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December 31, 2014

Gary Walcott, Acting Director
Office of Aging and Disability Services
Department of Health and Human Services
11 State House Station, 41 Anthony Avenue
Augusta, ME 04333-0011

Re: Draft Transition Plan for Complying with New Home and Community Based Services Rules

Dear Acting Director Walcott,

The Disability Rights Center (DRC) offers the following comments to the Draft Transition Plan for Complying with the New Home and Community Based Services (HCBS) Rules (Transition Plan).

Stakeholder Engagement

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.

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

Note:

Public hearing on January 16, 2015 from 9:00 am to noon at 19 Union Street Augusta in Conference room #110 to accept public comments on the HCBS Transition Plan.

Comments can also be submitted to: <http://www.maine.gov/dhhs/oms/rules/transition-plan.shtml>

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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 and/or family members or how many participated in this educational effort.

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.

Preliminary Considerations

In addition to the HCBS settings standards that are the focus of the Transition Plan, the new HCBS regulations also include standards for the person-centered planning (PCP) process and service plan applicable to HCBS waivers. 42 C.F.R. § 441.301(b)(6)(1)-(3). Unlike the settings standards, the PCP standards and procedures went into effect in March 2014. Although the transition plan procedure applies to the implementation of the settings standards, because Maine's waiver programs do not comply with the PCP standards, OADS should use the transition plan as an opportunity to address the changes necessary to policy and practices to meet the PCP standards, too.

Moreover, complying with the PCP standards is necessary to meet the requirements of the settings standards. The Transition Plan relies heavily on the Sections 21 and 29 PCP process in order to bring these waivers into compliance. Even with the robust and recently revised PCP process, the Transition Plan notes several modifications that are necessary to bring these waivers into full compliance. These modification to the PCP process include: "to reinforce an individual's option to receive services not tied to the setting;" "to include settings options that include a non-disability specific setting and a private unit;" "to include education on resource options available for financing room and board;" and "to incorporate standards relating to control over daily activities, physical environment and with whom to interact." See Transition Plan pp. 39-40. OADS should adopt similarly robust modifications for its other waivers to ensure compliance with the PCP process and service plan requirements and as a tool to ensure compliance with the HCBS settings rules.

As part of its formalization of its verification system, OADS should expand its developmental services grievance process to include all recipients of HCBS services. Individuals receiving services are in the best position to inform OADS if the services they receive are not in compliance with the HCBS rules.

Comments Related to the Scope of the Transition Plan

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.¹

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.

Similarly, OADS makes the cursory assumption that because its waiver for adults with brain injury (Section 18) was approved after the effective date of the rules, “program policies have already been determined to be in compliance with the new HCBS rule”, yet, does not indicate what entity determined it was in compliance with the rule. While the application appears to have been submitted after the effective date of this rule, there is no information contained within the application to suggest how Section 18 complies – or will come into compliance with this rule.

¹ 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.

Likewise, OADS appears to only cursorily examine the Section 20 policies and practices, asserting that because it was recently approved, CMS already applied many of the requirements during the waiver application process. Nevertheless, the only changes planned for the Sections 18 and 20 waivers are technical changes to policy and plans for formalizing verification systems. OADS should conduct a more thorough review of Sections 18 and 20 to determine whether there are policy and program elements that conflict with the new HCBS settings rule. It should also work with Section 20 program recipients to assess whether individual settings comply with the rule.²

Finally, although acknowledging that these rules would apply to state-plan funded residential settings (PNMIs) serving waiver recipients, the Transition Plan does not provide any information about whether the Section 97 policies and practices comply with the HCBS rules. The Department should do this analysis and make changes to policy where necessary, as well as work with recipients in these setting to assess whether they meet HCBS standard.

Transition Plan (pp. 16-23)

In general the Transition Plan seems to simply be a work plan to further assess Maine's home and community based settings and develop an updated transition plan in March 2016, two years following the effective date of these new rules. The only waivers that are part of the transition plan section are Sections 19, 20, 21, and 29.

