Survival Coalition
of Wisconsin Disability Organizations

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Department of Health Services
Curtis Cunningham
Assistant Administrator, Long Term Care benefits and programs
Family Care Waiver Renewal Comments
DHS/DMS/BAPP – Room 518
PO Box 309
Madison, WI 53701-0309

Dear Mr. Cunningham:

Thank you for the opportunity to provide ideas to improve the Family Care waiver. We look forward to the Department's continued discussions with advocates throughout the waiver development process.

Survival Coalition has organized its recommendations by the sections of the current Family Care waiver. We have also included recommendations on broader issues affecting long-term care participants that warrant modification in the current Family Care waiver and inclusion of new approaches within the renewed waiver.

Workforce shortages place greater number of people at risk of institutionalization

Wisconsin has a documented shortage of home and community-based (HCBS) workers—including direct-care workers, home health workers, job coaches etc.—that are critical to meeting the daily needs of Family Care participants and are essential to ensuring they can live and remain independent in the community.

In 2016, Survival Coalition conducted a statewide survey of more than 500 people who rely on direct care services and their families found 95% had trouble finding workers, 85% did not have enough workers to cover all their shifts, 43% couldn't find a worker 7 or more times per month, and 60% said they get sick more often when they do not have enough staff. The shortage of professional direct-care workers is currently at crisis level and is only projected to worsen. Survival Coalition is concerned that the shortage of home and community-based workers—especially when coupled with aging Family Caregivers and smaller family sizes--is reducing access to HCBS services, putting Family Care participants at greater risk of institutionalization and putting the state in danger of Olmsted violations.

Survival Coalition proposes the following ideas to incorporate into the waiver to stabilize the workforce and ensure that participant care needs are adequately reflected:

- Modify the "imminent risk of institutionalization" definition within the waiver to recognize the growing number of participants who meet nursing home level of care, and whose ability to live and work independently in the community is at risk without adequate HCBS services and supports.

- Survival Coalition supports Disability Rights Wisconsin's recommendations to correct the long-term functional screening process so as to: 1) end the discrimination against people with milder forms of I/DD; 2) formally recognize that use of adaptive equipment to complete activities of daily living indicates a need for assistance with the ADL; and 3) assure that the LTCFS assesses people with physical disabilities and frail elders in conformance with Wisconsin law, rather than more restrictively, as it does now.

- Include a tiered rate structure to provide enhanced wages for workers serving individuals or populations with higher health care and support needs.

- Include a tiered rate structure to provide enhanced wages for workers in areas with provider shortages.

- Modify background check requirements to ensure qualified workers are not being excluded from the workforce based on minor infractions.

- 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 fares[1].

- Establish a statewide contract with a proven interface[2] used by all MCOs that enables LTC participants to match their needs with available workers, schedule support, and track hours[3].

Development of additional provider capacity

Survival Coalition has consistently raised concerns about a shortage of quality providers for many waiver services across the state, with provider shortages significantly more pronounced in some geographic areas. Provider shortages are resulting in limits and delays in accessing many services and few or no options for specific services depending on the area of the state.

One of the great benefits of Family Care was the elimination of waiting lists for services and ensuring that all participants have access to the same service package no matter where they live. Survival Coalition fears that provider shortages threaten to undo these accomplishments in two significant ways:

- Provider shortages can effectively create a "hidden wait list" where eligible participants are not technically on a wait list but are unable to access the complete service package due to provider shortages.

[1] 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.
[2] My Support (http://www.mysupport.com/) is an example of a platform currently operating in California, New Jersey, and preparing to launch in January in Iowa.
[3] 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. Adequate rates would allow for providers to invest in technology to more efficiently schedule workers, provide visit verification to prevent and detect fraud, and automate billing and payroll functions that would create a timesheet to be easier for personal care workers to complete and reportable to the state.

- Needs, goals, and outcomes identified in care plans may be unattainable due to few or provider choices.

Ongoing assessment of provider capacity and gaps in capacity is needed as well as deliberate focus by the Department on developing and increasing the number of quality service providers. Survival Coalition recommends the following to assess current provider capacity and identify gaps:

- Hire an external contractor to conduct **ongoing statewide independent assessment of current Family Care provider network capacity,** calculate projections of needed capacity, and make recommendations to DHS, MCOs, and advocates that can inform actuaries and lead to more accurate capitated rate setting.

