INDIANA DISABILITY RIGHTS

August 8, 2025

Division of Disability and Rehabilitative Services
Family and Social Services Administration
Attn.: Bureau of Disability Services Waiver Notice and Public Comment
DDRSWaiverNoticeComment@fssa.in.gov

Office of Medicaid Policy and Planning
Family and Social Services Administration
Attn.: Holly Cunningham Piggott
INPathWays@fssa.in.gov

SENT ELECTRONICALLY

Re: Comments regarding the proposed amendment of five home and community-based services waivers

To Whom It May Concern:

Indiana Disability Rights (IDR) is the state's federally-mandated protection and advocacy system. IDR advocates with and for individuals with disabilities, including Hoosiers who participate in various Medicaid waiver programs. Specifically, IDR has represented individuals participating in the Family Supports (FS), Community Integration and Habilitation (CIH), Health and Wellness (H&W), Traumatic Brain Injury (TBI), and PathWays for Aging (PathWays) Waivers. In furtherance of its duty to systemically advocate for the rights of individuals with disabilities, including participants in the five forgoing waiver programs, IDR offers the following comments in response to recent amendments proposed by the Division of Disability and Rehabilitative Services (DDRS) and the Office of Medicaid Planning and Policy (OMPP).

On July 9, 2025, the Indiana Register published several notices on behalf of Family and Social Services Administration (FSSA) Secretary E. Mitchell Roob, Jr. Each notice announces the intent to amend components of the FS, CIH, H&W, TBI, and PathWays Waivers, effective December 31, 2025.[1] FSSA

[1] *See* Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Indiana Family Supports Waiver*, 20250709 IND. REG. 405250332ONA (July 7, 2025); Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Community Integration and Habilitation Waiver*, 20250709 IND. REG. 405250330ONA (July 7, 2025); Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Indiana Health and Wellness Waiver*, 20250709 IND. REG. 405250347ONA (July 7, 2025); Office of the Secretary of Family

4755 Kingsway Drive, Suite 100
Indianapolis, IN 46205
IndianaDisabilityRights.org

Phone: 317.722.5555
Toll Free: 800.622.4845
Fax: 317.722.5564

invites public comment through the end of business on August 8, 2025.[2] A brief and high-level summary of IDR's comments is provided in bullet-point format below. IDR's specific comments, as well as relevant reasoning justifying those comments, follows a summary. For the reader's ease, IDR has separated its commentary by waiver program.

Summary

In brief, IDR supports:

- FSSA's clear endorsement that HCBS Waiver participants can and should work, as well as its tandem efforts to support employment by adding the following services:
    - Benefits Counseling to each DDRS-administered waiver program;
    - Workplace Assistance to the CIH Waiver; and
    - Extended Services to the H&W Waiver.
- DDRS's decision to sunset facility-based Prevocational Services in favor of more individualized employment training and integration.

At the same time, IDR has concerns about:

- The introduction and maintenance of blanket limitations on certain HCBS Waivers, including:
    - Behavioral Support Services (monthly unit limit);
    - Home Modification and Assessment (lifetime financial limit);
    - Music Therapy (monthly unit limit);
    - Recreational Therapy (monthly unit limit);
    - Vehicle Modification (10-year financial limit);
    - the 40-hour limit on Attendant Care and Participant Assistance and Care services provided by legally responsible individuals; and
    - the 50-mile limit on Attendant Care providers transporting H&W Waiver participants across state lines.
- The proposed termination of Participant Direction Home Care Services without the introduction of a new service that would provide a comparable service to H&W Waiver participants.
- DDRS's interpretation of participant-direction, particularly in regard to adhering to principles that promote participant autonomy and the absence of government oversight/administrative requirements.
- DDRS's interpretation and inclusion of factors outside the statutory criteria when determining whether a CIH Waiver applicant meets the criteria for emergency placement priority.
- New procedures for determining a waiver applicant's level of care.
- Overly extensive newly introduced documentation standards for Attendant Care services.
- Foreclosure of the use of Attendant Care services while an H&W Waiver participant is at an acute care hospital.

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and Social Services, *Public Notice Regarding Amendments to the Traumatic Brain Injury Waiver*, 20250709 IND. REG. 405250348ONA (July 7, 2025); Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Indiana PathWays for Aging Waiver*, 20250709 IND. REG. 405250334ONA (July 7, 2025); and Office of the Secretary of Family and Social Services, *Public Notice Regarding Amendments to the Indiana PathWays for Aging Waiver*, 20250709 IND. REG. 405250331ONA (July 7, 2025).

[2] Id.

- The lack of transparency around provider compliance with the HCBS Settings Rule.

The remainder of these comments provide more extensive detail about IDR's reasoning.

Comments

FS Waiver

Employment. IDR supports DDRS's attempts to bolster opportunities for FS Waiver participants to obtain and maintain competitive, integrated employment (CIE). The agency's efforts are clear throughout the relevant proposed state plan amendment (SPA), from the statement that FS Waiver services "facilitate[] the individual's involvement in the community where they live and work,"[3] to the introduction of a Benefits Counseling service.[4]

Importantly, particularly in light of the U.S. Department of Labor's decision to rescind a notice of proposed rulemaking that proposed the cessation of 14(c) certificates, IDR appreciates DDRS's plan to discontinue the FS Waiver's current facility-based option for prevocational services.[5] Instead, the expectation is that participants graduating from high school will be steered toward CIE rather than sheltered work facilities and that participants currently engaged in sheltered work will be offered several services to explore and prepare for CIE opportunities. To that end, DDRS "will no longer approve new requests for facility-based prevocational services starting January 1, 2026."[6] Additionally, participation in prevocational services will be limited to an 18-month period.[7] Participants' receipt of prevocational services beyond 18 months is only permissible if their Individual Support Team (IST) agrees to a six-month extension, submits a plan to transition to CIE or a different FS Waiver service, and has submitted an application to Vocational Rehabilitation (VR).[8] Again, IDR is supportive of both DDRS's expectation that FS Waiver participants are capable of CIE and its attempt to address the many Hoosiers who have lingered – some for decades – in prevocational services without direction or goals.

