

Common Issues, Model Comments & State Samples for HCBS Transition Plans:

A Tool for Continued Advocacy from Comments on Draft and Final Plans through Implementation Changes

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In January 2014, the Centers for Medicare & Medicaid Services (CMS) released a final rule regarding the settings in which Medicaid-funded home and community based services (HCBS) under 1915(c), 1915(i), and 1915(k) programs may be provided.² The regulatory changes required by the final rule should improve HCBS services by providing opportunities for individuals to engage in community life, have access to the community, control their personal resources, and seek employment and work in competitive settings.³

The amended regulations allow states up to five years to evaluate and implement changes to their HCBS programs and they must describe this process in a transition plan that is put out for public comment and submitted to CMS for approval.⁴ This document is intended to help stakeholders recognize possible deficiencies in state transition plans and raise them as soon as possible, so that improvements can be made to the plans and during the implementation period. Accordingly, participants and others

¹ This model comments in this document were prepared with assistance from Samantha Crane and Ari Ne'eman from the Autistic Self Advocacy Network (ASAN) and the compilation of advocates' comments is an expansion of a document by Elizabeth Prialux from the National Disability Rights Network (NDRN).

² Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services (HCBS) Waivers, 79 Fed. Reg. 2948, 2988 (Jan. 16, 2014) (to be codified at 42 C.F.R. pts. 430, 431, 435, 436, 440, 441 & 447, *available at* <http://www.gpo.gov/fdsys/pkg/FR-2014-01-16/pdf/2014-00487.pdf> [hereinafter HCBS Final Rules].

³ See CMS, Informational Bulletin: Final Rule CMS 2249-F 1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and CMS 2296-F 1915(c) Home and Community-Based Services Waiver 1 (Jan. 10 2014), *available at* <http://www.medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-01-10-14.pdf>.

⁴ State transition plans are supposed to be due to CMS on March 17, 2015 or earlier if certain conditions for waiver or state plan renewal occurred. 42 C.F.R. § 441.301(c)(6)(ii)(B).

should review these plans closely and provide advice and information to their state agencies and CMS, depending on the status of the plan or implementation process.

Using this Document throughout Commenting, Final Plan & Implementation

In many states the comment period on draft plans has ended, but this should not discourage stakeholders continuing to provide input on plan implementation, including assessment processes, policy and rule changes, and heightened scrutiny

- **If your state has a draft transition plan or HCBS program out for public comment:** Use these comments and state samples as a starting point for identifying negative and positive aspects of your state plan to submit comments to your state, including any descriptions of settings that you believe may not meet the rules.
- **If the comment period on the draft plan has closed, but no final plan has been issued:** Similar to when a draft plan is out for comment, you can use these comments to look again at your state's draft plan and either submit additional comments to your state or prepare for sending comments to CMS when the final plan is submitted.
- **If your state has submitted a final plan to CMS:** Even though there is no official comment period, **CMS still wants to hear from advocates if there are concerns about a state's final plan.**⁵ In addition to the comments in this document, there may be additional issues with final plans such as:
 - The state failed to post an adequate summary of public comments
 - The state summarized comments in such a way that changed the meaning of your comments
 - The state did not respond to public comments as required⁶
 - The public comments posted show there was a lack of public participation in the process
 - The draft plan did not change in response to public comments and the state did not explain why there were few, if any, changes
- **If your state is implementing their HCBS transition plan:** As states move forward, there will continue to be opportunities to comment on transition plan updates as well as state-level regulatory and policy changes. These model

⁵ Advocates are encouraged to carefully review final transition plans and to write a letter to CMS with any concerns they have with the plan. The letter can be sent to hcbs@cms.hhs.gov. This letter can also include any specific settings advocates are concerned about, although in many states the identification of settings is an ongoing issue. For assistance with review of draft plans, final transition plans, implementation issues or advocacy strategies, including who to contact, email Elizabeth Edwards at edwards@healthlaw.org, who is part of a group of national advocates who are working together to review plans and serve as resources for state advocates.

⁶ 42 C.F.R. § 441.301(c)(6)(iv)(B); CMS, Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements 5 (Sept. 5, 2014), available at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/statewide-transition-plan-toolkit.pdf> [hereinafter CMS Transition Plan Toolkit].

comments can be used in these advocacy opportunities to continue to push the state forward on community integration and participant protections.

Document Organization

This document consists of two parts:

Part 1: The first is a set of model comments that are non-state specific statements of common problems in state transition plans. These model comments are not an exhaustive list, but are a compilation of common issues that advocates have identified in state plans thus far.

Part 2: The second part of this document is a compilation of comments from advocacy groups, organized into the same broad categories as the model comments. Both parts follow the following issue area organization:⁷

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This document should make commenting and advocacy on state transition plans easier by providing model comments that identify common issues and sample comments from other advocates about what advocates identified in their state transition plans. As always, it is advisable to include both the negatives and positives in a plan, so these common issues can also serve as a comparison.

Part 1: Common Issues & Model Comments

I. Insufficient Information in the Plan

A. Lack of Detail

The HCBS regulations require that states provide an opportunity for people who use HCBS to comment on the transition plans.⁸ The state’s plan only provides a brief, cursory description of high-level strategies. It is difficult for stakeholders (including program participants and their families, advocates, and providers) to determine if they will be affected or not. The plan does not provide sufficient detail to answer our questions and concerns about the state’s implementation plan.

1. Other Possible Issues to Include:
 - (a) It is not clear from the plan which services will be affected by the transition plan.

⁷ Click on the number to jump to the page.

⁸ 42 C.F.R. § 441.301(6); 42 C.F.R. § 441.304(e)-(f).

- (b) The plan includes a broad statement that an entire category of services or settings meets the regulatory requirements, but provides no explanation or methodology for how this conclusion was reached.
- (c) The plan does not clearly indicate how the state will improve access to more integrated services in order to replace any less integrated services that will no longer be covered.
- (d) The lack of specificity, including on subjects such as methodology, survey tools, qualifications or training of surveyors, and role of stakeholders, means that stakeholders are being asked to have faith in the state to operationalize components of the plan that no stakeholders have had a chance to review and comment on. This approach is very worrying generally, but especially when it concerns services, settings, policies and protections that are critical to continued community integration.

B. Inclusion of All Programs & Services

A transition plan should include all services that are affected by the HCBS rule changes. If certain services are to be excluded because the state has determined that they comply with the new rule or are not affected, the plan should include an explanation of the process and assumptions the state used to come to that conclusion.

1. Other Possible Issues to Include:

- (a) Improper presumption that because a waiver or state plan amendment was recently changed and included efforts to comply with the proposed rules that these programs meet the standards set by the final HCBS regulations.
- (b) It is not adequate for plans simply to require that settings comply with the HCBS regulations. States are expected to evaluate the extent to which its regulations, standards, policies, licensing requirements, and other provider requirements ensure settings that comport with the requirements.⁹ States should evaluate (at least) a significant percentage settings to determine if they comply with these policies and if the policies fully provide the protections for community-based services that the rules provide.

C. Need for Clear Milestones¹⁰

CMS has given states five years to come into compliance with the new regulations. The transition plan should include deadlines throughout those five years, including realistic deadlines for:

⁹ CMS Transition plan Toolkit, *supra* note 6, at 1-3.

¹⁰ Plans must include the timeframes and milestones for state actions, including assessment and remedial actions. If state standards must be modified, the state should propose a reasonable time frame for making these modifications and the state must include a complete timetable for coming into compliance. When a state plans to conduct an assessment after adopting new standards, the state is supposed to provide information on how, in the interim, “the state should provide information on how, in the interim, the state will communicate the need for change, educate providers, inform individuals and families, and establish a time frame for activities.” *Id.* at 1, 5; see also 42 C.F.R. § 441.301(c)(6)(ii)(A).

- Bringing previously non-compliant settings into compliance, which may include a date for compliance plans to be completed, reviewed by the state and available to the public;
- Building provider capacity to serve people in more integrated settings;
- Placing a moratorium on new placements in settings found to be out of compliance (this date may need to be after the development of new settings has begun or some existing settings are compliant);
- Additional comment periods for substantial changes to the state’s transition plan, assessment results have been made available, policies have been updated, etc.

These deadlines may vary by HCBS programs, i.e., states have different programs for people with developmental disabilities and people with physical disabilities, or for different types of services.

Deadlines will help states avoid disorganized and rushed efforts to come into compliance at the very end of the five-year period. They will also give consumers a better understanding of how their services will change over time and will help diminish consumer fears that they will be “dumped” by existing non-compliant providers starting in 2015. The deadlines should be staggered so that many individuals are not seeking placements at once and so that new placements may be developed to respond to need before deadlines are reached.

II. Public Comment & Education¹¹

A. Identifying Future Opportunities for Public Comment

CMS requires states to provide further opportunities for public comment when substantive changes are made to transition plans.¹² Because stakeholders need to be included at all steps of transition, the timeline should include many different comment periods at different stages. The transition plan should clearly set forth the actions or time intervals at which future comments will be accepted and the expected deadlines. Doing so will not only provide assurances that the state is planning for future comments, but will also give participants and advocates sufficient notice.

¹¹ 42 C.F.R. § 441.301(6)(B)(iii); § 441.710(3)(iii). At a minimum, the 30-day public notice and comment period must include at least two forms of public notice using two different methods of notifying the public and at least two ways for the public to provide input. The complete transition plan must be available for review by the public, including participants and individuals eligible to be served by the program. The plan should be available on the state’s Medicaid website, which should meet accessibility requirements, and through an alternative method for those without internet access. Tribal notification is not counted as one of the required public notices as that is intended to reach a more targeted group of stakeholders than general public notice. CMS, HCBS Final Regulations 42 CFR Part 441: Questions and Answers Regarding Home and Community-Based Settings 1-2, available at <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/q-and-a-hcb-settings.pdf> [hereinafter CMS Q&A].

¹² When a state submits an amendment or modification to a transition plan where assessments have resulted in a change in the findings or where more specific remedial action and milestones are added, the state must incorporate the public notice and input process. CMS Transition Plan Toolkit, *supra* note 6, at 7.

B. Sufficient Time for Commenting and Incorporating Changes

It is important that the timelines in the transition plans include enough time to consider stakeholder comments at every stage of the process. People need time to read the plan, understand it, and send in comments. States also need to make sure that they give themselves enough time to read all the comments they receive and make any necessary changes to their final plan.

C. Accessible Comment Mechanisms¹³

Efforts to include stakeholders must take into consideration the needs of the populations and communities from whom information is being sought. HCBS participants and their families have the most information about what needs to change in the current system and with individual settings to meet the new regulations. However, such input is limited if the mechanisms used by the state to ask for and gather information are not accessible for HCBS participants and their families. Any plan for stakeholder involvement should consider the barriers that many individuals have with modern mechanisms of commenting, such as email and internet-based submission. This concern includes how a request for public comment is distributed. Accepting comments only by email is not as effective as reaching out to individuals directly. Many individuals do not have easy access to electronic communication and may have difficult traveling to meetings, even regional ones, about the transition plan. Accordingly, at a minimum, the agency should provide a mailing address for paper comments and take comments via phone.

D. Public Comment Minimum Requirements

At a minimum, the 30-day public notice and comment period must include at least two forms of public notice and at least two ways for the public to provide input.¹⁴ The complete transition plan must be available for review by the public, including participants and individuals eligible to be served by the program. Meetings with selected representatives of types of stakeholders may be useful, but are not sufficient to meet the requirements of notice and comment.¹⁵ The plan should be available on the state's Medicaid website, which must meet accessibility requirements for people with disabilities, and through an alternative method for those without internet access. In the case of public forums, the plan must be available or distributed for comment.¹⁶

E. Public Comment-Outreach and Education

A state's plan for educating the community and seeking input should describe how a state's plan for gathering information from participants. Any process that does not

¹³ CMS expects the public input process to seek input from a wide range of stakeholders and that the process for individuals to submit comments is convenient and accessible for all stakeholders, particularly individuals receiving services. *Id.* at 7.

¹⁴ CMS Q&A, *supra* note 11, at 1-2; CMS Transition Plan Toolkit, *supra* note 6, at 6. The plan must be posted on the state's website in an easily accessible manner and include a website address for comments; the state must also provide at least one other option for public comment. CMS Transition Plan Toolkit, *supra* note 6, at 6.

¹⁵ *Id.*; CMS Q&A, *supra* note 11, at 2.

¹⁶ CMS Transition Plan Toolkit, *supra* note 6, at 6. Sate can use summary documents or offer explanations of the Plan's contents in addition to the document itself.

provide clear opportunities for program participants to understand the plan and provide input cannot be considered to be “sufficient in light of the scope of the changes proposed, to ensure meaningful opportunities for input for individuals serviced, or eligible to be served, in the waiver” as is required.¹⁷

1. Other Possible Issues to Include:

- (a) Limiting the participation of participants, families and advocates to the assessment process and public comment on transition plans, is insufficient. Participants and their families/friends as well as advocates have crucial information about whether a setting should be considered community based and should be included in the plan throughout.
- (b) The recognition of the need for public comment and inclusion of stakeholders in the assessment process is positive, but the lack of inclusion in such areas as policy development and rules changes could be detrimental to the successful identification of issue areas that need changes.

F. Continuing Education¹⁸

The state should have a continuing plan to educate HCBS participants, family members, providers, and community members so that they understand the transition process, what is changing, and the opportunities for involvement. Accessible educational opportunities will promote information flow to the state from the community and should help decrease misinformation and fears about changes. Although education is important in the early stages, the state should also inform participants near the end of the transition process so that they understand the new policies developed about their rights and enforcement mechanisms, such as how they may file a complaint, so that the HCBS programs continue to promote community integration.

III. Stakeholder Involvement¹⁹

A. Generally

Stakeholder involvement is critical to formulating a transition plan that fulfills the intent of the new HCBS regulations. A transition plan should first examine how current participants actually experience community inclusion, freedom of choice, and any barriers they encounter. The only people who can provide this information are the individual participants and, in some cases, their family members and friends. While

¹⁷ 42 C.F.R. § 441.304(f)(1).

¹⁸ See CMS Transition Plan Toolkit, *supra* note 6, at 5 (stating “state should provide information on how, in the interim, the state will communicate the need for change, educate providers, inform individuals and families, and establish a time frame for the activities.” (regarding an assessment after adopting new standards)).

¹⁹ Be aware of how a state is using the term “stakeholder.” In reviewing state draft transition plans, this term is used differently and is sometimes used to refer to HCBS providers and does not necessarily include participants. This document uses stakeholders to refer to those with an interest in the HCBS program, focusing on the important role of participants, their family members, and advocacy groups. If a transition plan generally refers to stakeholders, it should be clear somewhere in the document who the state is intending to include in that group and the role the group will play in planning, policy development, and implementation.

providers offer an important perspective, they cannot offer the perspective or the experience of the individual participant. The regulations focus on the individual's experience, therefore the transition plan should also do so. Some ways to improve stakeholder involvement would be to:

1. Educate participants about their rights to receive services in fully integrated settings so that they may provide meaningful feedback on their own experiences. This information is crucial to the state's compliance in the short and long term. Other states' plans include participant education so that individual HCBS participants, their families, and similarly situated stakeholders will be aware of the changes that will affect services.
2. Ensure that the assessment teams that are described in the draft transition plan always include consumer representation and meaningful consumer participation.
3. Develop a means for individuals to participate in their own self-assessment of the settings in which they live or spend their days. Participant assessments must be accessible to the individual and should be free from provider influence and be a part of the assessment validation process. We do not believe that provider self-assessment is at all adequate to determine compliance with the HCBS regulations.

