

P.O. Box7222, Madison, Wisconsin 53707

RE: Medicaid Program; Request for Information (RFI): Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services (CMS-2404-NC)

January 6, 2017

To Whom It May Concern:

The Survival Coalition, a Wisconsin group of more than 30 cross-disability organizations, appreciates the opportunity to offer input on the role CMS has in ensuring the Home and Community Based Settings (HCBS) rule is implemented by states with fidelity.

The HCBS rule is a crucial tool to move states towards ensuring HCBS Medicaid dollars are used to maximize the independence and contribution of people with disabilities and older adults to their communities. The HCBS rule is an asset to help each state Medicaid agency improve and evolve its service system.

Wisconsin has valued and invested in HCBS services as a mechanism to maximize people's independence and lower overall Medicaid spending by keeping people out of expensive institutions. For more than 20 years, Wisconsin has been expanding the Medicaid funded long-term care programs Family Care and IRIS; these programs have dramatically reduced high-cost institutional spending and kept people in their homes, jobs, and communities.

Survival Coalition supports Community Integrated Employment and Community Supported Living as the desired outcome for people with disabilities and older adults.

Since the HCBS rule has been finalized, Wisconsin has seen some progress with individual segregated facility-based pre-vocational and day service providers voluntarily shifting their business models to provide community integrated employment; some providers have fully shifted to community integrated employment models. Other segregated pre-vocational and day service settings have made no efforts to come into compliance.

Wisconsin invested heavily in a facility-based employment and day service model in the early 1980s, and that model has not significantly evolved or changed in the past three decades. In many areas of the state, a segregated sheltered workshop is the only choice presented or available to individuals and their families. Without robust and vigorous direction and oversight from CMS, Wisconsin's HCBS

Medicaid waivers will continue to be used extensively to pay for long-term segregated sheltered workshop placements.

While Wisconsin has some pockets of Community Supported Living, the majority of HCBS residential services are provided in settings that have the effect of isolating participants from the community, are often segregated by population, and are communal living arrangements. Many residential providers did not complete Wisconsin DHS's self-assessment on HCBS rule compliance. Survival Coalition believes many of these settings are not HCBS compliant, that strong oversight and direction is necessary to ensure these settings become compliant, and that a shift to community supported living as the preferred outcome will facilitate HCBS rule compliance.

Strong direction by CMS is needed to set the quality standards and community-based criteria that states must meet consistent with the intent of HCBS dollars. CMS is in a position to drive innovation in the states, provide technical assistance to states, and ensure that HCBS Medicaid recipients have access to similar quality services regardless of where they live.

In conjunction with strong direction, CMS should require State Medicaid Agencies to have transparency in their decision-making including meaningful opportunities for stakeholder engagement during all phases of the development and adoption of financing and service delivery design or changes, including concept development, contract specifications, evaluation, oversight and CMS review of waiver applications/state plan amendments.

Survival Coalition has prepared comments and recommendations for each inquiry area.

What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid long-term services and supports (LTSS) system to meet the needs and preferences of beneficiaries?

Under current federal Medicaid law, an institutional bias directs Medicaid funds to institutional services and community services are only available through waivers. Since Medicaid has become the core of federally supported LTSS, the philosophy of the Medicaid program must be changed to reflect the preference for individualized community-based services over institutional services.

Survival Coalition strongly supports reversal of the institutional bias in Medicaid law such that community living is the first and preferred option, provided that legislation is consistent with the goals of inclusive participation, self-determination, community integration, and independence.

We encourage CMS to take an active role with Congress to advocate changing Medicaid law to mandate HCBS and require states to have waivers to provide services in institutions and secure increased federal matching funding for HCBS incentive payments to states for community based services.