Similarly, IDR strongly supports DDRS's proposal to include Benefits Counseling as a FS Waiver service. IDR agrees that providing participants with assistance "understand[ing] the potential impact of employment on [their] public benefits, such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, Medicare, food/nutrition programs, housing assistance, ABLE accounts, and other federal, state, and local benefits" is critical in addressing the reluctance of some participants – as well as their guardians and family members – to consider CIE a feasible pursuit.[9] Indeed, when IDR conducted a survey of sheltered workers in 2016, the majority indicated a desire to work in the community, but shared

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[3] Division of Disability and Rehabilitative Services, *Application for 1915(c) Home and Community-Based Services Waiver: Draft IN.007.05.01 – Dec 31, 2025*, 6, available at: https://www.in.gov/fssa/ddrs/ddrs-policies/ddrs-draft-policies-for-public-comment/ (under the subheading "December 2025 Waiver Amendments, click the bullet point "FSW") (last accessed: July 29, 2025). For the reader's ease, this Application will be cited using the title "Proposed FS Waiver Amendments."
[4] Id. at 102.
[5] Id. at 14.
[6] Id. at 64.
[7] Id.
[8] Id.
[9] Id. at 102.

that their guardians or family members were afraid that doing so would leave them without important public benefits. DDRS clearly acknowledges this phenomenon, explaining that the "service is intended to address fears about work-related income compromising benefits."[10] IDR further appreciates that the service is available not just to participants "considering or seeking [CIE]," but also to those pursuing "career advancement" and "self-employment."[11] The near universal availability of this proposed service evidences DDRS's commitment to not only help participants get a foot into the proverbial door of CIE, but rather to support participants throughout multiple stages of their career.

IDR also notes a need for further clarity. For example, in discussing Person-Centered Individual Support Plans (PCISPs), DDRS highlights the importance of following the Charting the LifeCourse (CTLC) Framework, "comprised of eight principles and a set of tools that support the use and application of the principles."[12] IDR is curious how DDRS plans to leverage the CTLC Framework's employment tools, if at all, during PCISP development and review. This question is especially poignant, given that the FS Waiver's mandatory Case Management service requires case managers to "support[] individuals to explore existing programs including pre-employment, extended services, and volunteer opportunities" and "access[] training opportunities and "shar[e] information individuals need to work and build wealth."[13]

Blanket Service Limitations. DDRS's plan to place a blanket limitation on certain FS Waiver services may interfere with individual participant needs. Specifically, in this section IDR refers to the proposed 12-hour monthly service limit on Behavioral Support Services,[14] six-hour monthly service limit on Music Therapy,[15] the "aggregate of forty (40) hours per week" per relative or legally responsible individual limit within the Participant Assistance and Care (PAC) service,[16] and six-hour monthly limit on Recreational Therapy services.[17] No justification is provided to support these service limits, nor does DDRS explain how it determined the proposed service limitations will adequately meet participant need.

Of these limits, IDR is most concerned about those pertaining to PAC services. IDR notes that multiple clients have shared that hiring direct support professionals is nearly impossible in some areas of the state, given the absence of willing and available prospective employees and, in other areas, the absence of home health companies. Although DDRS's proposal to allow participants to self-direct PAC services may alleviate the difficulty of finding willing assistance, that assistance may very likely be in the form of family members. By limiting these individuals to providing only 40 hours of service per week, DDRS effectively exacerbates the caregiver shortage. Moreover, because Medicaid pays family members the same rate as non-related PAC staff, DDRS's attempt to limit familial assistance appears irrational – particularly when these family

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[10] Id.
[11] Id.
[12] Id. at 6.
[13] Id. at 63.
[14] Id. at 98. (Notably, within the 12-hour monthly limit, service components are also time-limited. "Consultation is limited to an average of three hours monthly…. The Functional Behavioral Assessment component is limited to a maximum of 20 hours per plan year…. Comprehensive Behavioral Supports are limited to an average of 12 hours monthly or a maximum of 144 hours per plan year. [Finally, t]he Clinical Supervision component is limited to an average of one hour monthly or a maximum of 12 hours per plan year." Id.)
[15] Id. at 143.
[16] Id. at 147.
[17] Id. at 153.

members are keeping FS Waiver participants in the community rather than in an institution (which would cost Medicaid far more).

Relatedly, DDRS asserts that Legally Responsible Individuals (LRIs) cannot provide PAC services at all, absent a determination that the care being provided is of an extraordinary nature. IDR is concerned that DDRS subjects these LRIs, too, to a 40-hour per week maximum, despite the determination that the participant requires extraordinary care. Earlier this year, as DDRS considered a definition for "extraordinary care," IDR offered feedback agreeing that certain indicators of medical complexity should automatically cause a participant to be deemed as a recipient of extraordinary care.[18] Yet, IDR further urged DDRS to consider other factors as indicators for the delivery of extraordinary care, including the documented absence of other available PAC service providers.[19] Whether a participant cannot find a direct support professional nor agency other than an LRI, is immunocompromised and must limit their exposure to outsiders, has incredibly complex or difficult routine that requires a very specific direct support professional, or has another valid reason an LRI must provide more than 40 hours of care per week, IDR urges DDRS to carve out an exception to the 40-hour limit on LRI-provided PAC services.

