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DRW RESPONSE TO REQUEST FOR IDEAS IN ANTICIPATION OF RENEWAL OF 1915(c) IRIS WAIVER

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Disability Rights Wisconsin is the designated Protection and Advocacy system for people with disabilities in Wisconsin. In that capacity, DRW was intimately involved in the planning and implementation of the IRIS Waiver. A DRW staff member has served on the IRIS Advisory Committee since the committee was formed in 2008. In addition, DRW operates the Family Care and IRIS Ombudsman Program, the statewide advocacy program for individuals under age 60 in Family Care or IRIS. We are, therefore, in a unique position to offer input on the impending renewal of the IRIS Waiver. We thank you for this opportunity.

In many respects Wisconsin's IRIS Waiver is a shining example of how a government program of services and supports can be self-administered by the people who participate in it, and benefit from it. Indeed, IRIS, as described in the Waiver document itself, is about as close to ideal as a large program could get. Thus, there is much in the current IRIS waiver which should be preserved. The actual reality of the IRIS experience is not, unfortunately, so rosy. While some of our comments are directed at specific sections of the waiver, others relate to how IRIS falls short of the program described in the Waiver document. We hope that DHS will use this opportunity to reflect on the IRIS participant experience, as well as the language of the Waiver itself.

At the outset we would like to indicate our strong endorsement of the comments submitted by **In Control Wisconsin** and **Save IRIS** on April 19, 2019. Their comments are comprehensive, detailed and reflect many of the ideas we would like to see carried forward into the next IRIS Waiver. Some of our comments borrow extensively from that document and we acknowledge their work.

1. <u>IRIS is for everyone.</u>

   As noted in the In Control/Save IRIS comments, it has been well understood that if self-direction is truly an option for people with cognitive disabilities, there will be instances when participants will need the help—sometimes substantial help—to augment their decision-making capacity. For the past 10 years the IRIS program has welcomed all comers, including those with very severe intellectual impairments. That principle must be preserved when the waiver is renewed. There must be no effort to adopt a prescriptive definition of self-direction that will have the effect of excluding people with intellectual disabilities from participating in the IRIS program. We strongly support the IRIS Waiver continuing to allow "direction of waiver services by a representative." Appendix E-1: (5 of 13).

2. <u>More flexibility is needed.</u>

   Greater priority needs to be placed on the participant experience and how DHS prioritizes its resources to ensure that all IRIS participants are able to create healthy, safe, self-directed lives. Currently, much of DHS' priorities and resources are spent collecting data, creating reports and tightening up definitions and services, which is making IRIS even more difficult for participants to navigate and understand. Too often IRIS policy changes are in reaction to a perceived (or actual) instance of a participant abusing the program. Rather than dealing with the individual situation, DHS tends to either change the policy, typically in ways that reduce flexibility and the ability of the rest of the IRIS population to access a service in an individualized way that does not constitute program abuse.

The example cited by In Control and Save IRIS (barriers to being able to nimbly redirect IRIS funds from one service category to another) is indicative of the lack of flexibility in the IRIS system. Another is the issue of the number of forms a recipient is expected to review, understand, and sign off on as a condition of enrollment or continued participation. Simply put, there are too many of them, they are not written in accessible language, and they intimidate participants. Further, some of the forms that are acknowledged during the application process have been used against the person in what we have seen as over zealous pursuit of alleged fraud or mismanagement of program funds. In general, greater DHS effort needs to be directed at streamlining processes and reducing paperwork.

3. Participants' control over their IRIS allocation needs to be strengthened.

   The IRIS allocation is a calculation that takes into account the person's likely care needs and to a much lesser extent, their quality of life and community integration goals. Because the algorithmic budget allocation calculation is not well-designed to account for the more amorphous and not easily quantifiable quality of life aspect of the IRIS experience, the allocations are by design, likely to underestimate the amount of funding it will take to achieve all of the participant's community integration goals, including even the most mundane ones. Yet, ICs view that allocation as a ceiling on the amount of funds a person may use and encourage budgeting that spends as little of the allocation as possible. In other words, when exercising their supposed budget authority, individuals typically start with a ceiling that is likely already low and then are pressured to spend as far below that ceiling as possible. Care plans are "nickel and dimed" first by the ICs and then, too often, by DHS reviewers.

