dressing, bathing, toileting, moving from one position to another) "significantly impaired."

- They must prove their functional condition makes it impossible to meet 80-hour community engagement requirements.

Survival Coalition is concerned that many people with disabilities, many of whom are already working some, will not be able to qualify for the medical frailty exemption or meet the 80-hour community engagement requirement or wage-based criteria under the three-part exemption criteria outlined in the rule.

Survival Coalition supports the use of the broad ADA definition of disability. The ADA definition of disability includes people with physical or mental impairments that limit one or more major life activities and includes people with a history of such an impairment or who are perceived by others as having such an impairment. The ADA definition includes people with health conditions—like cancer, diabetes, post traumatic stress disorder, major depressive disorder—that can re-occur or need ongoing management.

Survival Coalition acknowledges there are many health conditions and diagnoses, and people who have multiple conditions that cumulatively result in disability that meet the ADA definition. **Survival Coalition recommends** CMS direct states to use maximum flexibility to identify people who have illnesses, conditions (including multiple conditions that have cumulative impact), and disabilities that meet the ADA definition.

Survival Coalition is concerned that people who do not have a formal diagnosis, who do not have access to health care providers to obtain a diagnosis, who are in the process of obtaining a diagnosis, or who are in the process of getting a disability determinacy will not be able to prove they have the required disability this exemption requires. Wisconsin has a shortage of health care providers and specialists, especially for Medicaid patients. Wait times for appointments can be months, and this rule creates health care penalties for people who are delayed or unable to access the health care system because of lack of health care capacity. **We recommend a temporary exemption pathway that allows states to cover people who are in the process of diagnosing or documenting disabilities** that meet the ADA definition.

Under the rule, an individual may meet the ADA definition of disability but may not meet the "medically frail" definition. The rule uses narrower criteria ("one or more limitations on ADLs") rather than the broader category of ("limit one or more major life activities") in the ADA definition that better reflects the disability population. Survival Coalition is concerned the rule allows only a subgroup of people with disabilities who meet the ADA definition to qualify for the medical frailty exemption.

Many people with disabilities—including people with intellectual and developmental disabilities, and people with mental health conditions, and people with chronic health conditions—have invisible disabilities that may not "significantly" impact an ADL but may impact how much and what kinds of supports or accommodations they need to participate in community engagement activities, or intermittently interfere with their ability to participate in community engagement activities[1]. **Survival Coalition recommends the rule's definition of ADLs be broadened to reflect the functional criteria referenced in the ADA ("limit one or more major life activities" and "major bodily functions").** We believe this more accurately captures the variety of factors that limit people with disabilities to fully participate in community engagement activities.

Under the rule, it is unclear what degree of ADL impairment is "significantly impaired," how the degree of impairment is assessed, who assesses it, and what documentation would be accepted. Survival Coalition suggests the word "significant" is a relative term open to interpretation making it an inappropriate modifier on which to base exemption criteria. **Survival Coalition reiterates that the ADA definition of "major life activities" and "major bodily functions" is a better metric to assess functionality, and it should be sufficient to assess whether limits on major life activities or bodily functions are present or absent** rather than arbitrarily interpreting the degree of limitation[2].

The third criteria needed to qualify for this exemption requires a person with a disability who has functional limitations to prove they cannot meet the community engagement requirements. Many people with disabilities work but their disabilities and health conditions can limit the amount they are able to work or lead to temporary interruptions to work. The disability community has long advocated for improving the ability for people with disabilities to work as much as they can while acknowledging that Medicaid provides health care unavailable to the degree needed in other markets, and that health care is essential to maintaining individual's ability to work.

[1] People with disabilities experience barriers to employment that are directly correlated to their disability status, including lack of reliable transportation options for non-drivers, need for remote work options and accessible technology, and limitations that impact stamina for physical or mental activity. An individual's specific disabilities can limit what jobs they are able to do, and those limitations can narrow employment options. The workforce participation of people with disabilities is significantly lower (~23% versus ~66% in 2025) that for people without disabilities.