Absent Congressional action, Survival Coalition encourages CMS to use its agency authority to expand flexibility to states to shift their systems towards HBCS by doing the following:

- Decouple eligibility for HCBS waivers from eligibility for institutional services.
- Ensure that states have plans to provide services to individuals with disabilities who live with aging family care providers or who are in other crisis situations;
- establish policy to include HCBS under the equal access rule, which requires rates to be set to ensure equal access to services;
- Ensure full implementation of the amended Section 1915(i) Medicaid state plan option for home and community-based services that allows states to serve people who do not yet need an institutional level of care;
- Fully implement the Medicaid HCBS waiver program and State Medicaid plan Section 1915(i) option to promote competitive, integrated employment;
- Address unmet needs in the community by amending the Medicaid formula for cost-sharing with the states to provide a greater fiscal incentive for supporting individuals in the community rather than in institutions.
- Eliminate any incentives for institutionalization, and incentivize prevention of institutionalization and promotion of community relocation, specifically sustain/renew Money Follows the Person initiatives;
- Compel states to provide certain LTSS supports to people who are not financially eligible for Medicaid as a strategy to prevent total depletion of savings in order to access the public long term care system or a decline in condition that leads to rapid institutionalization. Light touch, low cost services can keep unpaid care providers functioning in their capacity as long as possible and to keep at-risk older adults off Medicaid as long as possible. Options for states should include:
 - Establish a Buy-In program for this population, and use a sliding fee scale based on income to establish premiums.
 - Amend state plans to provide services to people who do not meet institutional level of care.
 - Allow states to have more flexible asset limits for this sub-population to access limited low cost LTSS supports.
 - Establish Medicaid 1115 Demonstration Waivers, such as the one approved in Washington State, to include Medicaid fundable benefits that focus on

unpaid family care providers providing care for Medicaid beneficiaries and prioritize older adults at risk of fully depleting their savings to access Medicaid.

Require states to have a robust Self-Directed program with full budget and employer
authority as an equitable alternative choice for consumers and competitor to HCBS
managed care. Wisconsin's IRIS self-directed supports HCBS waiver program has achieved
improved HCBS access and has proven that quality is better when there is competition. It
has the added benefit of encouraging managed care organizations (MCOs) to improve and
expand their own type of self-directed service offerings. For some individuals self-direction
is more cost effective, and removes managed care overhead costs.

States like Wisconsin have invested in innovative systems, and should not lose the incentive to maintain and improve upon them. Wisconsin has elected to provide many services deemed optional under current Medicaid law. Many of these optional services reduce overall costs and have become best practice since Medicaid law was passed 50 years ago.

Many improvements are possible, however incentives and seed money are often necessary to accomplish system changes that can lead to better outcomes and cost-effectiveness. Without federal direction, states may be incentivized to do only the federal mandatory minimum, which currently includes high-cost institutional care.

Without a clear incentive structure that rewards continuous improvements and quality outcomes, states may lose flexibility to fund and evaluate innovative approaches that can improve care and lower costs. CMS must provide incentives to states to spur innovation, and must clearly articulate the outcomes that HCBS dollars should achieve. The HCBS settings rule establishes that services should be delivered in integrated settings; CMS can go farther and identify specific outcomes that states should be working towards.

- Specify outcomes HCBS Medicaid dollars should strive to achieve—community integrated employment, coordinated transportation, community supported living, etc.-- to drive measurable improvement and ensure that all states are working toward the same goals.
- Establish an innovation fund for which states can competitively apply for seed money.
- Grant demonstration authority on a national level to states to establish pay for performance structures for community integrated employment, and community supported living.
- Adjust the FMAP to reward states and providers for fully HCBS compliant settings and services where outcomes are clear and objective such as community integrated employment, or community supported living or their own homes. We suggest the bonus FMAP funds be passed on directly to the compliant provider.

What actions can CMS take, independently or in partnership with states and stakeholders, to ensure quality of HCBS including beneficiary health and safety?

CMS must clearly articulate and require a robust state oversight function with expectations and a strong role for state Medicaid agencies and outcome responsibilities. Survival Coalition recommends CMS conduct routine and thorough audits of state Medicaid agencies, and interview state stakeholders including the Protection and Advocacy Agency, Disabilities Councils, Ombudsman Program, and members of the disability and older adult advocacy community to assess how the system performs with regard to overall quality of life for participants and address recommendations that stakeholders have for improvement.

The is this for CMS or states?oversight responsibilities for HCBS should be similar to the oversight responsibilities for institutional providers. Oversight functions within state Medicaid agencies may be fragmented and separated by different services making it difficult to have a unified approach to evaluating overall program quality. It is critically important that health and safety should not be the only metrics by which a state measures its system and whether HCBS outcomes are being successfully achieved. For example, community connection and engagement are an important component of health and safety and should be addressed through specific metrics.

