INDIANA
DISABILITY RIGHTS

January 24, 2025

Division of Disability and Rehabilitative Services
Family and Social Services Administration
ddrswaivernoticecomment@fssa.in.gov
SENT ELECTRONICALLY

Re: Comments regarding Proposed Amendments to the Health & Wellness Waiver

Dear Director Mitchell,

Indiana Disability Rights (IDR) is the state's federally-mandated protection and advocacy system. IDR advocates with, and on behalf of, individuals with disabilities to ensure their rights are protected. These activities include the protection of rights in the health care sector, from providing legal representation to clients who have been wrongfully denied access to medical services or entitlement programs like Medicaid to engaging in workgroups to help shape policies that proactively support Hoosiers with disabilities, such as working with the Division of Disability and Rehabilitative Services (DDRS) to expand self-directed Medicaid waiver services. The submission of public comments is another systemic activity available to IDR, as well as the reason I write today.

Specifically, IDR offers the following comments in response to the Family and Social Services Administration's (FSSA's) proposed amendments to the Health and Wellness (H&W) Waiver. These amendments were announced in the *Indiana Register* on Christmas Day,[1] although the proposed amendments had to be accessed from FSSA's website or in person.[2] In brief, IDR's comments involve concerns regarding: DDRS and BDS's ability and desire to sincerely serve the H&W Waiver population; mandatory Care Management services and their (lack of) utility; reserved waiver capacity for assisted living facility residents; participant-directed services; and various, more discrete questions and concerns.

Communication between the State and H&W Waiver Participants

In establishing the proposed waiver amendments' purpose FSSA states that, in part, it "is proposing to change the name of the waiver from the A&D [Aged and Disabled] Waiver to the Health & Wellness

[1] *See* Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Health and Wellness Waiver*, 20241225 IND. REG. 405240569ONA (Dec. 25, 2024).

[2] *See* Family and Social Services Administration, *DDRS Draft Policies*, available at: https://www.in.gov/fssa/ddrs/ddrs-policies/ddrs-draft-policies-for-public-comment/?j=42537&sfmc_sub=24189437&l=1707_HTML&u=766843&mid=546006736&jb=2&j=42690&sfmc_sub=31353439&l=1787_HTML&u=768769&mid=546006736&jb=4001 (last accessed: Jan. 22, 2025) (click the link titled "H&W Waiver" to access a PDF of the completed Application for a §1915(c) Home and Community-Based Services Waiver).

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Waiver…"[3,4] IDR is concerned about this proposal, given that the new name does not coincide with waiver participants' preferences. IDR is aware of at least four H&W Waiver participants who repeatedly explained to multiple DDRS leaders that the terms "health" and "wellness" felt medical and unsupportive of the social model of disability. These comments were shared with DDRS leadership prior to any relevant waiver amendments. IDR also shared these concerns via previous comments about earlier proposed waiver amendments in December 2023.[5]

In addition to waiver participants' concerns about the medicalization of their routine daily needs (e.g. assistance with activities of daily living and instrumental activities of daily living), DDRS's refusal to consider and respond to feedback suggests a lack of respect for waiver participants' autonomy and desire to be involved in policy matters concerning their lives. As noted in the Organizational Structure paragraph of Appendix A-2, authority to administer the H&W Waiver was transferred from the Division of Aging (DA) to DDRS's Bureau of Disabilities Services (BDS).[6] Before that recent transfer, BDS was known as the Bureau of Developmental Disabilities Services and focused almost exclusively on serving individuals with intellectual disabilities. More than a year after the H&W Waiver's transfer to BDS, the subagency has not meaningfully attempted to learn about the H&W Waiver's population, nor taken action to change the culture of its staff. The result is that H&W Waiver participants are denied advisory status akin to BDS

[3] Division of Disability and Rehabilitative Services, *Application for a §1915(c) Home and Community-Based Services Waiver*, page 6, available at: https://www.in.gov/fssa/files/LCAR-H-and-W-Waiver.PDF (last accessed: Jan. 22, 2025).