[2] Survival Coalition notes that people with disabilities may experience fluctuations in functionality that temporarily impact or more permanently change their ability to participate in community engagement activities. People with intermittent, chronic, or progressive conditions may see their abilities decline on existing major life activities/bodily functions or become more limited on additional major life activities/bodily functions.

Survival Coalition is unclear how people with disabilities will prove a negative; we request specificity from CMS on documentation states will be able to evaluate that would prove an individual's inability to work without being subjective or rooted in bias. **Survival Coalition recommends working people with disabilities should be included in this exemption and not be subject to community engagement requirements unless they exceed the 80 hour threshold for at least six consecutive months. We further recommend** people with disabilities subject to community engagement requirements who have health or disability related events that change their workforce participation are automatically moved into this exemption category.

Almost 700,000 people are on state waiting lists to get into Home and Community Based Services (HCBS) waiver programs. To determine eligibility for HCBS programs, Wisconsin applies an income/asset test and conducts a functional screen which assesses whether the individual meets an institutional level of care. Only people who have an institutional level of care are eligible for HCBS programs. While Wisconsin does not currently have a wait list for adult HCBS programs, we have in the past and could in the future. Many people who were on an HCBS waiting list ended up in the "able-bodied" Medicaid program while they were waiting. **Survival Coalition recommends language be added to the rule that recognizes people who have been functionally evaluated and meet institutional level of care criteria who are on a wait list qualify for the Medically frail exemption.**

Wisconsin has a Children's Long Term Care (CLTS) program that serves children with delays, disabilities, special health care needs, and mental health conditions up to age 22. Some CLTS participants move into Wisconsin's HCBS waiver programs, but many move into BadgerCare. Survival Coalition is concerned there will be a population of 18-22 CLTS participants who do not meet the functional screen criteria for an adult HCBS waiver programs, are in the process of getting a disability determinacy from the Social Security Administration, or who will meet the rule's Medically frail exemption criteria for "disabling mental condition," or "serious or complex medical condition" but may not be able to prove they cannot meet the community engagement requirements.

Survival Coalition is also concerned that transition age children with disabilities may not be able to prove they are already meeting community engagement requirements or are exempt as a pre-condition to enter BadgerCare and could lose health care access as a result. **Survival Coalition recommends CMS allow states to an exemption pathway for transition age youth with disabilities who have applied for SSI/SDDI or are appealing a disability determinacy**.

Disabling mental disorder[3]

To qualify for this exemption, people must meet two separate criteria:

- They must have a "disabling mental disorder"
- They must prove their disabling mental disorder makes it impossible to meet 80-hour community engagement requirements.

Survival Coalition notes that the CMS rule does not define "disabling mental disorder" or provide states with guidance on what symptoms, behaviors, or diagnoses indicate the presence of a disabling mental disorder. **Survival Coalition recommends CMS provide more specific guidance for states that affirms all diagnoses** in the American Psychiatric Associations' *The Diagnostic and Statistical Manual of Mental Disorders* **are included and outlines additional observed or reported symptoms/behaviors that, if present, could affirm the probable existence of a disabling mental disorder.**

Survival Coalition recommends reported observations from caretaker relatives, family caregivers, guardians, school counselors, school psychologists, law enforcement, and licensed healthcare and mental health professionals (including psychiatrists, psychologists, psychiatric nurse practitioners, and primary care physicians) **should be accepted as confirmation of symptoms or behaviors**. Survival Coalition notes Wisconsin has a shortage of licensed mental health professionals, which can lead to delays and inability to access professionals needed for formal diagnosis.

