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DRW COMMENTS ON
RENEWAL OF FAMILY CARE HCBS 1915(c) WAIVER

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Introduction

Disability Rights Wisconsin appreciates the opportunity to comment on the proposed renewals of the Family Care HCBS 1915(c) Waiver.

As we indicated last year in response to DHS's request for ideas, Wisconsin is at a critical juncture in the evolution of its long-term care system. Family Care is now statewide. Managed care is the dominant model of long term care service delivery. This development comes with risks. The transfer of the financial risk to MCOs requires a redoubling of DHS's commitment to its oversight function. DHS is the party ultimately responsible for the health, quality of life and safety of the vulnerable citizens who rely on Family Care to meet their long term care needs. MCOs have financial incentives to save money anywhere they can. We have seen this play out in individual cases to the detriment of members. DHS needs to fully embrace its responsibility to assure that people relying on Family Care live full and meaningful lives—and not have a merely subsistence existence.

At the same time, the MCOs need to receive a capitated rate sufficient to allow them to fairly compensate the providers in their networks. The reality is that care of decent quality costs money, sometimes a lot of it. The capitated rate paid to MCOs needs to take into account the reality of what it costs to support people and the reality of what it will take to attract a sufficient workforce to care for the growing long-term care eligible population. The Family Care waiver can be the embodiment of loveliness on paper. But if there are not enough qualified workers to provide care, the member experience simply cannot measure up to the program's lofty ideals. Workforce is the critical issue facing Family Care and DHS must do more to address it.

This proposed renewal of the Family Care Waiver contains few substantive changes. Frankly, we had hoped to see a greater effort to improve the waiver and incorporate the many good ideas DHS received in response to its request for ideas. We urge DHS to resume the process of evaluating the Family Care program and its implementation and make policy changes necessary to improve the member experience. Stakeholders should be heavily involved at every stage of that process. Our specific comments follow.

Appendix A: Waiver Administration and Operation

6. Assessment Methods and Frequency

1. MCO Contract Period Extended to Two Years

The proposal increases the MCO contracting period to two years. We disagree with that proposed change. We also note that this significant change was not identified by DHS as a "major change" in the waiver. A 100 percent increase in the contract period is a major change. Lengthening the contract period further limits DHS opportunity to engage in oversight of its contracted MCOs. Annual contracting allows DHS to adjust contract language reasonably timely when it is determined that a provision is ambiguous or fails to achieve its purpose. From the MCO perspective, the MCO contract is the "law" it is required to follow. But it is not the law. When the actual law requires something that is either not included or erroneously worded in the contract, DHS must be able to make needed correction in a timely fashion. Two years is simply too long to wait to correct contract requirements that affect member health, safety and integration into the larger community. We have had annual MCO contracts since the inception of Family Care. There is no reason to change that requirement now.

- ***DRW Recommendation: The current one-year contract period be retained.***

2. Description of Ombudsman Program

The description of the Ombudsman Program (item 7) that it is only available to members age 18-59. The Board on Aging and Long Term Care provides similar services to people age 60 and older.

- ***DRW Recommendation: Make the suggested clarifications.***

Appendix B: Participant Access and Eligibility

Appendix B-6: Evaluation/Reevaluation of Level of Care

c. Qualifications of Individuals Performing Initial Evaluation
h. Qualifications of Individuals Who perform Reevaluations

These sections have been changed to add an experience requirement (1 year) to the qualification criteria for persons performing initial level of care determinations and reevaluations. We support these changes.

d. Level of Care Criteria
e. Level of Care Instrument(s)

The level of care criteria are appropriate and reference the proper institutional comparables (skilled nursing facility-SNF and intermediate care facility for individuals with intellectual or developmental disability-ICF/IID.) However, problems remain with the "Long Term Care Functional Screen (LTCFS)," the instrument DHS uses to implement level of care determinations.