CMS should require additional quality of life metrics (National Core Indicator data, outcomes such as integrated employment and community supported living, prevention and wellness, social domains), as well as metrics that measure the capacity of the system to meet participant's individual needs and offer genuine service choices. Time and distance standards, whether participants have equal or better access to settings and services that comply with the HCBS rule in letter and spirit, and whether HCBS providers are accepting new participants are all metrics that help assess whether provider capacity is sufficient to meet or adjust to changing service needs and provide choices for participants to live the most integrated lives possible. Program participants should also be informed about is the standards which are expected of providers.

At a minimum, CMS should require the following from State Medicaid Agencies to assess HCBS compliance and whether measurable goals that lead to more integrated lives are being achieved:

• Define "competitive integrated employment" using the federal Workforce Innovation Opportunity Act (WIOA) definition, and explicitly state that competitive integrated employment is the first and preferred outcome for all people with disabilities.

¹ Under WIOA, "competitive integrated employment" means work that is performed on a full-time or part-time basis (including self-employment) (A) for which an individual is compensated at a rate that –(I.) (aa) shall be not less than the higher of the rate specified in section 6 (a)(1) of the Fair Labor Standards Act of 1938 (29 U.S.C. 206 (a)(1) or the rate specified in the applicable state or local minimum wage law; and (bb) is not less than the customary rate paid by the employer for the same or similar work performed by other employees who are not individuals with disabilities, and who are similarly situated in similar occupations by the same employer and who have similar training, experience, and skills; or (II.) in the case of an individual who is self-employed, yields an income that is comparable to the income received by other individuals who are not individuals with disabilities, and who are self-employed in similar occupations or on similar tasks and who have similar training, experience, and skills; and (ii). is eligible for the level of benefits provided to other employees; (B.) that is at

- By 2019, require all working age (18-64) LTSS participants with to have an identified community employment goal in their care plans and a timeframe to achieve that goal.
- Require data reporting to enable State Medicaid agencies to assess the degree to which
 participants have progressed or achieved an employment goal², with annual progress
 reports to CMS.
- Establish a pay for performance system that rewards community employment outcomes and fading or elimination of publically funded employment supports while establishing natural, employer-based supports³.
- By 2025, CMS should establish a three-year time limit on HCBS-billable facility-based prevocational services and after that timeframe has been exceeded, only allow integrated employment services as billable under HCBS.
- Establish Community Supported Living as the first and preferred option for Medicaid reimbursable residential supports. Within the waiver, define "Community Supported Living arrangement services" using the definition included under 42 U.S. Code § 1396u⁴.
- Direct states to use of administrative Medicaid funds to be used for housing-related activities such as assisting with housing applications, developing a housing support plan, or providing tenant support services⁵.
- Require measurement of community-based housing outcomes⁶

a location where the employee interacts with other persons who are not individuals with disabilities (not including supervisory personnel or individuals who are providing services to such employee) to the same extent that individuals who are not individuals with disabilities and who are in comparable positions interact with other persons; and (C.) that, as appropriate, present opportunities for advancement that are similar to those for other employees who are not individuals with disabilities and who have similar positions.

² Data elements include: Number/percentage of working-age members (16-64) with disabilities working in Competitive Integrated Employment (CIE) at least 15 hours per week; For participants working in competitive integrated employment, average gross wages adjusted for length of time on job, number/percentage with some level of health care coverage through employer, number/percentage with paid time off, number/percentage who advanced in career during prior year (defined as achieving increased hours; additional part-time job; promotion with higher pay); Among working-age members (16-64) not engaged in CIE, the number/percentage with a goal in their Plan of Care/ISP to obtain CIE for at least 15 hours a week; Among working-age members (16-64) not engaged in CIE, the number/percentage receiving services to obtain CIE of at least 15 hours a week through the IHA or another recognized funding source; Number of participants receiving pre-vocational services, total length of time receiving pre-vocational services, number of hours per week of pre-vocational services received, and average gross wages adjusted for length of time on job delineable by individual and pre-vocational service provider.

³ Service codes in long-term care can be changed to pay for hours an individual works, rather than hours of service provided. This incentivizes obtaining more hours of employment for a LTC participant, finding a good job match that minimizes the need for support, and rewards fading of job coaching over time because the agency is still paid for the hours a person works regardless of services delivered. This model has already been successfully implemented in Wisconsin by one Wisconsin MCO.