The rule does not define when a mental disorder becomes "disabling." Many people have mental health conditions that interfere with normative comprehension, perception, and cognition, have behaviors that limit or interfere with one or more major life activities, or have episodic events that reduce their ability to participate in community engagement intermittently for the short or medium term. With consistent treatment many people who have conditions that would be disabling can be stabilized; these conditions can quickly become disabling if treatment is disrupted. **Survival Coalition recommends people with successfully managed mental health conditions that would be disabling without treatment are included in this exemption category.**

The rule does not give states guidance on the threshold that indicates an individual cannot meet the 80-hour community engagement requirement. The rule does not direct states on

[3] Many people with serious and persistent mental illness are in Wisconsin's BadgerCare program because the level of mental health care services they need are only available through Medicaid. BadgerCare is the health insurance that provides the treatment necessarily for these people to participate in community engagement activities to the degree they are able.

what documentation should be automatically considered as proof or what individuals can submit to the state to demonstrate their condition results in an inability to meet the community engagement requirements. Survival Coalition notes it is difficult to prove a negative.

Many people with disabling mental health conditions do participate in community engagement activities but may not reach 80 hours. Survival Coalition recommends working people with disabilities should be included in this exemption and not be subject to community engagement requirements unless they exceed the 80 hour threshold for at least six consecutive months. We further recommend people with disabilities subject to community engagement requirements who have health or disability related events that change their workforce participation are automatically moved into this exemption category.

People waiting for the Social Security Administration to issue a disability determination

Many people with disabilities meet the Social Security Administration's (SSA) criteria for Social Security Income (SSI) or Social Security Disability Insurance (SSDI), however the disability determination process is slow. Many people wait between 1-3 years to get through the process.

There are many people with disabilities in BadgerCare who are waiting for a disability determination from SSA. These include:

- Youth over age 18 transitioning from children's disability programs (like Children's Long Term Care or Katy Beckett) into adult Medicaid programs.
- People who have experienced traumatic medical events (traumatic brain injuries, debilitating injuries, strokes, etc.) that result in new or additional disabilities that limit major life activities and impact community engagement participation.
- People who have been diagnosed with progressive or ongoing conditions resulting in increasing levels of disability over time or intermittent interruptions in capacity.

Many people who are waiting for disability determination have had abrupt changes in condition/function that are ongoing and are generally not projected to recover to pre-event levels. Lags in Medicaid encounter data could delay documentation of diagnoses and limitations on activities of daily living. Many individuals in these populations would be unable to meet the 80-hour community engagement requirements and may not be able to prove they fit into a medically frail exemption category. These populations actively need health care coverage—adaptive equipment, therapies, medications, treatments etc.--while

they wait. The act of applying to SSA is an indication that individuals recognize their ability to participate in community engagement activities has changed to such a degree they believe they can no longer make substantial gainful activity. **Survival Coalition recommends that individuals who have applied to SSA for a disability determination should be exempt until the administrative process has been fully pursued.**

Serious or Complex medical conditions

There are many people who are actively ill or are managing complex medical conditions that impact their ability to meet community engagement requirements. However, the rule offers no guidance for states on how to determine what is "serious" or "complex." The presence/absence of a diagnosis is insufficient to evaluate an individual's overall health or condition. The term "serious" implies there is degree of impact or threshold must be reached for a condition to be considered "serious." **Survival Coalition recommends "serious and complex medical conditions" should include symptoms that are persistent or ongoing, acute flares of symptoms, and conditions with the potential to result in acute medical emergencies or disability.**

The term "complex" implies people experiencing multiple conditions or a constellation of symptoms that impact overall health or function on an intermittent or continual basis should fit into this exemption. Common "complex" scenarios that result in a cumulative impact on the health and function of an individual can include:

- People with disabilities who have multiple diagnoses and conditions that collectively contribute to overall health, stamina, and ability to consistently participate in community engagement activities. Separately, each diagnosis or limitation might not be sufficient to meet medically frail exemption criteria but considered together the additive impact results in a serious or complex medical condition.
- People with conditions that have gradations. The same diagnosis or condition can impact individuals differently depending on other underlying conditions, medical history, and characteristics/circumstances that are specific to the person. There are also many conditions where the initial gradation can change/worsen over time.
- People with stable or well managed conditions which can become serious or complex quickly for many reasons.
- Individuals who experience a loss of thrift (or failure to thrive) that may not be attributable to any diagnosis but are observed as a cluster of symptoms that indicate overall systemic decline.

