

April 3, 2017

Department of Health Services
Statewide Transition Plan – Comment
P.O. Box 7851
1 W. Wilson St., Room 518

To Whom it May Concern:

These comments are submitted by Disability Rights Wisconsin in its capacity as the Protection and Advocacy system for people with disabilities in Wisconsin.

We appreciate the efforts by DHS staff to craft a HCBS transition plan that attempts to achieve the goals set forth in the HCBS settings rule. Because Wisconsin has been a leader in the home and community based services realm, we have a regulatory and policy framework that goes a long way towards compliance with the requirements of the HCBS rule. But good regulations and good policy don't ensure that people's experiences will be compliant with the rule unless there is sufficient oversight by DHS.

As discussed below, we have a few suggestions for improvement to the technical process of determining HCBS compliance. But our main concern is that DHS develop an oversight capacity that will be able to assure that all of Wisconsin's Waivers allow people to live their lives with the same degree of dignity, privacy, personal choice and community involvement as we would all want for ourselves. We recognize that these are amorphous principles. It is not easy to craft objective, measurable criteria for evaluating them. But if we cannot be sure that these principles are being fulfilled, we will not know if we are complying with the mandate of the rule. We know that DHS is in the process of adapting and adopting a version of the National Core Indicators into its HCBS quality assurance regimen. This plan would be significantly improved if it specified how the results of using the NCI data will be incorporated into DHS's plan to continue to monitor its waivers for compliance with the rule and its laudable objectives.

A. Person-Centered Planning as a Compliance Technique

The plan relies heavily on the use of the person-centered planning (PCP) process to actually ensure that many of the HCB services are being provided in compliance with the regulation. While we absolutely support the use of PCP to tailor services to individual needs, we have identified three problems with the proposed plan.

1. Follow-up when Noncompliance Found

First, the plan does not indicate what will happen if, as part of an individual person-centered planning process, a setting or delivery of a service is found to be noncompliant. Will the care coordinator, case manager or IRIS Consultant be required to report to DHS? Will such a report

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trigger an onsite review? We assume that both will happen, but it needs to be spelled out in this plan.

2. Choice of Setting and Services

Second, the draft plan correctly indicates that “choice of setting, choice of providers, preference for a private room or a roommate, and financial support for access to activities in the community” are matters that are determined by the participant and the care coordinator in the context of the person-centered plan. The section in the plan acknowledging this fact needs to be strengthened by mandating that all participants be given, at minimum, the choice of at least one community integrated provider for each service in the participant’s plan. Failure to identify such a provider should result in a finding that the PCP process has failed to comply with the HCBS rule.

3. Ensuring the PCP Process is Not Used to Undermine the Rule

Person Centered Planning permits plans to include one or more exceptions to HCBS settings rule: For example, a resident diagnosed with an eating disorder may not be given access to food throughout the day if his or her person-centered plan provides an exception to the relevant HCBS settings rule. CMS requires waiver agencies to document that any modification of the additional conditions must be supported by a specific assessed need and justified in the person-centered service plan. The plan must also Identify a specific and individualized assessed need; document the positive interventions and supports used prior to any modifications to the person-centered service plan; document less intrusive methods of meeting the need that have been tried but did not work; include a clear description of the condition that is directly proportionate to the specific assessed need; Include a regular collection and review of data to measure the ongoing effectiveness of the modification; include established time limits for periodic reviews to determine if the modification is still necessary or can be terminated; include informed consent of the individual; and include an assurance that interventions and supports will cause no harm to the individual. See 42 CFR sec. 441.301 (c) (4)(xiii). A system of monitoring of these cases by the SMA should be described in this plan in order to prevent waiver agencies from circumventing the regulations by use of exceptions to the person-centered plan.

4. Changes to Service Authorization Methodology and PIHP (MCO) Contract

Third, the authority often cited for why this process will result in HCBS rule compliance is the pamphlet “Being a Full Partner in Family Care.” This pamphlet is neither a regulation, formal policy nor a contract provision. It is an informational pamphlet only. PIHPs (in Wisconsin, “MCOs”) are concerned with contract compliance, not adherence to aspirational statements in informational material. When a PIHP is considering which service or services it will authorize to meet the person’s outcomes, it uses the “Resource Allocation Decision Method” (RAD). The RAD is discussed in Article V, Section K. of the PIHP contract. It is within that process that the care team and the member decide which services the member will actually receive. Within that process the integrative nature of *residential* services is a specific consideration, albeit an equivalent consideration to “cost effectiveness.” It is not a specific criterion for any other

service. See PIHP Contract, Art. V. K. 2.(c). In this regard, the Wisconsin system is noncompliant with the HCBS rule. In practice, the absence of an “integration mandate” for nonresidential services results in integration being an inferior consideration to the consideration of cost effectiveness. We believe, to comply with the HCBS rule, that the integrated nature of the service should be elevated to the primary consideration in the RAD process, for both residential and nonresidential services. Cost effectiveness should only become relevant if alternative means of meeting the member’s outcome are equally integrative.

As an example, DHS encourages PIHPs to enter into “scope of services” agreements with residential providers that essentially require the residential provider to provide additional, nonresidential HCB services to their tenant/member. Typically, these agreements require the provider to also furnish transportation, day services, daily living skills training and/or sometimes employment. The PIHP may increase, somewhat, the rate it pays the provider to also furnish these additional services. But the small rate increase is insufficient to allow the residential provider to hire outside providers deliver them. Instead, the provider uses onsite facilities and existing staff to deliver them. The RAD process typically finds them to be sufficient to meet the member’s outcomes, so long as they superficially meet the aim of community integration. In practice, the bundling of those services results in the person being isolated in his/her residential placement. Day services, daily living skills training and employment services are provided onsite at the residential placement. The provider saves on transportation costs because it doesn’t take the person anywhere. It saves on personnel costs by having its regular residential staff provide the other services in addition to their residential care duties. The member’s individual preferences and choice are less likely to be honored, and frequency of services suffers. We believe that use of these “scope of services” contracts creates a direct contradiction to the HCBS rule.

