October 22, 2015

Alissa Deboy, Acting Director
Melissa Harris, Deputy Director
Disabled and Elderly Health Programs Group
Centers for Medicare & Medicaid Services
7500 Security Blvd.
Baltimore, MD 21244

Via Electronic Mail

Dear Ms. Deboy & Harris:

We would like to thank you again for making time to meet with us and discuss the implementation of the new Home and Community-based Services (HCBS) settings transition plans on September 24. Our coalition of disability and aging advocates has been working hard to ensure that the implementation of these new definitions fulfills the promise and the spirit of the regulations. This letter is intended to summarize the main points we raised during the meeting.

We appreciate that CMS appears to be setting strong expectations for states in reviewing their HCBS settings. The letters from CMS to the states clearly reflect information and feedback from state and national advocates regarding individual statewide plans and reinforce the message that states must meaningfully engage with the public throughout the transition process. We hope that this pressure will continue until states have revised their approaches to create assessment and remediation plans that will lead to improved community integration across all HCBS settings.

We were particularly pleased to see that CMS has pushed back on several states planning to evaluate only a sample of settings, to send out voluntary provider self-assessments, or presuming that certain congregate settings are compliant (and not subject to state review) simply because individuals owned their units in such settings. We believe such approaches would lead to settings escaping scrutiny and getting approved without adequate review. This is especially concerning when we think that many such settings are the isolating settings the review process is supposed to identify and remediate. Such settings evading review would set a bad precedent that undermines the intent of the new regulations. Starting the transition with skewed information about changes that must occur will lead to poor results even if the state executes perfectly all the subsequent steps.

Below we have listed a number of observations and recommendations to consider as states return the next round of statewide transition plans to CMS for your review. Several points request clarification of what appear to be discrepancies in CMS review standards, based on our reading of various state letters:

- **Continue to strengthen setting assessment methodologies.** We encourage CMS to continue pushing states to conduct a multi-pronged settings assessment that includes substantial direct input from individuals receiving Medicaid HCBS and minimizes potential coercion and conflicts-of-interest likely to lead to bias. These approaches should at least include a meaningful, independent and methodologically sound validation process with a mechanism to resolve discrepancies in data streams. Assessments must include every site or setting and identify a clear process to identify settings subject to heightened scrutiny that goes beyond simply identifying sites based on geographic location (For further discussion, see below.)

- **Require states to examine every setting.** CMS's response to several states clearly indicated that if provider self-assessment surveys were not mandatory, the state must have a plan to review the settings that do not respond.[1] Other letters, such as Alabama and Florida, ask states to ensure that assessments review all sites operated by a provider. Both points suggest that CMS wants to ensure that states review *all* HCBS settings. However, South Carolina has proposed to have providers with multiple locations to only assess a representative sample of the sites they operate. Texas similarly appears to propose reviewing only a representative sample of its settings. CMS's response letters to those states request more information, but do not clearly identify this approach as problematic, even though it means many settings in those states might escape direct review. We believe states should review each HCBS setting and that CMS should make that clear consistently across its response letters.

- **Require states to make individual setting assessment results available for public comment.** CMS noted in several letters that states must submit results from individual setting assessments to CMS and that assessment results must be posted for public comment. However, South Carolina's plan says the state will not make individual results available to the public. HCBS participants and their advocates will not be not able to provide meaningful comments if they have no access to the results for individual settings to agree or disagree with.

- **Continue to enforce that choice cannot validate the "community" nature of a setting, and require plans to ensure choice of non-disability specific settings.** Several states appear to be inappropriately relying on "choice" to justify segregated settings as community based. We commend CMS for clearly rejecting this approach in letters to New York and Kansas, where you made clear that an individual's choice to be in a given setting does not relate to the evaluation of that setting's institutional or community-based characteristics. However, in general the response letters were silent on the issue of providing meaningful choice as described in the regulations, including an option of a non-disability specific setting.[2] We mentioned this issue in

[1] *See, e.g.*, Response letters to AK, AL, MT, HI.
[2] Oregon is one example of a state that appears to be interpreting the requirement for a "non-disability specific setting" option to mean only that individuals must be offered choice from the "available settings." Missouri makes a similar claim in its transition plan.

our previous letter, but we continue to see few, if any plans that address the requirement that choice include a non-disability specific setting. Instead, plans focus on ensuring personal choice of setting. Importantly, very few plans examine the current capacity of non-disability specific settings or include mechanisms to increase this capacity as part of meeting the requirements of compliance with the HCBS regulations. If states are not including in their analysis of setting compliance whether or not the state has an appropriate array of settings to meet the needs of its HCBS participants and the requirement for the option of a non-disability specific setting, we believe that states will fail to meet that HCBS requirement and will be well into the five year period before realizing they have a problem.