First, the automation of the determination of target group in 2017 resulted in consistently incorrect eligibility determinations for people with milder cognitive impairments. People who should have been considered to meet the federal definition of developmental disability were routinely found to only meet the state definition. In Family Care this typically resulted in people with I/DD having their eligibility level reduced to non-nursing home level of care. At this level of care members are generally eligible only for case management—not the full package of Family Care services. This happened because the data points used to determine substantial impairment in the six major life activities (in particular, learning, and self-direction) were either inappropriate or incomplete. In May of 2017 we alerted DHS to the problems with the methodology and the appropriate means to significantly reduce the number of incorrect determinations. Since December of 2018 DHS and DRW have been working constructively and cooperatively to correct the problems created by the automation. We expect that the issue will be resolved in the very near future. We include this comment because the final changes to the computer logic have not yet been implemented. We have appreciated DHS's willingness to engage with us on this issue.

Second, for people with physical disabilities and frail elders, the LTCFS is not programmed in conformance with the DHS regulation (DHS 10.33) which defines nursing home level of care for the Family Care waiver. The LTCFS applies a methodology that is significantly more restrictive than the regulation it is supposed to be implementing. DRW brought this problem to the attention of DHS over eight years ago. Since then, DRW has represented hundreds of clients in fair hearings where ALJs have applied the regulatory definition to the facts as found in the long-term care functional screen report itself. In each of those cases, the ALJ has quickly found the person to meet the nursing home level of care. People who meet the eligibility criteria based on uncontested facts found in their functional screens should not have to go to a hearing to establish eligibility. This problem should have been fixed long ago.

It is our understanding that DHS, rather than correcting the LTCFS, may be contemplating amending DHS 10 to conform it to the flawed methodology in the LTCFS. This would be a grave mistake. The criteria in the current DHS 10 was carefully crafted with the input of people with disabilities, advocacy groups and DHS personnel who had intimate familiarity with when functional impairment reached a severity level high enough to warrant institutional placement. The DHS 10 criteria has been applied since the inception of the Family Care program at the beginning of this century. Significantly altering the eligibility criteria would result in large numbers of currently eligible people to lose their eligibility, even though their health has not improved and their care needs have not lessened.

Third, the LTCFS logic appropriately considers the use of certain adaptive aids to be evidence of need for assistance with the activities of daily living of bathing, toileting, mobility in the home and transferring, even if such aids allow the person to perform the ADL independently. But this treatment is not noted in the instructions to the LTCFS or in any DHS policy document. As a result, if a person is found ineligible for another reason (and there are several ways this could happen) the person "loses" the finding of need for assistance (because the screen itself indicates that the person can perform the ADL independently, due to the adaptive aid). Until DRW litigated the issue, people were required to prove at hearing that they needed human assistance to complete the activity in order to be found to have a need for assistance. All circuit courts that have reviewed the process have concluded that people need to be treated the same during the application process (where the equipment results in a finding of need) and at a hearing (where it was not). The screen instructions should be changed to require the screener to find that the person cannot be considered independent in the activity if the person can only complete the activity by using the adaptive equipment.

Finally, the application alleges: "The functional screen was developed with SMA registered nurses who evaluated Physician Plans of Care to determine Medicaid eligibility for nursing home residents. It has been evaluated by the SMA and determined to be valid, reliable, and to result in comparable level of care." In fact, the SMA has not tested the LTCFS for validity or reliability since 1999. Since 1999 the instructions to the LTCFS have been revised many dozens of times. Each revision has resulted in more detailed, and in our experience, more prescriptive instructions. For example, in October of 2003 the instructions were seventy-five pages long. The module on ADLs and IADLs was thirteen pages long. The current version of the instructions is one hundred and seventy-two pages long. The module on ADLs and IADLs is now forty-two pages. Given the changes to the computer algorithm that have occurred since 1999, the incorporation of the flawed target group determination into the screen, and the increasingly prescriptive instructions on ADLs and IADLs, it is necessary that the LTCFS again be tested for validity and reliability. We know from experience that it is an invalid tool for determining the proper target group for people with intellectual or developmental disabilities. We know that the screen has been programmed to be inconsistent with and more restrictive than, the regulation it is supposed to be aligned with (in other words it is intentionally invalid). Our experience with screeners indicates that the expansion of the instructions has caused confusion and inconsistency in how functional limitations are assessed and inputted into the screen. A systemic validity and reliability retesting of the screen is overdue and might disclose other serious problems with the process.