[4] For purposes of clarity, IDR will refer to participants of the former A&D Waiver and future participants of the H&W Waiver, including those currently receiving waiver services, as H&W Waiver participants throughout these comments. Because the name change has been informally used by DDRS for approximately one year, without formal statutory and regulatory recognition, H&W Waiver participants can justify calling themselves participants of either iteration of essentially the same set of services.

[5] Indiana Disability Rights, *Comments about Amendments to the Aged & Disabled Waiver*, page 2, electronically submitted on Dec. 14, 2023).

[6] *See* Division of Disability and Rehabilitative Services *supra*, note 3.

service recipients with intellectual disabilities and their family members,[7] treated paternalistically,[8] and many left feeling like misunderstood second-class clients.

IDR offers several examples of how BDS's decisions are unwelcoming to the H&W Waiver population. First, consider that the Notice regarding the proposed waiver amendments was published on a state holiday, December 25, 2024.[9] The Notice could have been published earlier, given that the proposed amendments were shared with tribal governments nearly two weeks earlier.[10] Further, although tribal governments are not required to submit public comment until February 9, 2025,[11] DDRS did not expand the 30-day mandated public comment timeline to enable more H&W Waiver participants to both enjoy the holidays and prepare written comments.[12]

In Appendix A-6-I, DDRS describes its public collaboration activities. Notably, "key stakeholders" are identified first as "nationally recognized organizations, professional trade associations, and leaders among the service providers."[13] Only at the very end of the bullet point does DDRS add "small groups of parents and providers," as well as "advocacy groups."[14] H&W Waiver participants, the most important

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[7] The DDRS Advisory Council, established by Ind. Code § 12-9-1, has authority only over the "system of support and services for people with intellectual and developmental disabilities." Ind. Code § 12-9-2. Importantly, unlike the federal definition of "developmental disability" which would apply to H&W Waiver participants with diagnoses like spinal muscular atrophy and childhood-onset spinal cord injuries, *see* 42 U.S.C. § 15002(8)(A), Indiana has narrowed the scope of developmental disability, such that it must be "attributable to: (A) intellectual disability, cerebral palsy, epilepsy, or autism; or (B) any other condition (other than a sole diagnosis of mental illness) found to be closely related to intellectual disability . . ." Ind. Code § 12-7-2-61(1). Its membership includes two individuals "with an intellectual or other developmental disability," two individuals who are "an immediate or extended family member of an individual with an intellectual or other developmental disability," and service providers within the intellectual disability community. Ind. Code § 12-9-3.

[8] BDS is used to family members and guardians of Hoosiers with intellectual disabilities being involved in health care and waiver service advocacy, having historically administered the Community Integration and Habilitation (CIH) and Family Support (FS) Waivers, both of which serve Hoosiers whose diagnoses meet Indiana's definition of developmental disability. BDS also has oversight over supported group living services for individuals with intellectual disability. Family members, guardians, and service providers are generally involved in these clients' respective support teams. In contrast, like older adults who have been transferred to the PathWays Waiver, many adults participating in the H&W Waiver are used to making their own decisions and advocating for themselves. BDS's repeated references to family members and participants' "circle of support" throughout the proposed waiver amendments are accordingly viewed as an expression of suspicion by BDS that the participants are incapable of managing their own affairs, as well as an unwanted encroachment on these participants' privacy. *See* Division of Disability and Rehabilitative Services *supra*, note 3 at pages 67 and 68.

[9] *See* Office of the Secretary of Family and Social Services *supra*, note 1.

[10] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 10.

[11] *Id*.

[12] *See id.; see also* Office of the Secretary of Family and Social Services *supra*, note 1.

[13] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 10.