Survival Coalition recommends conditions that require continual management, medication, intervention, medical follow-up to maintain the person's current health status or functional ability, and which can become conditions that pose imminent threat to life, limit major life activities, or result in greater health or cause new or deepening disability if care management is interrupted should fit this exemption category.

Caregiver exemption categories

The rule creates three separate exemption categories for people who are caring for a "disabled individual," with each with distinct requirements to prove they qualify for the exemption:

- **Caretaker relatives** must prove the person they are caring for meets the "disabled individual" definition, prove their relationship to disabled individual, must live with disabled individual, and demonstrate they provide care on regular basis that is not incidental.
- **Family Caregivers** must prove the person they are caring for meets the "disabled individual" definition, prove their relationship to disabled individual, must prove they provide at least 80 hours of care per month.
- **Guardians** must prove their ward meets the "disabled individual" definition, prove they have a court order that documents guardian status and that have been appointed to manage health and welfare of the ward.

Many people, especially older adults, may not understand that their condition meets the ADA definition of disability, which could jeopardize the ability for the caregiver to be insured through Medicaid while caring. **States should be required to clearly articulate the ADA definition of disability on websites, print communications, forms, and screening questionnaires** to clearly communicate in plain language to caregivers and people receiving care the breadth of conditions that are included in the definition.

Survival Coalition appreciates the use of the ADA definition of disability and the desire to protect privacy of individuals by requiring states to use the minimum amount of reliable data to confirm disability status. However, since the exemption is for the caregiver and their exempt status hinges specifically on whether the person they are caring for has a verified disability, it is difficult to assess how states will be able to meet this requirement without asking for specific documentation from the caregiver.

A subset of people who meet the ADA disability definition will be easily identified by meeting the definition of blind or having a disability determination from SSA. However, many people with disabilities including those who should qualify for a medical frailty exemption themselves (such as people with mental health conditions, functional limitations, chronic or progressive conditions, serious illnesses, complex medical conditions) may not have a disability determination from SSA.

Survival Coalition recommends any caregiver caring for a person who is on a waiting list for Home and Community Based Services, in a Home and Community Based Services program, or anyone who is on a waiting list for assisted living or skilled nursing facilities be automatically considered to be caring for a person with a disability. **Survival Coalition recommends** any caregiver caring for a person who is in Medicaid who meets the Medical Frailty exemption, or who has diagnoses/conditions consistent with categories of people eligible for a Medical Frailty exemption should automatically be considered caring for a person with a disability.

Caregivers who are insured through Medicaid may be caring for people with disabilities who are not in Medicaid. Many people with disabilities who rely on family caregivers or caretaker relatives may have Medicare or private insurance or be uninsured; states' limitations to accessing reliable data to verify disability status may require caregivers to provide additional documentation which increases the administrative burden on caregivers and states. **Survival Coalition recommends** CMS promptly confirm whether a person dually enrolled in Medicare and Medicaid or enrolled in Medicare meets the ADA definition of disability at state's request, and that private insurers are required to provide timely confirmation to state requests for confirmation that plan holders/members meet the ADA definition of disability.

Caretaker relative and family caregivers

Survival Coalition appreciates the breadth of relatives the rule lists as qualifying caretaker relatives.

Survival Coalition recommends states be required to document and report all unpaid care hours being provided in home and community-based waiver care plans as unpaid caregiver hours, and those hours are automatically applied to confirm caretaker relatives/family caregivers are providing care, and these hours are counted towards meeting Community Engagement requirements for caretaker relatives who are providing under 80 hours of care. States rely on unpaid caregivers to provide services and "natural

supports" for a wide range of care plan needs that would otherwise have to be met with paid Medicaid-funded supports.