Participant-Direction. IDR generally supports DDRS's introduction of a participant-directed (or self-directed) option for some services, including PAC, available through the FS Waiver. However, IDR has serious concerns about whether, as currently presented in the proposed SPA amendments, DDRS fully grasps the philosophy behind self-direction and, consequently, whether the new participant-directed option can reasonably be construed as self-direction.

Consider, for example, that "[a]ll direct care staff (including participant-directed staff) must be registered with DDRS and must complete competency-based training in accordance with [Ind. Code §] 12-11-16."[20] These requirements conflict with participants' employer authority; the state is encroaching on participants' autonomy as an employer, violating a core principle of self-direction. Beyond the overarching philosophical conflict, these requirements will constitute genuine burdens on FS Waiver participants and their employees.

Ind. Code 12-11-16-2 requires PAC service providers, including employees hired through self-direction per DDRS's interpretation,[21] to register so that substantiated claims of abuse, neglect, and/or exploitation committed by them can be tracked. Registry information will be available to DDRS staff "and authorized service providers."[22] Some potential hires are likely to forgo employment for various reasons related to the registry. Self-directed services are often informal; an employer may, for example, hire a neighbor to feed him dinner a few nights a week or hire a friend for help with PAC services while out in the community. The neighbor and friend are unlikely to work for other FS Waiver participants, as they are merely filling a gap rather than seeking a career as a direct support professional. Indeed, their interaction with the participant

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[18] Emily Munson, Michele Trivedi, and Amy Gaisser, *Letter to the Bureau of Disabilities Services in re. Proposed Definition of "Extraordinary Care,"* IND. DISABILITY RGTS., 3, June 13, 2025 (submitted electronically).
[19] *Proposed FS Waiver Amendments* supra, note 3 at 4.
[20] Id. at 148.
[21] The statute does not specifically mention direct support professionals hired through self-direction. However, it does give DDRS authority to adopt rules implementing a direct support professional abuse, neglect, and exploitation registry. *See* Ind. Code § 12-11-16-2(d).
[22] Ind. Code § 12-11-16-2(a).

may be sufficiently minimal that registration and other administrative burdens render their participation as a PAC service provider not worth the hassle. Obviously, this harms the participant. Other potential hires may fear unwanted solicitation by understaffed home health agencies or DDRS staff, declining an employment offer simply because they do not want to be on a registry. Perhaps the most compelling reason potential employees may refuse to accept an employment offer by a participant self-directing their services in light of this requirement is the fact that nearly 30% of the direct care workforce are immigrants.[23] Their proportional participation in the field is progressively increasing.[24] Notably, more than 300,000 of these immigrants are not citizens.[25] While some undoubtedly have legal status, as well as permission to work, others' employment may be unlawful. Such individuals – as well as some immigrants who may be here legally – are likely to be afraid to accept a job that mandates their inclusion in a government registry.[26] Thus, the burdens associated with registry enrollment, combined with the low probability that (1) a self-direction participant would hire an abusive, neglectful, or exploitative employee and (2) an employee hired by a self-direction participant would go on to commit an abusive, neglectful, or exploitative act against another Waiver participant, render DDRS's interpretation of the registry statute ill-considered.

Relatedly, the requirement that self-directing participants have their employees participate in mandatory "[g]eneral education and training in providing direct support to individuals with intellectual disabilities or developmental disabilities"[27] also violates employer authority. As DDRS maintains in Appendix E of the proposed SPA, FS Waiver participants who opt to self-direct are responsible for training employees.[28] The ability to train employees in the manner the employer deems fit is one of the major benefits of self-direction, in that the employer establishes their own rules and norms (and disciplinary procedures) rather than remain subject to those of third-parties like home health agencies. Training offered by a FS Waiver participant can be individualized to their actual needs and preferences rather than those of others. In contrast, DDRS and "stakeholders who do not have a conflict of interest" would essentially co-train employees hired through participant-directed services.[29] For these reasons, again, it is problematic that DDRS has interpreted a statute to further encroach on employer authority. IDR further notes that this requirement is likely to deter some potential employees from accepting a job offer, such as those who already have a thorough understanding of the employer and their needs (e.g., parents who have already cared for the participant for more than 18 years) and individuals who are busy but willing to serve as back-up staff in emergencies (who may be unwilling to commit to a formal direct support professional certification process). Again, DDRS's inability to recognize how its interpretations jeopardize key self-direction philosophies is concerning.

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[23] Priya Chidambaram and Drishti Pillai, *What Role Do Immigrants Play in The Direct Long-Term Care Workforce?*, KAISER FAMILY FOUNDATION, available at: https://www.kff.org/medicaid/issue-brief/what-role-do-immigrants-play-in-the-direct-long-term-care-workforce/#:~:text=Immigrants%20make%20up%2028%25%20of,2018%20to%2028%25%20in%202023 (Apr. 2, 2025).
[24] Id.
[25] Id.
[26] IDR does not endorse unlawful hiring practices, but simply notes the reality of caregiver demographics in the U.S. FSSA has long recognized the shortage of caregivers in Indiana. Adopting policies and practices that further restrict the pool of potential direct support professionals only worsens this crisis.
[27] Ind. Code § 12-11-16-3(a)(1).
[28] *Proposed FS Waiver Amendments* supra, note 3 at 239.
[29] Ind. Code § 12-11-16-3(a).

Further, IDR is concerned that BDS is relying on case managers to "provide detailed information [about participant-direction] during service planning development."[30] IDR seeks information as to how BDS will monitor case managers to ensure that participants are informed about this service delivery model. As advocates have repeatedly informed DDRS, care managers facilitating participation in the former Aged & Disabled Waiver almost never told participants that self-direction was an option. Part of this phenomenon may have been due to a relatively low participation rate, combined with high turnover of care managers, leading new care managers to be largely unaware of the availability of participant-direction. Thus, IDR encourages BDS to implement procedures that do not leave case managers as the sole gatekeepers to participant-direction. A simple solution may be developing a fact sheet about FS Waiver changes, including the new Benefits Counseling service and participant-direction opportunities, to each participant. This document could also be shared on the FSSA website for participants to find any reference individually.