- **Make clear that reverse integration, or bringing community members into a setting, is not sufficient to satisfy the community integration requirement.** In several response letters, such as Idaho's, CMS appropriately suggests that bringing community members into the setting would not be enough to qualify a setting as "integrated in the community." After all, such "reverse integration" is a standard practice for many institutional settings. We strongly support guidance from CMS that clearly states that a setting cannot be considered integrated into the community solely based on bringing community members in. Rather, settings must find meaningful ways to promote individuals interacting with broader community off-campus or outside of the setting, and not just for group trips.

- **Ensure that states provide a comprehensive crosswalk that matches state standards to each component of the federal HCBS regulations and subject it to public review.** We appreciate that CMS has clearly required states to develop crosswalks of specific regulations, include references to state policy manuals, and evaluate whether those standards comply, do not comply or are silent on the federal requirements. We have found the systemic assessment of standards and policies in many states to be exceedingly vague and difficult to evaluate. For example, California advocates analyzed just a small portion of California's systemic assessment findings—including the policies on provider accessibility—and found numerous contradictions or problems the plan had not addressed. We encourage CMS to continue to require states to include specific supporting detail in their statements of compliance, and that these detailed crosswalks be available for public review and comment.

- **We found incorrect comparisons and other mischaracterizations of the new settings regulations in several states.** Some states incorrectly compared HCBS participants against individuals not receiving Medicaid HCBS *in the same setting*, instead of using individuals in the community not receiving Medicaid HCBS as the benchmark.[3] We appreciate that CMS questioned Idaho's unclear comparison to "peers" and note that this also came up in a draft Arizona STP.[4] We have also seen

[3] CMS identified this issue in Idaho's statewide transition plan, and we have found similar mischaracterizations in draft transition plans from Arizona.

[4] We found additional issues in Idaho's most recently updated plan. For example, Idaho's provider self-assessment tool asks whether the individual is given the opportunity for community participation to the

states use other incorrect, or at least skewed, interpretations of the regulations in their transition plans. West Virginia's transition plan makes very broad statements about policy compliance, which are concerning, but the plan also misunderstands that a setting must be accessible to the individual, which is not always the same as compliance with Title III of the ADA. In North Carolina, in response to a comment about transportation and vans, the state responded to that the standard was whether "it is similar to the transportation provided to other Medicaid beneficiaries" as opposed to comparing to individuals not receiving Medicaid HCBS. In South Carolina, the state asks whether rules, policies, and regulations are a barrier to the settings standards as opposed to enforcing compliance with the regulations.

The Heightened Scrutiny Process

As we discussed in our recent meeting, we were disappointed that in the end, CMS' first heightened scrutiny review led to the approval of units on the campus of an intermediate Care Facility. We continue to believe this is a step backwards from prior policy. However, we do appreciate that CMS returned to North Dakota to do a second, more thorough, review of the setting, that the approval is tightly circumscribed, and that the letter sets a relatively high bar for the evidence needed to overcome heightened scrutiny. We also are glad CMS did not approve the adult day care facility on the same campus, due to lack of integration and overlap of staffing and scheduling with the ICF.

We want to emphasize two main points needed to strengthen the heightened scrutiny process moving forward:

1) **Messaging the right expectations for heightened scrutiny is critical.** CMS sets the tone for what is expected for heightened scrutiny and the evidence required to approve a HS setting. We urge you to establish and maintain strong guardrails and limitations for future changes to such settings based on the North Dakota process: every participant was interviewed; the local protection and advocacy organization and other local advocates were consulted; the state provided evidence that individuals worked in and otherwise accessed the community; and the approval limits the number of approved beds and requires that any change to the approved settings will trigger another review. These are the factors we hope CMS stresses to states, rather than an alternative we sometimes hear – that any currently existing setting, including presumptively institutional ones like this -- pass muster.