Authorized paid care hours in care plans are not always provided by professional paid staff because of limited provider capacity and shortage of care workers. Many unpaid family members fill in care gaps that are supposed to be provided by paid care. These hours should also count towards the number of documentable care hours for caretaker relatives. **We recommend CMS direct states to create a process for family caregivers and caretaker relatives to report hours of care they provided that were supposed to have been covered by paid workers.** We believe this reporting mechanism will also help CMS assess provider capacity and whether services that are authorized are being provided.

Family Caregivers and caretaker relatives may be providing care to individuals with disabilities who are on wait lists for home and community-based waiver services or facility-based care. **Survival Coalition recommends** CMS directs states to automatically count hours of care delivered for people with disabilities who meet institutional level of care who are on wait lists. **Survival Coalition further recommends** that parents and caretaker relatives who have children with disabilities over age 13 in Katy Beckett or other Medicaid programs that serve children with disabilities up to age 22 automatically have the hours of care they are providing count toward proving caregiver exemption status.

Many caretaker relatives may transition into family caregivers when individuals with disabilities move to independent residences. It is important for young people with disabilities to live independently--to pursue educational and job opportunities and be closer to transportation options—and to have the ability to successfully transition to independence before unpaid caregivers die or are no longer able to provide the same level of care needed. Often, family caregivers continue to provide care even after the person with a disability is living elsewhere. Likewise, family caregivers may become caretaker relatives when individuals with disabilities move in with them. It is important **as family situations change that the hours of care being provided follow the caregiver** and continue to be automatically counted towards meeting the caregiver exemption.

Guardians

Survival Coalition objects to the assumption the rule makes that guardians are providing direct care and the lower level of proof required to qualify for the caregiver exemption through this pathway is flawed, insufficient, and creates a pathway toward exploitation and abuse of people with disabilities for the purpose of obtaining Medicaid coverage. Under

this rule, anyone who is appointed as a guardian would be able to be exempt from community engagement requirements with minimal effort.

Individuals claiming a caretaker relative or family caregiver exemption must demonstrate their relationship with the disabled individual and must document actual care hours or at demonstrate the care they are directly providing is on a regular (not incidental) basis. There are no such requirements for guardians claiming a caregiver exemption.

Survival Coalition is extremely concerned that the current language in the rule provides an incentive for individuals to petition for guardianship[4] for the express purpose of securing an exemption pathway to unending Medicaid coverage. The pathway for guardians to qualify for the caregiver exemption is significantly simpler than the caretaker relative or family caregiver pathway. It appears all that is needed is the appointment letter from the court. There is no requirement to have a relationship (independent of being an appointed guardian) to the disabled individual or to provide care or document care hours.

The rule seems to assume that guardians are providing direct care. This is often not the case. The guardian has been appointed to fulfill a legal and administrative role. A guardian may be appointed to make decisions related to health and living situations, but that does not imply they have any role in the actual care. Sometimes guardians make decisions that ensure they will not be providing care directly. For example, guardians may decide to put their ward in a residential setting where care tasks are managed by paid staff.

Guardians do not need to be related to their wards or live with them. A guardian can be appointed to make decisions for multiple wards. Corporate guardians, public guardians, volunteer guardians, or any individual appointed to be an individual's guardian by the court. Family members may be appointed as guardians; again, that does not mean they provide care or live with the disabled individual.

Some guardians live in different states than their wards. States do not have a way to know whether the same guardian has wards in multiple states or whether that guardian has been disciplined by the courts, removed, or charged with abuse/neglect of their ward in other states. Courts may change the terms of the guardianship in ways that restore rights to the individual (i.e. remove decision-making authority from the guardian), or revoke or terminate

[4] Guardianship removes an individual's civil rights to make their own decisions about where they live, their health/long term care, and other live decisions that directly impact autonomy and quality of life and transfers that decision-making authority to another individual (the guardian). There is no more consequential decision a judge can make than declaring someone legally incompetent, removing their civil rights, and giving a guardian decision making authority over some or most decisions about another person.

the guardianship order. It is unclear how states would be notified by the courts of these changes that could impact exemption status.