BDS's Quality Assurance and Improvement Procedures. IDR is concerned regarding the length of time BDS allows providers to violate waiver standards. Specifically, BDS states that only after receiving "information regarding ongoing, systemic behaviors on the part of a provider," is a case manager required to "[a]ttempt to resolve the issue verbally with the provider."[31] Only if that is unsuccessful may the case manager address the issue in writing.[32] If the provider does not effectively address the issue, the case manager is finally permitted to report the provider to BDS.[33] The case manager cannot file a formal DDRS complaint until the local BDS office is unsuccessful in getting the provider to correct itself.[34] Even then, DDRS gives the provider multiple opportunities to draft and show compliance with a corrective action plan before reporting the provider to the sanctions committee. These procedures not only allow providers to be noncompliant for months at a time, but also jeopardize participants' rights – and potentially safety – in the process.

Additionally, IDR notes some concern regarding the composition of the Quality Improvement Executive Committee (QIEC), the body responsible for "identifying needed system improvements, and then designing, implementing, and monitoring" them.[35] The QIEC, per DDRS, "include[s] representatives from all of the entities involved in overseeing waiver services," namely OMPP, BDS, and the BDDS quality assurance and quality improvement (QA/QI) contractor.[36] IDR is concerned that the majority of these committee members view QA/QI through a very similar perspective, given that they are all part of FSSA, as employees or contractors. IDR suggests it would be helpful to have more voices within the QIEC, especially those of waiver participants. IDR further notes that, now that FS Waiver participants may self-direct multiple waiver services, participants opting for that delivery model also have a role in directly implementing and monitoring waiver services. They should also be permitted to share their ideas for systemic improvement in a meaningful way.

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[30] *Proposed FS Waiver Amendments* supra, note 3 at 237.
[31] Id. at 218.
[32] Id.
[33] Id.
[34] Id. at 252.
[35] Id. at 260.
[36] Id.; *see also* id. at 299-300 (reiterating that the QIEC is comprised of "entities within [FSSA]." The complete membership list is: BDS leadership; a BDS provider services representative; a BDS HCBS program representative; a BDS HCBS policy team representative; an OMPP representative; BDS's QA/QI contractor; and data analysts from BDS.)

Representation of waiver participants, by waiver participants, is particularly important given limited opportunities for their participation in shaping the direction and strategies used by FSSA, DDRS, and BDS. In particular, DDRS notes that it relies on a variety of third-party data, from surveys like the National Core Indicators (NCI) project to data from federal agencies, provider surveys, and provider workgroups.[37] Yet, of these resources, only the NCI project communicates directly with participants – and, even then, participants are not speaking with FSSA decision-makers. The NCI survey also targets only a sampling of participants, meaning that many may have pertinent ideas and information to share but lack the opportunity.

CIH Waiver

IDR echoes each of its FS Waiver comments that are relevant to DDRS's proposed amendments to the CIH Waiver. For example, just as IDR supports BDS's expectation that FS Waiver participants will pursue CIE, the agency also supports the same expectation for CIH Waiver participants.[38] Similarly, IDR supports the improvement and introduction of new employment services and supports to the CIH Waiver population, including the new Benefits Counseling service. Although these examples are both supportive of the proposed CIH Waiver amendments, IDR adds that applicable concerns and questions regarding proposed amendments to the FS Waiver also apply here.

Criteria for Emergency Placement. IDR maintains that DDRS is misstating the statutory criteria for emergency placement on the CIH Waiver (and reminds DDRS that this misunderstanding has been the basis of several judicial review cases in which IDR clients prevailed in becoming CIH Waiver participants.) DDRS correctly notes that eligibility for the CIH Waiver is provided by Indiana statute. Specifically, the General Assembly directed DDRS to obtain federal approval "to set an emergency placement priority for individuals in" four situations:

> (1) Death of a primary caregiver where alternative placement in a supervised group living setting:
>
> (A) is not available; or
>
> (B) is determined by the division to be an inappropriate option.
>
> (2) A situation in which:
>
> (A) the primary caregiver is at least eighty (80) years of age; and
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> (B) alternate placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.
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> (3) There is evidence of abuse or neglect in the current institutional home or placement, and alternative placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.

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[37] Id. at 300 and 312.

[38] DDRS, *Application for 1915(c) Home and Community-Based Services Waiver: Draft IN.006.05.01-Dec 31, 2025*, 6, available at: https://www.in.gov/fssa/ddrs/ddrs-policies/ddrs-draft-policies-for-public-comment/ (under the subheading "December 2025 Waiver Amendments, click the bullet point "CIH") (last accessed: Aug. 4, 2025). For the reader's ease, this Application will be cited using the title "Proposed CIH Waiver Amendments."

> (4) There are other health and safety risks, as determined by the division director, and alternate placement in a supervised group living setting is not available or is determined by the division to be an inappropriate option.[39]

Such are the actual criteria for the CIH Waiver's emergency placement priority.