Section 19

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.

² It is our understanding that no one is currently receiving waiver services through this program and, thus, are not suggesting that the Department work with individuals to assess whether the settings comply with the HCBS rules.

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.³

Section 20, 21 & 29

The plan states OADS will develop and conduct a provider web-based self-assessment survey and validate only 5% through Department staff, provider and consumer interviews. Although the summary on page 17 indicates that OADS will be conducting site visits and participant interviews, these elements are missing from the transition table. The Department should not solely rely on the assessments of providers.

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.

³ 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.

Detail for State Level Assessment (pp. 24-43)

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.

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.

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.

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. 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.

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"⁴ Maine's landlord tenant law. Because this will be a significant change for many providers, OADS

⁴ *Regulatory Requirements for Home and Community-Based Settings*. Retrieved December 29, 2014. <http://www.medicare.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>

should develop a training and education campaign for providers and service recipients about these changes and tenant rights.

Sections 18 & 20

In finding that these programs are largely in compliance with the new HCBS settings rules and only require only technical changes, OADS relies heavily on the waiver applications for these programs. 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 Maine Care 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.

Sections 19 & 22

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.

Sections 21 & 29

OADS found that its policies and practices under two of Maine's largest waiver programs for adults with intellectual disabilities and/or autism to be "significantly inconsistent with the requirements under the new HCBS rules" or "inconsistent with the new rules and coming into compliance is expected to have a significant

impact.” The Department acknowledges that Maine policy might be substantially in compliance but not all providers are in compliance with the policy, however the transition plan does not address the insufficient enforcement options in its policy.

Maine has determined that there are 1208 settings that while they are not disqualified, they are not in compliance; however, the Department believes these settings can be brought into compliance under its largest waiver program for adults with Intellectual Disabilities and Autism (Section 21). Further, Maine finds eight settings to be “presumed disqualified” under the adult support services waiver program for adults with intellectual disabilities and/or autism (Section 29).

While DRC recognizes that the State provides support in residential options ranging from “supported living; shared living; Family centered support; Group living; and Non-waiver residential services”, Maine does not provide choice for a person to live alone and receive 24/7 support under the Section 21 waiver. This is a substantial limitation on the person’s choice of residence and leaves the person at the mercy of their roommate’s status. In addition, Maine regulations instruct service providers to give notice to persons that they must leave the residence when funding stops. For some, this creates a nomadic culture of persons moving from place to place in an attempt to find a stable roommate. For others who are medically or behaviorally incapable of living with someone else, this requirement can prevent them from having the ability to live safely in the community.

Again, Maine missed key stakeholder input in their assessment of current home and community-based services. On page 21, the Department describes its process for identifying disqualified settings or presumed disqualified settings in the Section 21 and 29 waiver programs. It seems that Department’s plan to further assess these settings is solely through provider self-assessments. It is a good thing that OADS developed a participant experience assessment tool for measuring ongoing compliance with the HCBS rules. However, as stated previously, this tool should be used in the initial assessment and categorization of settings.

In sum, Maine’s transition plan for HCBS Settings compliance is inadequate. It does not create a plan to ensure that people are receiving services in settings that comply with the HCBS rules. OADS should make the following changes, along with those changes previously noted, to strengthen Maine’s transition plan:

Make policy changes to fully assess all settings for compliance with HCBS Setting rules including Section 18, 19, 20, and 32. Maine must not presume any setting meets HCBS rules unless people with disabilities and their families and service providers adequately assess the setting.

Convene a transition taskforce to create and conduct field assessment surveys and develop a comprehensive transition plan with ongoing quality monitoring measures. The taskforce must have representation from self-advocates, families, providers, and advocates.

Thank you for your attention to these comments.

Sincerely,

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

Katrina Ringrose
Advocate