   It appears that the operating assumption about IRIS participants is that if they are permitted to spend their allocations as they please, without undue interference from ICs or DHS, they will, perforce, spend every penny of it. We do not believe that assumption is evidence-based, but rather, is based on anecdotal experience of a few isolated cases of excess or irresponsible spending of IRIS funds. Such cases should be dealt with individually; they should not become the basis for general policy development. We believe DHS should loosen restrictions on ICs, allow participants more freedom to choose the exact services they actually want, hire workers at the wage they would like to pay, and *then* see if there is some serious increase in IRIS service costs. If there is, adjustments can be made that are based on data, rather than anecdote. If it does not, DHS will have many more happy IRIS participants.

   This is not necessarily a problem with what is written in the IRIS Waiver, but in how IRIS participants are being restricted in exercising their "budget authority."

4. Comments on specific services.

   a. *Support Brokers*

      The support broker service definition is brief and expansive. It should remain that way. One way to fulfill the promise of a self-directed program is to have certain critical service definitions broad, such that participants can, within reasonable parameters, define how that service is delivered and experienced. Support brokers

were an integral part of what was a very successful Dane County CIP 1 program. The transition to IRIS has seen a vast reduction in the amount of support broker use in Dane County. This has not been a good thing for IRIS participants or for Dane County. Dane County APS personnel have reported an increase in the number of incidents problematic behaviors by people with intellectual disabilities. They attribute at least part of that increase to the absence of support brokers to help people navigate unfamiliar or stressful social or work situations.

In our view, the use of support brokers should be encouraged in IRIS. And people who want support broker services should not have to regularly go to hearings to obtain even a few hours per month of support broker services.

b. *Wellness Inclusion Nursing (WIN) Services*

This is another service that was regularly, but sparingly, used in Dane County by the CIP 1 program, but actively discouraged in the transition to IRIS. The service was invented in Dane County through a collaborative effort by the county, DHS and the Waisman Center. Although provided by a nurse, it is quite unlike any nursing service that participants can access through their Medicaid cards. Nurses who have been trained in "IDD informed care" act as consultants for individuals with IDD who have cooccurring physical disabilities or chronic illnesses that regularly cause ER visits or hospitalizations. The WIN nurse helps individuals and residential support agencies identify and treat medical conditions before they require expensive, usually in-patient, medical care. By preventing these episodes, they keep individuals with IDD out of situations that are highly stressful, and out of settings that are not properly staffed to respond to them. And they save the Medicaid program money. Rather than trying to snuff the service out of Dane County, this service should be promoted by IRIS and supported such that it can begin to grow outside of Dane County. It is a humane and cost-effective means of assuring the health and safety of IRIS participants with IDD. It represents the type of creative problem-solving that Wisconsin HCBS programs have always been known for.

c. *Customized Goods and Services*

This unique IRIS service must be retained. It cannot become a casualty of the desire to align the IRIS service package with the Family Care service package. Any concern that CGS would become a "catch-all" service category to cover all manner of inappropriate services and goods has not materialized. The definition is a good one and the service is not overutilized. Yet it can be used for the odd service or good that completes a service plan or addresses a need that just cannot be met by the other IRIS services. It was an innovation when it was conceived and continues to be an effective way to help people truly choose the services that are right for them.

5. More coordination is needed with Medicaid Card Services – PDN in particular.

   We understand that IRIS participants are obligated to access Medicaid card services before using HCBS services, if the card service can address the need. That rule is meant to avoid duplicative services and preserve more scarce HCBS dollars. The purpose of the rule is not to limit overall services to less than what the person needs. But that is exactly the effect it has had when an IRIS participant qualifies for private duty nursing (a card service). The IRIS policy on the interplay of PDN with IRIS services (principally supportive home care) is not based in reality and actually causes people who qualify for 24 hours of PDN to be unable to access 24 hours of care. The existing policy should be discarded and a workgroup that includes advocates, PDN nurses, family caregivers, and participants should be convened to develop a policy that remains true to the "payor of last resort" principle, but recognizes that the acute shortage of PDN nurses may make it necessary to fill in gaps with less credentialed staff who have sufficient training to keep the person safe. The policy should also recognize that it is not *per se* duplicative for a supportive home care worker to be working in a participant's home while a private duty nurse is also there.

6. Change the Criminal Background Check policy to support Employer Authority.

   The existing Criminal Background Check Policy set forth in the Waiver and the Appendix to IRIS Work Instructions Section 6.1.B.1. has had the unintended consequence of disqualifying potential and existing participant-hired workers, many of whom are family members. The policy has also exacerbated the growing worker shortage and works to the detriment of people of color. The current policy states that people convicted of crimes listed in Wis. Stats. § 50.065 and DHS Administrative Code §12.12 are not eligible to work for people enrolled in IRIS and that these crimes are not appealable. The IRIS Work Instructions also include additional crimes not found in the statute and administrative code that are disqualifying but are appealable through DHS' Rehabilitative Review process.