Nonetheless, DDRS is attempting to further limit eligibility for emergency placement priority, as evidenced by its slightly – but consequential – description of this priority in its proposed amendments. DDRS states that CIH Waiver priority is available to "individuals with intellectual disabilities [who are . . .] associated with one or more of the following" criteria:

> 1. Death of a primary caregiver;
> 2. The primary caregiver is at least eighty (80) years of age;
> 3. There is evidence of abuse or neglect in the current institutional or home placement; and/or
> 4. There is evidence of other health and safety risks, as determined by the division director of [DDRS] where other available services through:
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> > (a) the Medicaid program and other federal, state and local public programs; and
> > (b) supports that families and communities provide;
> > are insufficient to address the other health and safety risks, as determined by the division director of [DDRS].[40]

DDRS's additional qualifiers for emergency placement priority do not exist in statute. Moreover, the agency, in its role as the ultimate authority for administrative review purposes, has interpreted its own standard to require applicants to proactively demonstrate the absence of other government, community, or familial resources. In doing so, applicants are expected to apply for every potential government program, even if the applicant is clearly ineligible, to procure a denial letter to show DDRS. Relatedly, if an applicant is potentially eligible for a disability-related good or service from another party, such as a local education agency, DDRS will maintain that the applicant is entitled to that good or service, regardless of whether the school system refuses to amend the applicant's Individualized Education Plan to provide it. DDRS also uses its restatement to justify its assumption that family members are willing and able to serve as unpaid caregivers.

State courts have overturned several cases upon judicial review, finding that DDRS had erred in denying emergency placement priority to several CIH Waiver applicants who met statutory criteria (but allegedly failed to meet DDRS's stricter interpretation of it). As such, IDR suggests that DDRS submit the relative statutory language to the Centers for Medicare and Medicaid Services (CMS) rather than its stricter qualifiers.

It appears DDRS is attempting to limit other priority categories through these proposed waiver amendments, too. Instead of simply repeating that CIH Waiver slots will be reserved for applicants whose primary caregiver is 80 years of age or older, DDRS again adds criteria that are neither present in statute nor its

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[39] Ind. Code § 12-15-1.3-15(c).
[40] *Proposed CIH Waiver Amendments* supra, note 38 at 36.

earlier recitation of reserved capacity criteria. It states that the primary caregiver, in addition to meeting the age threshold must be incapable of continuing to provide "care for the individual in question," and the applicant must be "in need of immediate care that cannot be provided in any other manner."[41] Apart from the fact that these additional criteria are statutorily unsupported, it is unclear how DDRS would assess whether a primary caregiver is incapable of caring for the applicant and how an applicant can prove that absolutely no alternative other than the CIH Waiver can provide immediate care. The additional criteria also ignore applicants' long-term needs.

Level of Care Redeterminations. IDR is concerned that DDRS's safeguard to ensure annual level of care redeterminations occur in a timely manner may adversely and abruptly curtail CIH Waiver participants' access to critical services and supports. DDRS reports "that the State's electronic case management data system is . . . programmed so that it does not permit State approval of a service plan . . . for which the level of care determination or redetermination has not been made within the past 12 months."[42] Given that a State-approved service plan is necessary for service approval,[43] IDR is concerned that CIH Waiver participants' services will be automatically terminated by electronic systems for reasons beyond their control. For example, if a case manager overlooks the need to conduct a redetermination by a particular date, or if a case manager is late in submitting redetermination documents, participants may face service termination.

IDR is also concerned about DDRS's ability to work around the electronic case management data system to promptly reinstate participant services. IDR is aware of multiple individuals with disabilities who had critical, life-sustaining waiver services erroneously terminated by the State's electronic data system. While FSSA and the Division of Family Resources (DFR) acknowledged that the terminations were inappropriate, DFR representatives told waiver participants that they could not change the data system's default denial setting and, consequently, reinstate services. It took FSSA between three weeks and seven months to fully restore waiver participation in these cases. Based upon FSSA and DFR's history of accidentally depriving waiver participants of services, IDR hopes that DDRS will analyze past mistakes and ensure that technology and automation do not lead to the automatic termination of waiver services and supports.

Participant-Direction. While IDR generally supports opportunities for CIH Waiver participants and their family members to exercise choice, IDR is concerned that DDRS plans to allow guardians of participants and representatives chosen by guardians or family members to engage in decision-making on behalf of participants through the new participant-direction model of delivery for three Waiver services.[44] In situations where participants choose to delegate a representative to make decisions about direct support personnel – as well as when guardians make those decisions on behalf of participants – the participant is clearly *not* directing their own services. Although CMS may allow representatives within participant-directed programming, logically, these representatives should only be used when the participant needs a reasonable accommodation from service rules and policies that would otherwise require their direct engagement; CMS's intent was surely not to defer to the wishes of guardians and family members. Indeed, DDRS

[41] Id.
[42] Id. at 53.
[43] Id. at 60 and 284.
[44] Id. at 312. Specifically, the three services that can be participant-directed within the CIH Waiver are Hourly Residential Habilitation and Support, Respite, and Workplace Assistance.

recognizes that the purpose of participant-direction is to give participants "[a]n opportunity to exercise more autonomy . . . ."[45]

Instead of a true self-direction program, it appears that DDRS is attempting to impose family-directed and guardian-directed service delivery models into the now-existing self-direction option available through the H&W Waiver. This expansive "participant-directed" delivery model will be universally applied across all DDRS-administered waivers, as well as the OMPP-managed PathWays Waiver. Yet, the safeguards allegedly necessary to curtail possible abuse and fraud within the family-directed and guardian-directed models – such as intimately involving case managers – fundamentally alter true self-direction principles. Allowing non-participants (who are not needed as a reasonable accommodation) to make decisions under a participant-directed delivery model not only jeopardizes participant autonomy but also, pragmatically, unnecessarily burdens those waiver participants who are perfectly capable of independently directing their services.[46]

H&W Waiver

Any IDR comments made in regard to proposed FS and/or CIH Waiver amendments apply to the H&W Waiver, as relevant. For example, IDR continues to support new waiver services that promote employment, including the addition of Benefits Counseling.[47] Further, IDR's concerns about the erosion of self-direction, expressed above in the sections pertaining to the FS and CIH Waiver, apply in regard to proposed amendments to the H&W Waiver.[48]

Notably, IDR's concerns about the 40-hour per week limitation on certain providers, specifically raised in regard to LRIs and their ability to serve FS Waiver participants receiving PAC in a paid capacity,[49] also apply to the H&W Waiver's pending 40-hour per week limitation on LRIs providing paid attendant care

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[45] Id.