- Include mechanisms for both providers and Family Care participants **to report and document services that have not been rendered or that have been performed by family members when professional service providers have been unable to provide services authorized in the individual's care plan.** Survival Coalition members hear from individuals and advocates that there is often a difference between the needs identified in care plans and the amount of services actually rendered. Survival Coalition is concerned that authorized hours that are unused in care plans are assumed to be unnecessary when in fact is it a reflection of a lack of capacity and does not capture what is happening to fill in gaps in paid care (family members stepping in, or gaps are not able to be filled and care needs are going unmet). Clear statewide data is necessary to reflect actual need and make more accurate actuarial projections that reflect the true costs of services that must be covered within the capitated rate.

- **Include ability for providers and Family Care participants to report and document services that have been delivered incompletely, late, or with personnel filling in for the individual's regular staff.** Survival Coalition members consistently hear from individuals that services—especially personal cares—are delivered late or with staff that has not worked with the individual before. Late services can result in missed medical appointments, declines in health conditions, missed employment and other opportunities that facilitate independent living in the least restrictive environment possible. Statewide data is needed to quantify the number of times providers are filling shifts in "crises" mode and are unable to have enough staff to deliver services as scheduled; Survival Coalition sees this as indicators of a lack of capacity.

- Include within the waiver **cyclical review of data** gathered by the Independent Assessor, provider and participant reporting of services delivered late or not rendered, and complaints made to the Ombudsman **and outcomes collaboratively with DHS, MCOs, and advocates to identify gaps, and opportunities to develop innovative approaches to improve provider capacity and outcomes.**

- Include a mechanism for DHS, MCOs, and advocates to **develop and implement plans to increase quality provider capacity** in geographic areas and service categories where a lack of capacity is identified. Plans should identify any specialty supports, services, or formulaic medications where the number of qualified specialists or providers is limited statewide. Implementation of plans should be outcome focused and require tracking of increases in the

number of quality providers, hours of service provided, timely delivery of services, and number of participants receiving services.

In addition to the above system changes, Survival Coalition recommends the following specific waiver changes to facilitate development of additional provider capacity:

- Include **minimum time and distance standards**[4] and other network adequacy standards within the Family Care waiver and Contract as metrics to assess whether the networks of their contracted plans are adequate. Require collection of data elements[5] that demonstrate that geographic access, provider-patient ratios, and timely access to care can be met for all services offered, or that a plan to increase provider capacity is being implemented.

- Incentivize services and supports that result in the greatest integration in the community in the least restrictive environments—including community integrated employment, integrated day services, and independent living. A pay for performance system should be in the waiver for providers and MCOs that demonstrate outcomes with a bonus payment system that rewards increasing outcomes over time.

- The waiver should establish a tiered bonus system that rewards MCOs that have higher ratios of service providers to participants, and community outcomes—participants successfully working in community integrated employment, living independently etc.—are high.

- The waiver should establish a rate enhancement for rural areas to incentivize development and increases in provider capacity.

Incorporating Home and Community Based Settings rule requirements into the new waiver

Survival Coalition appreciates the Department's commitment to implementing the Home and Community Based Settings (HCBS) rule in 2019. This waiver renewal should reflect the requirements of the HCBS rule and the waiver renewal should include revised and new service definitions, outcomes and metrics, and pay for performance and bonus payment structures to increase Family Care participants' community integration in the least restrictive environments. The HCBS rule represents an opportunity to shift service delivery in residential, day service, and employment to more integrated models.

Survival Coalition recommends the following specific waiver changes to facilitate Family Care services being delivered in more integrated settings and implementation of the HCBS rule:

- Require at least one non-disability specific integrated residential, day, and employment setting, and service delivery option is always available in all areas of the state without wait lists.

[4] Time and distance standards for community Integrated employment, transportation, personal care and home health nurse services should be available within 30 minutes or 15 miles of the residences or workplaces of 90% of enrollees or within 60 minutes or 30 miles of the residences or workplaces of 90% of enrollees in a region designated by the DHS as rural. Survival Coalition supports establishment of additional time and distance standards for other long term care services, and supports the exploration of additional network adequacy standards other than time or distance standards for LTC services that require the provider to travel to the enrollee to deliver services.

[5] Data elements should include increases in the number of quality providers, hours of service provided, timely delivery of services, and number of participants receiving services.

- Develop a rate structure that incentivizes individualized, community-based supports rather than congregant settings.

- Establish Community Supported Living[6] and residential supports provided by workers not affiliated by a provider agency—such as participant selected workers chosen by self-directed Family Care workers—as the first and preferred option for Medicaid reimbursable residential supports.