B. Appropriate Balance of Stakeholders

Input from all relevant stakeholders is important in a successful transition plan. However, reliance on providers or other potentially biased mechanisms will not provide a true picture of stakeholder opinion. Self-advocacy groups should be a key part of a state's communication plan and any stakeholder advisory group must have strong representation from participants, with such groups and their advocates not being outnumbered by provider interests. The HCBS regulations focus on an individual's experience and a system that responds to the voices of non-participants or non-participant advocacy groups would be contrary to the rule.

IV. State Administration

A. Identify State Partner Agencies

Participants in HCBS programs interact with multiple state agencies, including housing and employment. These agencies may be part of implementing services or simply have valuable information. A transition plan should include these state agencies and assign them appropriate roles. The new regulations will require changes within these agencies, especially for the on-the-ground personnel who will be responsible for administering the new requirements. These individuals have valuable experiences to share that will help make sure the state makes changes that will be effective for the program participants. These agencies will also be important in monitoring ongoing compliance so they should be involved early in the process.

B. Cohesive Transition Plan Across Agencies

Where different agencies operate different Medicaid HCBS programs, there should be an overarching transition planning group that has representation from all relevant state agencies and from all recipient groups (e.g., aging, physical disability, and developmental disability). Although planning should allow for different needs of different

participant populations, there should be consistency so that participants will not have different experiences of community based on the program under which they receive services. It is critical that policies, assessment tools, and other aspects of implementation are consistent in the evaluation of community and in the protections for participants, including compliance mechanisms.

C. Review of Provider Policies

The plan should set out a process and timeline for review of provider policies, including enrollment and applications. All standards for providers of HCBS should be evaluated for necessary changes to enforce compliance with HCBS regulatory standards. This would include administrative rules, policies, credentialing, licensing policies, required trainings, enrollment forms, compliance processes and reviews, and other provider resources. This identification process and subsequent changes should involve stakeholders.

D. Review of Funding Sources and Rates

The review of the HCBS delivery system for compliance with the HCBS regulations should take into consideration current funding sources and rates. The services must be sufficiently funded to achieve rule compliance and the funding structure, including any incentives, should be evaluated. The rules may change how services must be provided and the array of services an individual may need, so evaluation of rates, budget algorithms, and related financial pieces is important to successful plan implementation.

1. Other Possible Issues to Include:

- (a) The state should evaluate access to and funding of transportation, both Medicaid and non-Medicaid, including removing overly restrictive policies that limit access to transportation. This may include an evaluation of when an individual may access Medicaid funded transportation services to their HCB services and the access to transportation individuals have in residential programs, especially those in rural areas. Access to transportation is a crucial piece of meaningful community participation for people with disabilities and needs to be part of any evaluation of HCBS programs.
- (b) Any review of rates should consider the restrictions that staffing ratios for both residential and non-residential settings may have on the opportunities for choice that a person is allowed. For instance, if a person resides in a three-bed group home and there is only one staff person, the opportunities for a person to choose activities may be limited by the availability of staff, e.g., to accompany them on an activity. A review of services and rates should include acknowledgement that additional individual activities may be necessary to ensure compliance with the rules.
- (c) Current use of activities paid at a group rate as opposed to an individual rate must specifically be evaluated because such activities are more likely to limit choice and isolate an individual from the larger community.

E. Payment Source Discrimination

The Department should require that HCBS settings honor the new HCBS standards regardless of a participant's source of payment (including private payment and non-HCB Medicaid payment). If a setting provides services for HCBS participants and non-HCBS participants, that setting should meet the HCBS requirements for all residents. To allow a setting to create a non-community based environment for some will negatively affect the community nature of the setting as a whole. To allow a setting to meet the HCBS requirements only for the HCBS participants and treat other residents differently based on payment source would be contrary to both the letter and the spirit of the new regulations.

F. Residential Agreement Compliance

The Plan should include the development of a sample lease or residential agreement. The state should also develop a monitoring system that ensures these agreements are used and that they are signed by residents after understanding the protections offered by the agreement.

G. Appeals²⁰

Appeal processes included in transition plans should be transparent and provided equally. If a state permits appeals of determinations that a setting fails to comply with the community settings regulation, this appeal process should be transparent and include information from participants that is free from provider influence. To allow a setting to appeal a determination and submit evidence about the community experience of individuals in that setting without ensuring there is an opportunity for those individuals to provide unbiased information about their experience or their families or advocates to provide information would create heavily biased results. Where providers have appeal processes for determinations that a setting is not HCBS regulation compliant, HCBS participants should have the opportunity to appeal a determination that a setting complies with the HCBS regulations and does not need to change.

H. States May Set Higher Standards

The new HCBS regulations are an important step in increasing community integration for people with disabilities. It is important to keep in mind that these regulations establish minimum standards for determining what are community settings. A state that is working to achieve *Olmstead* compliance and set quality standards for community integration may, however, set higher standards or more restrictive requirements.²¹ The

²⁰ Advocating about appeals should be considered carefully, taking into account how helpful it may be for participants (i.e., versus a strong complaint process and good person centered planning) and the overall effect appeals would have on the number of truly community settings. Allowing appeals of the determination of whether a setting is compliant or not may result in noncompliant settings that successfully appeal the decision without changing their ways.

²¹ CMS Q&A, *supra* note 11, at 3. It is important to remember that CMS has said in guidance that the exploratory questions and guidance do not constitute guidance on states' obligations under the Americans with Disabilities Act and Section 504 of the Rehabilitation Act, as interpreted by the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999). See, e.g., CMS, Exploratory Questions to Assist States in Assessment of *Non-Residential Home* and

state should consider what will achieve the best long-term outcome for its citizens with disabilities and not limit itself to the minimum standards set by CMS.

1. Other Possible Issues to Include:

- (a) The HCBS regulations may only specifically apply to certain community-based services; therefore, the state should effectively use the resources reviewing policies, procedures, and rules with a broader vision. The time and resources spent examining the current system and making the changes necessary for compliance should include consideration of the needs of people who do not currently have access to HCBS services or just use community-based Medicaid services. Most importantly, the system changes should not be so specific to HCB services that they will impede, rather than encourage, further community integration efforts.

The HCBS rules represent standards that should apply to all people with disabilities in the state, each of whom should have opportunities to live, work and spend time in their community. The transition plan should take into consideration this broader vision.

V. Assessment of Settings²²

A. Clear Identification of Current Providers

The transition plan should identify the types of providers who currently receive funding, the services provided, sites at which services are provided, and the number of individuals served by this type of provider. This gives the public an opportunity to comment about specific settings.

Community—Based Service (HCBS) Settings 2, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/exploratory-questions-non-residential.pdf> [hereinafter CMS Non-Residential Guidance]. Although the rules can help move a state toward more integrated services, the state continues to have separate obligations under the ADA and *Olmstead*.

²² For more guidance to help inform your comments about specific settings in your state that may not meet the rules, see CMS, Regulatory Requirements for Home and Community-Based Settings, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/requirements-for-home-and-community-settings.pdf>; CMS, Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/settings-that-isolate.pdf> [hereinafter CMS Settings that Isolate]; CMS, Exploratory Questions to Assist States in Assessment of Residential Settings, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/exploratory-questions-re-settings-characteristics.pdf>; CMS Q&A, *supra* note 11; and CMS Non-Residential Guidance, *supra* note 21. As a brief reminder, CMS included the following on a non-exhaustive list of examples of residential settings that typically have the effect of isolating people from receiving HCBS from the broader community: farmstead or disability-specific farm communities; gated/secured “communities” for people with disabilities; residential schools; and multiple settings co-located and operationally related (i.e., operated and controlled by the same provider) that congregate a large number of people with disabilities together and provide for significant shared programming and staff, such that people’s ability to interact with the broader community is limited). CMS, Settings that Isolate, at 2-3.

1. Other Possible Issues to Include:

- (a) A plan should fully examine how a service is provided and the environment in which it is provided. To find an entire waiver category to be compliant with the HCBS regulations solely based on the service definition is an insufficient examination of whether the services is actually provided in a way that meets the HCBS rules.

B. Assessment of All Settings and Providers

The transition plan should include a comprehensive assessment process for *all* settings that provide HCBS, including residential and non-residential settings.²³ The state should not rely only on a random sample or other subset of HCBS providers. In addition to surveying provider-owned residential and non-residential residential settings, the transition plan should also discuss how other home and community-based residential settings, such as family homes or one-on-one day services, will be examined and determined to meet the new requirements of the regulation.²⁴

C. Stakeholder Input in Assessment Tools

It is important that assessment tools, including questionnaires, be developed with stakeholder input and be reviewed to ensure that the tools are valid; including ensuring that it does not encourage biased results. Any assessment process should be designed so that participants are encouraged to give input on their setting without being influenced by the provider or other parties that have a financial interest in the outcome of the assessment. It is also important that participants be provided background information on their rights under the rules so that they have an understanding of what they should expect of a provider under the rules and can have perspective about their current setting.

D. Stakeholder Input on Settings

Per CMS guidance, a state's assessment of which settings isolate individuals should be informed by public comments.²⁵ In order to sufficiently meet this standard of public

²³ States are expected to report the results of their review and analysis of all settings in which HCBS are delivered and settings in which beneficiaries receiving Medicaid HCBS services reside. This review is supposed to include public input. CMS, State Transition Plan Toolkit, *supra* note 6, at 1. As a reminder, even if a residential setting is not supported by HCBS funding, if a person who receives HCBS funding lives there, that setting must meet the residential requirements. See, e.g., 42 C.F.R. 441.301(c)(2)(i); 42 C.F.R. § 441.725(b)(1).

²⁴ Although the regulations allow states to presume a participant's private home or relative's home in which they reside meets the requirements of HCB settings, CMS guidance also notes that the person-centered planning process is an important protection to assure that such individuals have full access to the greater community to the same degree as individuals not receiving HCBS. "While a private home may afford the individual a home-like setting, the person-centered plan and provision of appropriate services that support access to the greater community are critical components to ensure community integration, especially for an individual with limited social skills." CMS Q&A, *supra* note 11, at 4.

²⁵ *Id.* at 14. This is supposed to occur before submission of the transition plan to CMS, but many states are behind on the assessment process and will not have done so before the initial

input, the transition plan should include a detailed plan to reach out to participants for feedback on individual settings. Participants may lack access to public hearings or written, internet-based comment processes. Some states have used focus groups, on-site interviews, and participant surveys in order to be more inclusive of consumers.

1. Other Possible Issues to Include:

(a) Opportunities for stakeholder input must be accessible to the individuals. Assessment tools, surveys, questionnaires and public forums that ask broad questions using the wording of the regulations likely lack the specificity and meaning that is necessary to get the requested feedback. For example, regarding “dignity and respect”, questions should be more specific about asking whether participants are addressed by name as opposed to last name, room, or some shorthand nickname, such as “hon”.

E. Use Objective Criteria to Identify Isolating Settings

In order to comply with the new rule’s requirement that the settings not be clustered together or have the effect of isolating consumers, the transition plan should include a plan to conduct a geographic analysis of setting locations. The analysis should be sufficient to determine not only whether settings are clustered together, but also indicators of community access, such as the proximity to public transit, schools, and local businesses. Some states are using GIS mapping and/or zoning information to help identify settings that should be more closely examined.

F. Unbiased On-Site Evaluations

The assessment process should be administered by an independent third party. At the very least, the on-site evaluations need to be done by an unbiased party and done in such a way as to ensure that participants are a main source of information.

Assessments that rely solely on providers will not be reliable, since providers’ stated policies or intentions are not necessarily consistent with the actual experience of the residents/participants. Any independent sampling process should be driven by, and include, input from consumers and stakeholders.

G. Validation of Assessment Tool

Any assessment tool used should be piloted and tested for whether it accurately identifies the nature of a setting. If the tool fails this test, it should be altered until it is a valid tool. The state should have a system to validate the provider assessments in a way that is statistically significant by provider type. If the validation system for a provider type category identifies a pattern of non-compliance, this should trigger a full review of that provider type category. The state may want to consider using data tools, such as

transition plan submission to CMS. However, the assessment process is an important piece of a transition plan and if a state was not at this point when submitting the original plan, there is an argument that the assessment process results will substantively change the plan sufficiently so as to require a new public comment period. See CMS Transition Plan Toolkit, *supra* note 6, at 7, (citing CMS, Steps to Compliance for HCBS Settings Requirements in a 1915(c) Waiver and 1915(i) SPA, <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/hcbs-1915c-waiver-compliance-flowchart.pdf>).

National Core Indicator (NCI) data, to help it determine whether the assessment results appear accurate.

H. Multiple Tools May Lead to Inconsistent Results

Developing survey tools for different programs, populations, or settings, e.g., for adult day health, may be both positive and negative. This approach allows a tool to address issues specific to a given class of settings, but it may also lead to inconsistent evaluations on the community nature of setting or how community “looks” across types of settings. The transition plan should address this potential lack of uniformity and include mechanisms to ensure consistency across survey tools, such as reviews by a consistent state entity or committee review for all plans. In addition, the assessment tools and process should have the same degree of stakeholder input, including meaningful input from participants, their families and advocacy groups.

I. Prioritize Segregated Settings Review

The state should prioritize review of assessment of settings—both residential and non-residential—that are “presumptively institutional” according to the new CMS regulations, such as gated communities, “villages,” or services provided on the grounds or near a hospital, nursing home or intermediate care facility. Under the new regulations, settings that are presumptively institutional cannot receive HCBS funding unless CMS finds that a specific setting does not actually have the qualities of an institution. This will not be true of most “presumptively institutional” settings. As a result, it will be important to assess these settings early to stop new placements in these settings and begin the process of helping people transition to integrated settings.

J. Transparent Assessment Results and Classifications

The results of the assessment process must be transparent to the public. For states that are assessing sites based on state standards, plans should provide the state’s best estimate of the number of settings that align with the rules, will require modifications, cannot meet the rules, and are presumptively not community but for which the state plans to submit evidence of their community nature through the heightened scrutiny process.²⁶ Any subsequent process such as appeals or remediation plans should be similarly public. States should post this information on its website and otherwise ensure it is accessible. The state should accept public comment/information and incorporate this information where appropriate to ensure a setting meets the standards of community integration.

