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DRW COMMENTS ON
RENEWAL OF IRIS HCBS 1915(c) WAIVER

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Introduction

Disability Rights Wisconsin appreciates the opportunity to comment on the proposed renewal of the IRIS 1915(c) Waiver.

As a member of the IRIS Advisory Committee DRW has already had an extensive opportunity to provide input on this proposal. We commend DHS for having been very open to IAC suggestions for changes and clarifications. This proposal is better for having been publicly discussed and closely scrutinized by the IAC.

We also note, however, that the proposal that is available for public comment has already been approved for submission to CMS by the Legislature's Joint Committee on Finance. Given that approval, it is unclear to us whether any comments made during this comment process could result in substantive change to the proposal. The lack of merit to the requirement that Joint Finance approve waiver requests aside, unless DHS were to resubmit the proposal to Joint Finance after public comment has closed and feedback has been incorporated, it seems highly unlikely that comments, regardless of their merit, will result in substantive change to the proposal. In the future we think the process should be reversed. The public comment period should come before the proposal is submitted to Joint Finance. That way changes suggested by the public could be considered on their merits.

Because we have already had an opportunity to provide input, our comments in this forum will be shorter than is our norm. Our specific comments follow.

Appendix C: Participant Services

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

Most of the service definitions have been substantially rewritten. As a member of the IRIS Advisory Committee we have had an opportunity to have input into these new definitions. Many of our suggested revisions were adopted during that process. During the earlier process DHS repeatedly told the IAC that it was not its intent to limit or restrict any existing coverage. Given that as a starting point, our comments will focus on problems remaining after completion of that process.

- Live-in Caregiver (p. 50): This service is restricted to "unrelated" caregivers. We strongly disagree with that limitation, which has no connection to a legitimate IRIS objective. A relation may well be the best and sometimes the only person who is willing to provide this service. The fact of familial relationship (which is defined in extremely broad terms) is not relevant to whether a participant has needs with ADLs which require a caregiver. The only possible legal limitation on relative service provision is the one that may be placed on legally responsible relatives. (see Wis. Stat. § 49.90(1)). The "relateive" limitation also conflicts with the later assurance that legally responsible relatives are permitted to be service providers who provide personal and supportive home

care—both of which are akin to the duties of a live-in caregiver. (pp. 158-159). The limitation of disallowing the service when the participant moves into the relative's home is sufficient to prevent the service from being a *de facto* subsidization of the caregiver's personal residence.

DRW Recommendation: Remove all references to "unrelated" persons in the definition.

- Assistive Technology-Ongoing maintenance costs of service dogs (p. 74): In the proposal, only the ongoing maintenance costs of service dogs that have been professionally trained will be covered. This is a change from current IRIS coverage and the effect is to essentially prohibit participants from using IRIS funds to pay the ongoing costs of service dogs trained by their owners or other nonprofessional trainers. We strongly object to this change.

  There is no policy justification is for distinguishing between similarly trained service dogs. Trained service dogs allow people with disabilities to be more independent and less reliant on paid human support. They are quite economical for the HCBS Medicaid programs, particularly if those programs did not bear the initial expense of purchasing them. Keeping such animals healthy and vaccinated, and thus able to continue providing service, is important regardless of who initially trained them.

  The new provision conflicts with the ADA and state law definitions of service dogs. Under the ADA a service animal is defined as: "… any dog that is individually trained to do work or perform tasks for the benefit of an individual with a disability, including a physical, sensory, psychiatric, intellectual, or other mental disability." 28 C.F.R. § 35.104. A similar definition exists in state law: ""Service dog" means a dog that is trained for the purpose of assisting a person with a sensory, mental, or physical disability or accommodating such a disability." Wis. Stat. § 951.01(5). It is our position that DHS cannot apply a definition of service animal that is more restrictive than the ADA definition. Doing so deprives some disabled HCBS Waiver recipients (those whose service dogs are not trained by professionals) of equal access to the full range of HCBS services. It thereby deprives a group of people with disabilities the opportunity to participate fully in the IRIS waiver in violation of Title II of the ADA. 42. U.S.C. § 12132. Specifically, it fails to "[a]fford a qualified individual with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others." 28 C.F.R. § 35.130(b)(1)(ii). Once Wisconsin Medicaid determined that it will pay the maintenance expenses of service dogs it cannot do more than what the ADA permits in terms of inquiry. It can ask if the dog is trained and it can ask if what it is trained to do benefits the person with a disability. It cannot require more.

  The distinction DHS has drawn relating to who trained the service dog also violates the constitutional due process requirement that Medicaid recipients are entitled to have decisions regarding level of service made according to reasonable standards. U.S. Const. Amend. XIV, § 1. Making payment of maintenance costs of similarly trained service

dogs contingent upon who did the training is not a reasonable or rational means of determining level of service. The arbitrary nature of using that standard for determining coverage of service dogs under the adaptive aids service category is demonstrated by the fact that the standard is entirely incompatible with (and much more restrictive than) the ADA definition of service animal.