[14] *Id*.

stakeholders, are not mentioned in the Appendix section until a later bullet point,[15] dedicated to DDRS's Building Bridges events. Critically, however, BDS conducted Building Bridges meetings well before it was delegated H&W Waiver administration responsibilities. Note that the purpose of those meetings is to provide "direct avenues for individuals and families to share their feedback on waiver services and supervised group living."[16] Although BDS may be willing to address H&W Waiver services within its group-home-and-CIH-and-FS-Waiver agenda, the H&W Waiver population generally believes these meetings are for the discussion of issues pertaining to peers with intellectual disabilities. Even changing the name of these events would demonstrate DDRS's acknowledgment of its new populations.[17] Similarly, the Appendix also cites the DDRS Advisory Council as a means for receiving feedback,[18] despite the fact that, as noted above, it has nothing to do with the H&W Waiver nor its population.

Notably, too, DDRS commits to respond to public comments received during the instant period by offering "reasons why comments are not adopted."[19] Only after rejecting comments comes the agency's commitment to include any modifications to its proposed amendments in an "[o]ptional field."[20] While DDRS is certainly not obligated to modify proposed amendments in accordance with public comments, its suggestion that comment rejection is the default reaction to public involvement is uninspiring and chills collaboration.

Care Management Services

Perhaps stemming from DDRS's paternalistic actions toward, as well as misunderstanding about, H&W Waiver participants IDR has several concerns with the Care Management service described in Appendix C-1/C-3. As noted, IDR is disappointed in DDRS's repeated instructions for Care Managers to "engage the individual *and their circle of support*."[21] Participants may wish to handle their services independently and that wish should be respected by both Care Managers and DDRS. Even more patronizingly, "Care [M]anagers are responsible for notifying families/guardians of incidents reported and sharing results of the provider's investigation."[22] IDR strongly suggests that Care Managers share incident reports and results with the H&W participant and, only if directed by them, share the same information with other parties, including family members.

Later, the service description states that Care Managers must "evaluate the effectiveness of all services," by "[m]onitoring the progress from identifying need [sic] to meeting goals/preferences identified by the individual," "[d]irect[ing] collaboration and coordination with providers to ensure services are within the individual's preference," and "[a]djusting action and service plan appropriately to identify changing needs

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[15] *Id*.

[16] *Id*.

[17] Not only the H&W Waiver, but also the Traumatic Brain Injury Waiver, was transferred from the DA to DDRS.

[18] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 10.

[19] *Id*.

[20] *Id*.

[21] *Id*. at page 67 (emphasis added).

[22] *Id*.

that meet the participant's needs."[23] IDR suggests that the participant should be granted a more active role in evaluating the effectiveness of services. Providers, for example, are not the appropriate source for determining whether participants' needs are being met; relevant information should come directly from the participant.

Indeed, Care Management does not "enhance the individual's functional and social well-being"[24] universally. To be frank, some H&W Waiver participants have shared that visiting with care managers can be burdensome. Others consider it a dreaded prerequisite to obtain needed services. Because IDR has witnessed this same feedback being shared with DDRS's leadership, it is concerning that the agency is continuing to require every participant to continue receiving Care Management without any re-imagination of the service. Especially in the midst of a billion-dollar Medicaid budget shortfall, universal care management may not be the best use of limited funds. Particularly among the H&W Waiver population, whose participants may live independently, and be employed, married, and managing their own family, having to justify to a Care Manager how many times they need help using the restroom each day can feel degrading and infantilizing. In those circumstances, the service is of more benefit to the AAAs than participants. Accordingly, IDR suggests that DDRS engage participants in a discussion about the feasibility of allowing participants to opt out of Care Management services. At the very least, DDRS could provide flexibility in the required "face-to-face contact every 90 days from the initial service plan activation."[25]

In addition to the issues described above, IDR is concerned that DDRS plan to make Care Managers "responsible for identifying when a participant is residing in a provider owned or controlled setting, monitoring home and community-based services (HCBS) characteristics, monitoring person-centered modifications to HCBS characteristics, and documenting" these determinations.[26] IDR questions whether Care Managers serving H&W Waiver participants have had sufficient training and testing to ensure their ability to reliably determine whether a provider is compliant with the HCBS Settings Rule. A Care Manager is not going to have access to critical assessment information, such as a provider's financial information or staff schedule. Further, unlike the State, which is in a position to demand these materials, a Care Manager is unlikely to successfully obtain provider policies, procedures, and other documents that are frequently deemed proprietary. As participants have not received training regarding the HCBS Settings Rule, Care Managers may not receive pertinent information about this issue during quarterly visits. For these reasons, IDR believes the State must maintain responsibility for ensuring that all HCBS providers maintain compliance with relevant state and federal law.