VI. Enforcement & Ongoing Compliance

A. Generally

A transition plan should explain how the state will make sure that providers are following the letter and intent of the rule. Including language in provider contracts about obeying the HCBS rules, ensuring providers have written policies, or similar activities, while important, are not sufficient to protect an individual’s experience in a setting without additional monitoring and enforcement. People who live in group homes repeatedly say

²⁶ CMS Transition Plan Toolkit, *supra* note 6, at 4.

that what is written in a policy, even if posted on the wall of the home, is very different from how staff act or their experience. For example, a resident may have the right to privacy, but he cannot take the phone to their room, close their door, or enjoy activities alone. Similarly, a person may have the right to leave the setting at any time, but if there is insufficient staff or they are unwilling to accompany that person, that person will be forced to remain in the setting. A state must also have a way to make sure that modifications in provider-controlled settings comply with rule and are not more restrictive than they need to be. Participants should have a way to complain about providers and the state should regularly ask participants about their experiences. Such information should be gathered in an unbiased, accessible way and should be taken into consideration when renewing providers and during that person's person centered planning process. There should be a continuum of remedies so that all types of problems may be addressed, rather than only serious violations being corrected.²⁷

B. Rolling Provider Compliance

The transition plan must ensure stability for individuals and not decrease their level of community interaction. If the plan does not provide that enforcement of setting compliance will occur on a rolling basis, there is a strong chance that setting compliance will bottleneck and there may not be enough alternatives developed as participants need new settings. The same is true if the provider compliance is heavily weighted to toward the end of the plan's timeline. The transition plan should tier provider compliance and begin compliance early so there will be sufficient time to identify the needs of the community and to develop new providers. Not knowing when individuals may be to change service providers or if there will be sufficient alternatives available creates uncertainty and fear that may be detrimental to stability in the community.

C. Complaint Mechanism

The state should develop a process for participants to complain or raise concerns about the community nature, or lack thereof, of a setting, including those settings the state presumes to be compliant with the rule. The complaint mechanism should provide meaningful feedback to the individual complaining.

D. Modifications Compliance

A key piece of the HCBS regulations is the limitation on when the additional requirements for a provider owned/controlled setting may be modified in a person's service plan. Because this protection of a person's rights to the community qualities of a provider owned/controlled setting is so important, a transition plan needs to be clear about the monitoring mechanisms the state will put in place to protect against abuse of this mechanism.

²⁷ CMS noted that ongoing compliance mechanisms are necessary. *Id.* at 1. "It should be noted that assessment of individual settings is not a substitute for ensuring that state standards, regulations, policies, and other requirements are consistent with Federal requirements and that the state has an oversight system in place to assure ongoing compliance with the requirements." *Id.* at 3.

E. Ongoing Transition

Although CMS requires states to come into compliance with the new HCBS regulations within five years, the state should consider extending the transition plan where necessary to ensure that its services meet the highest standards of community integration. For example, the state may aim to eliminate its most segregated settings within five years, but also include an eight- or ten-year goal to completely transition to self-directed, scattered-site services. Such extended plans are consistent with recent *Olmstead* settlements such as the one in *United States v. Rhode Island*, and allow states to use the new HCBS rules as a launching point for even more comprehensive reforms.

VII. Participant Protections

A. Individual Transition Plans and Protections

A transition plan must identify a timeline for creating a process to help individuals who may need to transition to different services. This plan must adhere to due process principles, providing reasonable notice to individuals and a proper process that ensures individuals will have access to appropriate alternative service providers that will meet their needs without a break in services.²⁸ Not knowing when individuals may begin to change services or if there will be sufficient alternatives available creates uncertainty and fear that may be detrimental to stability in the community. The transition plan for HCBS needs to ensure stability for individuals and not decrease their community interaction.

B. Using Person Centered Planning as a Tool

Person centered planning requirements in the HCBS regulations are currently in effect and states must be currently in compliance with them.²⁹ Under those requirements, participants' planning processes should comprehensively evaluate their current settings to determine if they comply with the HCBS regulations. To do so, the teams should consider whether the settings where individuals reside and spend their days are community-based, are the most integrated setting appropriate to their needs, whether they have sufficient supports for the most appropriate setting, and whether changes

²⁸ *Id.* at 5.

When relocation of beneficiaries is part of the state's remedial strategy, the Statewide Transition Plan should include:

- An assurance that the state will provide reasonable notice to beneficiaries and due process to these individuals;
- A description of the timeline for the relocation process;
- The number of beneficiaries impacted; and
- A description of the state's process to assure that beneficiaries, through the person-centered planning process, are given the opportunity, the information, and the supports to make an informed choice of an alternate setting that aligns, or will align, with the regulation, and that critical services/supports are in place in advance of the individual's transition.

Id.

²⁹ Although states have up to five years for transition plans regarding settings, the rules regarding person centered planning went into effect on March 17, 2014.

need to be made to their plans. If needed to address the address the issues above, the consumer's person-centered plan should identify whether a new setting and/or new supports are needed, what can be done immediately, tasks and assignees, and a timeline that will redress the issues as quickly as possible. In addition, the person centered planning provides opportunities for information gathering about consumers' experiences in their current settings and their preferred settings; this information will help identify compliance issues and help ensure the Department has a proper array of services and settings. While a person may not be able to change settings as new settings are developing or changing, the planning process should clearly identify setting needs and provide additional services if necessary.

VIII. Full Choice in Housing Options

A. Choice of Setting

The HCBS rule requires that individuals be provided a choice of settings, including a choice of non-disability specific settings and, in residential settings, a choice of a private unit.³⁰ The plan gives no indication that part of the assessment process will be an evaluation of the array of settings and whether the current capacity will meet the need. People cannot be offered that choice if there is not capacity. The state should evaluate its current capacity of non-disability specific setting and develop a plan to increase capacity as needed to fulfill this requirement.

1. Other Possible Issues to Include:

- (a) The lack of capacity is particularly acute for non-residential services, where the vast majority of settings are disability specific.
- (b) With respect to the option of a private unit, the state must ensure that all of its waiver programs offer and have capacity for this option.

B. Array of Setting Options is Critical to Community Integration

The plan should make sure that everyone, including those who need a lot of support, has the chance to live in their own homes instead of group homes or other settings that house only people with disabilities. Even if a group home has policies saying that they will respect people's freedom, privacy, and unique needs, in practice they are very restrictive. Whenever service providers group people with disabilities together in the same place, this environment tends to isolate them from the rest of the community. Grouping people together also makes it much harder for people to decide exactly which services they need, because people are limited by the needs or limitations of the staff.

³⁰ HCBS Final Rules, *supra* note 2, at 3030 (" Home and community-based settings must have all of the following qualities ... The setting is selected by the individual from among setting options including non-disability specific settings and an option for a private unit in a residential setting"); *see also* CMS Q&A, *supra* note 11, at 4 ("There is no minimum number of options, but an individual must be able to select among setting options that include non-disability-specific settings and an option for a private unit in a residential setting. The individual's person-centered plan should document options and different types of settings considered by the individual during the person-centered planning process, based on the individual's needs, preferences, and for residential settings, resources available for room and board.") As a reminder, non-disability specific setting is interpreted by CMS to mean a setting that is not limited to people with the same or similar types of disabilities. CMS Q&A, *supra* note 11, at 5.

For example, staff might not be able to leave the group home to help one resident go to the store, because they need to stay and provide services to someone else in the group home.

Instead, people with disabilities should be able to live in their own apartment or with family and friends. Instead of paying staff at a group home, the HCBS program would pay someone to come to people's homes and provide the services that they need. People would be able to choose who provides their services and when. They would also be able to decide which services they needed at which times. By choosing their own staff, people with disabilities would be able to make sure that the person who helps them on a daily basis is someone who works well with them and understands their needs

IX. Non-Residential/Day Services³¹

A. Plan for Fully Integrated Day Services

The transition plan needs to make sure that people are included in the community not just in terms of where they live, but also how they spend their day. Currently, many HCBS participants are getting group-based day services that are not really integrated because people spend most of the day at a center that only serves people with disabilities. When they go out on trips "into the community," they are in big groups that inhibit interaction with people outside of the group. The transition plan needs to closely examine the current day program services and establish a clear plan for moving towards integrated day activities that focus on supported and competitive employment.

Instead of funding sheltered workshops and "work crews," states should be transition to funding supported employment services that help people find and keep real jobs that pay real wages, alongside coworkers who do not have disabilities. In sheltered workshops, people with disabilities all work together – the only people without disabilities are supervisors and service workers. In work crew arrangements, people might be working in the same building as nondisabled people but they are still isolated because everyone on the work crew has a disability. Sheltered workshops and work crews also usually pay less than the minimum wage. These settings are not only segregated but also have a very bad record of helping people get competitive, integrated jobs. Many states, like Rhode Island, are already moving people out of sheltered workshops and into integrated employment.

³¹ In particular, watch for day programs that are operated in a facility or nursing home, or in an ICF/IID. Any HCB setting that is located in the building of any public or private institution, or on the grounds of a public institution, is presumed to have the characteristics of an institution and therefore does not qualify as a home and community-based setting, although a state can submit evidence to have the setting go through the heightened scrutiny process. If a day service is rendered by an ICF/IID, it is considered institutional, but if the service is provided by a licensed day service operated separately from the ICF/IID but in the same building, it will only be presumed to have institutional characteristics and the state may submit evidence of the community nature of the facility to go through the heightened scrutiny process. Dec Q&A at 10-11. For additional information about employment services, see CMS, Informational Bulletin on Employment Services (Sept. 16, 2011), <http://www.medicare.gov/federal-policy-guidance/downloads/CIB-09-16-2011.pdf>.

B. Reverse Integration is Insufficient

We do not believe that “reverse integration” (bringing people without disabilities into an otherwise segregated setting) is an acceptable strategy for turning sheltered workshops into “integrated” settings. Such activities do not provide opportunities for people to engage in community life or allow people to receive specific types of services (e.g. employment services, therapies, recreation opportunities, etc.) in the places where people not receiving HCBS typically go to get those services.³²

C. Closing the Door to New Segregated Placements

The transition plan should specify a point in the transition plan to stop new placements in sheltered workshops and to transition people currently in sheltered workshops into more integrated settings like supported employment. This point should be as soon as possible in the plan, taking into consideration the development of alternative services. This process should not be near the end of the transition period. For example, Massachusetts has created a plan, Blueprint for Success, which both diverts new admissions to sheltered workshops and includes a plan to completely transition all individuals in those segregated settings into integrated settings.

³² CMS guidance says that a state could allow pre-vocational services delivered in facility-based settings that encourage interaction with the general public, such as through interaction with customers in a retail setting. However, CMS specifically notes that “pre-vocational services may be furnished in a variety of locations in the community and are not limited to facility-based or site-based settings, and that states have flexibility in determining whether and when to use facility-based settings. *All settings must have the characteristics of HCB settings, not be institutional in nature and not have the effect of isolating individuals from the broader community.*” Dec Q&A at 10 (emphasis added). While some may interpret this guidance to support sheltered workshops, the settings must not have the effect of isolating individuals from the broader community and interacting with customers in a true retail setting is quite different from interacting with the public through limited visits with community groups. In addition, the interaction between customer and employee is likely much more of an interaction that is comparable to a person without disabilities, as compared to an interaction between a community service group coming in to “visit with” or “help” people with disabilities in a sheltered setting. For more information, see CMS Non-Residential Guidance, *supra* note 21.

Part 2: Appendix-Advocate Comments by Topic

The following is a compilation of comments made by other advocates on their state transition plans, grouped by topic. This list is not exhaustive and some of the issues raised in these comments may have been resolved by later transition plan drafts for that state or the viewpoint of the advocates may have changed.³³ Some of these comments are not state-specific. These comments are intended to provide an example of issues other advocates have identified and to be used as a resource in thinking about how to respond to issues in your state. In an attempt to make the comments fit within categories, some of the comments may not be the full paragraph or it may combine paragraphs for ease of identifying the source. These comments were collected mostly from documents placed on hcsadvocacy.org. The source of the comment is indicated in () after the comment.³⁴

I. Insufficient Information in Plan

A. Lack of Detail

- MPAS is very disappointed that the draft plan contains no narrative that could explain the rationale or details of the plan. The plan format is disjointed, non-specific, and extremely confusing. The timelines in the plan are inconsistent and appear to be out of chronological sequence. A narrative could have assisted interested parties in providing more substantive comments and feedback. Given the significant scope of this project, it is our opinion that Michigan's Plan amounts to a "large chart" that lacks a detailed clarifying narrative. It is inconsistent in providing direction and guidance and it is not an acceptable plan. (MPAS (MI P&A))
- As we pointed out in earlier comments, the state is following an extremely compressed timeline for the development of this initial transition plan. We repeat our request that the state seek additional time from CMS so that this initial transition plan can address issues in a less cursory fashion. As the entire transition process will require multiple years and utilize additional iterations of the transition plan, there is no reason why submission of the original draft transition plan cannot be pushed back by one or two months. Outreach to HCBS consumers and their families has been minimal, and consumers have voiced frustration at inability to access the draft plan.¹ CMS should allow the state more time to reach these stakeholders and allow them to provide input on the services that are critical for them. Such a moderate delay would be in the best interests of the state, providers, and consumers. Under the federal regulations, the public

³³ Although the topics have been changed and more samples have been added, this compilation builds upon one originally created by Elizabeth Prialux from the National Disability Rights Network. If comments are included and an organization would like to have them deleted or changed, please contact Elizabeth Edwards at the National Health Law Program (NHeLP) at edwards@healthlaw.org.

³⁴ Unless indicated in the footnote as an explanation, all of the footnotes in this section are part of the original comment. If P&A is indicated in () that indicates the Protection and Advocacy system for the indicated state. For a listing of the P&A agencies, see <http://ndrn.org/en/ndrn-member-agencies.html>.

input process must be “sufficient in light of the scope of the changes proposed, to ensure meaningful opportunities for input for individuals serviced, or eligible to be served, in the waiver.”² We believe that, under the state’s current compressed schedule, the public input process does not meet this requirement, with the result that consumers do not have an adequate opportunity to be heard.(CA)³⁵

B. Need for Clear Milestones

- Ohio should not rush its efforts to ensure compliance with the new CMS rules. It must commit to make the changes necessary to ensure true community integration for waiver enrollees throughout the state, however long it may take. More immediate changes that do not achieve full compliance should not be pursued. However, at the same time, Ohio should implement benchmarks and timelines to make sure sufficient progress is being made, and these should be transparent to people with disabilities and the broader public. (Disability Rights Ohio (DROH))

C. Inclusion of All Programs & Services

- Out of the seven waiver programs, Maine appears only to have given its full attention in this Transition Plan to the Sections 21 and 29 waivers; OADS should conduct a thorough analysis of all waiver programs. Maine purports that two programs are currently in full compliance: one covering consumer directed personal assistance services (Section 22) and one for children with intellectual disabilities or autism (Section 32). In doing so, OADS attempts to create an exception from the HCBS rules that does not exist. Namely, that if services are not provided in a provider-owned or controlled setting, these rules do not apply. This is incorrect. Instead, the HCBS rules apply to all settings where HCBS services are provided and there are additional requirements if a residential setting is owned or controlled by a provider agency. Thus, OADS should review the Section 32 waiver to determine whether there are program elements that conflict with the new HCBS settings rules.³⁶ OADS also appears to incorrectly limit its analysis of the Section 19 waiver to its day health services. The rationale for limiting its analysis seems to be that because Section 19 does not allow any services to be provided in a provider-owned or controlled residential setting, these rules do not apply. Because many of the standards set for in the rule encompass more than the physical location where services are delivered, OADS should review all Section 19 policies and practices to determine whether they comply with the settings rules. (ME P&A)

³⁵ Explanation: (CA) is used to designate comments submitted by a coalition of advocates that includes Disability Rights California, the National Senior Citizens Law Center, the National Health Law Program, California Foundation for Independent Living Centers, California State Council on Developmental Disabilities, Congress of California Seniors, and Disability Rights Education and Defense Fund.

³⁶ It is our understanding that there are no children receiving waiver services through the section 32 waiver and, thus, are not suggesting that OADS work with individuals and their families to determine whether settings are in compliance with this rule.

- The scope of the Transition Plan for Section 19 services is far too narrow. The HCBS rules require the state to interpret the term “setting” broadly and to assure that all policies ensure that every setting where HCBS services are provided conform to the requirements contained in the setting rule. As a result, OADS should review its Section 19 policies and practices to determine whether they comply with the HCBS rules.³⁷ (ME P&A)

II. **Public Comment & Education**

A. **Identifying Future Opportunities for Public Comment**

- Clear milestones, particularly with expected dates, will help stakeholders know when to expect changes and facilitate meaningful comment on these steps. We applaud the plan’s recognition that the waivers and the plan itself will need to continue to evolve, include greater specificity, and continue to require public comment. It is also positive that the State plans to include greater specificity and milestones for achieving compliance. These milestones should include realistic timelines for bringing settings into compliance; building provider capacity; public input for changes to policies, rules, and standards; and public education. (Disability Rights North Carolina (DRNC)/NHeLP)
- Deliverables. Each transition plan should state that DHS will make public all deliverables (after public comment). Examples are lists, reports, tools, standards, applications, forms, letters, training curriculum, findings, provider termination and sanction process, and other deliverables. DHS should distribute deliverables through its website, advisory groups, email, and other venues. (Disability Rights Network of PA(DRNPA))
- Transition implementation will involve many changes to policies, procedures, and processes. Throughout these changes there must be transparency so that all parties affected will understand what alterations are being considered and how parties may provide input. A lack of transparency causes confusion and misinformation, which can be very destabilizing. (CA)
- An initial step in transparency is creating a communication plan that will identify how and when information will be available to the public. Such a plan will ease concern stemming from lack of knowledge about state action and allow stakeholders to plan for providing feedback. This feedback is critical to the state understanding the effect of changes and what consumers identify as necessary to achieve the integration promised by the federal regulation. While transparency may seem initially laborious, it is necessary to successful long- term implementation. Without transparency, the state may spend significant resources going back to duplicate efforts after information has been received subsequent to initial decisions. (CA)

³⁷ For example, OADS should examine whether its policies encourages the provision of services in all settings that optimize autonomy and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact.

B. Sufficient Time for Commenting and Incorporating Changes

- The first opportunity stakeholders had to comment on the plan was on December 19, 2014 at the OADS community forum. The Department didn't make the draft Transition Plan available to the public until December 15, only four days before the scheduled community forum. Considering that there are approximately 6,500 individuals who will directly be affected by these new rules, it did not appear that the community forum was well attended. It is likely that this is because people were only provided one week's notice of the date. People were not provided enough time to review and understand the Transition Plan in order to provide informed and thoughtful feedback. As individuals and their families commented at the Public Forum, they had great difficulty understanding the Transition Plan. Further, given the short duration of this one forum, which sought statewide input, individuals were not provided with sufficient time to discuss their concerns with the Department. OADS should issue its promised plain language summary of the Transition Plan immediately. At the community forum, OADS announced that it would accept informal comments on the plan through the end of the month. This allowed only a week and a half for comment and there was a major holiday in the middle of that time. It seems likely that very few people will provide feedback both due to the short notice of when comments will be accepted and because it is not enough time for people to digest and understand the plan, especially in the absence of a plain language version. The only additional opportunity for comment stakeholders will have is through the formal rule making process in January. At a minimum, OADS should engage in an extensive education and outreach campaign to encourage input from stakeholders and their families during the formal comment period. (ME P&A)
- The Table 2.1 Statewide Transition Plan Timeline on page 4, First Round Changes does not include input from stakeholders. P&A suggests adding the opportunity for stakeholder input throughout every round of change. Pursuant to the Timeline, the first opportunity for public comment on round one is during the regulation public comment period scheduled for April 15, 2015. The public always has the opportunity to comment on regulatory changes under KRS 13A. We urge DMS to include stakeholder comments at a much earlier time. It's much more productive to make sure the ingredients agree with the palate before the cake is baked. We make the same comment for Heightened Scrutiny in 2016 and the Second Round Changes in 2017, 2018, and 2019. The opportunity for stakeholder input should be during the assessment phase, the drafting phase, and the implementation phase of this Transition Plan. (KY P&A)

C. Accessible Comment Mechanisms

- The state should develop multiple means of accepting stakeholder input. As we stated in earlier comments, the state should not rely exclusively on submission to an e-mail address, as many consumers may not have meaningful access to the internet or to e-mail. One good option is the convening of focus groups for the sharing of personal experiences. Focus groups should be local for, and easily accessible to, consumers, with consideration of issues that may affect a consumer's ability to participate in such a focus group, such as accessible and

public transportation, prior notice provided, time of day, and the incorporation of translation for individuals with communication disabilities and/or Limited English Proficiency. At a minimum, the state should be prepared to accept and distribute assessment information for stakeholder input through multiple channels, such as: mail, website, a dedicated telephone number and fax.

D. Public Comment Minimum Requirements

- Although it appears that Maine will likely meet the bare minimum standards set forth in the HCBS rules, there has not been adequate stakeholder input to ensure its success. As the Transition Plan acknowledges: “Input from stakeholders is critical to the successful development of the transition plan” and “without input from people that receive services and those that provide them, our picture is incomplete.” The picture is indeed incomplete, only a very small fraction of the approximately 6,500 waiver recipients and their family members know of, let alone have participated or are likely to participate in the development of, the Transition Plan. (ME P&A)
- Overall MPAS has been disappointed with the level of stakeholder engagement allowed by the parties responsible for the development of the plan. To our knowledge there were only three (3) statewide stakeholder meetings. The first was a preliminary meeting simply educating stakeholders on the new rules and Michigan's responsibilities under these rules. This meeting amounted to only a dissemination of information that could have been obtained by visiting the CMS website. There was an attempt at a second statewide stakeholders meeting, however this meeting was plagued with technical difficulties that prevented any meaningful questions or interactive dialog. This second attempt failed to engage stakeholders' input. The third and final statewide conference call, which was intended to go over the draft plan, was scheduled before the plan had been released. In other words, the stakeholders were asked to comment on a plan that had not been seen. The third meeting did yield some conversation but nothing of significance since the details of the plan were yet unknown. It is worth noting that the department did attend other events to discuss the development of the draft plan. MPAS attended several of these gatherings but was underwhelmed with the amount of new developments or details. We also had concerns with, what seemed to be, very inconsistent messages delivered to different audiences. (MPAS)
- Ohio has provided many different ways (telephone, meeting, mail, fax, and email) for individuals to comment on its draft transition plan, though smaller, more intimate meetings with stakeholders are preferable so more people have a chance to engage in the discussion. (DROH)

E. Public Comment-Outreach and Education

- We appreciated that the listening sessions started with a brief overview, but this did not help individuals understand the standards set by the rule as to the community nature of a service setting. Without an understanding of the expectations of what community should look like, it is very hard to provide comment about what needs to change. We think the State is to be commended

for creating a person-first version of the transition plan, which we understand is something different than what other states have done. However, we would ask that the State take that effort a step further and develop materials that would be accessible to individual participants and their families about the standards the rules are trying to set about community integration and engagement so that people will have a better context about what to expect. Although the person-first version is much more accessible than the original version, it is still seven pages long and very text heavy. (DRNC/NHeLP)

- We urge the state to include consumers and disability advocacy agencies as an integral part of the communication and implementation process for informing participants of the rules. These stakeholders have expertise in language and other accessibility practices for individual with cognitive and intellectual disabilities. Stakeholder participation would also help ensure that communication is done efficiently to reach various disability communities. (KY P&A)
- As we have commented before, the state should provide education on the HCBS regulations so that participants and other stakeholders may provide more meaningful feedback on their own experiences. Georgia's transition plan, for example, provides for stakeholder training and education from September 2014 through April of 2015. Any training should include person-centered planning, consistent with the draft transition plan's discussion of person-centered planning on page 14. Training also should include a discussion of the significance of the Olmstead decision and an individual consumer's right to live and receive services in the least restrictive setting. Education should include clear information about what may be changing (and what is not) and, once the procedures are developed, how a consumer may complain about a community-setting that is not following the rules. (CA)

F. Continuing Education

- The plan must include continued outreach, training and education, including training so that individuals and families will understand what changes they can expect to see and what will affect their services. The plan was explicit about education and outreach plans for the providers, but it completely lacks a similar plan for individual participants and their natural supports. Information sessions and training to individuals and families should be planned for when providers may begin to change or when rules are changing. Lack of knowledge often creates fear and unrest. Because the focus of the rule is the individual, the plan must continue to focus on the individual. Trainings should be planned in such a way as to ensure statewide participation (including for those with limited technology access) and could serve as an opportunity for the State to receive feedback about the transition process. (DRNC/NHeLP)
- Education and technical assistance should be for all stakeholders. The State's plan for educating and providing technical assistance, including facilitating peer support is an important piece of plan implementation. Providers need to understand how to comply with the new policies and rules, as well as the intent of the rule. Facilitating change among providers should help to decrease provider talk about shutting down, which should help stem participant fear about not

having services or somewhere to go. We think that similar assistance needs to be available to participants and their families. Each LME/MCO and Lead Agency should have a designated individual who is clearly identified as a resource for individuals and their families. While we understand the role that case managers and care coordinators will play in this process, there needs to be an additional level of expertise that can be accessed for individuals to ask more advanced questions or to validate information provided by a case manager/care coordinator or a provider. An individual at the state level should also be identified as a point of contact. (DRNC/NHeLP)

- OADS should also make a practice changes to expand its proposed case manager training to include all of the HCBS standards, not just individuals' ability to select a provider. OADS should also offer this or a similar training to services recipients so that they know their rights under the HCBS rules and what to do if their provider is not complying with them. (ME P&A)
- The transition plan should contain a robust process for providing ongoing education, through language and in a format that is easy to understand, for people with disabilities and their families about the new CMS rules, what changes will be made to the system and the timelines involved, the importance of the *Olmstead* decision, and each person's right to live and work and spend their time in the most integrated setting in the community. There have been reports of widespread confusion and misinformation about the new CMS rules. Many people mistakenly believe that services will be instantly terminated or programs will be immediately closed. Ohio should also ensure that these ongoing education efforts are designed to reach people with disabilities and their families; web-based person-centered planning resources, for example, will not simple not be effective in a lot of situations. (DROH)
- Engagement. Pennsylvania has included an outreach and Engagement section in each transition plan which is a good start. Plain and person-first language should be used. [In addition to the state's plan to provide] information to members of the Long-Term Care Subcommittee of the Medical Assistance Advisory Committee [the state should employ] email lists, service coordinator visits, local meetings, work groups and advisories, and letters.... The [State] should involve self-advocates and independent living groups. Peer training should be funded, especially for those in segregated settings, to complement DHS's own obligations to educate. (Disability Rights Network of PA)
- We urge inclusion of consumers and disability advocates as part of your communication plan. This will ensure that the state can maximize consumer education and outreach opportunities through webinars and conferences of self-advocacy and disability advocacy agencies. (KY P&A)

III. **Stakeholder Involvement**

A. **Generally**

- The lack of information and clarity about whether the groups who have been included in the general stakeholder meetings are included in such areas as policy development, education, and rules changes is limiting and could be detrimental to the successful identification of issues. Participants, their families and friends,

as well as advocates, know what needs to be changed to meet the obligations of the rules; input from these groups should be included throughout the planning and implementation process, both directly and through stakeholders. To this end, we ask that the State ensure that there is participant and advocacy involvement in all subcommittees and any review of policies, procedures, or training materials. (DRNC/NHeLP)

- IPAS would like to stress the importance of including waiver recipients, their families, and advocates as a substantial part of the transition process. In many instances, when participants and/or their families are included, it is later in the process after the providers have had their input. (IPAS)³⁸
- Reliance on web-based information severely limits outreach to participants and their families. We appreciate that the State has made a dedicated website for the transition plan and intends to use this website to post updates, information, etc. This is an important step as it will help facilitate ongoing engagement. Many individuals with disabilities and their families are not frequent visitors to the NC DHHS website and in fact, may have limited Internet access. This is especially true for individuals in residential facilities, many of whom are reliant on providers to inform them about changes that may affect them. Although some providers will inform individuals and their families of possible changes to their services, the outreach and engagement cannot solely rely on Internet and provider networks to reach individuals. We would ask that the State use the methods available to it, including LME/MCO and lead agency contact mechanisms, which may use case managers and care coordinators, to spread and collect information. A strong, effective communication plan that provides information, as well as asks for information in return, is critical to the level of stakeholder input that the rules require. (DRNC/NHeLP)
- IPAS requests that to the greatest extent possible, materials developed and proposed changes to policy and procedures, regulations, etc., should include key stakeholders, with an emphasis on service recipients, and their families and advocates, in all stages of development and planning. The materials should be freely accessible on the state's website and the process should be as transparent as possible. (IPAS)
- In part, the low number of stakeholder participants is due to the Office of Aging and Disability Services' (OADS) failure to engage in a meaningful partnership with stakeholders from the start. It does not appear that there was any stakeholder involvement during the assessment and drafting phases in the development of the Transition Plan. Instead, OADS sought stakeholder input only after it had drafted its Transition Plan. The HCBS rules were issued in January 2014, and went into effect in March 2014. OADS' first attempt at stakeholder input did not occur until the end of October. In late October, OADS conducted a series of four webinars that provided an overview of the transition plan, only one of which was geared towards participants and family members. The transition plan does not indicate what outreach OADS undertook to inform participants

³⁸ IPAS is the Indiana P&A.

and/or family members or how many participated in this educational effort. (ME P&A)

- Generally, there seems to be a lack of input from individuals, families, and advocates specific to policies, trainings, etc. The focus is more on providers (which seems contrary to the federal regulations). For example, for the assessment of settings, surveys were developed, distributed, and analyzed without input from essential stakeholders (i.e., consumers, families, and advocates). This was an important piece of the process and, like person centered planning, should involve all key stakeholders. DHS should include consumers, families, and advocates as key stakeholders throughout the process. (ND P&A)
- Policies. People with disabilities and other stakeholders need to be involved before policies become final. [Pennsylvania] transition plans now provide for Identification, Assessment (Internal Assessment, Modification of Provider Enrollment Process), and Remediation Strategies for regulations, waiver service definitions, licensing requirements, provider standards, and other policies. The plans should state that DHS will notify the public about proposals to revise policies and will have public comment periods. All proposed changes should go through public comment via the Pennsylvania Bulletin and regulatory review process. (DRNPA)
- We would also suggest adding a public comment link on DMS' homepage to make it easier for the public to make ongoing comments and view what other stakeholders and providers are saying about the changes. We recommend that Kentucky establish an online survey tool to allow participants and families the opportunity to provide comments about the plan and the rollout. Ask these two fundamental questions—"what do I like now and what would I like to change." (KY P&A)

B. Appropriate Balance of Stakeholders

- We particularly appreciate the State's efforts to involve stakeholders early in the process with the HCBS Stakeholder Committee and its welcoming of input from all sources. We believe an important aspect of the Committee is that it is a good balance of participants, advocacy groups, and providers. The rules focus on the waiver participant's perspective, and we appreciate that the makeup of the Committee respects the importance of participant and advocacy perspectives. We understand that this is also an important issue for providers, but we urge the State to continue on this path of focusing on what individuals and advocates are saying as opposed to the interests of those with a financial interest in the outcome of how the rules are implemented. (DRNC/NHeLP)

IV. State Administration

A. Identify State Partner Agencies

- The transition plan should include a strategy to gather information about the availability of community programs which could be modified to include waiver participants. These might include community day programs, such as those run by Area Agencies on Aging, country recreation commissions, and church groups. The transition plan should also include a timeline to investigate whether Medicaid

transportation can be used to get people to community activities other than medical, if activities are part of individual's plan. (SC P&A)

- The transition plan should address the need for DHHS to work with DHEC and other members of the Adult Protection Coordinating Council to assess the need for changes in the system for investigating abuse/neglect/exploitation of vulnerable adults. SLED data show that many cases occur in CTH IIs. As individuals move into smaller facilities there will be a need to determine the best way to protect individuals. P&A believes that procedures to protect individuals in the community are an essential part of person-centered planning and DHHS quality control. The transition plan should also consider development of an adult abuse registry as a means of protecting waiver participants. DHHS should increase coordination with the Vocational Rehabilitation Department to increase training and employment opportunities outside the DSN Board framework. DHHS should work with the Governor's office to implement the National Governors' Association employment initiative.³⁹ (SC P&A)
- It should also work with other state agencies and policymakers to expand access to transportation (public transportation in rural areas is an enormous need, for example). Access to transportation is a crucial way of ensuring meaningful community participation for people with disabilities. (DROH)
- As we have pointed out previously, the state's HCBS waivers involve state agencies other than those that administer the waiver. The assisted living waiver, for example, is administered by the Long-Term Care Division of the Department of Aging, but the licensure and inspection of Residential Care Facilities for the Elderly (RCFEs, the facilities where assisted living services generally are provided) are handled by the Department of Social Services (DSS). Likewise, the DD Waiver is administered by the Department of Developmental Services (DDS) but community care facilities funded by the DD Waiver are licensed by DSS. DSS is heavily involved in the setting of facility standards and, accordingly, it should be actively involved in the development and implementation of the state's transition plan. This is especially the case if DDS, in conjunction with DHCS, will be taking an active role in ongoing monitoring and enforcement of the transition plan as a part of its licensing function. More generally, the state's development of the transition plan should include any state entity that is closely involved with a setting's operation, including collaborating or partnership entities, such as those relating to housing or employment. (CA)

B. Cohesive Transition Plan Across Agencies

- Although there are some similarities, the transition planning process appears to be completely separate for these two systems. There should be an overarching transition planning group that has representation from all relevant state agencies and from all populations of people with disabilities enrolled in Ohio's waiver

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http://www.nga.org/files/live/sites/NGA/files/pdf/2013/NGA_2013BetterBottomLineWeb.pdf?utm_source=WhatCounts+Publicaster+Edition&utm_medium=email&utm_campaign=Governors++Working+to+Enable+People+with+Disabilities+to+Get+Jobs&utm_content=A+Better+Bottom+Line:+Employing+People+with+Disabilities

programs (people with developmental disabilities, people with physical disabilities, people age 60 and older). (DROH)

- It is not clear if the State Monitoring Review Process will include on-site visits, but it is critically important that this Process have sufficient oversight and controls to make sure that the different LME-MCOs/Local Lead Agencies are applying assessments consistently and using the same definitions of what is sufficiently community based. There must be geographic, waiver type, and setting consistency to ensure the accuracy and integrity of the data collected and any future analysis or implications. We remind the State, as the single state agency, it is ultimately responsible for compliance with Medicaid regulations. We encourage the State to maintain control of the State Monitoring Review Process. (DRNC/NHeLP)
- As set forth on page 3 of the draft transition plan, the state's HCBS waivers are administered by various state entities. The MSSP Waiver, for example, is administered by the Long Term Care and Aging Services Division of the Department of Aging, while the HIV/AIDS Waiver is administered by the Office of AIDS of the Department of Public Health, and the DD Waiver is administered by the Community Services Division of the Department of Developmental Services. We believe that each of these state agencies should follow consistent principles in implementation of the federal regulations. It should not be the case that, for example, the Department of Aging follows certain principles and/or implementation policies and procedures while the Department of Developmental Services follows different principles and policies. The new federal regulations are based on important overarching principles, and it is important that those principles be honored consistently across state government. (CA)
- Consistency among departments in the early part of the transition plan is especially important so that programs move forward in implementation in a similar way. Assessment tools and on-site reviews should use the same tool, with supplemental pieces if necessary for different programs. Any supplements or changes to an assessment should be cleared through a process that maintains consistency, includes public comment, and ensures that community is judged consistently for all types of consumers. Allowing for differences in populations and individuals must not degrade the ideals of community life and engagement. In the near term, involvement of all relevant state entities is essential for development of the best possible transition plan. For the longer term, the involvement of all relevant entities will be essential for, among other things, ensuring ongoing monitoring and compliance. (CA)

C. Review of Provider Policies

- Because service recipients and the direct staff assisting them are unlikely to be aware of the standards set forth in the applications, OADS should make policy changes to incorporate the HCBS standards into State regulation. For example, sections 18 and 20 of the MaineCare regulations say nothing about how an individual's rights to privacy, dignity and respect, and freedom from coercion and restraint will be ensured. The regulations also say nothing about how the setting is required to optimize an individual's initiative, autonomy, and independence in

making life choices. Yet, for these and other HCBS standards, the Department indicates that there needs to be no policy change. This is incorrect and OADS should explicitly incorporate the standards into the applicable regulatory sections. (ME P&A)

- It also accurately acknowledged, to its credit, that there is a “significant bias toward facility-based supports” in existing adult day waiver services through the DD system, including adult day support and vocational habilitation programs, and that self-reporting for these settings “significantly underrepresents” those which have the qualities of an institution. (DROH)
- Also, the Transition Plan subcommittee completed reviews of state systems and residential and non-residential settings, but it does not appear people with disabilities or their families participated in this review process. Involvement of people with disabilities through the entire process for ensuring compliance with the new CMS rules is crucial. This includes the assessment process for evaluating settings, revising administrative rules, the formation of workgroups, and, most importantly, on-site evaluations of settings subject to the heightened review process. (DROH)
- A new overarching administrative rule specifying the settings in which HCBS may not be provided is incomplete. It should replicate the new CMS rules and also describe the settings and the nature of the individual’s experiences which will qualify for HCBS funding. (DROH)
- Table 5.5 Potential Provider Actions for Compliance (page 33) under the first box (rule one) which discusses assistance in securing supportive employment, accessing transportation, and exploring community opportunities, we suggest the addition of a long range goal of increased funding opportunities for supported employment; increased Medicaid payment rates for personal assistance services and other means of incentivizing access to personal assistants; and elimination of policies that create unnecessary limits on access to transportation. (KY P&A)

D. Review of Funding Sources and Rates

- As a general comment, we would like to express our appreciation for the State’s approach that this plan requires a full evaluation of the system to ensure compliance with the rule. The plan to closely examine current rules, policies, provider qualifications, and rate structures as they relate to the vision, outcome measures, and core compliance indicators is very encouraging. In particular, the inclusion of rate structure in the plan is important because the rule may change how services must be provided and the array of services an individual may need.⁴⁰ (DRNC/NHeLP)

⁴⁰ As a reminder, the alignment of payment structures and goals is considered an essential element of Medicaid managed long term services and supports (MLTSS) and therefore must be evaluated for the Innovations waiver. That analysis should be extended to the CAP-DA waiver to ensure successful implementation. According to CMS guidance, “States must establish payment rates that support the goals and objectives of their MLTSS programs and these essential elements. In keeping with the intent of the ADA and Olmstead decision, payment structures must encourage the delivery of community-based care and not provide disincentives, *intended or not*, for the provision of services in home and community-based settings.” CMS,

E. Payment Source Discrimination

- The Department should require that HCBS settings honor the new HCBS standards regardless of a participant's source of payment (including private payment and non-HCB Medicaid payment). A contrary interpretation would condone payment-source discrimination that would be contrary to both the letter and the spirit of the new regulations. (CA)
- In order for a facility to be considered community-based, it must meet the HBCS standards for a community setting for all residents, regardless of a resident's payment source. The federal regulations set forth five qualities of community based settings, with additional requirements for provider owned or controlled settings. The setting must meet these five requirements to provide community based services and adhere to the regulations regarding provider owned or controlled settings. A facility must comply with these regulations for all residents, regardless of payment source, in order to remain faithful to the regulations. If a facility does not meet the requirements of community based settings for some, those characteristics will affect the experience of other consumers. For example, the rules require that a setting ensure the individual's rights of privacy, dignity and respect, and freedom from coercion and restraint.⁴¹ If a facility is allowed to use restraints on a non-HCBS funded resident, that will affect the experience of the HCBS-funded resident and cause the facility to have characteristics of an institution. Another example would be a facility with different rules for privacy. If the HCBS funded residents see others being punished or chastised for trying to take the house phone into their room for private phone calls, the HCBS funded residents are not likely to assert their right to privacy. As a practical reality, many individuals do not want to assert rights or privileges that their housemates may not have, especially if they consider their housemates their friends. The community nature of a setting is supposed to focus on the experience of an individual. If the treatment of non-HCBS funded individuals does not meet the community-based setting requirements, these non-community characteristics will affect the experience of all residents, regardless of funding source. The Department should require that HCBS settings honor the new HCBS standards regardless of a participant's source of payment (including private payment and non-HCB Medicaid payment). A contrary interpretation would condone payment-source discrimination that would be contrary to both the letter and the spirit of the new regulations.⁴² (CA)

Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Support 8-9 (May 20, 2013), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf> (emphasis added).

⁴¹ See, e.g., 42 C.F.R. § 441.301(c)(1)(4).

⁴² Explanation: For more information about payment source discrimination, see Eric Carlson, Just Like Home: An Advocate's Guide for State Transitions Under the New Medicaid HCBS Rules 18-19 (June 2014), http://justiceinaging.org/wp-content/uploads/2015/03/Just-Like-Home_-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf.

F. Residential Agreement Compliance

- Maine intends to require unlicensed residential facilities to utilize residential agreements and also plans to develop a checklist for case managers to review its compliance with the HCBS standards. Maine must ensure that residential agreements are in place for all individuals who are not covered by landlord tenant laws. These agreements must “provide protections that address eviction processes and appeals comparable to those provided under”⁴³ Maine’s landlord tenant law. Because this will be a significant change for many providers, OADS should develop a training and education campaign for providers and service recipients about these changes and tenant rights. (ME P&A)
- With regard to determining compliance with having a lease agreement, IPAS feels there is too much reliance on provider self-report and requiring submission of a standard lease agreement. There should also be a process to verify that the lease has been signed by the resident. (IPAS)
- The transition plan should have a short deadline for development of appropriate language to comply with the requirement for a legally-enforceable tenancy agreement (SC P&A)

G. Appeals

- Accurate assessments of providers are key to implementation, and these assessments must be transparent so that interested parties have opportunities to provide additional information to the state. A key feature of transparency is to publish the list of providers and whether or not, even initially, they meet the community-based setting requirements. Any appeal process must also be transparent and involve setting consumers.

H. States May Set Higher Standards

- We also appreciate that the State is using this process to evaluate its systems and policies. Although we recognize that these rules technically only apply to North Carolina’s 1915(c) waiver programs, the rules represent standards that should apply to all people with disabilities in North Carolina, each of whom should have opportunities to live, work, and spend time in their community. In North Carolina tens of thousands of individuals with disabilities are either waiting for waiver services, receiving minimal non-waiver services, or are residing in institutional settings because they do not have meaningful alternatives or the proper community supports. The time and resources spent examining and changes to our system necessary to comply with the HCBS rule should include consideration of the needs of people who do not currently have access to our waivers so that the State is moving forward on community integration and so that the system changes are not so waiver specific that they will impede, rather than encourage, further integration efforts. (DRNC/NHeLP)

⁴³ *Regulatory Requirements for Home and Community-Based Settings*. Retrieved December 29, 2014. <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/requirements-for-home-and-community-settings.pdf>

- The Final Rule offers South Carolina the opportunity to develop a long-overdue comprehensive plan to comply with *Olmstead* for all Medicaid participants, not just those receiving waiver services. It also offers the chance to reduce fragmentation of services by addressing the needs of the individual across settings. The transition plan should require a statewide, coordinated approach so that public and private providers work together across existing organizational structures; for example, many DSN Boards are too small to develop a full array of residential and day services. We urge DHHS to take a comprehensive and far-reaching view of the services and supports needed to make people with disabilities part of the community. We also urge DDSN to offer meaningful participation in the development and implementation of all aspects of Final Rule implementation. (SC P&A)
- Indeed, although these new rules technically only apply to Ohio's 1915(c) waiver programs, they represent standards that should apply to all people with disabilities in Ohio, each of whom should have opportunities to live and work and spend their time in the community. Notably, there are tens of thousands of people across the state who are not enrolled in any waiver program, who are unnecessarily institutionalized or otherwise segregated from their communities, and who, because the way in which Ohio administers its services and programs, do not have any meaningful alternatives. Their lives are regimented and their rights to autonomy and independence and individual initiative are inhibited. The state must commit to fixing this broken system so that all people with disabilities are able to live their lives in accordance with the principles of the new CMS rules. (DROH)

V. Assessment of Settings

A. Generally

- We are encouraged by the State's vision for the transition plan overall and urge the State to carry this vision through the assessment process. If the State becomes overly focused on provider compliance, it will miss the forest for the trees. We strongly urge the State to continue to focus on system reform and compliance, as that is what will bring the providers into compliance and will ensure ongoing compliance. We strongly believe that focusing on individual providers will not be the most efficient mechanism for overall plan implementation. (DRNC/NHeLP)
- The Plan contemplates both provider and State development of "remediation strategies" to address identified shortcoming. This "targeted" approach to "fixing" specific instances of non-conformity with CMS standards is logical component of the Plan. However, the Plan could be strengthened through identification of systemic initiatives designed to increase the State's capacity to offer an array of conforming settings. This would be particularly informative in the context of employment. (DE-Disabilities Law Program-Community Legal Aid Society, Inc.)
- We have significant concerns over the use of provider self assessments. It is clearly within a providers' best interest to deem themselves "in compliance" with the new rules. Self assessments simply constitute an unacceptable conflict of interest. We would prefer a stronger reliance of an objective evaluator performing

onsite assessments at every residential and non-residential setting receiving any 1915(c) waiver dollars. Moreover, in the current draft plan, it is unclear whether or not every provider will perform a self assessment or if there is a statistically significant random sampling. (MPAS)

- This section refers to settings "assumed to be in compliance". At the beginning of this plan, it is not wise to assume compliance at any setting and at the January 2016 juncture, a comprehensive onsite assessment, performed by an objective party using a well-developed and vetted assessment tool should have already determined compliance. In the rules, CMS does make an allowance for settings that are assumed to not comply with the new rules. There is no counter assumption for settings that are "assumed to be IN compliance. (MPAS)
- The input of providers is important (valuable information was obtained regarding common barriers to compliance with the new CMS rules, including "changes to person-centered plans, improved linkage to the community, and staff development and training") but wholly insufficient. There is an inherent conflict when asking providers to evaluate their own compliance with the new CMS rules; there is a risk that some providers would report information in a biased, self-serving manner to avoid any repercussions or having to make changes to their programs. Also, providers may, and often do, have a much different perspective than the people who actually receive HCBS services. Ohio's decision to rely so substantially on provider self-assessments produces a misleading, overstated figure of the number of settings that comply with the new CMS rules. Ohio should have included input from people with disabilities and their families as the foremost part of its assessment process, which would have presented a much more accurate picture of the characteristics of residential and non-residential settings. Discussions with people with disabilities, free from provider influence, is essential since they can provide their own accounts of the nature of their experiences as enrollees in waiver programs and identify any obstacles to true community integration. Each person has a unique and important perspective on whether the settings in which they are receiving services actually is integrated in and supports access to the broader community, provides them opportunities to engage in community life, and allows them independence in making life choices, as is required by the rule. Their viewpoint is essential. As the transition plan already correctly acknowledges, "integration is about what the individual experiences, and must be understood as being individual-specific." (DROH)⁴⁴
- P&A has concerns with a couple of services under the Aged and Disabled Waiver. P&A disagrees with DHS when it states that adult residential care settings can fully comply with the regulatory requirements, even with remedial

⁴⁴ To evaluate waiver programs administered by the Ohio Department of Developmental Disabilities, Ohio distributed a survey to residential, vocational, and day services providers "to assess their locations to determine level of compliance" with the new CMS rules (county boards of developmental disabilities apparently were also given the ability to assess these same locations, but there is not additional information on this). For the NF-LOC system, Ohio also significantly relied on provider assessments, although information from the PASSPORT administrative agencies was also utilized. (Explanation from DROH comments)

strategies and timelines, when these settings serve between 10 and 36 individuals each. With only one of these twelve settings serving less than 11 individuals, these are, just based on size, mini-institutions. These settings appear to congregate individuals with traumatic brain injuries and other disabilities and need heightened scrutiny. Individuals receiving services in such settings should be able to receive these same services in their own homes or apartments. Other key stakeholders need to be included—consumers, families, and advocacy organizations (not just DHS and providers as listed in Table 7) in assessing compliance with the federal regulations. (ND P&A)

B. Clear Identification of Current Providers

- The transition plan should identify the types of providers currently receiving HCBS funding, the services provided, sites at which services are provided, and the number of individuals served by this type of provider. This information should be publicly available as it gives the public an opportunity to provide information to the state about specific settings. (DRNC/NHeLP)
- While Kentucky’s decision to utilize state quality assurance staff to verify the results of the provider self-assessment should be applauded, the initial categorization of settings was done without any input from participants, their families, or disability advocacy organizations. The specific providers that fall into each category should be made public, and public input should be sought before the categorization of settings is finalized. (KY P&A)
- Accurate assessments of providers are key to implementation, and these assessments must be transparent so that interested parties have opportunities to provide additional information to the state. A key feature of transparency is to publish the list of providers and whether or not, even initially, they meet the community-based setting requirements. Any appeal process must also be transparent and involve setting consumers. (CA)

C. Assessment of All Settings and Providers

- The transition plan should include a timeline for DHHS to develop a comprehensive oversight process to ensure compliance with the Final Rule. Such oversight might include unannounced visits to person-center planning meetings to determine whether the process is truly individualized, regularly reviewing a sample of plans to determine what kinds of choices were offered to participants, and interviewing recipients. (SC P&A)
- As noted above, OADS needs to expand its policy analysis to determine whether the regulations ensure that providers comply with HCBS settings rules when delivering services in an individual’s own home or apartment. In conducting this analysis, OADS will find that applicable Maine Care regulations say nothing about the individual rights contained in the HCBS regulations. As with Sections 18 and 20, OADS should explicitly incorporate these standards into the applicable regulatory sections. (ME P&A)
- Assessment. We appreciate that the Pennsylvania Aging and Independence transition plans now provide that DHS will issue a Provider Self-Assessment Tool, and perform a subsequent on-site assessment of every waiver setting. [We

urge that] the transition plans should state that the Provider Self- Assessment Tool will be issued to every provider enrolled in each waiver to ensure a comprehensive assessment of settings....The transition plans should be clear that, pursuant to the new regulations, every setting in which any waiver service is provided – residential and non-residential, licensed and unlicensed – will be evaluated. For all transition plans, [the Pennsylvania P&A] appreciates that [the state] presumes that the services provided in a person’s home are compliant. [The state] should still assess to ensure that such settings comply with the requirements for all settings, including person-centered planning and community access. (DRNPA)

D. Stakeholder Input in Assessment Tools

- Implementation Materials. Pennsylvania transition plans list tools and other materials that will be developed or revised, for example, a Provider Self-Assessment Tool, Participant Monitoring Tool, Provider Enrollment materials, an “updated QMET on-site monitoring tool” and Provider Termination and Sanction Process. Pennsylvania transition plans also include a “QMET CAP process” and Quality Improvement Structure. The plans should describe how [the state] will distribute draft or revised versions of these materials for public comment. If these materials exist and will not be modified, they should be attached to the plans. (DRNPA)

E. Stakeholder Input on Settings

- In several instances, the federal regulations set standards that are broad and non-specific. For example, settings must support “full access ... to the greater community,” provide opportunities to “engage in community life,” and ensure “rights of privacy, dignity and respect.” An assessment tool, in addressing such requirements, should provide greater specificity by using examples. Regarding dignity and respect, to pick one example, an assessment tool might inquire whether HCBS participants are addressed by name, or whether staff instead refer to participants by last name or room number, or as “sweetie,” “hon” or some other shorthand nickname. Regarding privacy, similarly, an assessment tool might ask whether participants’ personal information (medication lists, for example) are posted in public view. On the issue of accessibility, an assessment tool should ask whether participants are able to independently go to and enter all areas of the residence when they wish, including using elevators, because they may not realize that having to wait in the hallway for someone who can see or reach the buttons is a facet of inaccessibility. These examples are a non-exclusive list. The overarching point is that, in some instances, developing an assessment tool with the bare language of the federal regulations will not be productive. Both providers and participants will need more detail as to the types of practices that are considered compliant or non-compliant. (CA)
- The Plan contemplates use of participant surveys to gather information as well as survey-based NCI data. As a supplement to this planned assessment process, the State could consider establishing an online survey tool (e.g., through SurveyMonkey) to allow individuals the opportunity to comment on specific

programs. Some individuals may be more comfortable with the ease and anonymity of completing an online survey and the questions could be more targeted to CMS standards than the NCI survey. (DE)

- ULS strongly supports the Transition Plan's requirement that every individual receiving HCBS be surveyed. ULS also supports stakeholder involvement in the development of a survey tool that will be used in the assessment process. ULS encourages DDA to include specific provisions in the Transition Plan requiring that family members/significant others be given notice of the opportunity to contribute to the assessment as well as be permitted to do their own assessment of the provider. (DC P&A)
- Maine must do better in assessing current settings and verifying the provider self-assessment. Near total reliance on the provider self-assessment is insufficient. Service providers cannot objectively determine their own compliance with the rules because they stand to benefit from a determination of compliance. They are also not in a good position to make judgments about whether and how an individual has access to their community and can exercise their rights. Finally, to truly assess an individual's satisfaction with a setting, the survey should inquire about the individual's comfort and experience with a provider. For all waivers, OADS should convene an advisory board, which includes consumer representatives, to develop and coordinate the assessment of current HCBS settings including on site surveys of these settings. (ME P&A)
- For those waivers it deemed necessary, OADS conducted an initial categorization of settings without any input from participants, their families, or advocacy organizations. Certainly people who live in a setting that OADS categorized should have the opportunity to comment on whether the categorization it is correct. The specific providers that fall into each category should be made public, and public input should be sought before categorization of these settings is finalized. (ME P&A)
- Prior to the state asserting that all existing settings where HCS waiver services are delivered can be considered in compliance with the HCBS settings regulations, the state must include [the prospective of] waiver participants. It is essential that the assessment of these settings include the perspective of the people living under the current state regulations.... It would be good to know the extent to which the participant experience differs from the intent of rule language in order to make improvements. Please find a way to solicit and integrate waiver participant perspectives into this process. Focus groups and participant surveys are being used by other states and may be a good way to achieve an inclusive process. (Disability Advocacy Agency Group Comments (TX))
- The state finds it sufficient to have the residential providers complete a self-assessment. The agency's directions for completing the self-assessment tells the provider to ask themselves if the individuals served, their representatives, family, or independent monitors would agree with their assessment. A more direct survey could have been provided to the actual individuals, representatives, family, or independent monitors. Reliance on provider self-assessment skews the results of the findings and diminishes the conclusions drawn from the data. The

providers' self-assessments should be posted publicly for verification and peer review. (Disability Rights FL)

- The state proposes that providers assess themselves for compliance. Self-assessment is not appropriate and greatly risks self-serving reporting of compliance to avoid legal obligations. (DRFL)
- The compliance data for the Transition Plan comes mostly from provider surveys. See IV. Provider Assessment, pg. 14. The state should develop a means for consumers to participate in their own self-assessment of the settings in which they live or spend their days. Participant assessments must be accessible to the individual, free from provider influence, and part of the assessment validation process. In addition to consumer surveys, require consumer and stakeholder focus groups. These focus groups could be used to provide the consumer input that, as stated above, should be a meaningful component of the Heightened Scrutiny determination in 2016 and the Second Round changes in 2017, 2018, and 2019. (KY P&A)
- We appreciate that the workgroup developed a web based survey for providers that reflects the requirements of the new rule and that 100% provider participation was achieved. We also appreciate that the veracity of the survey responses were checked by state QA staff. The categorization of settings is too important however to be done without a consumer review of these settings. Total reliance on provider and QA team expertise to categorize these settings is insufficient. First, service providers are not objective, because they generally will benefit from a determination of compliance. Second, service providers are not necessarily in a good position to make judgments about whether and how a consumer has access to the community and can exercise rights; and third to truly assess resident satisfaction with a setting the survey should inquire about the individuals comfort with a provider. (KY P&A)
- The state's draft transition plan says on page 11 that "[s]takeholders will be encouraged to participate and provide input to the assessment process." For this input to be to be meaningful, the assessment process must be consumer-friendly. We recommend that assessment tools be specifically designed for use by HCBS participants and their family members. For example, assessment tools may be developed with a question-and-answer format that uses no jargon, assumes no preexisting knowledge of the federal regulations or the relevant public policy, and uses plain language and real-life examples so the questions will be understandable and meaningful. (CA)
- The state should take steps to ensure that consumer input is not improperly influenced by service providers. It would not be a reliable process, for example, to have consumer assessments obtained by a HCB service provider, since such a service provider would have a clear interest in the consumer's conclusions. For assessment results to be trustworthy, assessments must be administered by persons or entities without a conflict of interest. (CA)
- The draft transition plan, on page 13 states that "[t]he on-site evaluations will be conducted by a survey team that includes representation from at least two of the following: State personnel, service recipients or their family members, case managers or other representatives of case management entities, licensing

entities, representatives of consumer advocacy organizations, and/or other stakeholders.” This strategy, however, does not provide for adequate input from consumers, whose interests are at the center of the new federal regulations. Ideally, every team would include a consumer or a representative of a consumer advocacy organization. The current draft, however, contains no assurance that any team would include a consumer or a consumer advocacy representative.(CA)

F. Use Objective Criteria to Identify Isolating Settings

- We urge the State to use objective measures to help identify problems and indicate overall assessment inaccuracy, such as GIS mapping and NCI data; to use non-biased, educated, accessible participant assessments; to have statistically significant validation procedures; and to have a high degree of transparency in the assessment process so that the community can alert the State to issues. (DRNC/NHeLP)
- As part of the transition plan to improve meaningful choice for participants, P&A suggests review of the National Core Indicators Data on choice of home and work.⁴⁵ Graphs 15 and 16 show that only about half of those surveyed indicated they had a choice of where to live and who their staff are. Even fewer could choose their own roommate (Graph 17). Only 43% could choose their own day activity (Graph 20). South Carolina offers very few individually-supported or competitively-paid jobs (Graph 27); 64% want a job in the community (Graph 35). These and additional graphs throughout the report should help establish priorities for the development of community-based employment and day activities. (SC P&A)
- The state should utilize a variety of methods to determine compliance about the largest possible number of settings. This may include a self-assessment tool for both consumers and providers, as well as the consumer and family input process, person-centered planning process, and at least for DD Waiver Funded Settings, the National Core Indicators (NCI) already conducted by area boards. NCI, using the crosswalk tool developed for the HCBS rules, can be useful to flag potential problem areas, realizing the sample size is likely too small to provide useful information on specific settings or types of providers. Like used in Indiana's transition plan, the NCI may be useful in indicating inaccurate self-assessments. (CA)

G. Unbiased On-Site Evaluations

- The draft transition plan on page 13 refers to a sample of settings being selected for on-site evaluations. We recommend that the state conduct as many on-site evaluations as possible, across every HCB setting category, in order to get the most accurate information about HCB settings. We also remind the State that if it is planning to submit any sites to the heightened scrutiny process, it should perform an on-site assessment of that site.⁴⁶ (CA)

⁴⁵ <http://www.nationalcoreindicators.org/states/SC/>

⁴⁶ CMS, Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements 4 (Sept. 5, 2014) ("In instances

- In addition to DHHS assessments of existing facilities and services, DHHS should contract for trained external reviewers who can assess the opportunities for interaction outside the facility or program. While self-assessment is a valuable first step in prioritizing assessments, all programs and facilities should be reviewed by an independent assessor. (SC P&A)
- The scope of this plan seems to be limited to changes that will be necessary for adult day services provided under Section 19. OADS should conduct site visits to the adult day health centers and interview participants. OADS should change the plan to indicate that it will conduct site visits at **all** day health centers and that it will interview **all** waiver recipients in these settings. (ME P&A)
- Ohio determined that it would conduct on-site evaluations of the miniscule number (approximately 1% in the DD system) of residential settings which providers conceded should be “presumed to have the qualities of an institution” or which cannot meet the new CMS rules. Because of the clear conflict of interest of relying on providers to self-assess their compliance with the new CMS rules, as stated above, on-site evaluations should be expanded to include a broader sample of residential settings. Otherwise, too many residential settings will escape further meaningful assessment based on the provider’s own assessment. Again, the main focus of on-site evaluations absolutely must be the people who are receiving HCBS services. It is axiomatic that any evaluation of the nature of experiences of people with disabilities enrolled in waiver programs should include their own perspectives. (DROH)
- In doing a survey with a sample of residents residing in each of these 4 settings (four people?), it is important to consider the frame of reference shared by these individuals. A former LSTC resident, asked now about available choices, likely would compare current “choices” to those available at the LSTC. This is the individual’s likely frame of reference. A survey might be more or less reliable depending on the way it was conducted. The methods used are not part of the information so far disclosed by DHS. This denies the public a meaningful opportunity to comment upon the methods and the reliability of the results. A reliable method of surveying former LSTC residents might need to be individualized and conducted by independent surveyors.⁴⁷ ... These residents are

where a system review identifies settings which are presumed not to be home and community based and the state intends to submit evidence that the setting is home and community-based and does not have institutional characteristics, CMS would expect an onsite assessment that supports the state’s assertion.”)

⁴⁷ Explanation: This comment is in regards to the state’s evaluation of settings (residential and non-residential) on the grounds of a state ICF/IID.

P&A has concerns with a couple of services under the Traditional IID/DD Waiver. P&A disagrees with OHS when it says residential habilitation settings, located on the grounds of or adjacent to an ICF (the Life Skills & Transition Center (LSTC) AKA the Developmental Center), does not have the effect of isolating the residents from the community. While some of the buildings on the grounds are being sold or put to other uses because of a goal to downsize, undoubtedly these residents are living in an apartment or home on the campus of a State institution. The question is “why”? The plan (Table 8) states, “they are afforded maximum independence, control of their own

stigmatized by the mere fact of where they live. The fact that some individuals without disabilities may live or spend time on the campus does not meet the test for compliance. This setting should be moved to the category of settings that do not/ cannot meet HCBS requirements. With regard to day supports, also under the Traditional IID/DD Waiver, P&A disagrees that this service can be justified as a community-based setting. Once again, DHS uses a two-sided argument (Table 8). It states that the 17 individuals in the day program "have maximum independence" but also states that they are "assessed at least annually to determine if alternative setting in the community are appropriate". Again, they reportedly have choices to do what they want but are not able to receive a similar service in the community vs. on the institution's campus and through the institution as the provider. This setting should be moved to the category of settings that do not/ cannot meet HCBS requirements. P&A agrees with DHS on the identified list of settings that do not I cannot meet HCBS requirements. However, as stated previously, other settings should also be on this list. (ND P&A)

- We also urge on onsite check of the one setting that is said to fully align with the rule and a percentage of the settings found to be aligned after a few modifications. We understand that QA staff has a deep knowledge of the settings; however, they are used to evaluating and viewing the settings with an eye toward compliance with HCBS requirements, and may not have looked for policies and practices that might violate the new rules. (KY P&A)
- We respectfully suggest that the number of on-site evaluations should not be based ONLY on statistical-significance algorithms. The most powerful result of an on-site evaluation is moving that setting towards compliance. The purpose of on-site evaluations is not merely to reach conclusions regarding the settings generally. Thus, the number of on-site evaluations should not be limited to the number of evaluations needed to obtain statistical significance for evaluation findings. Indeed, statistical significance is not meaningful for information obtained from the on-site surveys. Assume, for example, that a statistically-significant sample found that a majority of RCFEs were out of compliance with a particular provision of the federal regulations. The response to this finding certainly would not be to disqualify RCFEs, or some significant percentage of RCFEs, from HCBS reimbursement. Instead, the state would seek to demand compliance on an ongoing basis for those RCFEs seeking to participate in the assisted living waiver. (CA)

schedules, and access to food/visitors at any time" and yet "the individuals who currently reside in these settings are assessed at least annually to determine if alternative service settings in the community are appropriate". It seems to be a two-sided argument by DHS - the residents can do whatever they want but they are not able to live in a similar setting off of the campus. "Why not"? It is P&A's understanding that this service, on the campus, was initiated to be a transitional placement for individuals between the institution and a community placement. It is also P&A's understanding that some of the residents in this setting have been there for years.

Comments of the ND P&A (available upon request).

H. Validation of Assessment Tool

- The plan regarding assessment tools includes a piloting of the provider self-assessment, which is necessary to ensure that the tool provides sufficient indicators of the true nature of the setting. It is positive that this accuracy is measured to some extent by the experience of the individual participant, especially considering that the rule is intended to focus on the individual's perception of their experience. It is not clear that the validation of the assessment will include other stakeholders, if the team will include other participants or advocacy groups, whether the initial assessments and validation report will be public, if the validation will be conducted for a statistically significant number of providers by provider type, or if the pilot process will be repeated if the results are negative. It is incredibly important that the validation of the assessments is done in an unbiased way that ensures that the participants are informed of what they should expect, not simply whether they "like it" or "get to have choice in what they do" as many may not have the perspective of what degree of choice they should be able to expect under the rules. (DRNC/NHeLP)
- IPAS is pleased with the use of NCI data to assess compliance. The state's use of the NCI survey (National Core Indicators) is helpful because it demonstrates that there needs to be significant change in a broad range of topics. However, there is concern with the use of the 90-day checklist as an indicator of compliance given that in several instances the results were contradictory with the NCI data. In the preliminary settings analysis, IPAS would like to see more substantive comments regarding how compliance will be determined in all instances where there is no NCI data and no 90-day checklist data. (IPAS)
- It is good that Maine has included a plan for developing a verification tool, but prior to issuing the plan for formal comment, the State should provide the details of how this verification will happen. (ME P&A)
- In addition, questions arise as to what happens when the findings of the "validating" entity do not match the findings of the provider self assessments. If, in fact, a validated sampling is used, how are the other compliant or none compliant providers (who were not a part of the sampling) then identified? Also, once these results are released to stakeholders, is there a plan to appeal a finding? If so, how does that work and who handles the appeals? (MPAS)
- As mentioned previously, there may be issues with self-assessments based on the types of questions asked or sources of bias. On-site assessments must be compared to original self-assessments so that the reliability of self-assessments can be determined. If accuracy is low, the Department must reassess the process used and develop corrective policies to more accurately determine the community nature of the settings. This may include increased on-site evaluations or conflict-free interviews during the person-centered planning process to examine the consumer's experience more in-depth. (CA)

I. Multiple Tools May Lead to Inconsistent Results

- It is not clear if the State Monitoring Review Process will include on-site visits, but it is critically important that this Process have sufficient oversight and controls to

make sure that the different LME-MCOs/Local Lead Agencies are applying assessments consistently and using the same definitions of what is sufficiently community based. There must be geographic, waiver type, and setting consistency to ensure the accuracy and integrity of the data collected and any future analysis or implications. We remind the State, as the single state agency, it is ultimately responsible for compliance with Medicaid regulations. We encourage the State to maintain control of the State Monitoring Review Process. (DRNC/NHeLP)

- Consistency among departments in the early part of the transition plan is especially important so that programs move forward in implementation in a similar way. Assessment tools and on-site reviews should use the same tool, with supplemental pieces if necessary for different programs. Any supplements or changes to an assessment should be cleared through a process that maintains consistency, includes public comment, and ensures that community is judged consistently for all types of consumers. Allowing for differences in populations and individuals must not degrade the ideals of community life and engagement. (CA)

J. Prioritize Segregated Setting Review

- Prioritize individual assessments of programs and facilities that are identified as presumptively institutional. This will allow the Department to take speedy steps to come into compliance with the HCBS regulations. (DRNPA)
- The timeline for compliance is very extended. We are particularly concerned that changes to non-compliant settings that are considered to be “more complex, and therefore more challenging to implement” will not begin until 2018. We believe that Kentucky must address the most problematic settings far earlier in the process to give the state and HCBS service system time to reach compliance by 2019. (KY P&A)

K. Transparent Assessment Results and Classifications

- It is unclear if the LME-MCO's/Local Lead Agency's assessment process plans will be public and open for comment. As part of the validation process, agency remediation plans, and provider remediation training, there should be both a posting of this information to the web-portal and an opportunity for public feedback. If the assessment process is all done behind closed doors, the State is turning its back on valuable information from participants and advocates about settings and how they truly function. These rules are about the individual's experience and the State should always be seeking information about the individual's experience, as opposed to a provider's interpretation of the individual's experience. (DRNC/NHeLP)
- Michigan's draft plan states that the Michigan Department of Community Health (MDCH) will be responsible for designing and implementing remedial strategies for settings found to be out of compliance. Does that indicate that MDCH will have a specific plan for each non-compliant setting and a strategy to assure that each setting comes into compliance in a timely manner? Will there be benchmarks in place for each setting specific to their level of compliance and

who is responsible for monitoring the progress for compliance? Will that information be public? (MPAS)

- As stated above, Ohio's decision to rely on provider self-assessments to determine which settings will be subject to heightened scrutiny is deeply flawed. Ohio should include people with disabilities and their families as well as advocacy organizations and the general public in identifying settings that should be presumed to have the qualities of an institution and which settings should be subject to the heightened scrutiny process. (DROH)
- P&A has a comment regarding the assessment process. On page 3, the plan says that the Department has conducted site visits to all Aged and Disabled Waiver adult residential service providers and adult day care settings that are not located in a hospital or nursing facility and that the Department will conduct site visits of IID/DD waiver settings for which the State is utilizing the heightened scrutiny process. Will the information from these site visits be made public to give stakeholders a chance to comment on (or even disagree with) the findings? (ND P&A)
- The process should be transparent. I initially asked for the provider and consumer surveys and results at the public meeting held by DHS on Sept. 11th. I was told these would be provided. I again asked for the information at the public meeting held by DHS on Oct. 15th. I was told this would have to be addressed with the Developmental Disabilities Division (DDD) Director who was not able to be present that day. I received an e-mail from the DDD on Oct. 24th, asking me what I was specifically wanted. I responded on Oct. 25th, delineating my specific questions. I received a response to some of my queries on Nov. 12th. I still do not know how many consumers were surveyed, how they were selected, what settings the consumers were surveyed about, and who helped with the survey if needed (or completed it on behalf of the consumer if they were unable to do so). The information I requested should have been made available to all stakeholders (e.g., posted on the DHS website) and in a timely manner. P&A did not have adequate time to analyze the information it did receive prior to submitting its public comments. (ND P&A)

VI. Enforcement & Ongoing Compliance

A. Generally

- The full plan needs to explain how you will make sure that providers are really following the rule. It is not enough to simply make sure that providers have written policies saying that they will do things like respecting people's privacy, helping people find competitive employment, and so on. People I know who live in group homes especially have told me that what is in the written policy is very often very different from how staff actually act. For example, some group homes will say that residents can leave at any time, but they won't have enough staff to accompany people when they want to leave. This means that people often have to wait a long time until someone can help them go somewhere, or are even forced to just stay at home instead. There needs to be a way for HCBS users and their advocates to complain about providers that aren't actually following the

rules. Because some people might not know how to send in a complaint, the state should also interview service users on a regular basis to make sure that providers are following the rule. (ASAN)

- The transition plan should include a timeline for DHHS to develop a comprehensive oversight process to ensure compliance with the Final Rule. Such oversight might include unannounced visits to person-center planning meetings to determine whether the process is truly individualized, regularly reviewing a sample of plans to determine what kinds of choices were offered to participants, and interviewing recipients. (SC P&A)
- Overall, the Transition Plan lacks any enforcement mechanism. For all waivers, OADS should make policy changes to include methods to penalize providers who do not comply with the HCBS rules. (ME P&A)
- The transition plan should include a timeline for DHHS to develop a comprehensive oversight process to ensure compliance with the Final Rule. Such oversight might include unannounced visits to person-center planning meetings to determine whether the process is truly individualized, regularly reviewing a sample of plans to determine what kinds of choices were offered to participants, and interviewing recipients. (SC P&A)
- Therefore, the Transition Plan should include specific steps that DDA will take to ensure that the providers actually meet the standards required by the rule. The Transition Plan should include deadlines and list specific graduated penalties for failure to meet those deadlines, including increased oversight and delineated restrictions that will be placed on a provider's license and certification. (DC P&A)
- With all settings, P&A recommends that there be an identified mechanism for a complaint process. This would help with ongoing compliance and, more importantly, give individuals an opportunity to address problems in their setting. (ND P&A)
- [The State should include] strong monitoring with input from participants and family members. The transition plans should also state that monitoring and oversight reports will be made public regularly. [The State] should use Relay and other effective communication to ensure access to its hotline for reporting non-compliance. [the State] should also allow for email and communication with Service Coordinators for reporting non-compliance. (DRNPA)

B. Rolling Provider Compliance

- The transition plan must ensure stability for individuals and not decrease their community interaction. If the plan does not provide that enforcement of setting compliance will occur on a rolling basis, there is a strong chance that setting compliance will bottleneck and there may not be enough alternatives developed as participants need new settings. The transition plan should tier provider compliance and begin compliance early so there will be sufficient time to identify the needs and to develop new providers. Not knowing when individuals may begin to change services or if there will be sufficient alternatives available creates uncertainty and fear that may be detrimental to stability in the community.