[46] For several months, a group of H&W Waiver participants who self-direct their attendant care services, caregivers, and other waiver participants met with DDRS Director Kelly Mitchell and BDS Program Manager Heather Dane. To IDR's knowledge, the three participants currently self-directing provided the only insights DDRS and BDS received from individuals with direct lived experience using the delivery model in Indiana, as opposed to from out-of-state consultants with professional affiliations (i.e., ADvancing States representatives) and third parties (i.e., Indiana disability organizations managed by people without disabilities or people whose disabilities would not qualify them for participation in an HCBS waiver). The three H&W Waiver participants regularly and strenuously advised DDRS and BDS against case manager involvement, and urged the agencies to take a different approach in regard to family- and guardian-direction, rather than transform the existing self-direction model to include them.

[47] DDRS, *Application for 1915(c) Home and Community-Based Services Waiver: Draft IN.004.07.05-Dec 31, 2025*, 86, available at: https://www.in.gov/fssa/ddrs/ddrs-policies/ddrs-draft-policies-for-public-comment/ (under the subheading "December 2025 Waiver Amendments, click the bullet point "H&W") (last accessed: Aug. 6, 2025). For the reader's ease, this Application will be cited using the title "Proposed H&W Waiver Amendments."

[48] Indeed, because the H&W Waiver population is primarily comprised of the target demographic for self-direction service delivery, and because some H&W Waiver participants have been self-directing their attendant care services for decades, many of the concerns IDR has previously raised in regard to the expansion of participant-direction are especially relevant, and uniquely harmful to, these participants.

[49] *See* page 4.

services.[50] If anything, IDR's concerns about the limit are heightened because H&W Waiver participants' complex physical conditions may require individual caregivers to spend significant time providing hands-on care. A morning routine for someone with a spinal cord injury, for example, may require waking them, giving them time to prepare for the disconnection of their C-PAP machine, administering an enema, transferring the participant into a sling, using a Hoyer lift to transfer the participant into a shower chair, wheeling them over the toilet, waiting while the participant urinates and completes a bowel routine, wiping the participant, wheeling them to the shower, bathing them, drying them, wheeling the participant back to their bedroom, transferring the participant back into bed, rolling the participant to ensure no issues with skin integrity, holding up clothing so the participant can choose their outfit, dressing the participant, using a new sling (or, having earlier thrown the wet sling in the dryer, waiting for it to be "dry enough" before using it) to transfer the participant to their wheelchair, taking out the sling, positioning the participant comfortably, applying makeup, styling hair, preparing a high-protein breakfast of scrambled eggs, sausage, and fortified orange juice, cutting the food into bite-sized pieces, feeding the participant, cleaning up the kitchen (and participant, depending on the caregiver's feeding skills), gathering the items the participant needs for work, starting the vehicle and tying the participant's wheelchair down inside of it, and driving the participant to their office. Just getting this participant out-the-door easily takes three or four non-stop hours of attendant care. Requiring high-acuity H&W Waiver participants, who need more hands-on and, often, more physically burdensome care to adhere to the same 40-hour limit as someone who may only need a total of, say, three hours of waiver services has a discriminatory effect.

Attendant Care Transportation Limit. DDRS notes that attendant care services may include incidental homemaking and transportation. Nonetheless, that "transportation is limited to 50 miles of State geographic limits."[51] IDR notes this 50-mile limit seems arbitrary and to conflict with H&W Waiver participants' constitutional right to travel. IDR suggests that it would be helpful if DDRS explained its justification for this service limit.

Attendant Care Documentation Standards. IDR strongly opposes DDRS's proposed requirement that "[e]ach staff member providing direct care or supervision of care to the individual must make at least one entry for each hour of service. All entries should describe an issue or circumstance concerning the individual."[52] First, IDR asks DDRS whether it intends to enforce this standard on H&W Waiver participants who are self-directing their attendant care. If so, this standard would serve to further erode the participant's ability to manage their own care as they see fit. That is, the more the State establishes administrative requirements, the less opportunity the participant has to make decisions about how they and their caregivers do business. It is not unreasonable for a self-directing participant to be frustrated that their caregiver's paid time is being used to create case notes rather than provide hands-on care. This frustration is further exacerbated by earlier-referenced policies restricting LRIs to providing a maximum of 40-hours of weekly care. Moreover, while DDRS's likely justification for this requirement is to ensure Medicaid is only being billed for approved services or to alert oversight entities to participant jeopardy, those capable of managing their own attendant care are also generally capable of terminating staff involved in fraudulent activity (as well as simply refuse to sign incorrect timesheets) and seek medical or legal protection when needed.

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[50] *Proposed H&W Waiver Amendments* supra, note 47 at 62.
[51] Id. at 61.
[52] Id.

Even if attendant care provided via participant-direction is exempted, it remains problematic due to privacy concerns. Very few participants want anyone, let alone an electronic database, to have information about how they spend each hour of each day, which would be the consequence of this standard for H&W Waiver participants with significant care needs. This standard effectively allows the State to enter participants' lives, homes – even into their bathrooms! IDR urges DDRS to reconsider this proposed amendment.

