December 12, 2014

Rebecca VanAmburg, MPH
Office of Health Services
Maryland Department of Health and Mental Hygiene
By email to Rebecca.vanamburg@maryland.gov

Re: HCBS State Transition Draft Plan

Dear Ms. VanAmburg:

Maryland Disability Law Center (MDLC) offers the following comments to the Department of Health and Mental Hygiene (DHMH) as you draft a Transition Plan pursuant to the Final Rule on Home and Community-Based Services (HCBS) promulgated by the Centers for Medicare and Medicaid Services (CMS), 79 FR 2947 (2014).

MDLC firmly believes in the underlying goals of the final CMS regulations, which will provide people receiving services with greater autonomy, respect and freedom of choice. MDLC’s recommendations are as follows:

1. Establish Fundamental Principles for Maryland’s HCBS Services Including:
   - The right of each person to be supported in community settings of their choice during the day, in the evening and on weekends, that are not designated places only or primarily for people with disabilities.
   - For those who choose to work, the right to work in inclusive community settings.
   - The right to earn at least minimum wage for paid work.
   - The right to privacy, including in living units shared with a roommate.
   - People who choose to live alone will receive the supports they need to do so.
   - People who need to leave an institutional setting will receive the support services they need to live in the community with reasonable promptness.
   - People will receive the communication support they need to access integrated services.

2. Create an advisory group or groups of stakeholders to provide information to DHMH about waiver service delivery and the impact of changes under the transition plan.
   - The group should include, in addition to advocates for people with developmental disabilities, people with disabilities and family members,
advocates for people in the Autism Waiver, the Community Based Options Waiver, the Traumatic Brain Injury Waiver and the Medical Day Waiver. We strongly suggest inviting the Legal Aid Bureau Elder Law Task Force, the Office of the Ombudsman and Voices for Quality to send representatives, especially to provide advice about assisted living.

- The advisory group or groups should have meaningful input on any data collection or assessment tools and procedures. Input from this group will better ensure that the state has the insight on the practicalities of service delivery which is necessary to collect significant and accurate data.

3. **Consider Stakeholder Views and Adopt an Ongoing Process for Obtaining Meaningful Stakeholder Input.** The public needs more time to understand and provide feedback to DHMH on implementation of the rule change. Based on the limited knowledge of the rule that the audiences displayed at DHMH’s listening sessions, it is clear that people receiving services and their families need more familiarity with the rights established by the CMS rule in order to provide informed comments. As part of its transition plan, DHMH should continue to educate the public and gather more information about individual views to inform DHMH policy and services as it strives to comply with the rule. As part of this education and information gathering:

- DHMH should prepare and disseminate more education about the rule. The information should be accessible in various formats and disseminated through all available means such as advocacy organization listserves, provider agencies, webinars and public meetings.

- DHMH should use multiple forms of communication to solicit feedback from stakeholders, including audio formats.

- To obtain more information from people receiving services and their support network, DHMH should reach out and meet with these individuals where they live, work or gather for meetings.

- DHMH should offer accessible transportation to public meetings and/or equipment for listening to a webinar.

- During the rule implementation period and thereafter DHMH, should continue to collect more information from people receiving services.

4. **Collect adequate information to establish a baseline for assessing its compliance or planning.** CMS expects states to determine the current level of compliance within their systems. This is a critical step in addressing the opportunities for change in the current service delivery system, and as such DHMH must be more comprehensive in its approach.
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- DHMH needs to better assess current compliance with the rule. The DHMH surveys distributed to individuals, providers and case managers were too flawed to use as a baseline measure. For example, the key term “unit” was not defined in the survey for participants who were asked to comment on the attributes of their living units. Provider agencies were asked to describe their residential “facility”, though Developmental Disabilities Administration Medicaid waiver providers typically own several or many homes, each with different attributes. The survey for case managers asked questions that were likely to yield responses that demonstrate full compliance with the rule. Also of concern was the very low response rate from people receiving services. A more accurate means of assessing compliance would be to discuss planning methodology with people receiving services and provider agencies and to review individual plans.

- DHMH gathered no information about the location of and service delivery of day and employment services. DDA is clearly not in compliance with this rule because many people still spend much of their day in facility based programs that offer little community access. DHMH is required to comply with the rule requirements though CMS has not issued its guidance on day and employment services yet. Because DDA currently has very little data on the integration of its employment services and none on the integration of its day program services, it is urgent that DHMH obtain a better compliance picture of all of its day services.

5. **Develop a Timeline for Benchmarks for Compliance with the Rule Requirements.** DHMH needs to set compliance goals that are aligned with assessment and remediation timelines. DHMH should publish its benchmarks and actual ongoing compliance. For example, a benchmark could be that by January 2016, 70% of individuals in residential programs will have a lease or other similar agreement. DHMH should consult with the Advisory Group to address unexpected obstacles or challenges to compliance goals for suggestions of strategies to enhance compliance.

6. **Develop a Methodology for Measuring Ongoing Compliance with the Rule Requirements.**
   - DHMH should develop the necessary policies and procedures to address monitoring and compliance during and after the transition period.
   - DHMH should designate the agency or agencies that will be responsible for compliance monitoring, as well as how the agencies will remediate any findings of noncompliance.
   - DHMH should use the advisory group or groups to work with the agency/agencies responsible for compliance monitoring to ensure data measurement reflects actual services and conditions.
• The assessment process should use a tested and validated tool for measuring the integration of settings.
• DHMH, providers and individuals need to be educated to use any assessment tool appropriately.
• Providers should be required to conduct individual site assessments, which should be reported to DHMH as part of compliance measures.
• DHMH should conduct site visits as a compliance measure.
• A significant component of ongoing compliance monitoring should include evaluations by people receiving services, collected in a manner that avoids the influence of providers.
• People receiving services must be able to submit complaints about compliance issues, have those complaints investigated, and obtain resolution of fundamental systemic or individual rule violations.
• DHMH should be prepared to provide assistance when needed in order to ensure standards are met and the person receiving services is benefiting from the goals of this rule change.

7. **Offer Providers the Technical Assistance Needed to Comply with the Rule Change.** DHMH will need to provide technical assistance and support to provider agencies out of compliance with the new rule requirements. In particular, DDA will need to collaborate with its provider agencies to revise its infrastructure to support more individualized support services in more diverse settings than providers currently offer. The current rate structure with built-in assumptions about staffing ratios needs to change. Transportation needs to be addressed as well.

8. **Create Procedures for Protecting the Due Process Rights of People in Services.** If a person asserts that a setting is not compliant with the rule and DHMH disagrees, he or she should have appeal rights.

9. **Accept More Public Comment and Amend Timelines for Public Comment.** In view of the late date that DHMH plans to release its draft Transition Plan for comment, individuals, advocates and other stakeholders should have a longer comment period. After incorporating public feedback on the initial draft Transition Plan, the state should invite another comment period. The state can then revise the plan as needed, even if it needs to request that CMS accept an amended plan.

10. **DHMH Should Implement the Person Centered Planning Requirements of the Rule.** DHMH should provide information to the public, including timelines, training requirements for providers and dissemination of rights information to people receiving services, about how it plans to implement the person centered planning requirements of the rule.
Conclusion

The new HCBS regulations represent an opportunity for DHMH to vastly improve the quality of choices offered to individuals while valuing their freedom of choice and individuality. DHMH with the help of stakeholders can create meaningful change, so thank you for considering our comments as you draft the HCBS State Transition Plan.

Sincerely,

Nancy Pineles
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Attorney