- ***DRW Recommendation: Correct flaws in the functional screen itself and in the instructions to the LTCFS. Engage with stakeholders at every stage of development of policy or regulation that relates to functional eligibility. Any changes to eligibility criteria should not result in any currently eligible people becoming ineligible. Test the revised screen for validity and reliability.***

Appendix B-7: Freedom of Choice

The description of the procedures for informing applicants about long term care options has been pared down significantly. One of the casualties of that paring was specific mention of the IRIS program as an alternative to both Family Care and institutional services. We are concerned that the omission may lead ADRCs to believe that they need not mention the IRIS program when discussing long term care options with potentially eligible persons.

- ***DRW Recommendation: The language from the current waiver was better and should be retained.***

Appendix C: Participant Services

Appendix C-1/C-3: Provider Specifications for Service

For the most part, the service definitions have not changed. We support the amended definition of supportive home care to include “bed bug inspection and extermination.” In addition, several other service definitions have been amended that were not identified as significant changes by DHS. They include:

- Case management: Broadened and clarified qualifications of those seeking to case manage in Family Care; added “development of a plan to assure continuity of the member’s independence, care, living arrangements and preferences in the face of changes in circumstances” to the list of care manager responsibilities. The former should result in hiring of more qualified care managers at MCOs. The latter will be good for members facing residential placement changes. We support both changes.

- Prevocational services: Added several specific skills to the list of required employment skills to be addressed by this service, including "establish appropriate boundaries" with supervisors, co-workers, and customers;" "express and understand expectations;" and "manage conflicts." These are all excellent additions. We support them.

- Support broker: This service definition was **not** changed. We are pleased to see this non-change. The current simple, broad definition is appropriate and allows for the creative use of this service.

- Adaptive aids: Added that adaptive aids can be used to increase abilities to perform IADLs (not just ADLs); added "The adaptive aids service includes the evaluation of the adaptive aids needs of a member, including a functional evaluation of the impact of the provision of appropriate adaptive aids in the customary environment of the member." We support both additions. In addition, the language related to coverage for service animal purchase and maintenance has been revised and clarified. The revised service definition makes it clear that any trained service animal, regardless of who trained it, is eligible to have its maintenance costs covered by Family Care. We support the change.

  CLARIFICATION STILL NEEDED: Several MCOs have adopted service authorization policies which restrict payment of maintenance costs of service animals to those animals that have been purchased from and/or were trained by agencies that train service animals for others. These policies conflict with the ADA requirements for determining whether a dog may be classified as a service animal. Under the ADA a service animal is defined by the service it has been trained to provide—not by who provided that training. Thus, a service animal that has been trained by its owner (or another nonprofessional trainer) to, as examples, detect the onset of a seizure or pick up a dropped utensil, is a service animal. As stated earlier, the revised service definition makes it clear that any trained service animal, regardless of who trained it, is eligible to have its maintenance costs covered by Family Care.

  - ***DRW Recommendation: The "provider qualification" section should be revised to clarify that the "reputable provider with experience providing and training service dogs" requirement applies only to the initial purchase of service dogs by the MCO. It does not serve as a limitation on which service dogs may have their ongoing maintenance costs reimbursed. In addition, DHS should review all MCO service authorization policies to identify, and compel revision of, any that limit reimbursement of maintenance costs to dogs that have been trained and purchased from a service dog training entity.***

- Consumer education and training: Language has been added to this definition that recognizes the value the ability to self-advocate plays in the lives of people with disabilities. We support the addition.

- Home modifications: The Assistive Technology/Communication aids definition includes language verifying evaluation of needed equipment is included (not just the equipment itself). Similar language is not in the home modification definition. It should be added.

  - ***DRW Recommendation: add the following after the first sentence:***

    "Includes evaluation of the environmental accessibility needs of a member, including functional evaluation of the impact of the provision of appropriate home modifications in the member's home or customary environment."

- Supportive Home Care: The addition of "bed bug inspection and extermination" to the list of SHC duties is a good one. We support the change.

Appendix C-2: General Service Specifications (1 of 3)

Section a. expands background check requirement to workers hired by self-directing members. We support the change. We note, however, that background check requirements have the potential to limit the available workforce. If the new policy has the effect of disqualifying a significant number of caregivers who have been providing care under the old policy, DHS will have to reevaluate the policy and attempt to mitigate its effects.

Section c. states: "A community character is maintained in such situations by requiring private rooms or independent apartments within the facility." We see a significant number of AFHs and CBRFs that do not have private rooms. Or they may have one private room, but member is not offered that room.