Finally in regard to Care Management services, IDR expresses its support of the conflict-of-interest provision that prevents Care Management providers from also providing direct services to H&W Waiver participants.[27] Because IDR believes this protection is so vital, it does not support DDRS's decision to continue the DA's practice of exempting certain AAAs from it. IDR specifically asks whether DDRS has plans to phase out the AAAs' exemption from conflict-of-interest practices, as the grandfathered practice benefits AAAs at the expense of participants.

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[23] *Id*.

[24] *Id*. at page 68.

[25] *Id*.

[26] *Id*.

[27] *Id*. at page 69.

Reserved Capacity for Assisted Living Facility Residents

Next, IDR notes concern with reserving waiver capacity to provide assisted living services to newly eligible waiver participants, as proposed in Appendix B-3.[28] FSSA is facing extreme budget constraints and eliminated certain waiver service arrangements as cost-cutting measures.[29] Therefore, DDRS's decision to fund assisted living services is puzzling. Assisted living services have one of the highest reimbursement rates under the H&W Waiver,[30] and the growth of that service will put further pressure on FSSA's budget. IDR suggests that allowing newly eligible participants to access H&W Waiver services such as attendant care, in addition to assisted living services, may result in less cost.

Indeed, FSSA has recognized that most older adult Hoosiers prefer to live in their own homes rather than elsewhere.[31] Although this subpopulation within the former A&D Waiver was transferred to the PathWays Waiver, there is no reason to suppose that younger Hoosiers prefer more institutional settings. Lest FSSA note that assisted living facilities are treated as home and community-based settings in Indiana, IDR notes that, as recently as 2024, multiple assisted living facilities appeared noncompliant with the Home HCBS Settings Rule.[32] IDR recalls that the assisted living facility associated with Dyer Nursing was located in the same building as a skilled nursing facility, which seems to clearly conflict with the Centers for Medicare and Medicaid Services' (CMS) restriction on categorizing a nursing facility as a home and community-based setting.[33] Other assisted living facilities in Indiana that were opened to heightened scrutiny undoubtedly have "the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS" and, therefore, should be presumed institutional.[34]

CMS requires:

> The State [to] ensure that the setting chosen by the individual is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings,

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[28] *Id*. at page 34.

[29] Perhaps most controversial among these measures was FSSA's decision to cease allowing the parents of minor waiver participants and participants' spouses from providing attendant care. *See* Family and Social Services Administration, *Medicaid Forecast Update and Initiatives*, available at: https://www.in.gov/fssa/files/MedicaidForecastUpdatesandInitiatives.pdf (Jan. 17, 2024).

[30] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 279-292 (see column titled "Avg. Cost/Unit" to compare service unit costs and projected costs).

[31] *See* Division of Aging, *Draft State Plan on Aging Federal Fiscal Years 2023-2026*, page 3, available at: https://www.in.gov/fssa/da/files/2023-2026-State-Plan-March-2022-Draft.pdf (Mar. 2022).

[32] *See*, for example, Indiana Disability Rights, *Comments regarding Ossian Health Heightened Scrutiny Review*, electronically submitted to spacomment@@fssa.in.gov on Feb. 23, 2024; *see also* Indiana Disability Rights, *Comments regarding Dyer Nursing Heightened Scrutiny Review*, electronically submitted to spacomment@@fssa.in.gov on Oct. 15, 2024.

