August 1, 2023

Curtis J. Cunningham
Assistant Administrator for Benefits and Service Delivery
Division of Medicaid Services
Wisconsin Department of Health Services

Re: Family Care Waiver Renewal Input

Submitted electronically to: DHSDMSFCRenewal@dhs.wisconsin.gov

Thank you for the opportunity to submit our ideas regarding the future direction of the Wisconsin Family Care and Family Care Partnership long-term care programs as the Department prepares its application to CMS for renewal of the Family Care waivers. We appreciate your consideration of our ideas and look forward to working with you throughout the renewal process.

The Greater Wisconsin Agency on Aging Resources (GWAAR) and the Wisconsin Aging Advocacy Network (WAAN) offer several recommendations to improve the Family Care waiver and program.

**Improve Support for Program Members**

The Family Care Waiver application includes assurances that provider networks are robust enough to ensure access to all needed services and a choice of providers. Unfortunately, there are numerous examples of inadequate provider networks and an inability and/or unwillingness to authorize and arrange for services with non-network providers. Some of these examples include lack of/limited transportation options, lack of/limited personal care workers, lack of/limited respite providers, and lack of/limited behavioral health services.

As a result, some members are going without services, relying more heavily on already over-extended family caregivers/informal supports, being moved far away from their home communities and support to receive needed services, and/or being asked to find their own providers if they wish to receive the services. We recommend:
- Improving metrics to determine network adequacy including reporting on the number of service hours (or other measurements) authorized vs. the number of service hours received.

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

- Including mechanisms for both Family Care providers and participants to report and document services that were not received, delivered incompletely/partially, late, provided by substitute staff or were completed by family members or informal supports because paid/authorized providers were unable/unavailable.

- Requiring collection of data elements that demonstrate geographic access, provider-client ratios, and timely access to care can be met for all services offered, or that a plan to increase provider capacity has been developed and is being implemented.

Retroactive Medicaid coverage is available for those receiving care in institutions for up to 3 months prior to the date of application, but for those receiving care in the community retroactive eligibility is not even available back to the date of their application. This presents significant barriers for those individuals for whom the application process takes longer than 30 days, yet they have no funds to purchase needed services. The lack of retroactive eligibility can be especially important for individuals residing in assisted living facilities who have run out of private resources and need services in an assisted living facility. Therefore, we recommend:

- Reinstatement of retroactive eligibility for Family Care benefits back to application date. Retroactive coverage is available for those receiving care in institutions for up to 3 months prior to the date of application, but for those receiving care in the community retroactive eligibility is not even available back to the date of their application. This presents significant barriers for those individuals for whom the application process takes longer than 30 days, yet they have no funds to purchase needed services. The lack of retroactive eligibility can be especially important for individuals living in assisted living facilities who have run out of private resources and continue to need assisted living facility services. Delays in completing the application process can occur for a variety of reasons (both applicant and systems issues), those wishing to receive their care in the community should not be penalized. This is a significant equity issue.

Services such as home-delivered meals, assistive technology, durable medical supplies, and training for unpaid caregivers are eligible Family Care program services, yet these services are often denied, delayed and/or under-utilized. We recommend:
• DHS increase oversight of denials, complaints/appeals, and under-utilization of specific services and analysis to watch for patterns or trends related to frequently denied or delayed services. This would help to identify where additional training or stronger contract language may be needed.

• The Family Care waiver should mandate and fund an Ombudsman to Family Care participant ratio of 1:2500.

New Services to Help Program Members

Family Care members often have chronic and/or disabling conditions. Many also take medications that can result in numerous side effects (weight gain/loss, joint pain, etc.). We recommend:

• Adding health and wellness services (fall preventions, yoga, fitness training, weight management, music therapy and other programs and services) specifically to the Family Care benefit and an increased emphasis be placed on preventive care and wellness services.