⁴ https://www.law.cornell.edu/uscode/text/42/1396u

⁵ CMS encourages the use of Medicaid funds for these purposes. California, New York, and Tennessee — are addressing the housing needs of dually eligible beneficiaries who use LTC. https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf
⁶ Number of people with I/DD living in CBRFs, AFHs, Community Supported Living, Family Homes; number of people transitioning into each setting type; reason for transition; length of time participant resided in setting; distance from public transportation option or response time of closest transportation provider; distance from employment setting; Distance from other community settings that can help residents meet their needs without Medicaid services (grocery stores, community centers, family).

- Require State Medicaid agencies to work with families to develop a clear succession plan to
 ensure their children can live in community supported living and avoid the potential of
 decades of high cost, restrictive residential placement.
- Provide annual bonus payments to states for each participant that is living in Community
 Supported Living for one, five, and more than ten year benchmarks.

An external, independent Ombudsman Advocacy Program is also essential to ensure that HCBS services are being delivered appropriately. A quality Independent Ombudsman Program should be mandatory for all states with the following features being required:

- Ombudsman must be independent of the State Medicaid Agency, any managed care entities, and any other provider;
- Ombudsman must be statewide, with ombudsmen available to provide in-person advocacy;
- Ombudsman must take all calls for assistance to ensure no waiting for or rejection of services;
- Ombudsman must participate in and generate regular, active outreach to enrollees, MCOs, ADRCs, providers, and others;
- Entities must be required to cooperate with the ombudsman program and seek resolution of cases;
- Ombudsman must track trends and quality data and report back to State Medicaid Agency and independently to CMS;
- Ombudsman must be kept apprised of and current on new policies, rules, regulations, and structural changes by CMS and State Medicaid Agencies;
- Ombudsman must work collaboratively with the State Medicaid Agency and other agencies to advise on potential impacts of policy/rule/regulatory/structure development;
- Ombudsman must have access to the State Medicaid Agency and the State entity regulating insurance to resolve complex enrollee or entity issues;
- Ombudsman must adhere to legal casework practices and protect private information;
- The Ombudsman must have the right to represent consumers at all due process steps; and
- CMS should mandate a minimum ratio of 1 Ombudsman per 1000 LTSS enrollees.

What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste and abuse in HCBS?

Survival Coalition supports efforts to fight waste, fraud and abuse in the state's Medicaid program. However, focus on fraud, waste, and abuse has sometimes resulted in an additional barrier to accessing services that participants need, has interfered with self-direction, and has unfairly implied that participants have engaged in deliberate malfeasance when mistakes or clerical errors have been made.

There are examples of overreach by state Offices of the Inspector General (OIG) that unfairly penalize providers and have a negative impact on consumers. In Wisconsin, two courts have found that Wisconsin's OIG recoupment practices exceeded its authority by requiring Medicaid providers to pay back significant sums of money for clerical errors instead of legitimate fraud. These types of recoupment practices are contributing to the direct care workforce crisis by driving dedicated providers and caregivers out of the profession. Likewise, in Wisconsin, the prior authorization system, particularly for long term care type services such as therapies and personal care, has become so onerous that it resembles a front end fraud investigation rather than an honest attempt to determine whether a recipient will likely benefit from the proposed treatment or service.

Survival believes that recovery efforts should be limited to instances of actual fraud such as situations where care was not provided or when a provider claims an inaccurate or inappropriate amount for the service that was provided. Any prior authorization of HCBS should be personcentered and there should be a rebuttable presumption that the service will serve the person's long term care goals.

Federal and State OIG offices should offer trainings and technical assistance to providers to ensure they understand Medicaid regulations.

What are specific steps CMS could take to strengthen the HCBS home care workforce, including establishing requirements, standards or procedures to ensure rates paid to home care providers are sufficient to attract enough providers to meet service needs of beneficiaries and that wages supported by those rates are sufficient to attract enough qualified home care workers.