[33] 42 C.F.R. § 441.301(c)(5)(i).

[34] *Id*. at § 441.301(c)(5)(v).

> engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.[35]

DDRS's proposed H&W Waiver amendment in regard to reserved capacity for assisted living residents seems to conflict with these assurances. Many of these individuals reside in non-integrated settings with limited, if any, transportation into the community. IDR is unaware of any assisted living facility that facilitates residents' engagement in competitive integrated employment. In short, the move toward reserving waiver capacity for those in assisted living facilities seems a regression from CMS's clear direction for States to promote full integration of Medicaid waiver participants.

Self-Directed Services

IDR is supportive of maintenance of Participant-Directed Home Care Services (PDHCS). However, IDR has some concerns regarding components of its description. For example, Appendix C-1/C-3 states that, as a condition of receiving PDHCS, a "participant must also receive home health State Plan services."[36] The length of the proposed amendments, coupled with the truncated time to review them prior to the public comment deadline has left IDR without time to find the appropriate citation. Nonetheless, the undersigned is confident that CMS prevents States from requiring that Medicaid waiver participants receive certain State Plan services as a condition of participating in self-directed waiver services. The legal conflict, coupled with the proposed mandate's encroachment on the self-direction of services, leads IDR to suggest the quoted language be removed from the service definition.

Relatedly, IDR has concerns about the Office of Medicaid Planning and Policy's (OMPP's) approval of individual PDHCS caregivers. Many of OMPP's requirements are incompatible with participant autonomy and self-direction. For example, DDRS requires that caregivers hired to provide self-directed attendant care "must enter into the IHCP [Indiana Health Care Provider] agreement in order to become a paid caregiver."[37] PDHCS caregivers are not currently required to complete this paperwork, yet IDR is not aware of any related problems. Such caregivers already complete a more-than-20-pages application for the fiscal intermediary after getting hired by the participant. IDR asserts that requiring more red tape is inappropriate in this environment of extreme caregiver shortages and State directives to limit bureaucratic requirements.

Next, DDRS would require caregivers – who have already been hired by participants self-directing their services – to verify their completion of "a competency evaluation program or training and competency evaluation program approved or conducted under section of [sic] 10.2.2 of the American Association of Respiratory Care [] or Clinical Practice Guideline" or "program that includes CPR [cardiopulmonary resuscitation], basic first aid, and any applicable DME [durable medical equipment] training."[38] Again, these requirements neither respect participants' autonomy to create their own hiring criteria, nor are they relevant to the needs and wishes of all participants. DDRS should by now be aware that many H&W Waiver participants are considered "medically fragile," and performing CPR on them may be more catastrophic than the underlying source of the response. This requirement also undermines those

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[35] *Id*. at § 441.301(c)(2).

[36] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 122.

[37] Id. at page 124.

[38] *Id*.

participants who have “do not resuscitate” orders. Moreover, what if a self-directing participant wants to hire a caregiver who can meet the participant’s needs but cannot physically perform CPR? This restriction also limits participants’ hiring authority.

OMPP additionally proposes mandating that caregivers serving self-directed participants “coordinate information about the participant’s care, including backup plan, with any and all other providers and care manager [sic] rendering services to the participant.”[39] This responsibility, too, belongs to the self-directing participant. Perhaps they do not want a particular caregiver to know that they were also working with a different caregiver. Perhaps one caregiver does not want their contact information shared with others, and has requested privacy as a condition of hiring. Some PDHCS participants may wish to delegate coordination to a caregiver of their choice, but they should not be forced to do so for a variety of reasons.

IDR also has concerns about potential restrictions on PDHCS participants’ budget authority expressed in Appendix E-1-d. First, the section states that self-direction participants must acknowledge “that each paid caregiver cannot provide more than 40 hours of service in one week, and the participant will arrange for service from another provider if additional services are required.”[40] Not only does this proposed restriction undermine hiring and budget authority, but it also may prevent participants in rural areas from being able to self-direct their services if they cannot find sufficient staff. Similarly, other participants may be forced to receive agency-based attendant care if they have a few dedicated workers who are willing to participate in self-directed caregiving only. Particularly because PDHCS participants have their own budget, IDR believes they should have the ability to decide whether paying a caregiver over time best meets their needs.