   The policy should be changed to reflect self-direction and employer authority. Participants/employers should have the ability to make informed decisions about hiring people with criminal backgrounds similar to agencies and individual self-directing services in Family Care. FEAs could provide background check information directly to the employer and require a signed acknowledgment of receipt. ICAs could then work with the employer to develop risk agreements that outline steps to minimize risk. If DHS determines that there is a subset of crimes, such as violent crimes, that require a third party rehabilitative review process, it should be consistent with that utilized by other Wisconsin Long Term Care programs.

7. Add Community Supported Living as a service in IRIS.

   This is another example of an area where Family Care members and providers are allowed to flexibly combine multiple components of supported living in one billing code, but a comparable code is not available in IRIS. By forcing people to track and bill every

element of supported living separately, IRIS participants are subjected to a level of inflexibility which interferes with self-direction and budget authority.

Several years ago, DHS invested significant resources in the development of a service definition for Community Supported Living (CSL). The definition was a good one. But the service was never added to the IRIS Waiver because of unresolved issues about how the rate for the service would be determined. We advocate resuscitation of the effort to add CSL as an IRIS service. In the alternative, IRIS should develop a way for a CSL provider to integrate multiple existing IRIS services into a coherent wraparound support strategy for a person and build a flat, blended rate for this package of services, rather than having to itemize the time spent on each service and be rigidly bound to that precise set of time slots for each of the component services every day. We assume this is the way it is done in Family Care, since the Family Care Waiver does not have Community Supported Living as a covered service either.

8. Allow IRIS participants to utilize ride services such as Uber and Lyft.

   Specialized Transportation services should be updated to expand qualified providers to include rideshare services such as Uber and Lyft. This could be more convenient and cost-effective for many individuals, which could save Medicaid dollars and positively impact the transportation challenges and shortages which many IRIS participants experience around the state. It also is consistent with the concept of budget authority and employer authority.

9. Correct the current inequity regarding transportation reimbursement for participant-hired independent workers.

   The most cost-effective option for many IRIS participants to get to work is for their participant-hired worker to drive them to their job. Unfortunately, current IRIS rules only allow the worker to be reimbursed for the first half of the trip when the participant is in the vehicle, not for the worker's drive home, and of course the reverse for the return home. Unless this is corrected, many individuals will be forced to spend 3-4 times as much in using a specialized transportation vendor.

10. Remove unnecessary barriers to participants receiving Work Incentive Benefits Counseling (WIBC), which are also barriers to people pursuing and retaining paid employment.

    It is well-known that one of the major obstacles for working age IRIS participants to pursue community employment is the fear of losing SSI or Medicaid. This fear can be alleviated for most people by receiving WIBC services. We also know that a relatively high percentage of currently unemployed IRIS participants have not had a work-related benefits assessment.

    The existing IRIS Service definition should be clarified to ensure that people understand they can utilize IRIS funding for WIBC services as a Supported Employment or Vocational Futures Planning and Support (VFPS) services without being required to go to

DVR first. This clarification is needed because DVR will not open a case for someone who's only interested in WIBC services (which may be the situation for someone who is already working or who is fearful of losing benefits and not yet ready to apply for full DVR services).

Another idea we encourage DHS to consider including in the Waiver is the creation of a toll-free Work Incentives Benefits Counseling Hotline, which people could call to get answers to basic benefits questions. The Hotline would provide the type of "benefits-light", myth-busting information that is often all people need to dispel their fears when they are beginning to consider work. The Hotline would also provide information about the availability of in-depth Work Incentive Counseling Services for those who need it, and it would serve as a referral source for existing WIBC services such as DVR (available to people with an open DVR case), Work Incentive Planning and Assistance Program (WIPA, a free SSA service with limited capacity that prioritizes people currently working), and LTC-funded WIBC services. People would be more likely to use this type of WIBC service because it wouldn't impact their IRIS budget; wouldn't require them to go through their IC to authorize the service; wouldn't require them to locate a provider who is willing to complete the paperwork set-up process with their FEA; and wouldn't require them to apply for DVR services before they are actually ready.