The section also says DQA requires facilities to "act to promote integration and participation in the community." While a DQA complaint can be filed due to "issues and concerns involving quality of care or quality of life" it seems DQA is often too busy even to handle much more serious complaints regarding abuse, neglect, poor care, unsafe conditions, etc. and likely would have insufficient capacity to address a "facility doesn't sufficiently promote community integration" complaint.

- ***DRW Recommendation: DHS needs to acknowledge the incapacity of DQA to actually monitor the full range of facilities over which it technically has oversight and respond adequately to complaints that do not involve abuse, neglect, poor care or unsafe conditions. A specialized investigative unit in the Division of Medicaid Services should be created whose charge is to investigate complaints of lack of integration and other violations of the HCBS rule.***

Appendix C-2: General Service Specifications (3 of 3)

Section e. This section expands specific policy relating to "usual familial responsibilities" from parents of minor children and spouses to <u>all</u> relatives. We disagree with this change. The only relatives who have a legal responsibility to care for a member are parents of minors and spouses.

Brothers, sisters, aunts, uncles and cousins have no such responsibility. There is no such thing as "familial responsibilities" between adults who are not married to each other. While these other relatives may choose to provide some support naturally, they are not, and cannot be, required to. The proposed waiver language change follows policy guidelines issued by DHS. MCOs have used these guidelines to compel "natural support" or reduce the hours of supportive home care workers because they have classified work on behalf of the member as something that falls within the broad, undefined category of "family responsibility." We strongly object to this change. Rather than conforming the Waiver to this flawed policy, DHS should rework the policy to conform to the current language of the waiver, which correctly applies the concept of "familial responsibility" to those family members who actually have such responsibility.

- ***DRW Recommendation: Retain current waiver language and fix the current, inconsistent and overly broad policy.***

Appendix D: Participant Centered Planning and Service Delivery

Appendix D-1: Service Plan Development (4 of 8): The CMS requirement for providers to sign and distribute the member-centered plan is unfortunate. We objected to this requirement when it was proposed by CMS. This federal requirement adds an administrative burden without improving care or quality. It will require MCOs to create and staff a system to track and ensure compliance for more than 55,000 care plans and an untold number of providers that may be required to sign (multiple) plans. DRW, like the Survival Coalition, is concerned this will cause a shift of MCO resources from providing actual services/supports authorized in the plan to an administrative task that does nothing to improve services to members or even enhances the quality of administration. We are unaware of any supplement to the capitated rate to account for creating the apparatus, implementing, and ongoing administration of this requirement. MCOs may not be able to absorb these additional administrative costs in their existing budget; that leaves them with few options to cover costs. We are concerned that this may divert funding from other administrative functions that have a direct correlation to quality and service delivery.

- ***DRW Recommendation: DHS should exercise maximum discretion to minimize the impact of this change on Family Care members and MCOs.***

Added new language requiring IDTs to review and update Member Centered Plans upon the request of the primary medical provider. This is in addition to the existing requirement to review/update upon change in condition or member request. It is important to respond to concerns by medical providers. They may identify a new need. We support this change. But it is also important that decisions do not move away from members in a situation where the plan is changed in a way with which they might not agree.

- ***DRW Recommendation: Clarify by adding:***

  "Regardless of who initiates a review and update of a member centered plan, the member remains at the center of the decision making."

Appendix D-1: Service Plan Development (5 of 8): Added language when describing back up plan that includes family members as part of that plan. We are concerned with an overreliance on family members during a time when it is difficult to find reliable workers. Family members may or may not be able to provide back up and should be considered, but never required to do so. We understand that it is very difficult to maintain staff available to fill in unexpectedly. By the same token, it is often difficult for family members to step in without advance notice. IDTs should be directed to include family members in problem solving to develop back up plans, but they should refrain from expecting them to be the primary back up. Also added helpful detail about identifying risk. We agree that an eye should be kept on potentially risky situations. We recognize the difficult balance of taking care not to be over-intrusive while making sure people are healthy and safe. The language directing IDTs to coordinate with Adult Protective Services is a good addition.