Survival Coalition cautions against establishing too many additional requirements for workers, such as licensing, as this could lead to further narrowing of the potential pool of workers, especially if new requirements are imposed independently of reforms, such as increases in compensation that would improve career viability for the HCBS homecare workforce. Requirements that create bureaucracy, time windows that keep people from being hired, or do not necessarily provide information on whether the worker can perform the job participants need, serve as an additional impediment to attracting and retaining new workers. Survival Coalition asserts that paid family care providers should be part of the eligible workforce.

- CMS should require states to develop and implement a plan to remediate all relevant components that drive the workforce crisis, including low wages and reimbursement rates, high turnover, and inadequate training, and heavily involve stakeholders, including participants, advocacy groups, workers, and providers, in the development of that plan;
- CMS should require state reimbursement rates for services to incorporate any local, state, and federal minimum wage increases or changes in employment standards such as overtime pay;
- CMS should set a basic minimum wage that is appropriate for the region and labor market for the worker and also set an allowable administrative rate for providers.
- CMS should set the federal matching rate for HCBS waiver services higher than state plan services rate, and require the increased percentage of federal match to go directly to the wage component for workers.
- CMS should incentivize states to develop worker co-ops as a strategy for workers to
 collaborate together for a better benefit package and other strategies that create better
 worker retention.
- Require states to develop tiered rate structures to provide enhanced reimbursement for workers serving beneficiaries with more complex needs, workers with selected advanced skills, and provider's costs for worker benefits such as tuition assistance, performance-based bonus payments, or higher wages for shiftwork.⁷
- Establish a Medicaid reimbursement rate for transportation costs associated with personal care workers commuting to client homes. These costs should at minimum include gas, millage, and public transit system fares⁸.
- Require use of Medicaid funds to subsidize professional training for workers.
- Allow and encourage states to use federal Medicaid match to pay co-pays or premiums for worker health insurance⁹ including private plans, Medicaid Programs, or the Affordable Care Act exchanges¹⁰.

⁷ CMS Guidance, Suggested Approaches for Strengthening and Stabilizing the Medicaid Home Care Workforce August, 2016, https://www.medicaid.gov/federal-policy-guidance/downloads/cib080316.pdf

⁸ Currently, the workforce is only reimbursed for travel time and not mileage. Travel time reimbursement often does not cover the cost of gas and wear and tear on the vehicle.

⁹ State Medicaid Agencies may, with the consent of the individual practitioner, make a payment on behalf of the practitioner to a third party that provides benefits to the workforce such as health insurance, skills training, and other benefits customary for employees (42 CFR 447.10(g)(4)).

¹⁰ 36% of direct care workers are on Medicaid, Medicare, or other public coverage for their health insurances, and 51% rely on some form of public assistance program. The median annual income for home care workers is \$13,000, just \$1300 above the federal poverty line for a single household and almost \$3000 below the federal poverty line for a two person household. 24% of direct care workers live in households below the federal poverty line. (U.S. Home Care Workers: Key Facts http://phinational.org/sites/phinational.org/files/phi-home-care-workers-key-facts.pdf)

- Allow and actively promote participants in self-directed programs to hire "individual" service
 providers so that participants can choose agency or participant hired workers, including
 relatives and friends not affiliated with agencies. Continuing to use willing workers
 connected to an individual's network expands the pool of available workers.
- Encourage managed care entities to incorporate workers not affiliated with a provider agency, including willing family members, into their provider networks and allow LTSS managed care participants to have full budget authority to hire their own workers.
- Require states to establish a statewide contract with a proven interface that enables both provider agencies and LTC participants to match their needs with available workers, schedule support, and track hours (to avoid overtime),¹¹ to serve as the CMS suggested open registry of workers for public use. Allow Medicaid administrative match to be used by states to implement these systems and pay for ongoing operating costs¹².

¹¹ Applications have been developed that match participants and workers by via profile information (care needed, geography, availability), enable participants to self-direct and hire workers that fit their needs and personality, enable personal care agencies and workers to track hours to prevent incurring overtime expenses, and enable provider agencies and managed care organizations to reduce administrative overhead while tracking workflow and billable Medicaid expenses. My Support (http://www.mysupport.com/) is an example of a platform currently operating in California, New Jersey, Iowa, and preparing to launch in Delaware and Maryland.

¹² CMS Guidance, Suggested Approaches for Strengthening and Stabilizing the Medicaid Home Care Workforce August, 2016, https://www.medicaid.gov/federal-policy-guidance/downloads/cib080316.pdf