11. <u>Improve the Accessibility Assessment (AA) and One-Time Expense (OTE) processes.</u>

    Current IRIS policy requires people to obtain AAs and three contractor bids for all Home Modifications services regardless of cost, and any Adaptive Aids that either require a One-time Expense request because the person's IRIS budget estimate is not sufficient to cover the item or it costs more than $1000. The $1000 threshold is not in the Waiver; however, it's included in DHS' Guide to Accessibility Assessments, P-00699. Through an informal review completed by the IRIS Contractors AA/OTE Workgroup, it was determined that the average time frame between an IRIS participant identifying the need for a Home Modification or Adaptive Aid and having a project located is approximately one year. To streamline this process, the Workgroup recommends the following changes:

    a) the policy for contractor bids should be changed from three to two
    b) DHS should allow exceptions to the two contractor requirement when the person can document that s/he can only find one willing contractor
    c) Delete the Waiver language which states that "Home Modifications are considered a one-time expense". OTEs are not a service – they are the process used to adjust someone's budget estimate to ensure that they are able to purchase the goods and services necessary to meet their long-term care outcomes. The determination of whether an AA is required should be dependent on the nature of the item/service, not whether the person's budget has the funding available to pay for it.
    d) Streamline the bidding process as follows:

-identify items (e.g. grab bars and lift chairs) that are standard enough in price that a usual and customary range could be utilized without bids

- identify items that tend to be standard in type and only require an AA if there are health and safety concerns

- explore the idea of a gatekeeper to assess and/or approve adaptive aids or home modifications that do not require an individualized AA or contractor bids

- develop fact sheets to educate people about the proper use and installation of items that tend to be standardized and may not require an AA

e) Remove the statement "Home modifications are generally not available on rental units" because most people don't own the dwelling where the modifications are requested (the AA and OTE request forms already account for this by requiring landlords to sign the form that they are aware of and approve of the home modification).

f) The Waiver language about home modifications being ADA compliant should be removed because the modifications made to private dwellings are not covered under the ADA.

g) DHS has an unwritten IRIS policy that AAs expire after one year, which is problematic given the delays which people typically encounter in obtaining an AA. Rather than requiring someone to obtain a new AA, DHS should have an expedited process for the assessor to review and/or extend the AA situations where nothing in the person's situation has changed.

12. Vocational Futures Planning and Support (VFPS) services should be more flexible – this is another way that DHS could help to increase the employment rate of IRIS participants.

VFPS is a team-based, comprehensive employment planning and support service that is grossly underutilized. Changes to the existing IRIS Service Definition should be made to make the service more flexible, sustainable for providers, and understandable for participants. The Waiver identifies eight strategies providers must have available for people when developing employment plans: skills assessment, barrier identification, asset education, benefits analysis, career exploration, job-seeking support, job follow-up, and long-term support. The above strategies should be examples of team-based strategies, not required strategies for every VFPS provider.

The Waiver can also be modified to allow for flexibility in the makeup of the support team. For example, if assistive technology is needed and the provider doesn't have an in-house technology consultant, it should be acceptable to assist the person by securing the necessary assistive technology services from an outside provider or subcontract provider. Similarly, if the VPS provider does not have an available Work Incentive Benefit Counselor on the employment support team, it should be acceptable to facilitate a referral to an outside WIBC provider.

The VFPS services have been successfully utilized as a transition service for young adults leaving high school. The VFPS Service Definition could be modified to expressly provide for time-limited transition coordination services in situations where the school lacks capacity to provide the level of support needed to adequately prepare the person to transition directly to work, to begin services with DVR and/or to utilize other IRIS-funded services such as prevocational or supported employment.

13. Change the DHS definition of Competitive Integrated Employment (CIE).

    The DHS definition for CIE is not consistent with the U.S. federal definition in Chapter 16 Voc. Rehab and Other Rehab Services section which applies to WIOA. Consequently, the DHS definition is also not consistent with the CIE definition used in the 2017 Wisconsin Act 178 (Employment First) which specifically references the U.S. code above. As Act 178 requires DWD, DHS, and DPI to share data and report back to the legislature it does not seem advisable to have two contradictory definitions of CIE across various state agencies and initiatives. We recommend that DHS adopt the federal definition of CIE referenced in Act 178 (without adding to it). This will ensure accurate and consistent measurement of baseline data and progress in improving CIE outcome statewide.

14. Clarify and enforce the Notice of Action requirement as provided in Medicaid regulations. (*this relates to Additional Requirement G. in the waiver re a participant's right to a fair hearing)*

    We continue to hear recurrent reports of IRIS participants being denied a service and not receiving a legally required Notice of Action (NOA). In some instances, the IC explicitly denies the service; in other instances the denial is essentially the result of active discouragement of the participant by an IC to request the service. This is particularly noticeable in requests for Budget Amendments. But under the principle of budget authority and employer authority, the latter example essentially amounts to a denial. We also do not believe that ICs should be acting as gatekeepers for participants who clearly want a particular service. We ask that DHS clarify the NOA requirement and monitor ICAs to ensure that it is being followed.