2) **CMS must do all it can to ensure that all settings that should be presumed institutional undergo meaningful heightened scrutiny or transition away**

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extent that they desire as opposed to whether the individual has the same degree of opportunity for community integration as an individual not receiving HCBS. The standard is problematic because the answer depends on the expectations of the beneficiary, A person accustomed to very little choice in their community engagement may respond that they have what they desire or will be very pleased with being offered slightly more. Unless an individual is fully educated about their rights under the regulations and what that means for their everyday life and choices, a standard should not be based on desire or satisfaction.

from Medicaid HCBS funding. Based on the response letters to states, CMS has clearly noted both the importance and the current inadequacy of nearly all states' plans to identify settings that should be subject to heightened scrutiny if they are to continue receiving HCBS funding. While several states have developed GIS or other mapping tools to find clusters of HCBS participants or settings co-located with institutions, we have yet to find any states with a clear mechanism to assess other settings that have the effect of isolating HCBS participants. Like you, we are worried that many of these settings will slip through an ill-designed settings assessment process and continue to receive HCBS funding. We are also concerned that some states, like Idaho, presume they will have no settings to go through heightened scrutiny. We are concerned that such an approach reflects a lack of planning and, more importantly, indicates a misunderstanding at the state level as to when heightened scrutiny is triggered. Although a setting may do many things to become more community-based and reach compliance, if it is isolating or otherwise meets the heightened scrutiny criteria, it must go through the CMS process.

We believe that all gated communities, farmsteads, or similar communities must undergo heightened scrutiny to receive Medicaid HCBS funding. Several states are classifying these settings as individual apartments/units that they presume to be compliant without further review. We believe this assertion is based on a misreading of the November 2014 Q&A guidance, and you have already helpfully pushed back on this interpretation in several response letters. We encourage you to issue broader guidance clarifying the policy and the potential consequences: that a setting that should have undergone heightened scrutiny, but did not, will no longer be able to receive Medicaid HCBS funding after March 2019.

Because of the highly segregated nature of these settings, we think successfully overcoming the institutional presumption will likely be rare. To do so, the setting must show that it consistently provides residents with community integration that involves participation in the broader community and meaningful community interaction (e.g., a trip to the store once a month in a small group is not enough). Specifically, such experiences and activities should not occur solely in groups and must be at the individual's choice. The goal should be to show that participants' integration into the community is the same as that of non-HCBS recipients, despite the geographic, architectural, and functional features of the setting.

The evidence provided on these activities needs to be specific about frequency, who from the facility goes, how the activities are arranged, whether the activities are selected from a limited menu, whether the activities include outside competitive integrated employment, how long are they away from the facility, what types of activity it is and how it is meaningful integration for the individual(s) involved. Limited information about attending church, holiday parties, or community days is insufficient. What may be enough of a description of community activities for a review of a setting that is presumed to be community-based but is under review by a state should not be even close to sufficient for a setting trying to show that it overcomes presumed institutional

characteristics. The information must not be provided in the aggregate, but be specific to how individual residents experience the setting. And finally, states must obtain and present their evidence on HS settings as independently and transparently as possible, to minimize potential conflicts-of-interest.

In the rare instance that a setting can meet the heightened scrutiny standard, any approval of such a setting must clearly set forth the number of individuals served and the specific features that provided the basis for the decision that the setting overcame the institutional nature of the facility. This information must be sufficiently specific to provide enough information to establish the minimum standard the facility must meet on an ongoing basis to continue to overcome the nature of the facility. To do otherwise would allow settings to improve sufficiently to pass heightened scrutiny, but do less as time goes on if the approval is open for interpretation.

Building New HCBS Capacity and Tiered Standards

Finally, we were happy to hear that CMS is considering developing guidance on new construction for HCBS settings. We agree with your suggestion that evaluating new construction is not the same as assessing current settings, and that it should be held to an even higher standard. Building new HCBS capacity that from the outset would be presumed institutional (and thus trigger heightened scrutiny) runs counter to the intent of the regulations, and more specifically undermines the requirement that every individual have the option to choose a non-disability specific setting. We thus urge you to make any pending guidance on this issue as strong as possible to discourage states from building any new capacity that would not further the rules' intent of creating more opportunities for community integration in HCBS-funded settings. We are particularly concerned that because the regulations are focused on the experience of the individual, it would be nearly impossible to provide approval of such settings based on a promise of the individual's experience or the setting's programming. In addition, we have seen the plans for a few such proposed facilities (or "communities" as they are called by developers), such as one in Nevada, that echo common institutional architectural approaches, despite their outside appearance. Such settings would do little more than replace state-run institutions with private institutional facilities that, if approved as HCBS settings, would undermine the definition the regulations seek to implement. We also recommend that CMS guidance address new construction that is being funded with all charitable dollars, but which will still have to comply with the rule because services provided in these settings are likely to be funded with HCBS dollars.