- Clarify existing service definitions such that assistive technologies and individualized home monitoring/response services are available to Family Care participants, and incentivize as a mechanism to decrease reliance on congregant settings.

- Reward MCOs for piloting of integrated community day programs that meet service delivery outcomes including independent living skills experience and training; opportunities to build relationships and natural supports; opportunities to explore and engage in activities/interests of the person like in adult education, volunteering, community activities, and recreation/leisure opportunities. Pilots should be directed to develop and leverage non-governmental partners to expand the community options and opportunities available for people with I/DD. collect data elements to measure performance and outcomes.[7]

Recommendations by Family Care waiver sections

Participant Access and Eligibility.

- Require MCOs to have all provider entities as part of their contract requirements perform a self-assessment of their cultural and linguistic competence using an evidence-based tool [8].

- Enable Family Care participants to self-identify any cultural preferences, linguistic preferences, and any other information they feel pertinent to delivery of individualized services.

- Add language translation and interpretation as a Medicaid service. These services should be available upon request, apply to both written materials and any verbal meetings, and be guaranteed to be delivered in a timely manner for any language (including ASL) requested.

- Use the same reimbursement rate for institutional and Home and Community Based (HCBS) services. Establishing the same acuity-adjusted Per Member Per Month (PMPM) payment rate

[6] Community Supported Living is defined as a partnership between any person needing support to live in their own home and an entity providing individualized assistance.

[7] Data elements include: How many and what types of community organizations or other partners does the pilot program have a relationship with; Hours of service delivered in each type of community organization or partner; Number and types of activities offered per month; Number of people participating in each type of activity; Number of people with I/DD in any small group; Number of people with I/DD doing individual activities; Ratio of staff to people with I/DD; Number of hours people with I/DD were engaged in activity without paid support there; How and who chose the activities and developed ideas for activities; Number of relationships individuals engaged in the community; Number of hours spent in the community and doing activities; Proportion of hours spend in activities designed for people without disabilities

[8] Georgetown's Cultural Competence self-assessment is an example of an evidence-based tool (https://nccc.georgetown.edu/assessments/)

for institutional and HCBS services creates strong incentives for MCOs to avoid institutional placements and to transition Nursing Facility and other institutional residents to HCBS settings[9].

- Include bonus payment incentives to reward MCOs with high community transition rates. In addition to holding MCOs at full risk for Nursing Facility admissions, employ an HCBS reconciliation process to encourage MCOs to return institution residents to the community with appropriate services and supports[10].

- Include the current institutionalized population in the state centers for the developmentally disabled and other ICF-IDs in the capitated rate, creating an incentive to deinstitutionalize that population.

- Create an incentive payment structure for MCOs to reimburse costs associated with the care planning that takes place before individuals enroll in Family Care and relocate from institutions, as well as actual relocation costs.

- Reinstate retroactive eligibility back to application date. Retroactive coverage is available for those receiving care in institutions, but not those receiving care in the community. This is a significant equity issue.

- Survival Coalition supports Disability Rights Wisconsin's recommendations on improving mental health and/or substance abuse disorder supports and services for participants. . Survival recognizes the need for increased oversight and accountability to ensure that Family Care members have adequate access to mental health services, including the continuum of psychosocial rehabilitation services which can advance recovery, and go beyond the medical model. This will require better coordination with MCOs, ADRCs, and County Behavioral Health Services to ensure that Family Care members have equitable access to Medicaid behavioral health benefits such as Comprehensive Community Services (CCS) and Community Support Program (CSP), which are administered by counties.

Participant Services.

- Add a service definition for accessibility assessments. Services include assessment of the need for, arranging for and providing modifications and/or products that would provide for improvements to a participant's living quarters and/or increased independence, community inclusion, or safety. These Accessibility Assessments will provide recommendations for the

[9] New Mexico adopted this strategy when it launched its Coordination of Long-Term Services (CoLTS) program. The CoLTS program uses a blended payment rate that incorporates NF and HCBS payment data for all beneficiaries who meet nursing home level of care criteria. This payment rate is not adjusted when a beneficiary enters an NF; consequently, participating, at-risk health plans have strong incentives to provide the additional supports that high-need enrollees require to avoid admission to a nursing home or to transition from a nursing home to the community. CoLTS payment rates are renegotiated annually based on service patterns. Arizona uses a similar approach in managing its Arizona Long Term Care System. (http://www.ncd.gov/publications/2013/20130315/, page 98).