The HCBS transition plan should acknowledge that, for the services DHS considers the PCP process to be the failsafe guarantor of the HCBS rule, it will be amending the RAD service authorization process and specifically elevating the importance of HCBS rule compliance in the process. At a minimum, it will clarify that the integrative nature of the proposed service is a superior consideration to that of cost-effectiveness. These changes should be made to Article V, section K. of the PIHP contract. Specific cross-reference to the HCBS rule and a requirement that all providers and PIHPs comply with it, should be added to the same contract section.

B. Review and Validation of Self-assessments: P. 12

We are pleased to see that DHS will be conducting on-site validation reviews of a representative sample of settings that have self-assessed as being in full compliance with the HCBS rule. Two important items are, however, missing from the proposal.

First, the proposal needs to explain what it considers to be a “representative” sample size. The sample must be sufficient to ensure that DHS is obtaining an accurate picture regarding the accuracy of the self-assessment process.

Second, the proposal lacks an explanation of what will happen if it is found that a significant percentage of the randomly sampled settings incorrectly self-assessed as being in compliance. Ideally the plan should identify how specific percentages of incorrect self assessments will impact future DHS action. From our standpoint, if 5% or more of the self assessments are found to have incorrectly self-assessed, then there is a significant problem with the self-assessment process and further examination is required. The level of that examination would depend on the percentage of incorrect self-assessments discovered. For instance, if between 5 and 20% of the sample indicated an incorrect self-assessment, the plan might say that DHS would immediately expand the sample size to determine if such a pattern of incorrect self-assessment stayed the same, fell or rose. If it stayed the same or rose, the self-assessment process should be deemed invalid. If the initial percentage was 21% or higher the process should be immediately deemed invalid. If the self-assessment process is deemed invalid the plan should then require that all settings that self-reported as complying be subject to heightened, on-site scrutiny. Obviously, DHS can determine the thresholds it wishes to apply, but some clear criteria should be identified.

C. Monitoring Compliance in the IRIS Program: P. 16

In the explanation of how DHS will monitor IRIS compliance the proposal says “the SMA may use a third-party entity to review and verify compliance beyond that documented by the regulatory entities described above. The SMA may also use state oversight staff or engage a third party for monitoring of entities that are not currently regulated.” We are concerned with this section’s use of the term “may” rather than “shall” or “will” (which are the terms used elsewhere in the plan). As written, this section indicates indecision on the part of DHS as to how it will monitor IRIS compliance and includes the possibility that it will not monitor IRIS at all. We assume that was not DHS’s intent. At this late date, indecision is not an option. This section needs to specify the plan for monitoring the IRIS program.

D. Consumers Need to be Part of Ongoing Compliance Effort

The Plan states that education and surveys of potential residents, their families and others who support them, will be done. Consumer education is critical to ensuring the success of the regulations. DRW also recommends focus groups consisting of residents to inform the state of how the HCBS rules are being implemented. In addition, there should be a procedure for residents, guardians and others to file complaints when rights ensured by the HCBS rules are violated.

E. Clustering

A major community integration problem that has developed in Wisconsin that was not specifically contemplated in the HCBS settings rule relates to the clustering of AFHs and small CBRFs. This occurs when one provider purchases or rents a group of properties in close proximity to each other (i.e. next to one another or on the same cul de sac) and then populates all of them with HCBS Waiver recipients. Typically, the residents of these homes are people with developmental disabilities. This geographic arrangement permits the provider to easily deploy staff to any of the homes as circumstances may require and allows it to more easily transport

people in groups to day programming and other activities. Because these properties have individual addresses and typically house 5 or fewer residents, they may present as community integrated settings. And they may be compliant with the technical regulatory requirements associated with their size. In fact, they are compounds that, when considered together, crowd out the natural community and take on characteristics of institutional placements. The transition plan should acknowledge the existence of these settings and, when doing site reviews, look at all of them to determine if the physical arrangement results in a setting that impermissibly restricts individual choice and relegates the residents to what is essentially a congregate living experience. A search of AFH and CBRF addresses would yield the location of these compounds.

F. Prevocational/Sheltered Employment: P. 99

We are pleased to see acknowledgement in the plan that prevocational employment runs the risk of trespassing on the HCBS rule. Wisconsin's significant reliance on congregate, subminimum wage facilities to provide "employment" to people with developmental disabilities has long been violative of the spirit of HCB services. Now it is in violation of an actual federal regulation. The remediation plan is vague about what DHS proposes to do to fix the problem. It is imperative that DHS develop strict standards for when HCBS funds will be allowed to support sheltered workshops that are perpetually preparing people for work that they seldom even seek, let alone obtain. At the same time, the facility profits from the subminimum wage labor these people provide. The process for creating these standards must be transparent and be made with a concomitant commitment to fully support people to work for real pay in the community. The problem of sheltered employment cannot be dealt with in isolation. Defunding the workshops without significantly improving supported employment opportunities will have the tragic effect of further isolating people and relegating them to boring and unfulfilled lives. It is time for Wisconsin to have a serious conversation about the role of prevocational employment in achieving the actual goal of employing all people with disabilities in decent paying, productive and satisfying work. This regulation compels us to start that conversation—and finish it by March 17, 2019.

Thank you for the opportunity to comment on this transition plan.

Respectfully Submitted,

A handwritten signature in black ink that reads "Mitchell Hagopian". The signature is written in a cursive, flowing style.

Mitchell Hagopian
Attorney