As we pointed out above, we would like to see CMS more actively engage states to develop strategies to build more integrated HCBS capacity over time, especially in states that need to build non-disability specific settings to meet the available options requirement. This could mean phasing out sheltered workshops and transitioning to supported employment, shifting away from congregate care models that group older adults or individuals with disabilities in a single setting, or simply increasing the reliability and quality of home-based care. Your guidance permitting states to develop tiered standards for new HCBS capacity is a significant step in the right direction on this issue.

We understand that several states, such as New Jersey, Ohio and Massachusetts, have expressed interest in using the HCBS settings transition as a springboard to instituting broad system reforms that increase.[5]

We found few direct references to building integrated capacity in any state plan. New Jersey is clearly pushing a tiered standards approach for new congregate settings in its DD waiver by limiting the size of new group homes and requiring new non-congregate settings meet the integrated housing definition in HUD's § 811 Project-based Rental Assistance (PRA) Program, which requires no more than 25% of units in a new multifamily properties to be used for supportive housing for persons with disabilities.[6] We see these as positive steps and hope that other states will be encouraged to use this as an example of how to ensure their HCBS programs increase the availability of integrated settings so every participant has a meaningful choice.

Transparency and Public Education

We are very pleased that CMS has created a website where its responses to states are made public along with links to each state's transition plan. As we have previously discussed and as your response letters have made clear, transparency in this process is critical. We continue to have difficulties in some states tracking new developments in HCBS transition plans. Indeed, several states that should have already updated their plans based on the timelines provided in your response letters appear not to have done so and have not updated their websites to reflect any plan revision processes or extensions granted.[7]

For example, a fairly exhaustive search of Arkansas' Medicaid and Office of Long Term Care websites found no references at all to the state's HCBS transition plan save for an out of date public notice with a link that landed on the state's Medicaid provider login page. A more recent announcement for an HCBS transition planning work group meeting was found on a completely different website related to the state's payment reform initiative. Missouri, by contrast, has three separate HCBS settings transition web pages spread across three departments: Social Services, Mental Health, and Health & Senior Services. While each has a link to Missouri's transition plan, the rest of the information is not consistent across these three sites.[8] Notably, the state's consumer

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[5] We are encouraged by Ohio's efforts to increase integrated employment opportunities and integrated wrap-around supports in its Adult Day and Transitions DD waiver, to correct the current bias toward facility-based options. We would like to see more plans recognize their state's efforts to improve integrated employment opportunities for people with disabilities. For an overview of state activities, *see*, University of Minnesota, RTC on Community Living Research Policy Brief, *Employment First Across the Nation: Progress on the Policy Front* (2014) http://rtc.umn.edu/prb/214/.

[6] New Jersey Dep't Human Servs., *Statewide Transition Plan*, 14 (April 17, 2014), http://www.state.nj.us/humanservices/dmahs/info/hcbs_trans.html.

[7] Alaska, Georgia, North Carolina, North Dakota, Tennessee and Wyoming are all past due based on the timelines in the letters, but have not posted new plans or any information about what the state is working on in regards to transition plan revisions (as of October 1, 2015).

[8] *See* MO Dep't Mental Health, HCBS Transition Plan (last visited Oct. 14, 2015), http://dmh.mo.gov/dd/hcbs.html; MO Dep't Health & Senior Servs., *HCBS Transition Plan*, (last visited Oct. 14, 2015), http://health.mo.gov/seniors/hcbs/transitionplan.php; MO Dep't Social Servs., *Missouri*

education materials are only mentioned (and linked to) on the Mental Health page, which focuses on individuals with developmental disabilities.[9] A user checking the other two department pages would have no idea that these online resources are available. The state also appears to have limited its HCBS participant survey tool to DD waiver participants, since it is not available on the other sites. If the state website is this confusing or obscure for experienced advocates, we can only imagine how difficult it would be for an older adult or person with a disability to access information if they require alternative formats or do not have ready access to the internet. As states move into the next round of public comment nearly two years into the transition plan, there should be no excuse for having anything less than a simple, well-publicized, one-stop source for all the relevant information and developments of their statewide planning. Such a page should be easily found through a search of the state Medicaid agency's website.