Home Modification and Assessment Service Funding. IDR notes that DDRS's lifetime limit for Home Modification and Assessment (HMA) services is $20,000 per participant.[53] Yet, that sum is insufficient to cover some of the modifications that DDRS specifically allows. For example, DDRS allows the "[i]nstallation of [a] vertical lift and/or stair lift . . . in lieu of a ramp" when a ramp is infeasible to meet the participant's needs.[54] However, earlier this year, IDR heard from an individual in the process of obtaining home modification through Vocational Rehabilitation. The architecture of the individual's home did make a ramp infeasible, requiring the home modification assessor to obtain bids for a vertical lift. The lowest bid was more than $30,000. IDR suggests that DDRS allow participants using HMA services to request an exemption to the $20,000 lifetime cap so that permitted goods can be fully covered by the H&W Waiver.

Termination of Participant Directed Home Care Service. IDR ardently encourages DDRS to reconsider its proposal to terminate the H&W Waiver's current Participant Directed Home Care Service (PDHCS). IDR reminds DDRS that this unique program was created as a response to then-Aged and Disabled Waiver participant Karen Vaughn's successful Olmstead litigation against FSSA.[55] Since its inclusion as a H&W and PathWays Waiver service, IDR is aware of only a small contingent of participants eligible to participate in PDHCS.[56] Notably, participants have found PDHCS to be empowering and the only HCBS waiver service that is truly tailored to meet their needs; the initial pilot and consequent rollout as a waiver service has been extremely successful. As such, IDR questions why DDRS would eliminate this service for eligible participants.[57] It seems that doing so will increase the likelihood that the few current PDHCS participants will be institutionalized.

OMPP may claim that, aside from the human toll, the institutionalization of these participants has no bearing on the budget, as PDHCS participants work with the same annual budget that a nursing facility would receive for their care. Yet this assumption is false. Neither FSSA nor any of its divisions has maintained fraud or abuse within PDHCS participants' budgets. Indeed, an IDR employee who uses PDHCS shares that she prudently uses only one-third of her budget, while fairly compensating caregivers, and the remaining two-thirds is returned to FSSA at the end of the budget cycle. Although but one anecdote, this

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[53] Id. at 116. (Although a participant can access an additional $1,000 per year to maintain and/or repair existing home modifications purchased by the H&W Waiver.)
[54] Id. at 115.
[55] *See Karen D. Vaughn v. John J. Wernert, M.D. et al.*, No. 1:16-cv-03257-JMS-DLP (S.D. Ind. Jan. 9, 2019).
[56] *Proposed H&W Waiver Amendments* supra, note 47 at 296 (showing that, in the prior two years, just four and three participants, respectively, needed this critical service).
[57] Specifically, IDR notes that, unlike most other H&W Waiver services, "PDHCS may be provided twenty-four (24) hours per day, seven (7) days a week." Id. at 132. Thus, PDHCS participants are among the most vulnerable; DDRS recognizes the service is critical to "meeting the chronic personal needs of the participant to maintain a level of function . . . to avoid unnecessary institutionalization." Id. Similarly consider that the average PDHCS consumer used 14,022.4 units of service compared to the 4474.6 units of service used by those receiving attendant care.

situation demonstrates that PDHCS has been a wonderful development for H&W Waiver participants, caregivers, and the State.

DDRS has not announced how participant budgets will be developed outside of PDHCS. The average cost of one PDHCS service unit was most recently logged at $14.91.[58] However, that average cost of self-directed attendant care services is projected to be just $8.52 per service unit.[59] The lower reimbursement rate will necessarily require current participants using PDHCS to hire new caregivers, willing to accept lower reimbursement rates. Again, this jeopardizes these participants' well-being, safety, and quality of care, as well as heightens the risk that they will be institutionalized – particularly in the middle of a direct service staffing crisis.

More technically, IDR also questions why DDRS plans to eliminate PDHCS one day before instituting all other proposed H&W Waiver amendments; the proposed SPA states that termination will be effective "as of 12/30/2025,"[60] rather than December 31, 2025.[61]

Vehicle Modification Service Funding. IDR is concerned that the $15,000-per-decade capitation on funding for vehicle modifications is insufficient to meet some participants' disability-related needs.[62] A participant who cannot transfer from their wheelchair for transport generally requires an entire package of vehicle modifications, including the installation of an automatic ramp or lift, removal of the passenger seat and middle row of seats, and wheelchair tiedowns. If the participant is tall, they may also need the floor of their vehicle lowered or the vehicle's roof raised. Such extensive structural modifications are expensive, easily costing more than $15,000. For that reason, IDR suggests that DDRS create an exception process for participants who need vehicle modifications that cost more than $15,000 to be effective. Such an exemption process was similarly recommended by IDR in regard to the HMA service lifetime limit.[63]

Refusal to Allow Services in Acute Care Hospitals. IDR is concerned that DDRS will not permit H&W Waiver participants to use attendant care while in an acute care hospital. Given that many participants are medically complex and physically disabled, they likely need assistance during an emergency room (ER) visit and/or hospital stay. Participants may wait hours in an ER before even making it to an exam room; during that time, they may need assistance drinking, eating, repositioning, or engaging in another activity that hospital staff are unlikely to provide. During diagnostic testing, participants may need a caregiver to ensure that transfers to and from various medical devices is safe and smooth.

Even if DDRS only intends on this prohibition being applied after a participant is admitted to the hospital as a patient, it is still problematic. In theory, hospitals have certified nursing assistants (CNAs), techs, and "sitters" available to fulfill the role that an attendant caregiver would ordinarily provide a patient with a disability. However, funding realities, hospital policies, and the national nursing shortage often mean that

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[58] Id. at 296.
[59] Id. at 297.
[60] Id. at 296.
[61] *See*, for example, id. at 107.
[62] Id. at 152. Although IDR raises this concern within the context of the H&W Waiver, whose population, as a whole, likely requires the most expensive vehicle adaptations, the same concern applies to all HCBS waiver participants who need extensive vehicle modifications.
[63] *See* page 12.