Appendix D-1: Service Plan Development (6 of 8): The application retains the limit of requests for new IDTs to 2 times per year, but adds "…if IDTs are available." This caveat may be necessary in sparsely populated areas, or where a PIHP/MCO has a low census. However, this also allows PIHPs to refuse to provide a new IDT for a member for reasons less legitimate. It would be helpful to add "…unless there is a strong and justifiable reason that IDTS are not available." Consistent inability by an MCO to be able to offer a member choice in their IDT should be a quality measure that is indicative of lack of quality. Workforce issues should not be addressed by diminishing choice on the part of members, especially when there is little in this application that addresses the workforce issue in a positive way.

- ***DRW Recommendation: Incorporate the above suggestions.***

Appendix E: Participant Direction of Services

Appendix E-1: Overview (4 of 13): The narrative was changed and adds more forceful language about the IDT's responsibility to explain the member's right to self-direct services. And it includes more specificity about what that explanation entails. These are good amendments. However, the requirement to provide an explanation of how the budget is calculated has been removed. As discussed in more detail below; it is the budget calculation itself that is often the barrier to choosing self-direction. Members need to understand how the budget is derived and they need an avenue to request a change in the budget if it isn't adequate to meet their needs.

- ***DRW Recommendation: Restore language from the current waiver that requires IDTs to explain how the SDS budget was derived.***

Appendix E-1: Overview (6 of 13): the application asserts that the only services that cannot be self-directed are residential services and care management. In our experience, the only Family Care service that is ever self-directed is supportive home care. DHS needs to do a better job of requiring MCOs to make self-directed services a part of the Family Care narrative and return to the ideals of finding solutions through creativity and individualization of services.

Appendix E-2: Opportunities for Participant Direction (3 of 6): The application requires DHS to describe in detail the methods used to calculate participant directed services and requires that information about these methods be available to the public. The current waiver, and this application, identifies three possible ways MCOs might calculate a participant directed service budget, depending on the nature of the need to be met and the service or services required to meet it. The common denominator for all three methodologies is, that the budget should be reflective of what the MCO would be paying for the same service.

In the "ideas" paper we submitted in October of 2018, we identified two concerns with the current system.

First, it is unclear which, if any, of the three methods an MCO is actually using. Our experience with MCOs is that participant directed service budgets are arbitrary and are frequently inadequate to meet the participant's actual need.

Second, information about these methodologies (or the ones actually used by MCOs) has never been made publicly available. The only information relating to SDS budgeting on the DHS website is a "best practice manual" for IDT staff entitled; "Self-Directed Supports in Family Care, Family Care Partnership and PACE." This manual appears to be advisory and contains no actual description of the budgeting methodology that MCOs are required to be using. Instead, it states, when describing steps involved in setting the SDS budget: "Inform the member about the process the MCO uses to develop the member's SDS budget. The process will vary in each MCO, and staff should refer to the SDS policy and procedure for their MCO." Some MCOs have general information about the right to self-direct their services, but information about the methodology the MCO uses for calculating the SDS budget is not included. In our experience, MCOs do not release the specifics of their methodologies even when a member contests the budget by requesting a fair hearing. The lack of transparency makes it difficult for clients to know how to challenge the SDS budget they have been assigned. This has a chilling effect on clients exercising their right to appeal.

In October of 2018, we urged DHS to clarify the authority and discretion (if any) an MCO has in setting a self-directed services budget. Unfortunately, the prosed application contains the same narrative as is in the current waiver.

- ***DRW Recommendation: We continue to urge DHS to require that the SDS budget for the service be sufficient to meet the member's related outcomes. Per the waiver requirement, DHS should publish a detailed, understandable description of the methodology(ies) it requires MCOs to use. Members or their representatives should be able to calculate their own self-directed service budgets based on information readily available to them. An MCO's SDS budget methodology is not a trade secret.***

Appendix E-2: Opportunities for Participant Direction (4 of 6): The narrative fails to explain how a member can request an adjustment in the budget amount. That opportunity needs to be included. It also fails to state explicitly that the member has the right to appeal the budget calculation if the member disagrees with it. The language about appealing the member centered plan is vague. Members should be give a notice of action with opportunity to appeal whenever there has been a SDS budget determination.