We also continue to believe that CMS needs to be actively involved in educating the public and ensuring that they understand the importance of the rule, the ongoing process in their state, and addressing any misinformation. Based on all of our outreach, few stakeholders yet understand the ongoing nature of the transition planning process and the multiple opportunities for public comment. Along with any additional guidance on new construction of HCBS settings, we urge you to finalize and release the consumer-friendly documents explaining the purpose and process of transition planning. We think those would be incredibly helpful.

Responses to other CMS questions and additional topics

In response to your questions, we addressed above some of the few states that appear to address building new HCBS capacity in their current transition plans. While we see this as a real priority, we have not encountered many states that directly address the issue.

We also have limited examples from other states that appear to be encouraging ongoing individual feedback to report non-compliant settings. Idaho's most recent plan, currently up for public comment, includes several feedback approaches including ongoing annual participant surveys, solicitation of input from advocacy groups and university research centers and an open door comment process.[10] Idaho also plans efforts to educate participants. While that plan leaves room for improvement, it will include information on how to complain if any of the HCBS requirements are met.[11]

Home and Community Based Services (HCBS) 1915(c) Waiver Settings Statewide Transition Plan (last visited Oct. 14, 2015), http://dss.mo.gov/mhd/providers/pages/hcbs-transition-plan.htm.

[9] MO Dep't of Mental Health, HCBS Transition Plan (last visited Oct. 14, 2015), http://dmh.mo.gov/dd/hcbs.html.

[10] Idaho Dep't of Family Welfare, *Idaho State Transition Plan – Coming Into Compliance with HCBS Setting Requirements: Public Notice and Request for Comment*, 38 (Sept. 11, 2015), http://healthandwelfare.idaho.gov/LinkClick.aspx?fileticket=P9pgdlusndk%3d&tabid=2710&portalid=0&mid=11464.

[11] *Id.* at 30. Idaho's education plan indicates an individual will be provided information about the HCBS requirements, such as an FAQ or pamphlet, and then the provider and recipient will sign a form

These approaches, if coupled with robust participant outreach and education efforts, represent a good start to actively seek input from individuals receiving HCBS.

Moving forward, we hope to work with CMS to help identify strategies that states can use to ensure compliance with corrective action plans. We believe having a strong compliance mechanism will be important, especially in states that have poor assessment validation processes or encounter significant discrepancies between provider self-assessments and other mechanisms for evaluating setting compliance.

We are also very concerned about provider appeals of corrective action plans. Oregon, one of the few states to provide any meaningful detail about its remediation process, describes a process for providers to challenge the Corrective Action Plan. Without careful protections, such a process could become a huge loophole that allows powerfully connected providers to water down the findings of an assessment and continue the status quo. Because many states have not yet provided details on their own approach to remediation, we urge CMS to get ahead of the issue and ensure the integrity of the assessment does not get compromised through an appeals process.

Conclusion

Thank you for the opportunity to provide this additional feedback on the HCBS settings transition planning process. We look forward to continuing to work with you to uphold the intent of the new HCBS regulations to push states toward more integrated, more reliable HCBS programs that promote better options for older adults and individuals with disabilities to live independently, get the care that they need, and have full access to the benefits of community living. If you have any further questions, please contact David Machledt (machledt@healthlaw.org; NHeLP), Elizabeth Edwards (Edwards@healthlaw.org, NHeLP) or Alison Barkoff (alisonb@bazelon.org; Bazelon Center for Mental Health Law).

Sincerely,

American Network of Community Options and Resources (ANCOR)
Association of People Supporting Employment First (APSE)
Association of University Centers on Disabilities (AUCD)
Autistic Self Advocacy Network (ASAN)
Bazelon Center for Mental Health Law
Coalition to Promote Self-Determination (CPSD)
Justice in Aging (formerly the National Senior Citizens Law Center)
National Association of Councils on Developmental Disabilities (NACDD)

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acknowledging their understanding of the requirements. Handing someone information about the requirements is not the same as ensuring their understanding of those requirements, including whether they know how to register complaints about noncompliance. Idaho's plan fails to address the accessibility of this information, including cognitive accessibility, nor does it include measures to assure the person will be provided help to understand the information before being asked to sign the acknowledgement.

National Consumer Voice for Quality Long-Term Care
National Disability Rights Network (NDRN)
National Health Law Program (NHeLP)
TASH
The Arc of the United States

Cc: Ralph Lollar, DEHPG
James Toews, Senior Advisor to DEHPG (on detail from Administration on Community Living)
Regan Rush, U.S. Department of Justice