CNAs and techs are used to support nurses execute more medically-oriented tasks, rather than be available to patients who need assistance with tasks like their hygiene routine, ordering meals, eating, and repositioning on an as-needed basis (rather than on a two-hour schedule). IDR is aware of patients who have gone without meals in acute hospital settings because no one feeds them before the cafeteria staff returned to collect their tray. Eating is one of several critical activities of daily living that could better be provided by attendant caregivers than hospital staff unfamiliar with participant needs. Indeed, H&W Waiver participants likely would prefer to receive assistance from their own caregiver, who has an established routine with the participant and knows their preferences, rather than from a new stranger each shift of their stay. This preference would only be magnified in an acute hospital setting, as the participant is presumably ill and further limited by the physical inaccessibility of their environment. For the foregoing reasons, IDR suggests that DDRS reconsider this limit in its entirety or, alternatively, allow for an exception process in which participants who have a compelling need (i.e., those who require significant assistance completing activities of daily living and those who have significant communication difficulties) can receive attendant care services while hospitalized.

Response to Appendix C-4-a. CMS asks whether DDRS places any limits on the amount of H&W Waiver services that a participant can access.[64] Initially, DDRS checked a box indicating no "limit[s] on the amount of waiver services except as provided in Appendix C-3."[65] Yet, DDRS's sole response to Appendix C-3 is: "'Service Specifications' [are] incorporated into Section C-1 'Waiver Services.'"[66] By checking the box for no additional service limits, rather than the box for "Applicable," DDRS escapes having to delineate whether services are limited by: setting limits on the maximum amount that one or more waiver service may cost; limiting the maximum amount of collective waiver services available to each participant; setting participant budgets based on the level of support they need; or establishing another service limit.[67] Because DDRS has established the first kind of limit on several services, including HMA and Vehicle Modification services, its response to Appendix C-4-a is confusing. This confusion is amplified by the fact DDRS includes a narrative about PDHCS funding in the unchecked box indicating the use of another kind of limit.[68] IDR advocates for greater transparency when it comes to service limitations and budgeting.

Compliance with the HCBS Settings Rule. CMS's revised waiver amendment template now requires States to attest to compliance with the federal HCBS Settings Rule.[69] It further requests a description of how such compliance is established and ensured.[70] For several years, IDR has been concerned that FSSA's Division of Aging and OMPP have not been rigorously enforcing the Rule, particularly as it applies to assisted living facilities (ALFs). Since ALFs have been eligible for heightened scrutiny review, IDR has dutifully provided public comments expressing concerns about ALFs co-located with (and sometimes within) nursing facilities, mingling funds with nursing facilities, sharing staff with nursing facilities, applying a single set of policies across the ALF and nursing facilities, denying unregistered visitors, and otherwise undeniably in violation of the Rule. Once submitted, IDR is unaware to what extent FSSA reviews, responds to, or seeks to remediate the ALFs issues of noncompliance.

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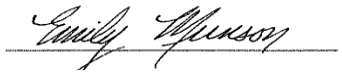
[64] Id. at 179.
[65] Id.
[66] Id. at 179.
[67] Id.
[68] Id.
[69] 42 C.F.R. § 441.301.
[70] *Proposed H&W Waiver Amendments* supra, note 47 at 181.

Importantly, DDRS's answers do not alleviate IDR's concerns.[71] First, it acknowledges reliance predominantly on four tools: provider applications and reverifications, in which the provider self-attests to its compliance with the Rule at least every four years; service plan development and reviews, in which the case manager completes a systemic verification process if the participant's chosen residential setting is provider-owned or controlled and FSSA reviews a sampling of these plans, annually; the provider compliance review process, which includes FSSA reviewing providers' compliance with state and federal rules and asking participants if they are receiving quality services, and occurs every three years; and complaint investigations, in which a case manager or BDS staff investigate noncompliance.[72] IDR notes that a provider could be out of compliance with the Settings Rule for multi-year stretches, and that outside of the complaint process, there are limited opportunities for participants to communicate with FSSA to share their perspective on service quality and unmet needs.

IDR is especially concerned that DDRS admits its reliance on the complaint investigation process to identify noncompliant providers. Unlike the FS and CIH Waiver populations, when the Settings Rule went into effect, H&W Waiver participants and their family members were not involved in education about the new law. Resultantly, IDR expects that many ALF residents are unaware of the treatment to which they are entitled under the Settings Rule. Pragmatically, because participants may not know their rights are being violated, they are unlikely to file a complaint with their case manager or DDRS. IDR encourages FSSA to be more transparent about the HCBS Settings Rule and to engage more frequently with H&W Waiver participants.

In closing, IDR appreciates the opportunity to share its feedback on proposed HCBS waiver amendments with FSSA prior to their potential implementation. Should there be any questions regarding the above comments, or should FSSA personnel wish to discuss any of IDR's suggestions in greater detail, please do not hesitate to contact Policy Director Emily Munson at emunson1@indianadisabilityrights.org.

Sincerely,



Emily Munson
Policy Director

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[71] By the effective date of the proposed waiver amendments, the Division of Aging will be moved under the DDRS umbrella and become the Bureau of Better Aging. DDRS will be renamed the Division of Disability, Aging, and Rehabilitative Services (DDRS). FSSA, *Introducing Indiana's Bureau of Better Aging and the Division of Disability and Rehabilitative Services* [sic], listserv email sent Aug. 1, 2025. Because this announcement was delivered at the end of the public comment period, IDR has attempted to avoid confusion by using agency names established at the beginning of the public comment period and use within the proposed amendment documents throughout these comments.

[72] *Proposed H&W Waiver Amendments* supra, note 47 at 181.