[10] In addition to holding health plans at full risk for NF admissions, the Arizona Long Term Care System (ALTCS) program employs an HCBS reconciliation process to encourage plans to return NF residents to the community with appropriate services and supports. The state establishes an assumed, plan-specific ratio of HCBS recipients to NF residents by geographic area. If a health plan serves a higher ratio of enrollees in HCB settings than the state benchmark, Arizona reimburses the plan for a portion of the savings achieved through a reconciliation process. Conversely, if a plan falls below the state-established target ratio, the state may recoup a portion of the differences in rates paid to the plan. (http://www.ncd.gov/publications/2013/20130315/, page 99).

safest and most cost-effective ways to address the disability-related barriers. The Assessments may include the following components: Adaptive Aids, Assistive Technology/Communications Aids, Home Modifications, Environmental Accessibility Adaptions. Vehicle Modifications.

- Include access to the Adaptive Aids program and diagnostic capacity housed within Central Wisconsin Center to all Family Care participants.

- Add a robust definition of evidence-based future planning services and require Family Care participants, their care team, and involved family members to develop a clear plan to ensure the participant to develop the skills to live and work independently (e.g. in non-congregant settings) and/or continues to live and work independently. Key aspects of future planning include: financial planning and benefits; future living arrangements; future employment and vocational preferences; decision-making supports; and healthy aging.

    - Future planning services should include and require training on alternatives to guardianship including Supported Decision-Making agreements, as well as the use of Supported Decision-Making concepts within the person-centered planning process.

    - Future planning services should also require training for providers and guardians on limited guardianship, duties and required responsibilities of guardians under the law and limits of guardian's decision-making authority, and responsibilities of providers to document and confirm identity of the guardian and the scope of the guardian's authority.

    - Future planning services should include concrete future planning activities, including development of a Letter of Intent to clearly outline basic components of an individual's daily life and preferences to aid in transitions if/when a new caregiver steps in or other actions to include residential planning, legal financial planning.

- Create an incentive structure that rewards care plans and families for community integration efforts that result in reportable outcomes (specifically integrated employment, transportation to employment, integrated day services, living in non-congregate residential settings.)

- Add a service definition to provide caregiver training for unpaid caregivers.

- Add a service definition to provide Family Care participants with disabilities who are parents supports on parenting, parent mentoring, and education on parenting. Parenting supports may include the provision of resources, training, technical assistance, adaptive strategies and equipment to support and enhance parenting abilities.

- Add a service definition to provide training for Family Care participants on establishing boundaries, employer/employee expectations, interpersonal communication skills, conflict-management skills, and maintaining positive relationships with HCBS service workers.

- Modify the service definition for housing counseling to include identifying affordable housing, including checking and matching for section 8 public housing vouchers.

- The waiver should include a mechanism within the rate setting formula to adjust direct care worker pay rates upward in counties adjacent to borders of other states (Iowa, Minnesota, Illinois, Michigan) so Wisconsin direct care worker rates are competitive with the rates in adjacent states.

- Clarify the transportation services definition to ensure purchase of public transit system fare cards, costs associated with volunteer drivers (including gas and mileage), and shared ride services are included as a Medicaid reimbursable service.

- DHS's Family Care contract should contain specific language requiring all working-age Family Care participants to have a community integrated employment goal within their care plan, integrated employment outcome targets, performance metrics for employment services, specific data collection[11] and reporting requirements, and tie employment outcomes to performance incentives

- Revise the employment services definition to differentiate between services involved in reaching community integrated employment outcomes and revise the rate structure such that higher payment rates are paid for community integrated employment focused services.

- The waiver should encourage MCO employment service provider contracts to have higher payments for competitive integrated employment outcomes, and which factor in the individual's acuity into the rate-setting methodology.

- The community integrated employment/supported employment service definition should be expanded to provide employment services for all working-age Family Care participants who are eligible at the non-nursing home level of care.

- For Family Care participants utilizing pre-vocational services, participants should be provided with targeted information to facilitate individuals making progress towards community integrated employment goals.

- Include or revise caregiver and consumer education services to be inclusive of evidence-based peer-led support interventions. Training services for unpaid caregivers should be updated to reflect support for evidence-based practices to meet main caregiver needs and to reduce burnout.[12]

- Include a specific definition for Remote Support Technologies and Remote Support Services that outline a combination of technology and direct care support that can facilitate a person's

[11] Required data elements should include: number/percentage of working-age members (16-60) 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 (16-60) 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 (16-60) 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.

