March 9, 2015

Teri Morgan
Department of Medical Assistance Services
600 East Broad Street, Suite 1300
Richmond, Virginia 23219
ATT: HCBS Final Rule

delivered via email to: HCBSComments@dmas.virginia.gov

Re: Comments on Virginia's Draft Statewide Transition Plan

Dear Ms. Morgan:

These comments are submitted on behalf of Justice in Aging. Justice in Aging (formerly the National Senior Citizens Law Center) is a national organization that uses the power of law to fight senior poverty, including a focus on securing access to affordable health care. We have significant expertise in consumer rights in assisted living facilities, and so focus our comments on the Alzheimer's Assisted Living Waiver section of the Draft Statewide Transition Plan (transition plan).

There is a need for increased stakeholder input beyond provider self-assessment.

We applaud the Department for completing on-site visits in addition to analyzing provider self-assessments when conducting initial assessments of the Alzheimer's Assisted Living (AAL) waiver settings. It is not clear, however, whether and to what extent individuals and their families have had an opportunity to provide input during the on-site visits.

The Setting Characteristics Assessment currently includes "interviews with site administrators/families." (p. 24) We urge that interviews include individuals as well, and that the Department increase individual participation in the assessment process. Stakeholder involvement including individuals is critical in formulating a transition plan that fulfills the intent of the HCBS rule. The 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 individuals and, in some cases, their family members and friends. While providers offer an important perspective, they cannot offer the perspective or the experience of the individual. The HCBS rule focuses on the individual's experience, therefore the transition plan should also do so.

Education and outreach is critical for meaningful individual participation in the assessment process. The Department should 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 individuals, their families, and similarly situated stakeholders will be aware of the changes that will affect services.

Additionally, we ask the Department to develop a means for individuals to conduct their own self-assessment of the settings in which they live. Participant assessments should be accessible to the individual and free from provider influence. Participant assessments can be an important part of the assessment validation process, as we do not believe that provider self-assessment is at all adequate to determine compliance with the HCBS rule.

In making this recommendation and the recommendations below, we of course understand that Alzheimer's disease and similar dementias have an impact on an individual's relationship with others and how he or she can respond to a question. We also understand — and we cannot emphasize this enough — that a truly community-based setting can be a tremendous benefit to individuals suffering from dementia. The transition plan should take extra care to ensure that participants' experiences, observations, and preferences are recognized and honored.

Careful attention is needed regarding secured units.

We appreciate that the state is looking carefully at the issues surrounding HCBS rule implementation for people with Alzheimer's disease. We are concerned, however, by the too sweeping conclusions regarding locked settings. The transition plan on page 19 states broadly that "[i]ndividuals require safety mechanisms regardless of the setting they are in to prevent wandering (therefore use of secured units or buildings is necessary)."

This generalization is much too expansive, particularly in the context of a rule to integrate people with disabilities with the broader community. Alzheimer's disease is progressive and, contrary to the above-quoted statement, not all individuals with an Alzheimer's diagnosis require secured units or buildings. Furthermore, in our experience, assisted living facilities sometimes try to move individuals with dementia into locked units contrary to the wishes of the individual and his or her family. We encourage the Department to examine carefully the concept of and procedure related to secured residences.

The right to privacy is as important for people with Alzheimer's as for any other population.

We are also concerned by the relative disregard of privacy rights. The transition plan on page 19 states, "[r]esidents like being congregated with other people and the need for increased privacy has historically not been a concern."

This statement is very concerning. People with Alzheimer's disease have a right to privacy to the same extent as all other individuals under the HCBS rule. The relevant provision makes it clear that an "individual's rights of privacy, dignity and respect, and freedom from coercion and restraint" are not part of the additional conditions that can be modified through the person-centered planning process. 42 CFR § 441.301(c)(4)(iii).

The Federal HCBS rule applies to all assisted living residents where waiver participants live.

The Department should require that AAL settings honor the new HCBS rule for all residents regardless of a participant's source of payment (including private 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. Further, allowing 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.

Conclusion

We strongly urge bringing individuals and consumer advocacy groups "to the table" for further dialogue with the Agency and input for improving Virginia's draft transition plan before a final plan is developed and submitted to CMS. As discussed above, the provisions related to the Alzheimer's Assisted Living Waiver deserve particular attention. Thank you for your consideration of these comments.

Sincerely,

Eric Carlson
Directing Attorney

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Skadden Fellow