It should be stressed that we are not suggesting that the coverage for maintenance costs be expanded to include the costs of emotional support animals.

DRW Recommendation: Explicitly reverse the erroneous and illegal requirement that payment for such costs may only be made for dogs trained by professional trainers. Make it clear within the service definition that the costs of maintaining service dogs are covered by IRIS regardless of who trained them.

- Community Involvement Support (p. 82): Only two types of community engagement activities are specifically identified as covered: health club memberships and camps. Other activities require specific approval from DHS/IRIS. We believe the list should be expanded to include additional activities, including social activities and clubs that are not specifically physical-fitness related. It should not be necessary to get state approval for IRIS to pay the annual fee for say, a membership in a chess or other gaming club when membership in that club is necessary to promote a participant's mental health. It should also specifically include support with voting.

  DRW Recommendation: The service definition should be revised to include memberships in clubs and other activities that support the person's mental as well as physical health. It should also specifically support voting activities. The prohibition on coverage of "recreational or diversional" activities should be changed to "This service must contribute to the community functioning of the participant and may not be primarily recreational or diversional in nature." This will distinguish activities where the individual is an active participant from those where they are audience members or attending primarily for entertainment purposes.

- Community Transportation (p. 87)**:** This service needs to be expanded to include unloaded miles. In rural areas it is often not cost effective for a provider to transport someone if payment is based only on the miles involved in the actual transportation of the participant. The cost of getting to and from the person's home (or destination when picking up at the end of the activity) may actually exceed the miles involved in the participant's transport. That cost needs to be factored into this service. The payment could be at a lower rate or limited to areas defined by IRIS as rural, but there needs to be some recognition that there are extra costs associated with the transport of people in rural areas.

  DRW Recommendation: Amend service definition to include payment for unloaded miles in rural areas.

Appendix C-4: General Service Specifications (1 of 3)

Section a. Additional Limits on Amount of Waiver Services (p. 168): This section erroneously states that the participant may only appeal a "one time expense" or "budget adjustment" when the request has been denied. The appeal right actually extends to cases where the request has only been "partially approved." This section is inconsistent with the discussion of the appeal right for OTEs and BAs found in **Appendix E-2, sec. b. iii.** (p.198) where it is correctly described as applying to both denials and partial approvals.

DRW Recommendation: Amend language to make it clear that partial denials of OTEs and Bas are appealable.

In the same section there is inaccurate language regarding whether residents of adult family homes or residential care apartment complexes can access the BA or OTE process. The proposal says they never can. In fact, that prohibition has not been program policy for some time. While residents of such facilities cannot use the BA or OTE process to cover the basic cost of the facility, current IRIS practice allows BAs when the individual experiences a change in condition resulting in increased service needs and costs to the provider; when reasonable rate increases reflecting increased costs of doing business over time are requested; and when the person already resides in an AFH or RCAC at the time of referral. And OTE and BA requests are appropriate when they relate to a service or item that is not considered part of the daily or monthly rate paid to the facility. For example, a participant should be able to use the OTE process to pay for a repair of the lift function on a modified vehicle owned by the participant.

DRW Recommendation: The final paragraph should be amended as follows:

Participants who reside in adult family homes or RCACs are generally not eligible ~~for~~ to use the BA or OTE process to cover the basic cost of the facility. ~~requests~~. Exceptions are considered by the SMA for those participants for whom their budget is reduced following an annual LTCFS; when the individual experiences a change in condition resulting in increased service needs and costs to the provider; when reasonable rate increases reflecting increased costs of doing business over time are requested; when the person already resides in an AFH or RCAC at the time of referral, and they are unable to negotiate a rate within the new budget and may be required to relocate as a result; and when an expense relates to a service or item that is not considered included in the periodic payment to the facility.

Appendix E: Participant Direction of Services

Appendix E-1: Overview (12 of 13) m. Involuntary Termination of Participant Direction (p. 195):

This section contains 10 reasons for involuntary termination from the IRIS Waiver. The first nine reasons identify specific conduct or conditions. The tenth reason is a broad, catch-all reason which makes the first nine reasons irrelevant and allows IRIS to, at its sole discretion,

involuntarily terminate a participant for any noncompliance with any IRIS program requirement. This catch-all reason is far too broad. It should be eliminated. If it is not eliminated, it should be modified by the addition of "substantial, material, and repeated" to the beginning of the reason.

DRW Recommendation: The tenth reason for involuntary termination should be eliminated. If it is not eliminated it should be revised as follows: "<u>Substantial, material, and repeated</u> noncompliance with IRIS program requirements outside of reasons above."

ERRATA: In the course of reading the application we noted the following typos:

- ***p. 48: first paragraph, "performing" is misspelled.***
- ***p. 53: extra capital P in first word.***
- ***p. 139: paragraph following bullets, last sentence is missing a "to" after "prior"***
- ***p. 174: in text box for g., "ICAs" requires an apostrophe since it is a possessive, not a plural, reference***
- ***p. 175: in text box for a., first sentence, "regularly" should be "regular"***