The same section requires PDHCS participants to acknowledge that a Care Manager will check on them “at a minimum of 31-day intervals and will file an incident report to the State to report any quality-of-care issues or lapses and participant/employer responsibilities.”[41] Once again, IDR believes that this new level of oversight is inappropriate. Current PDHCS participants are managing their care without participant-created problems. They have had to troubleshoot problems created by the fiscal intermediary and State agencies. Indeed, these participants often know more about self-directed care than most Care Managers.[42] Mandating this level of oversight is yet another unnecessary and burdensome bureaucratic hoop DDRS is asking wheelchair users to jump over.

Miscellaneous Issues

Finally, IDR has several briefer concerns and technical questions regarding the proposed waiver amendments:

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[39] *Id*.

[40] *Id*. at page 196.

[41] *Id*.

[42] Although DDRS maintains that "Care Managers are responsible for assessing individual interest in PDACS and providing [participants] with information regarding the philosophy of self-direction and the availability of PDACS," this is failing to happen in several regions throughout the state. IDR has received numerous complaints of care managers claiming a participant cannot self-direct their care (without a formal assessment or offering the appointment of an authorized representative) or even that self-directed services are unavailable (given the individual Care Manager's prejudice against it).

- Appendix B-6-c states that the Level of Care Assessment Representative's (LOCAR's) contractor assessors must meet two of five qualifying criteria.[43] One criterion is to be a registered nurse with one year's experience in human services. A second criterion is to have a Master's degree in any field. IDR questions why a nurse would need to have a year of experience whereas an individual with a Master's in Physics does not. Similarly, a third criterion is possession of an associate's degree in nursing. Again, why does a more qualified registered nurse need experience that a less experienced licensed practical nurse can avoid? These qualification criteria strike IDR as arbitrary if DDRS's objective is to ensure assessors are qualified to determine applicant's functional capacity.
- Appendix B's Quality Improvement Section b-ii states that if a redetermination of waiver eligibility, based on level of care (LOC), reveals that a participant is ineligible, "any claims submitted will be denied back to the date of expiration of the prior LOC period."[44] IDR questions which party will be responsible for the payment of these claims. It seems unfair for a participant to be responsible if they received Medicaid services following a good faith attestation of eligibility from the LCAR contractor's assessor. Given that the individual is ineligible for LOC reasons, rather than financial reasons, the individual likely lacks the means to pay for out-of-pocket services.
- Appendix B-8 states that "BDS staff members utilize locally available interpreters associated with community or neighborhood organizations and church groups for interpretation of non-English languages."[45] IDR requests more information about how BDS assesses the qualifications of these interpreters, to ensure they have the relevant skill and fluency to communicate detailed information about the H&W Waiver and services, as well as ensure these interpreters are maintaining applicant and participant confidentiality. Given that the State contracts with an interpreting business that has a wide variety of on-hand interpreters, it seems logical that BDS would use that professional contractor while communicating with applicants and participants.
- IDR also notes concern that Appendix B-8 requires the LCAR contractor's call center to offer "automated telephone menu options in English and Spanish."[46] While automated telephone options likely ease the burden on the LCAR contractor, having to navigate an automated menu by pressing telephone buttons creates a barrier for some individuals whose physical disabilities prevent them from reaching and pressing telephone buttons. Ironically, these individuals are just the kind of people who participate in the H&W Waiver. Should FSSA's current contract be closed for amendment at this time, such that the contractor is required to maintain an automated menu, IDR suggests that FSSA asked the contractor to ensure the menu can be operated not only through buttons but also by voice. Given that both FSSA and the area agencies on aging (AAAs) have historically had difficulty consistently providing reasonable accommodations to the H&W Waiver population, such as following requests for email communication, IDR believes this issue, while small, is significant.
- IDR is concerned about several attendant care service limits, as established in Appendix C-1/C-3. First, IDR asks why DDRS wants to limit attendants' ability to transport participants more than 50 miles outside of Indiana's borders.[47] IDR notes that many H&W Waiver participants are employed and may need to travel more than 50 miles for business trips. This situation appears to conflict with DDRS's recent efforts to expand employment opportunities for individuals participating in the CIH and FS Waivers. Second, IDR reiterates its concern that parents of minor children and