[12] Family Support Promising Practices (University of Illinois-Chicago; National Council on Aging): http://fsrtc.ahslabs.uic.edu/wp-content/uploads/sites/9/2017/11/Family-Support-Promising-Practices-Report-Final-11.30.17.pdf)

independence and allow them to live in the least restrictive setting. Family Care should allow for the waiver of certain residential licensing policies that currently prohibit use of remote support technologies in otherwise appropriate circumstances.

Participant-Centered Service Planning and Delivery.

- Require all working-age Family Care participants to have a community integrated employment goal within their care plan.

- Require all care plans to include the transportation services needed to support community integration, community integrated employment, and all care plan goals.

- Require all care plans to include all transportation services needed for participants to receive their supports and services (integrated day services, habilitative and rehabilitative services, therapies, medical appointments etc.);

- Require care plans to factor in transportation services for care plan goals, supports, and services when making residential placement decisions.

- Include Supporters identified in Supported Decision-Making agreements—as directed within the supported decision-making agreement—within Person-Centered Planning and participant directed services.

- Provide training on Remote Support Technologies and Remote Support Services including the benefits and variety of such technologies and services to Care Managers, providers, families, and participants.

- Require discussion and evaluation of the use of Remote Supports and other technology in individual Person-Centered Planning and care plan meetings as a legitimate option when appropriate.

Participant-Direction of Services.

- The waiver should provide information that supports alternatives to guardianship—including Supported Decision-Making agreements--to ensure that members maintain autonomy and choice in making decisions about their lives and care plan.

- The waiver should provide information that supports independent living services that encourage independence such as money management and budgeting, and limit use of rep payees to where this level of oversight is clearly justified.

- The self-directed services definition should clarify that all Family Care participants may self-direct any and all services and supports.

- The self-directed services definition should ensure participants have full budget and hiring authority[13]. LTC participants should have the ability to spend their budgets as they see fit and hire the people they want to provide supports.

- The self-direction service option must allow participants to set their own goals. When a goal is required as part of a care plan (as Survival Coalition proposes for community integrated employment for working-age participants and transportation) self-directing participants may set goals that meet care plan requirements.

- The waiver must specify that participants who are self-directing services are not required to consult with and/or seek approval of the interdisciplinary team for decisions.

- The waiver must ensure that people only receive services they want and need (not services someone else thinks they need).

- The Family Care contract should include a data collection and reporting requirement on the number of people self-directing all services, and the number of people self-directing some services with the ability to delineate which service types are being self-directed.

Participant Rights.

- The waiver should guarantee participants that a person's services should not be reduced, changed, or ended without a documented change in their needs that can be independently reviewed and challenged.

- The Family Care waiver and contract should specifically ensure all individuals, including high-cost individuals, have the right to live in the community, and that services are delivered in the least restrictive setting possible.

- DHS's Family Care waiver should mandate and fund a ratio of 1 Ombudsman per 2500 Family Care enrollees.

Quality Improvement Strategy.

See also all of Survival Coalition's specific recommendations in the "Development of additional provider capacity" section; availability of quality providers is directly correlated to quality improvement.

- Promote qualified providers by requiring training to be certified as a "preferred provider" through a quality checklist that includes track record of performance-based outcomes.

- Require MCOs to post community integrated employment outcomes data on a publicly accessible, searchable website such that LTC participants can compare individual employment providers and MCOs when deciding which option to choose.

- Require data collection and reporting of key non-clinical quality of life indicators and participant experiences[14]

[13] Budget authority" = decision-making authority over how the Medicaid funding in individual's budget is spent. "Employer authority" = decision-making authority regarding who provides services and how the services are provided. Participants ca recruit, hire, train, supervise, and fire the people who provide your services, including parents, spouses, and relatives.

Financial Accountability.

- Focus on expenditure data collection to support shift of funds toward the highest return on investment services in long-term care. Specifically, track expenses for integrated employment compared with all other day services.

Survival Coalition is comprised of more than 30 statewide disability organizations that advocate and support policies and practices that lead to the full inclusion, participation, and contribution of people living with disability.

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[14] Non-clinical quality of life indicators must be included, using recognized sources like National Core Indicators, Council on Quality and Leadership indicators, and Program Operations Manual System measurements. CMS expects states to measure the quality of programs as it relates to providing supports that ensure quality of life for participants. CMS Guidance to States bulletin on long-term care: http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf): http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf