

June 10, 2015

Alissa Deboy, Acting Director
Melissa Harris, Deputy Director
Disabled and Elderly Health Programs Group
Center for Medicare & Medicaid Services

Via Electronic Mail

Dear Ms. Deboy and Ms. Harris:

Thanks very much to you and your staff for meeting with our coalition of disability and aging organizations on May 27, 2015 to discuss the Home and Community Based Services (HCBS) settings regulations. We appreciated the opportunity to share our perspectives on states' transition plans (both positive and concerning) and to hear updates from you. As promised, we are following up our meeting with a letter providing more detail on a number of the issues we discussed.

As we shared with you, our coalition of disability and aging organizations has reviewed many state transition plans. Our goal is to ensure that all HCBS settings will meet or surpass the minimum requirements set forth in the recently effective regulations. Over the last several months, we have worked directly with numerous state advocates to assist them in assessing and commenting on their states' draft transition plans. Through this collaboration, as well as our review of many of the final statewide transition plans recently submitted to CMS, we have identified a number of trends – some positive and some concerning – on how states propose to implement the new settings requirements and prepare for the coming changes.

The new regulations offer a much needed opportunity to advance community integration. However, one year into the transition process, many states' plans and responses to comment indicate a reluctance to conduct the systemic evaluations and public engagement necessary for positive, meaningful change. Instead, many states' transition plans propose to make minimal modifications; use questionable standards and interpretations of the regulations; make broad assumptions regarding compliance without evidence; and, disappointingly, seem likely to ultimately fail to meet the intent of the regulations.

We are particularly concerned with states' approaches to assessing and identifying settings that require changes and the failure to include a meaningful system to track ongoing compliance. The planning process in many states lacks transparency and robust and meaningful stakeholder engagement, particularly from HCBS participants whose experience is central to the requirements. We have also seen some positive features of plans that we think CMS could encourage other states to incorporate.

Below we have outlined several issues areas we think are key to a successful transition plan, including examples from specific states:

- 1. An effective process to identify of all the HCBS settings that either cannot comply with the new regulations or will need to implement changes to come into compliance with those regulations.**

- a. Provider Self-Assessments*

Despite obvious conflict-of-interest issues, which several states acknowledge in their plans, a majority of states are relying on provider self-assessment tools as the primary mechanism to identify settings in need of change. Many states are not gathering any additional information from other sources, including from those without a financial interest or third parties who are truly independent, to gain a more accurate understanding of settings' compliance. CMS has good reason to strongly encourage states to design some process to verify the results of any provider assessment and to resolve inconsistencies.¹

Indiana, one of the few states to include data that compared results across two different types of assessments in its DD waiver, found striking differences. The results emphasize the importance of multiple sources of information, strong validation methods, and the value of piloting assessment methodology. Indiana compared results from a case manager 90-day checklist against state-wide DD participant-reported data collected by the National Core Indicators survey. In seven of the eight categories that allow for direct comparisons, the results from NCI showed compliance below the state's chosen threshold (85%), while the case manager checklist came in above that threshold.² If Indiana relied solely on the DD case manager checklist, it would not have identified significant HCBS compliance issues at all. This reflects our concern with potential conflicts-of-interest in provider self-assessments, as well as the importance of including a valid assessment methodology and verification process if the state chooses to utilize provider self-assessments. Many states are falling short in both regards. CMS should ensure that no state's assessment methodology relies solely on provider self-assessments.

¹ In the *HCBS Basic Element Review Tool for Statewide Transition Plans Version 1.0*, CMS, one of the questions for reviewers asks if the state identified a validity check and statistically significant sample (p. 17). The questions from this review tool do not provide clear guidance about the extent to which CMS expects states to describe their sampling and validation processes. Given the widespread problems and the importance of compliance assessment, we recommend that CMS require states to this type of information in their transition plans. .

² It is impossible to tell how great the discrepancies are based on the data provided. The categories showing disagreement are: Visitors at any time, control of schedule of activities, facilitates choice of services and providers, allows greater access to the community, control of personal resources, provides opportunity to seek employment, and setting is integrated with and supports access to the broader community. Only "ensures right to privacy, dignity and respect" came in above the 85% threshold in the NCI data, and agreed with the case manager survey findings.

b. Questionable Methodology

Not only are some states failing to include multiple, independent sources of information and a robust verification process that triggers a broader review to resolve any inconsistencies, but the provider self-assessment design and methodology itself is often questionable. Some states are not utilizing a full provider self-assessment, or even a reasonable sampling methodology. Texas proposes to send self-assessments to an unspecified “sample” of providers, while Alaska’s provider assessment was fully voluntary. Alaska’s survey collected responses from only one in five providers. Neither of these plans describe their sampling methodology nor whether their sample would include an appropriate selection of types of providers, populations served, services provided, size, geographic location, etc. to ensure that the sample was truly representative. Unfortunately, these two states are hardly unique. Only a handful of states, notably Michigan, have explicitly described their sampling methodology and their plans to extrapolate results to other providers not captured in the sample.

Providers with settings that may not meet the new requirements have less incentive to return the surveys or may generally prefer to not draw attention to potential issues. The minimal overall response in voluntary surveys, coupled with this potential response bias, undercuts the validity of the results and, ultimately, any subsequent transition plan because it is based on incomplete and potentially inaccurate assumptions of current compliance. To alleviate some of these problems, CMS should require states to collect survey responses from all HCBS providers, as a number of states have proposed to do. At a minimum, CMS should ensure that survey methodologies are structured to yield unbiased results that can reasonably be considered representative of the whole body of HCBS providers.

c. Assessment Design

We have identified several common issues with the design of provider self-assessment questionnaires. First, CMS’s exploratory questions, which have been widely used as the basis for assessment tools, are directed to the participant. This creates some confusion when the same question is directed to a provider who may serve multiple participants. When the state asks “Can the client choose what, when, where and with whom to eat?” a provider might interpret this as “Can some/most clients choose what, when, where and with whom to eat?” and answer “yes” even when some participants may not have those choices. To remove this ambiguity, states should formulate the question to inquire, “Can *all* participants choose...”

A second concern with the assessment design involves vague questions to which it is highly unlikely anyone would respond “no.” Nevada’s provider survey asks the *provider*, “If the client has concerns, is s/he comfortable discussing them?”

and “Is the client free from coercion?” Predictably, all 146 responding providers answered “Yes.” Seventeen of the 44 questions in Nevada’s survey produced no or only one negative response (n=146). These throwaway questions provide no useful data, unnecessarily lengthen the survey and cannot be expected to produce honest answers, even from a well-intentioned provider. Questions should be designed to elicit more specific detail that would be a proxy for the desired information, such as, “What policies are in place to ensure that residents can voice complaints about interactions with staff? Have any such complaints been lodged?” These examples are designed to elicit whether the policies and practices at the setting actively support the intent of the HCBS regulations, as opposed to Nevada’s questions, which, if anything, indicate where existing policy and practice conflict with the HCBS regulations. Perhaps the most comprehensive provider and participant assessment tools we have come across are from the state of Michigan. But even that provider assessment asks, “Are recipients treated with respect?”

Finally, many provider assessments only ask whether the provider is currently in compliance without asking a follow up inquiring whether they can come into compliance within a set reasonable time period and what they will do to comply. Stark yes/no questions on compliance may incentivize aspirational responses that do not reflect current conditions and could significantly skew results. Providers may also vary greatly in how they answer this type of broad question. In addition, adding the question about potential compliance should help a state get results that more accurately reflect the degree of needed changes. In comments to plans, advocates and providers have raised concerns about the survey methodology, but there seems to have been little response from the states.

d. Participant Surveys

A robust participant survey could help to resolve some of the shortcomings that the provider self-assessment cannot effectively address, and we ask that CMS require some level of participant survey matched against provider surveys. Nevada conducted a participant survey with more than 1000 responses (a 20% response rate.) However, the state does not indicate how it will resolve discrepancies between the provider self-assessment results and the participant survey. For example, on the question of providing choice of roommates, 49 providers responded “yes” and only 6 responded “no.” However, more than a third of participants with roommates reported having no choice (397 “yes” and 200 “no.”)