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[43] *See* Division of Disability and Rehabilitative Services *supra*, note 3 at page 44.

[44] *Id*. at page 52.

[45] *Id*. at page 55.

[46] *Id*.

[47] *See id*. at page 61.

spouses cannot be paid for providing their loved one with attendant care.[48] In addition to concerns about whether participants who previously depended on parents and spouses can obtain sufficient and quality attendant care from other providers, the ban seems arbitrary considering that legal guardians of participants can be paid to provide up to 40 hours of attendant care each week.[49]

- IDR has significant concerns about DDRS continuing to allow Skilled Respite services to occur "in a HCBS certified facility."[50] The words "HCBS" and "facility" are incompatible. Instead, IDR suggests that any respite services for individuals aged 22 and younger should be occurring in their familial home. DDRS claims that institutional respite "provide[s] support to families in an effort to avoid institutionalization of their children."[51] Yet, the service *is* short-term institutionalization. IDR requests that DDRS explain how it determines when Skilled Respite in a facility is an "alternative" to institutionalization rather than simply the only nearby location from which families can receive Skilled Respite services. Relatedly, IDR is aggrieved that DDRS's justification for these short-term institutionalizations focuses on the needs of participants' family members, rather than the needs and desires of the actual participant. As always, IDR encourages FSSA and all of its subagencies to consider the service recipient with a disability over any other involved party when it comes to designing disability-based programming and services.
- Appendix C-1/C-3's description of Home Modification Assessment services states that there is an annual financial limit of $628 on these services, "unless the DA requests an additional assessment in order to help mediate disagreements . . . ."[52] IDR questions whether the reference to the DA is an anachronism, and whether it should be replaced with a reference to DDRS or BDS.
- IDR doubts that a 10-year maximum budget of $15,000 is sufficient for vehicle modifications.[53] IDR suggests that DDRS create a mechanism for participants to request an exception to the budget limit.
- In Appendix C-5-2, DDRS explains its plan to ensure compliance with the HCBS Settings Rule. However, IDR notes that few members of the public understand the details of DDRS's plan. IDR has submitted public comments in response to the heightened scrutiny review of well over 20 providers. In many of these cases, IDR concluded that the majority of those settings remain too institutional in nature to comply with federal HCBS requirements. However, IDR has not received a response to any of its public comments, nor has FSSA released information about whether any of the reviewed settings were granted an exception, remedied, or had their Medicaid contract terminated. Although DDRS suggests here that complaint investigations will be used as a measure of provider compliance,[54] IDR disagrees because H&W Waiver participants have not been substantively informed of the HCBS Settings Rule and their rights under it. Without this necessary foundation, DDRS will not receive settings-related complaints.

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[48] *See id*. at page 63.

[49] *Id*.

[50] *Id*. at page 78.

[51] *Id*.

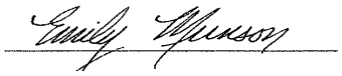
[52] *Id*. at page 103.

[53] *Id*. at page 146.

[54] *Id*. at page 169.

IDR appreciates the opportunity to share its concerns with FSSA, DDRS, and BDS. Our staff is available at your convenience to answer any questions about these comments or provide further detail regarding them. Should you wish to discuss the proposed waiver amendments further, please do not hesitate to contact me at emunson1@indianadisabilityrights.org.

Sincerely,



Emily Munson
Policy Director