- ***DRW Recommendation: This section needs to be rewritten to incorporate the above omissions.***

Appendix G: Participant Safeguards

Appendix G-2: Safeguards Concerning Restraints and Restrictive Measures (2 of 3)

The waiver proposes to reduce the frequency of MCO reporting of restrictive measures from monthly to quarterly. This is a major change that was not identified as such by DHS at the beginning of the application. We strongly object to this change. This is a further relinquishment of oversight of MCO performance by DHS. We have recently seen an increase in the number of abuse and neglect allegations involving Family Care members. MCOs have inconsistent records of responding to such incidents. Lax DHS oversight of MCOs in the area of restrictive measures will, in turn, result in lax oversight by MCOs of provider use or abuse of restrictive measures.

- ***DRW Recommendation: Retain current requirement that MCOs report on use of restrictive measures on a monthly basis.***

Mental Health Services

A high percentage Family Care program participants have identified mental health and/or substance use needs. This includes participants in long term care who have a dual diagnosis of intellectual disabilities and co-occurring mental health needs. Because people with mental illness is not one of the covered target groups in Family Care, there is little in either of the Family Care Waivers that specifically addresses mental health care. But the reality is that many members may require IDD-informed behavioral health services and supports. To emphasize the importance of this aspect of the family Care reality, we restate the ideas relating to mental health services and supports that we proffered in October 2018. Many of these ideas were advanced as possible additions to the Family Care Waiver. Unfortunately, none of them are included in the proposed Family Care waivers. In the areas of provision and service coordination with mental health providers there is significant room for improvement in Family Care.

Assessing and Monitoring the Membership. Given that such a significant number of Family Care members have behavioral health needs, DRW recommends that the waiver include a requirement for DHS, MCOs, and counties to work together to assess how effectively mental health and substance abuse disorder needs are being addressed. This should include reporting on and analysis of utilization of mental health and substance use disorder services, including those administered by counties; and developing a trauma informed approach to interview members with mental health needs to better understand their perspective on supports from Family Care, and identify gaps or barriers. This data should be used to review the current provision of behavioral health services and to advance needed changes.

Trauma Informed Care. There is a high prevalence of trauma in this population, often related to experiences of abuse or involuntary and coercive treatment. Training on trauma informed care needs to be provided to all members of MCO Interdisciplinary Teams (IDT) and all IRIS Consultants. It should also be provided to all direct care staff. IDT members and ICs need to be familiar with the impact of mental illness on a client's interactions and behaviors, as do the direct care staff who work with enrollees on a daily basis, such as personal care workers or supportive home care workers. In some cases, staff have refused to provide care to a client because they don't like how they are treated by the client. It is important that everyone who is involved with people with disabilities, many of whom have experienced trauma and loss, have an understanding and sensitivity to these issues. MCOs and ICAs should provide this training to their staff and require it of direct care staff in their contracted networks. There should be a mechanism to expect this for IRIS providers. Additionally, this training should be provided with frequency, due to high staff turnover.

Recovery training. All MCO IDT members and mental health and substance abuse treatment professionals must have basic knowledge of recovery concepts, evidence-based practices for mental health and substance abuse treatment, and trauma informed assessment and services. The mental health field has developed a recovery-based philosophy, substantial knowledge about the long term effects of trauma, and information about what services are most effective for persons with mental illness or substance abuse. This includes access to a variety of community based, integrated living and vocational services. This knowledge must be the foundation for the services provided to persons with mental illness or substance abuse by the MCO. The waiver should include these as requirements in sections relating to the provider qualifications

Reasonable Accommodations. MCOs need a better system of documenting a member's reasonable accommodations so that care teams and contracted providers can meet this need respectfully. For example, some members have experienced severe trauma or PTSD, and cannot work with male staff. Often, these accommodations are "lost in the shuffle of paperwork", and not shared with the care team or providers, resulting in triggering the member's trauma symptoms. Sections of the waiver relating to care plan development should be specifically reflective of the requirement that accommodations of mental health needs must be considered and included in an MCO member's individualized service plan.

Improved Access to a Continuum of Mental Health Services

More oversight and accountability are needed 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. Untreated or insufficiently treated mental illness contributes to worsening mental health, and higher utilization of crisis services, as well as generally poorer health outcomes, such as diabetes and heart disease.