- IPAS is concerned with the timelines for completion of CAPs that stretch into 2018. Given the likelihood of some facilities requiring substantial correction, the timeframe seems tight to ensure compliance by March 17, 2019. (IPAS)
- The transition plan should have a timeline to develop smaller scale settings than the four bedroom group home that has been the model for many years. Possibilities might include townhouses or large apartments or houses that include some residents without disabilities. (SC P&A)
- The transition plan timeline must consider when provider review and compliance deadlines will occur. Transition plans should allocate adequate time, and provider compliance plans should not all terminate around the same date as such an action could create more instability than is necessary. The initial provider review process and timelines must not end before a process is available to help consumers smoothly transition to new services or providers. The transition plan for HCBS must ensure stability for individual consumers.⁴⁸ There should be protections in place for consumers who reside in facilities that may choose to close or change populations served. (CA)

C. Modification Policies

- IPAS is also concerned that the plan doesn't address how the state will implement and monitor any individual modifications to the additional requirements for provider-owned settings. This information should be addressed in the transition plan before it is submitted to CMS. (IPAS)
- Moreover, in provider-owned or provider-controlled residential setting, the new CMS rules require that additional conditions must be met, including the existence of a legally enforceable lease agreement and protections, the freedom of privacy in the sleeping or living unit but also the right to have visitors, entrance doors lockable by the individual, a choice of roommates for those sharing units, the freedom to furnish and decorate the sleeping or living unit, the freedom to control one's own schedules and activities and to have access to food at any time, and physical accessibility. Modifications to these conditions, according to the new rules, must be supported by a specific assessed need and justified in the individual's person-centered service plan. Ohio should clarify that an individual has a right to due process upon proposed modifications to these conditions. This must include prior written notice and an opportunity to challenge any proposed modifications with which he or she disagrees. (DROH)

D. Complaint Mechanism

- The Transition Plan needs to include a formal procedure that will enable individuals who are segregated, as well as their family members/significant

⁴⁸ CMS has issued guidelines in the Statewide Transition Toolkit regarding what is required in the plan when relocation of beneficiaries is part of the state's remedial strategies. These protections should be part of all state plans because it is likely that at least some consumers will have to move or change settings. CMS Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements 5 (Sept. 5, 2014).

others, to file a grievance or file a complaint for a provider's segregating conduct and its failure to meet the requirements of the CMS Rule. DDA should have a formal grievance process to give voice to those who have complaints. (DC P&A)

- There should also be an enforcement mechanism for waiver enrollees to challenge any setting that is not compliant with this new administrative rule and also additional oversight to ensure compliance. At the same, it should contain guidance to providers on how they can ensure they are complying with the new CMS rules. (DROH)
- All the waivers should include an ongoing mechanism by which a recipient, secondary consumer, or the now mandated independent case manager could grieve a provider's lack of compliance with the HCBS Final Rule, Transition Plan, or waiver. Waiver providers currently have grievance systems, but we suggest including language in the waivers about informing the recipient about his or her rights under the Final Rule and how to grieve lack of compliance. These stakeholders will be among the first to know if a provider is not complying with the Final Rule, the Transition Plan, or waiver. Assisting a recipient with this grievance process should be a regulatory responsibility of the independent case managers. This process should be ongoing and available anytime the recipient needs an avenue to address a concern. (KY P&A)

E. Ongoing Transition

- Identification, revision, and creation of necessary policies and procedures to address monitoring and compliance during and after the transition period. Compliance with HCBS regulations will be ongoing and the Department must develop a mechanism to receive and act on complaints during the transition period itself as well as in 2019 and beyond. Participants must be able to submit complaints regarding settings, have those complaints investigated, and receive resolution of the issue where there is evidence of fundamental systemic or individual violations such as a lack of choice in roommates, access to food, schedules, visitors, or means of effective communication. This complaint process must go outside of the setting. There must also be a system that requests information regarding participant satisfaction, possibly incorporated into the person centered planning process so as to avoid conflict of interest issues and allow for an examination of other options. Compliance monitoring may incorporate provider recertification, service coordination activities, and more. (NHeLP/CA)
- Establishing settings' compliance should not be a one-time activity; to best protect HCBS participants, they should have access to a mechanism that can investigate complaints and compel compliance. Because DSS has a preexisting duty to monitor the settings that it licenses, and DDS performs quality assurance reviews, these departments are well-equipped to include compliance with the HCBS regulations as a component of their ongoing interactions with owners and operations of HCB settings. (CA)

VII. Participant Protections

VIII. Full Choice in Housing Options

A. Choice of Setting

- The HCBS rule requires that individuals be provided a choice of settings, including a choice of non-disability specific settings and, in residential settings, a choice of a private unit. Many individuals and families are unaware of the current array of services that may be available, so the State must improve its information delivery in this area as well as assess the array available, including whether there are available placements. The Plan gives no indication that part of the assessment process will be an evaluation of the array of settings. People cannot be offered that choice if there is not capacity. North Carolina must evaluate its current capacity of non-disability specific settings and develop a plan to increase capacity as needed to fulfill this requirement. The lack of capacity is particularly acute for non-residential services, where the vast majority of settings are disability specific. With respect to the option of a private unit, the state must ensure that all of its waiver programs offer and have capacity for this option. (DRNC/NHeLP)
- The transition plans should provide for a policy that no new participant can get services in a noncompliant or presumptively non-compliant setting. The plans should also state that DHS will not allow new providers, provider moves, or expansion of providers in settings that are non-compliant or presumed non-compliant. Presumptively non-compliant settings should not remain in the system. The QMET on-site monitoring tool to be used in on-site visits to thoroughly evaluate [disability specific housing]. The state should also carefully assess campuses that have residential and/or non-residential waiver services on the campus or next to the campus. These concerning settings exist across Pennsylvania. They isolate individuals with disabilities in an artificial environment away from the community. While some people may leave the setting for a few hours a day that is very limited community access. Bringing individuals from the community onto the segregated site periodically does not resolve the isolating nature of the site. If for some reason [the state] wants to ask CMS to retain a presumptively non-compliant provider in its system, DHS should share with the public the evidence it intends to submit to CMS and follow all public notice and public comment requirements. (DRNPA)

B. Array of Setting Options is Critical to Community Integration

- To provide people with disabilities with real choices where they reside and receive the services they need, Ohio needs to ensure adequate capacity of scattered-site housing in the community. This is imperative, especially since the new CMS rules state that an HCBS setting should be one that “is selected by the individual from among settings options, including non-disability specific settings and an option for a private unit in a residential setting.” The draft transition plan failed to discuss this important topic. Ohio must also evaluate its current capacity for non-disability specific, non-residential settings and provide people with real

options for working and spending their days in integrated community settings. (DROH)

IX. Non-Residential/Day Services

A. Plan for Fully Integrated Day Services

- The inclusion of integrated day and competitive employment is a positive step forward in working toward compliance with not only the letter but also the intent of the rule. Choosing the word “opportunities” leaves the impression that the focus is on an opportunity rather than the outcome. We urge the State not to design any system that does not focus on outcomes. (DRNC/NHeLP)
- With regard to the Adult Day Services and Structured Day Program services, IPAS would like to see substantive comments regarding how these programs will be assessed for compliance. It is our experience that these programs, in particular, are most problematic with regard to HCBS rule requirements. The plan seems to presume that because the services are supposed to be community-based that they meet the HCBS standards, which assessment may determine to not be true. (IPAS)
- For all waivers that provide employment supports, OADS should change its policies to ensure that no HCBS employment or work supports will be paid to programs pay employees subminimum wage. (ME P&A)
- There is no indication as to how the non-residential services will be evaluated for their compliance with the new rules. It seems awkward at best to assume that a single evaluation tool could adequately assess both a group home and a sheltered workshop. The draft plan indicates that both residential and non-residential settings under the Habilitation Supports Waiver (HSW) funds have already been identified. How was this done? What tool was used? Why has this information not been made available? (MPAS)
- [The Plan] also accurately acknowledged, to its credit, that there is a “significant bias toward facility-based supports” in existing adult day waiver services through the DD system, including adult day support and vocational habilitation programs, and that self-reporting for these settings “significantly underrepresents” those which have the qualities of an institution. (DROH)
- Ohio’s preliminary assessment of the adult day waiver service (ADWS) settings (both work and non-work settings) in the developmental disabilities system should have concluded that the vast majority, if not all, of these facility-based settings are “settings that isolate” that are presumed to have the qualities of an institution and therefore should be subject to heightened scrutiny. These are settings designed specifically for people with developmental disabilities and provide little interaction with nondisabled peers (besides staff) and the broader community. Also, like residential settings in the developmental disabilities system, a sample of on-site evaluations for these day programs should be completed, not simply those small number of settings which providers reported are presumed to have qualities of an institution or which cannot meet the new CMS rules. (DROH)

- After reading the Transition Plan, we are not sure whether congregate day programs in Kentucky will continue to be funded by DMS. Many Kentucky waiver participants go to Adult Day Training, Adult day Health Care, or work at 14(c) sheltered workshops that receive DMS reimbursement. The state must recognize in their plan that some of these facilities might need to be decertified if they cannot meet the standards of the new regulation. Since these settings are designed exclusively or primarily for people with disabilities, the plan should address in detail how the adult day services and non-residential settings will be modified to assure that participants have the opportunity to interact routinely with people without disabilities. (KY P&A)

B. Reverse Integration is Insufficient

- Currently, waiver participants are given few, if any, choices of activities during the day. Many HCBS participants are getting group-based day services that are not integrated because people spend most of the day at a center that only serves people with disabilities. When they go out on trips “into the community,” they are in big groups that inhibit interaction with people outside of the group. Or, there is purported “community involvement” because the participants work in the backroom or stocking shelves in a store that is open to the public, but with little actual interaction with people without disabilities. In some cases, community groups visit the center as a service project. Many are never presented with the option of seeking competitive employment or learning what steps would be required before that is a realistic option. The implementation of HCBS must mean an end to this lack of choice. We recognize this will require significant shifts in the provider network and service array and urge the State to choose a path of slow and steady progress toward compliance on this front. We caution especially against reverse integration as a solution. If providers of substantially segregated services may be deemed in compliance with HCBS because they invite community groups into the segregated facility for cultural or service projects, there is no real progress toward integration and this use of “reverse integration” does not meet the intent of the rules or the mandates of Olmstead. North Carolina should be like other states that are moving away from sheltered work. To do otherwise is merely delaying changes that must eventually occur. Therefore the transition plan needs to closely examine the current day program services and establish a clear plan for moving towards integrated day activities that focus on supported and competitive employment. (DRNC/NHeLP)

C. Closing the Door to New Segregated Placements

- The transition plans should provide for a policy that no new participant can get services in a noncompliant or presumptively non-compliant setting. The plans should also state that DHS will not allow new providers, provider moves, or expansion of providers in settings that are non-compliant or presumed non-compliant. Presumptively non-compliant settings should not remain in the system. The QMET on-site monitoring tool to be used in on-site visits to thoroughly evaluate [disability specific housing]. The state should also carefully assess campuses that have residential and/or non-residential waiver services on

the campus or next to the campus. These concerning settings exist across Pennsylvania. They isolate individuals with disabilities in an artificial environment away from the community. While some people may leave the setting for a few hours a day that is very limited community access. Bringing individuals from the community onto the segregated site periodically does not resolve the isolating nature of the site. If for some reason [the state] wants to ask CMS to retain a presumptively non-compliant provider in its system, DHS should share with the public the evidence it intends to submit to CMS and follow all public notice and public comment requirements. (DRNPA)

X. Other Issues/Comments

A. Using the HCBS Evaluation to Address Person Centered Planning Issues:⁴⁹

- The basic underpinning for the successful implementation of a plan to transition to truly integrated community based supports and services is inextricably linked to the integrity with which the Person Centered Plan is conducted. The integrity of the Person Centered Plan cannot be compromised or limited by the array of services offered by the provider. Our preference is to allow the Person Centered Plan to be facilitated by a person or agency that is independent of the service providing agency and is selected by the beneficiary. (MPAS)
- DRNC/NHeLP comments on Person-Centered Planning Issues: Evaluating and Using Person-Centered Planning. The rules regarding person centered planning are already in effect, but it is positive that the State plans to continue to evaluate how that process can be improved. Advocates urge the State to fully evaluate whether the current process, particularly for the Innovations waiver participants, is truly serving the needs of those individuals and if it is really encouraging community integration. Currently the individual, family member, or provider has to actually find the necessary services and advocate for them (even when they do not always have the knowledge or ability to do so effectively). Advocates also urge the State to incorporate into the plan the use of the person centered planning process to perform an individual assessment by participants, as well as encourage the State to continue this process through the validation period and ongoing monitoring. The role of the LME/MCOs makes this a critical opportunity to gather data from individuals about their experiences and gather information about providers for future enrollment renewals.

⁴⁹ Explanation: States are already supposed to comply with the person centered planning regulations and changes to come into compliance are not supposed to be included in the transition plan. However, this does not mean that states cannot fully evaluate the functionality of their current PCP processes as they are evaluating changes to the PCP process. MPAS, Disability Rights NC, and the National Health Law Program used the public comment process on the transition plan to urge the states to include an evaluation of how the current process is working and whether it is fulfilling or hindering the goals of the programs and to push for changes to the current processes.

Person-Centered Planning versus Care Coordination. As stated, we are generally optimistic about the State's plan for HCBS transition and are encouraged that the State is looking systemically at the provision of HCBS. We strongly ask that as part of this review the State look closely at the effectiveness of care coordination in helping an individual access his or her community. As advocates, we have been disheartened and frustrated by how care coordination functions for Innovations waiver participants and strongly believe it is a considerable impediment to community integration. This is especially true because the State does not have independent advocates or Ombudsman services available to participants to help them navigate the system, understand their rights, and help resolve any problems that arise between the participant and the LME/MCO.

No matter the expertise or intentions of a care coordinator, there is an inescapable conflict in having care coordination performed by an LME/MCO employee, especially without an independent ombudsman available to help navigate those issues. We hear time and time again from individuals and parents who characterize their experience talking to their care coordinator as talking to a brick wall. Participants and families feel that every time they ask a question, they are either told that policies do not allow that person to receive a particular service, or they are handed a list of providers for a particular service. Consequently, the individual or family member becomes responsible for locating a new provider, without any knowledge of whether that provider would serve the individual's needs or is taking new clients. Individuals and family members distinctly feel that they do not have an advocate in their care coordinator and that the care coordinator is always going to support their employer, the LME/MCO.

As advocacy organizations and consumer groups, we are overwhelmed with requests to help individuals because "the care coordinator is doing a horrible job" or "only tells them no." We hear from our clients, multiple times, daily, that care coordinators have provided inaccurate, misleading, or absurdly sparse information. Although care coordination may be inescapable, the State must take responsibility for ensuring that HCBS participants are actually able to access services and necessary information. In addition, the person-centered process needs to truly meet the definition and intent. The current process does not do so. We recognize that the rules seem to allow a LME/MCO to provide person-centered planning, but the State should not assume that the LME/MCOs are doing so in a way that meets the rule. The current function of care coordination does not do so, and this needs to be reevaluated. In addition, we strongly urge the State to follow the CMS guidance that independent advocacy or Ombudsman services be available at no cost to participants.⁵⁰ This advocacy must be accessible and, more importantly, be knowledgeable about an individual's rights

⁵⁰ CMS, Guidance to States using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Support 10-11 (May 20, 2013), <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/1115-and-1915b-MLTSS-guidance.pdf>.

and have clear, realistic standards for enrollee to advocate ratios. Other states, such as Wisconsin, have had such systems with good success, and we encourage the State to follow such models.

B. Offering Expertise and Assistance:

- MPAS also appreciates the demands on the Michigan Department of Community Health in planning and managing this vast, overarching paradigm shift in the design and delivery of supports and services to eligible populations. This endeavor, like others of its size, will prove to be time consuming and complex, but it will inevitably result in increased levels of independence and community inclusion for people with disabilities. Throughout this process, MPAS enthusiastically offers its expertise and support. The following comments regarding the draft statewide transition plan, although direct, are intended to be a constructive critique as Michigan moves forward in an expeditious yet responsible manner. (MPAS).