Improve Service Delivery

Individuals in need of long-term services and supports (and their families and caregivers) need comprehensive and unbiased information to help them make informed decisions regarding how and from whom they wish to receive their long-term care services. Whether navigating the maze of resources independently or with the support and assistance of their local Aging and Disability Resource Center (ADRC), it is important for people to have information about available resources, eligibility criteria, cost of services, application process, and quality of services. This should include additional information currently unavailable on the MCO scorecards, as well as information regarding managed care organizations (MCOs) and other providers who have been determined by the Department of Health Services (DHS) or the Centers for Medicare and Medicaid Service (CMS) to be deficient or out-of-compliance in one or more areas of their service provision. To improve transparency, access to information and opportunities for consumers to make informed decisions, we recommend:

• Additional information be made available on the MCO scorecard including profit/loss figures, rates of service denial, data related to the percentage of grievances/appeals, and specialty services.

• Information regarding agencies/organizations (such as MCOs) and other state regulated providers under a Corrective Action Plan should be available online to the public and ADRC staff to allow individuals to make fully informed decision regarding which program to enroll in, which agency to select, and from whom they wish to receive
services. Any sensitive personnel or other identifying information could be removed before posting.

Top reasons for disenrollment from Family Care and Family Care Partnership include death, moved to another service area, and \textbf{change in living arrangement} (institutional setting or incarceration). Many of the changes in living arrangement are temporary in nature (less than a month) and rarely are members interested in changing programs or providers at the point they are again eligible for service. To ensure a smooth transition and continuity of care, we recommend:

- Creating an option to “pause” an individual’s program membership for a short period of time (2 weeks, 1 month, etc.). Pausing membership instead of disenrolling and shortly reenrolling the individual would improve the transition between locations, ensure continuity of services, and reduce the resources needed to complete the re-enrollment process.

Care/case management available from MCOs is a critical and valued service for many Family Care members and their families. Care managers provide assessments and care plan development to ensure members receive services based on their need, situation, and preference. Unfortunately, some Family Care case managers are difficult to contact and/or don’t make contact in a timely manner when members are trying to reach them. This is especially difficult when members have a time sensitive need or request. Members not receiving timely contact from their case manager often reach out to their local ADRC or other community providers/resources to try to get their needs met, but often the case manager is the only one who can provide the needed assistance. Additionally, we received reports of individuals needing to cancel, reschedule, or miss appointments and meetings when their case manager was not responding to requests for needed transportation. We recommend:

- Implementation of adequate back-up systems to ensure members have contact information for an MCO staff member who can assist them when their case manager is unavailable (vacation, sick, training, etc.).

- Creation of an option for members to self-direct their transportation services using an approved budget and plan for authorized transportation services.

- Require care plans to include the transportation services necessary to support community integration and \textit{all} care plan goals to achieve a self-reported high quality of life for Family Care participants.

- Unbundle transportation services from residential care provider reimbursement to establish improved tracking of participant transportation needs, utilization/access to transportation services, and costs associated with meeting transportation needs to ensure
Family Care participants remain connected with their communities and able to achieve established care plan goals.

Improve Services to Better Reflect Different Cultures, Backgrounds, or Values

To ensure that low-income adults with disabilities of all ages can receive home and community-based services (HCBS) that enable them to live independently and fully participate in their communities as they choose, the Family Care program and policies must be evaluated to ensure biases and inequities are not being preserved or causing unintended inequities. We recommend:

- Input from a diverse cross-section of HCBS users and providers be specifically sought out (given the low attendance of Family Care members at the Family Care Waiver renewal listening sessions) to ensure the community voice and voice of lived experience is included when designing or modifying HCBS programs and policies.
- Require provider networks to include supports that are culturally appropriate and meet the complex and diverse needs of members.
- Assess the current Family Care program information to ensure information regarding services and processes can easily be found online, is available in print (including large print and Braille) for those without access to online materials and are available in the languages needed.
- Require MCO staff and HCBS providers to receive cultural competency training and require providers to deliver services in a culturally appropriate manner (including culturally relevant activities and delivery of culturally appropriate meals).

Thank you for the opportunity to provide input on the next five-year Family Care Waiver renewal. We look forward to continuing to work with you to further improve Wisconsin’s Family Care program and long-term care system.

Contact:

Janet Zander, Advocacy & Public Policy Coordinator
Greater Wisconsin Agency on Aging Resources, Inc.
janet.zander@gwaar.org; 715-677-6723 (home office), 608-228-7252 (mobile)