Ideas to address this include:

- **Better coordination with MCOs, ADRCS and County Behavioral Health services:** In Wisconsin, counties play a key role in the delivery of mental health and substance use services. Some Medicaid behavioral health benefits such as Comprehensive Community

Services (CCS) and Community Support Program (CSP) can only be accessed through counties. These evidence-based services should be available to eligible individuals in long term care - when appropriate and with the consumer's consent. To date, CCS and CSP are rarely available for participants in long term care, and consumers continue to experience barriers which limit access to these services. The waiver should address the need to ensure long term care members have equitable access to these services, and should include increased accountability for MCOs and care team members, ADRCs, and County Behavioral Health administrators to provide access.

- **Peer Specialist Services.** Certified Peer Specialists should be added as a Family Care waiver service. DHS had previously proposed adding Peer Specialist Services, but the proposal did not move forward. Certified peer specialists are individuals who have lived experience with mental illness and have had formal training in the peer specialist model of mental health support. They use their recovery experience and training to assist in the support of other peers in mental health recovery. Certified Peer Specialists work within a team structure to support individuals in their recovery goals. DRW has some concerns with how Certified Peer Specialists have been used in the past. For example, they have been used as supportive home care workers or home health aides (administering medications, transporting clients, and doing household chores). We have also seen examples of specialists being asked or required to divulge confidential information, and, generally to be accountable to facilities or case managers, rather than to the peer being supported. We want to ensure that misutilization does not occur in the Family Care program. This will require training on recovery and the role of a Peer Specialist for care team members, and MCO behavioral health specialists. Specifically, MCOs should be trained using the CPS Employer Toolkit.

  Services provided to participant peers should be directly related to the recovery plan that is developed by the participant with facilitation of the Certified Peer Specialist. The key aspect of a Certified Peer Specialist is that they provide services in the following areas:

  - Use their own recovery as an experience tool
  - Provide information about mental health resources
  - Assist in supporting individuals in crisis as bridges to resources and in achieving services that are provided in the framework of recovery and trauma-informed approaches
  - Assist/facilitate peer's self-direction and goal setting in their recovery goals
  - Communicate effectively with other providers while holding to confidentiality ethics of the Peer Code of Conduct

- **IDD Informed Psychotherapy.** The waiver should address the need to increase provider capacity for community based, IDD-informed psychotherapy. Effective mental health care for individuals with IDD, requires providers who are knowledgeable of the behavioral health challenges experienced by individuals with IDD and the options to approach those challenges in community settings. Psychotherapy provided by a clinician who is experienced serving persons with IDD and behavioral health needs should be considered, especially when there is a history of trauma. Psychotherapy can be key to development of greater resilience and related skills.

- **Community- based, IDD specific crisis response:** Effective Crisis Response requires advance crisis planning and coordination with law enforcement, community mental health practitioners, and counties who have statutorily defined responsibilities for providing crisis care. Specialized Crisis Response services for individuals with IDD should allow care givers to access additional supports in the community. This should include crisis consultation and coordination, and additional staff support or temporary out of home placement in safe houses/crisis homes for individuals with IDD. Such a response assures continued participation or a quick return to community life. One such program is the Community Ties program operated by the Waisman Center, primarily in Dane County. This program has traditionally been covered through the service category "counseling and therapeutic resources." It is a cost-effective program that keeps people out of mental health institutions, most of which are unprepared to treat people with I/DD. DHS should encourage the expansion and creation of programs which meet this critical need.

- **Independent Living**. The next Family Care waiver should include incentives for MCOs to support independent living such as the Supported Independent Living ("SIL") model. SIL—and other community supported living models— promote independent living in apartments with individualized wraparound supports brought in. While this service would be available and valuable to all Family Care members, it is particularly helpful to people with disabilities who have co-occurring mental health conditions. SIL must be adequately funded, however, to avoid low quality services, which are sometimes experienced in the interest of cost savings.

Support for Parents with Disabilities Enrolled in Long Term Care

We continue to urge DHS to consider adding a service definition (or expanding an existing service definition) to provide the option of parenting supports for Family Care participants with disabilities who are parents, and where such support would help the member to achieve their outcomes. Such services must be highly individualized to the needs of the parent, but might include In-home visits to teach parenting skills, parenting classes, and mentoring. This could include the option of residential settings that can provide wraparound support for parents and children, such as in adult family homes.