Many states that include participant surveys give no indication whether those surveys will be matched with associated providers or if they are just considered in the aggregate by provider type. Also, some states plan to actively follow up with providers to get assessments returned, but such plans are rarely duplicated for participant surveys. Very few plans mention participant education, which is an

important component of valid participant surveys. If a question asks whether a participant can have visitors, they may answer yes to that question even if the setting sharply restricts visitors to Sunday afternoons. Without context and education of what the regulations require, participant surveys may provide inaccurate information.

Any meaningful participant survey must include a mechanism to ensure freedom from bias, which may include an independent third party conducting the survey. Although this issue is sometimes raised in comments, few plans acknowledge it explicitly. In comments to Colorado's plan, providers expected that families and individuals would likely be contacting them for assistance with surveys. In North Carolina, a response to a comment indicated that the State planned to not have the provider or direct care staff assist individuals who may need help to complete the survey, although this was not mentioned in the plan. The state plan in North Carolina also indicated that the provider was supposed to gather information from other sources and indicate those sources on the assessment, but it is not clear from the assessment or assessment instructions that a provider is supposed to do this or how.

North Carolina's response to comments recognizes that individuals may not be comfortable responding to surveys honestly to their provider. In the description of how a participant survey will be used or carried out, each plan should include a description of how individuals will be able to respond freely and will be free from influence, including wrong information about the meaning of the question. Participant surveys should also include information on who filled out the survey, if other than the participant, and what other parties may have been present, if any.

e. Validation Mechanisms and Piloting

These issues described above underscore the importance of a meaningful system to validate the assessment process. Approaches include matching participant surveys against associated provider surveys (e.g. Michigan) or comparing provider self-assessments to other sources of information, such as licensure review and/or site visits. Notably, Oregon plans to consult with advocacy organizations on providers' attestations in self-assessment responses. Nevada's transition plan includes on-site reviews of all non-residential HCBS settings and at least 50% of all provider settings, though it is not clear how thorough these reviews will be. Generally, the states that plan to use site visits for validation offer little detail on site visit protocols, training provided for onsite reviews, how the state will ensure consistency across the state and across programs, and similar issues. Plans very rarely mention training of reviewers, including site reviewers, compliance plan reviewers, or those providing assistance to providers, nor do most plans describe methods to ensure consistency among reviewers or programs, as should be required of the single state agency.

A vital component of validation is a process to address and resolve inconsistencies. For example, California's transition plan includes a mechanism to expand the setting review if it finds inconsistencies in the assessment results. Alternatively, Michigan and Georgia plan to pilot their assessment process on a smaller scale, validate, and report to stakeholders before conducting the full assessment. This piloting gives the state a chance to fix any issues before using resources to do the full statewide assessment, though the state will have to work to meet its deadlines.

2. A thorough review of state policies and regulations to ensure they are updated to embody both the letter and spirit of the new HCBS settings regulations.

Several states have indicated that their review only identified state policies that directly conflict with the new regulations, rather than a more nuanced approach that focuses on implementing policy changes that would actively enforce the goal to promote the integration of HCBS participants in broader community life. In contrast, states like North Carolina propose to evaluate the whole system and include an examination of provider rates. In our review of public comments, many providers questioned whether the current rates would be sufficient to pay for implementing necessary changes. North Carolina's plan to evaluate the rate of pay, which considers how much providers rely on group versus individual rates, seems like an important factor that other states should consider.

The changes to the service system may require an examination of the use of group versus individual services, whether those services meet the requirements, and whether the rates allow for the necessary staffing to carry out the HCBS requirements.³ This evaluation should also include transportation needs, as we have seen concerns with the lack of transportation raised in public comments in many states. Most of these states have done nothing to address these concerns through their response to comments or substantive changes to their transition plans. These factors, along with others like access to affordable, accessible housing, all affect individual choice and opportunity.

As we discussed at our meeting, it is critical that CMS ensure that states' policies and regulations affirmatively incorporate and support all the HCBS settings requirements to ensure ongoing compliance with the regulations. In addition, to ensure ongoing compliance, states should really be looking at their HCBS system to make sure the pieces are working to achieve the overall goals of an HCBS program and compliance with the regulations.

³ North Carolina's response to comments was somewhat concerning in that it seemed to rely on the idea that group rate can apply to very small groups, but it is not clear that the rate really accounts for the staffing and other costs of the service for a small group as compared to the provider efficiencies gained with larger groups.

3. **Meaningful stakeholder engagement and education.**

The degree of stakeholder response and involvement in the transition planning process varies considerably between states. CMS must work with states to ensure meaningful and ongoing stakeholder engagement as substantive changes are made to plans (as required by the regulations themselves). Plans demonstrating inadequate public comment should be sent back. Several states received little substantive response, including comments complaining that the public process was opaque. Other states have received hundreds of comments that reflect significant misunderstanding of both the letter and the intent of the new regulations. Many states seemed to rely on the mechanisms through which they regularly communicate to providers and did not ensure that their outreach actually reached participants and their families. Texas, for example, only alludes to education efforts for providers and MCOs, but not for participants.

a. Reliance on Provider-Targeted Mechanisms and Formal comments

States relying solely on a formal commenting process, as opposed to accepting input (including in the form of questions and concerns) at public meetings or via phone, constricted feedback from participants and families and focused on provider feedback. For instance, transition plan information is often posted on the provider sections of state Medicaid agency webpages and not on the corresponding consumer or general information pages. A state focused primarily on provider feedback, whether intentional or not, will consequently receive comments skewed toward that perspective, which may negatively influence transition plan development and implementation. In contrast, some states such as Michigan, created communication plans that presumably examined the best way to communicate with different stakeholders, including consideration of many participants' lack of access to internet or email-based notices from a state listserv. Also, North Carolina created a version of the transition plan targeted to participants and accepted comments through more informal processes at information sessions held across the state and specifically held meetings for participants and their families.

b. Minimal State Responsiveness to Comments

State responses to comment also vary. Wyoming's response is a notable positive model. Not only did it include an engaged reply to the received comments, but it also contextualized the comments by discussing how each issue fit into the goal and intent of the HCBS regulation. Wyoming's response demonstrates how a state can use the public process as an opportunity for outreach and education as well as an accommodation of public feedback.

The public process in most states is not nearly the model that Wyoming represents. Texas and Montana are among the states that declined to change their transition plan at all in response to public comment, deferring most

decisions to future revisions. Other states provided skeletal plans vague enough to render meaningful comment difficult to impossible. Several states, including Texas and Montana, made no changes to their final plan in response to public comment, and then buried that information in their response to comments.

c. Mechanisms for Ongoing Stakeholder Involvement

It is becoming increasingly clear that the transition planning process will be iterative and ongoing throughout the four remaining years. We encourage CMS to push states to develop advisory committees with substantial representation from participants and consumer advocate groups to supplement the public comment process. An advisory group with balanced interests and strong participant representation could help infuse consumer perspectives into the fabric of the planning process, from design of provider/resident assessments to the activities of site review and the development of plans to minimize the impact of transfers for individuals in settings that cannot meet the new HCBS regulations. Such groups can facilitate communication and consumer buy-in and create an infrastructure to build up institutional knowledge about the transition process as it progresses.

Several states have developed a broader approach to public comment. North Carolina says it is using a “no-wrong door approach” in that it is not only accepting comment through the formal comment process, but will consider comments and questions received through other mechanisms and plans to do so, at least in some way, on an ongoing basis. It is not clear if North Carolina is holding over comments collected in one period that may be relevant at a later stage, but the response to comments reflects a referral process that seems to work toward this idea. It is reasonable for stakeholders to believe that they would not need to repeatedly make the same comment at each stage. This is particularly important for early comments collected on particular settings that should be considered in evaluating later assessment results.

4. Lack of outreach and education plans going forward.

Few transition plans include an active outreach and education plan that will help HCBS participants and the broader public to understand the letter and the spirit of the new regulations and engage with the ongoing transition planning process. Plans can be difficult to find on state websites; hearings are few and poorly advertised, and the opportunity to comment on waivers and transition plans is often confusing.

We are concerned that the lack of effective outreach undermines all the other facets of the planning process because it inhibits effective public involvement. CMS should not approve state plans that do not clearly lay out a strategy to inform and engage HCBS participants about the new regulations, the transition process and the opportunities it presents. Additionally, this outreach program

should be multi-faceted and must be made accessible to people with limited English Proficiency and people who require alternative formats.

States that make a serious effort to inform participants will limit misunderstandings, improve response rates, and reduce the fear of change. Without this crucial context, participants will not know how best to engage the public process, to respond to assessments, or to become involved with ongoing efforts to monitor compliance. Notably, Nevada responded to reports of confusion with its provider self-assessment by redesigning and redistributing the assessment to include explanations of the context for each question, even if these explanations were not ideal. However, the state did not do the same for its participant survey, meaning many of the respondents may have lacked the appropriate context for their responses.

5. Transparency: Making public a list of settings presumed to be institutional in nature (subject to heightened scrutiny) as well as a list of settings that must implement changes to come into compliance.

The next step for many states is to complete the provider assessment phase of their transition plan. Part of this assessment will single out settings that must implement changes to come into compliance with the new regulations and settings presumed to be institutional or have an isolating effect that states may opt to submit through the heightened scrutiny process. Few plans to this point have reached the point of naming particular settings, but we are concerned that states have not fully planned this process and may not open their assessment results for public review.

a. Plan to Identify Settings that Isolate

Very few states provide any information about how they will identify settings that isolate or the characteristics they will consider as indicators for settings that isolate, which could only be approved through the heightened scrutiny process. In contrast, Iowa sets forth information about using GIS data to analyze locations of provider sites and member addresses to identify potential areas with high concentration of HCBS. Unfortunately, Wyoming's plan for assessing settings lost some of its stronger features from draft to final plan, such as flagging sites in an industrial park and other relevant zoning codes. But the state still plans to use distance from other residences or businesses, including other providers and other non-subjective measures. States should not only describe a plan and timeline for identifying settings that isolate, this plan should include objective measures to help identify settings that need a closer look beyond answers to self-assessments, especially given that many self-assessments ask very little, if anything, about features that may isolate such as distance, security measures, location, or proximity to other providers.

b. Stakeholder Involvement in Setting Classifications

Unless the provider assessment results are transparently posted with an opportunity to comment, advocates and HBCS participants will have little ability to provide their first hand perspective on the merits or problems with the state assessment process. Nevada is the only state to date that has posted question-by-question results from its voluntary provider self-assessment. The results are not stratified by provider or provider-type. Michigan promises to post results when available. CMS should require all states notify participants, advocates and other stakeholders when the assessment process is complete and clearly post lists of settings that do not require changes as well as those that require changes, along with the basis for these decisions. Participants and advocates should have the opportunity to weigh in on these lists and any associated evidence provided.

In addition to assessment results, the validation process should transparently explain the effectiveness of the assessments and address inconsistencies. CMS should require states to disclose all evidence submitted to CMS to justify how a setting actually overcomes the institutional presumption and provide the public with an opportunity to comment on each of these settings. Any public comment about a setting should be provided to CMS or any summary of comments should specifically include all comments about specific settings or types of setting. A stakeholder's claim that a setting does not meet regulatory requirements should be enough to trigger a response and enhanced focus from the state. The onus is on the state to know the intricacies of the rule and prove that such a setting complies, not on the layperson to prove that it does not.

Clear timelines are a critical element of settings transition transparency. Each plan should provide start and end dates for surveys, setting assessments, reports to the public, opportunities for public comment on assessment results, and when stakeholders must submit to the state settings that are of concern. Most stakeholders seem to be operating on the assumption that the state assessment process will be sufficiently public that they will have the opportunity to see the state's list of providers and then provide the state with information as to where there is disagreement. If stakeholders do not know when a state intends to finalize assessment results or when it plans to choose the settings to submit for heightened scrutiny, they cannot provide this information. Most states do not specify when they will submit settings to heightened scrutiny, if they will do so all at once, or if it will be done in stages.

Some states plan to allow providers to appeal designations without giving similar appeal rights to individuals (or some method of input). Most of these states give no indication of the efforts that will be undertaken to support the designation, such as interviews with participants or community opinion of a setting. We are particularly concerned that appeals, without transparency and without more information about a state's effort to defend the designation, will lead to providers appealing away a designation without substantial evidence to support the appeal.

6. Need for increased capacity of HCBS services and settings options.

One of the principles underlying the HCBS settings rule is ongoing monitoring of setting compliance, quality improvement and the creation of new integrated settings options. A few plans, including Mississippi and Indiana, have suggested using existing participant survey tools, such as the National Core Indicators, as part of their ongoing monitoring process. This is a positive step, but for the most part, these mechanisms provide statewide, rather than provider specific data, and it may be only partially applicable to the settings regulations.

In addition to establishing a robust system to ensure ongoing evaluation of compliance for HCBS-qualified settings, transition plans should include a clear plan to support the expanded use of more integrated settings going forward. The transition process is not intended as a one-time affirmation, but rather the first step in an ongoing process to expand HCBS options that actively promote community access, independence, and quality care. The settings regulation requires that each HCBS participant be able to select from among “setting options including non-disability specific settings.”⁴ These settings include HCBS that support people in their own apartments and homes and in typical jobs in the community. To achieve these goals, states should have a system in place to evaluate the status of availability of non-disability specific and independent settings options for each participant and a plan for improving the array of truly integrated options over time.

7. Back-loading the schedule deadlines.

Many of the transition plans submitted do not require settings to come into full compliance until the final months prior to March 2019. States must prepare for the situation that some settings will not be able to comply with the new regulations and participants in those settings will have to transfer to a compliant setting. States must develop a plan to facilitate these transitions and minimize the disruption to HCBS participants. However, because so many states have back-loaded the compliance schedule, we have concerns that there will not be adequate time to plan for smooth transitions – including giving individuals a meaningful choice of alternative settings – for any participants who might switch settings. In addition, there are similar due process concerns for states that assume all settings will come into compliance and no plan for due process protections for residents that may need to switch settings will be necessary. This seems to be an overly optimistic assumption and puts individuals unnecessarily at risk.

Mississippi provides a notice period of at least one year and Michigan sets a realistic timeline to complete remediation so that there will be adequate time to

⁴ 42 C.F.R. § 441.301(c)(4)(ii).

plan smooth transitions. States that having rolling compliance rather than waiting until all providers have been assessed or completed compliance plans seem to have a plan that is not only more manageable, but also avoids a bottlenecking of provider issues. The earlier states identify settings that need to implement changes or will be phased out, the more chance the state will have to roll out new settings that better satisfy or exceed the new regulations.

We hope that this information on state trends is helpful in your process of reviewing statewide transition plans.

Finally, we would like to emphasize a few additional points that we raised in our meeting. First, we again request that CMS be transparent in its review of statewide transition plans. We encourage you to publicly post information about the status of CMS actions and timeframes for additional action. This includes not only CMS approvals but also when CMS sends a plan back to a state for further work and public comment. Second, as we have discussed, states are closely watching the first few actions by CMS; this is one reason we were so concerned about the precedent and message sent by CMS' actions in North Dakota. We encourage you to consider approving plans that are strong and well-considered up front. In addition, we continue to believe that it is critical that HHS (whether it is CMS or ACL) issue information about the HCBS regulations, and particularly the ongoing opportunities for public comment, in a format that is understandable to Medicaid participants and their families.

Please do not hesitate to contact us if you have any questions. You can contact Elizabeth Edwards at the National Health Law Program (NHeLP) at edwards@healthlaw.org or 919-968-6308 x 104, David Machledt at NHeLP at machledt@healthlaw.org or 202-289-7661 x 304, or Alison Barkoff at the Bazelon Center at alisonb@bazelon.org or 202-467-5730 x 1309. We look forward to meeting with you again soon.

Sincerely,

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)
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