Guardianships are rarely reviewed or revoked so one piece of paper guarantees exemption status potentially for decades. Often, people with disabilities and older adults are put under guardianship unnecessarily, and these appointments are rarely reviewed, changed, or revoked. There are many cases where guardians are making decisions that the court has not given them authority to make, and cases of guardians abusing their wards.

At minimum, Survival Coalition recommends guardians be held to the same standards as caregiver relatives, and either must live with their ward and provide daily care that is not incidental or provide the same level of documented care hours required of family caregivers. Courts should be required to inform states of any sanctions, conduct review, or revocation of a guardianship order. States should also be required to periodically review the terms of all guardianships to ensure individuals are not being coerced into giving up their rights or having their civil rights removed as a mechanism to obtain or preserve exemption status from the community engagement rule.

Community Engagement

Employment

Survival Coalition notes that certain job training programs under Title I of the Workforce Innovation Opportunity Act (WIOA) are listed as ways individuals can meet community engagement requirements, but Vocational Rehabilitation Services which are listed in Title IV of WIOA are not included. In Wisconsin, Vocational Rehabilitation provides active support and on-the-job experience opportunities for people with disabilities who want to work and need help to get or keep a job because of disability specific barriers. They also work directly with employers to expand job opportunities for people with disabilities. **Survival Coalition recommends that work hours supported by Vocational Rehabilitation Services that are delivered in Community Integrated Settings should count** towards meeting community engagement requirements.

Survival Coalition is concerned that the allowance of "unpaid work other than community service" could create an exploitative pathway for unscrupulous people to extract unpaid labor for the promise of providing documentation to get or keep Medicaid coverage. We appreciate the examples given in the rule that intend this provision to apply to unpaid internships, but caution that without additional parameters any employer would be able to extract labor for health care documentation. In the past, exploitative arrangements have

been used to keep people with intellectual and developmental disabilities[5] trapped for decades in jobs that were compensated with food, lodging, and a subminimum wage monthly stipend.

We further note that individuals who provide unpaid labor are at risk of losing health care coverage if the employer does not provide promised documentation, resulting in increased leverage for employers and no recourse for individuals who have provided labor and not gotten documentation. Individuals bear all consequences for employers' failures.

Survival Coalition recommends states is required to have an Ombudsman for Medicaid participants and complaint process for participants to identify employers who have received unpaid labor and which have not adequately documented or provided documentation in a timely way that has impacted the participant's ability to demonstrate compliance with community engagement requirements. **We recommend** CMS require states to track all employers who are receiving unpaid labor in exchange for documentation and apply additional scrutiny on these employers including: metrics on how many unpaid employees/paid employees are employed by the business; the length of time an unpaid employee has remained unpaid; trends that demonstrate a shift in the number of paid to unpaid employees; trends that demonstrate a shift in the number of unpaid employees that become paid employees.

Survival Coalition is concerned that many individuals who are compliant with community engagement requirements could have their coverage jeopardized by an employers' failure to provide documentation in a timely way or states' administrative errors. Many individuals work for multiple employers and each employer will need to provide documentation of hours in a timely manner; a mistake by one could cost the employee health care coverage.

Likewise, many participants are hourly workers whose work hours or shift schedules are determined by the employer. Employers can decide to change hours/shifts on short notice. Participants who are operating with the understanding that their work schedule totals at least 80 hours could have their health care coverage jeopardized by employer decisions that are outside of their control.

Survival Coalition recommends the rule add "Hold harmless" provisions and require continued coverage for an employers' failure to provide documentation in a timely way, employer shift changes that cause loss of expected hours, and state's administrative errors. We further recommend **adding a retroactive coverage** requirement if a participant

[5] https://www.courthousenews.com/decades-of-abuse-at-iowa-turkey-farm/
https://www.nytimes.com/interactive/2014/03/09/us/the-boys-in-the-bunkhouse.html

has lost Medicaid coverage because of employer or state administrative mistake and a process for immediate reinstatement of eligibility for these individuals.

Thank you for your consideration,

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