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Department for Medicaid Services HCB Final Rule Statewide Transition Plan Commissioners Office 275 E. Main Street, 6W-A Frankfort, KY 40621

Via U.S. Mail and e-mail CMSfinalHCBRule@ky.gov

RE: Comments on the Proposed Statewide Transition Plan

Here are Kentucky Protection and Advocacy's comments—submitted pursuant to the Department for Medicaid Services' (DMS) Public Notice—on DMS' Statewide Transition Plan for all Home and Community-Based Services waivers.

We commend Kentucky for several positive elements of the Transition Plan. It uses multiple sources of information for its evaluation of settings, including review of regulations, information from state staff who conduct on-site licensing visits of these settings, and engagement with providers. The Plan proposes to build an on-going monitoring of compliance with the HCBS regulations into its oversight system. It outlines a relocation process for individuals who are being provided services in settings that cannot come into compliance with the regulations and includes an initial analysis and transition plan for non-residential settings.

Our concerns and suggestions follow. II. Introduction, page 1 shows that Kentucky has six 1915(c) HCBS waivers. Per the Center for Medicare and Medicaid (CMS), Kentucky has seven approved 1915(c) HCBS waivers. http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-State/Waiver-Descript-Factsheet/KY-Waiver-Factsheet.html#KY0967. The seventh waiver is HCBS Transitions which provides services for individuals with physical disabilities (and the aged) that have left medical facilities through the Kentucky Transitions Program.



II. Introduction, Page 2 indicates that the Supports for Community Living (SCL) program participants are individuals who have an intellectual disability. It is well settled that the SCL program is for individuals with an intellectual or developmental disability. See KRS 205.6317(1)(a) and *Department for Medicaid Services v. Bratcher*, 424 S.W.3d 430 (Ky. App. 2014). Please add "or developmental disability."

A. Purpose, page 2 states that DMS submitted the Michelle P. Waiver (MPW) transition plan on August 28, 2014. The MPW plan is nine pages long and it lacks specificity. It looks more like a plan to make a plan, i.e. a work plan rather than a transition plan. Will the MPW transition plan be updated with more specifics or is the specificity deemed to be found in the Statewide Plan? Here is a link to the MPW transition plan -

http://chfs.ky.gov/NR/rdonlyres/23113EB2-DBFB-4BD7-930E-7882920BAD85/0/KYInitialHCBFinalRuleTransitionPlan 2014725.pdf

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.

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.

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.

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 roll-out. Ask these two fundamental questions—"what do I like now and what would I like to change."

Under B. Monitoring Process Assessment on page 11, 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.

Under IV. Provider Assessment A. Residential Settings Page 14, we appreciate that the workgroup developed a web based survey for providers that reflects the requirements of the new rules 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 expertize 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.

We also urge an on-sight check of the one setting that is said to fully align with the rule and of a percentage of the settings found to be able 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.

On page 7 Table 3.1 ABI and ABI-TLC and on page 10 SCL both note that an individual can select a non-disability specific setting and a private unit. The ABI and SCL waivers have typically offered 3 person residential settings with each person being a waiver recipient. Does this mean an ABI or SCL wavier recipient can choose to live alone without a housemate with a level of support up to 24 hours? The Remedial Strategies section of the Transition Plan (see page 23) indicates that a requirement for an individual to choose to live alone or with a roommate will be added to the waivers. Does this mean alone in a room in a house occupied by two other waiver recipients or does this mean alone in a room in a house occupied only by the recipient and his or her staff as needed? Will recipient be able to choose to live in their own house without any housemates after DMS adds the clarifying language to the waivers?

Also a recipient can have visitors at any time. Historically, the 3 recipients in the home would go to a day program or other service in the community, thus relieving the need for 24 hour staff presence at the home. Will this on-demand visitation require providers to staff a residence as needed?

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 recipients 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.

Regarding Table 5.3 Potential Participant Actions for compliance on page 29 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 individuals with cognitive and intellectual disabilities. Stakeholder participation would also help to ensure that communication is done efficiently to reach various disability communities.

Under B. Provider Level Remedial Strategies (2) page 31) the state includes as part of its "communication plan to stakeholders and providers... use of webinars, presentations at conferences and provider association meetings." We urge inclusion of consumers and disability advocates as a standing 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.

The description of how the state will engage in the heightened scrutiny process leaves out any mention of consumer input which is a required component of the heightened scrutiny review process. See Number 1 Settings Presumed Not to Be HCB (page 32).

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.

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. (Plan at p. 5-6) 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. We also recognize, however, that CMS is still providing ongoing guidance to the states about its new rule. Thus, Kentucky's Transition Plan will be fluid.

I look forward to your responses. Please let me know if you have any questions or concerns.

Kindest regards,

William S. Dolan

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