

Ms. Emily Palmiero
DOH OALTC
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Albany, NY 12260

Dear Ms. Palmiero,

Thank you for the opportunity to comment on the HCBS Final Rule Statewide Transition Plan (STP). I am writing on behalf of LeadingAge New York, which represents over 400 not-for-profit and public providers of long term care and senior services throughout New York State, throughout the continuum. We offer comments on three sections of the STP; those that address Adult Care Facilities and Assisted Living Programs, Social Adult Day Care programs and Managed Long Term Care providers.

I. Adult Care Facilities and Assisted Living Programs

LeadingAge New York has been in dialogue with the Department of Health (DOH) over the years as the state works to come into compliance with the federal home and community based services (HCBS) settings rule. We have appreciated this approach as we work together to understand and implement the rule. We offer specific comments on the Special Needs Assisted Living Program as well as some general suggestions.

a. The Special Needs Assisted Living Program

While LeadingAge NY was aware of most of the activities outlined in the STP, there was one aspect that surprised and concerned us. The STP which asserts that “Special Needs Assisted Living Programs” do not and cannot, by definition, fully comply with the HCBS Final Rule. The STP notes that the delayed egress door locks to deter elopement and other potential safety breaches, make these settings unable to comply with the rule and therefore ineligible for Medicaid funded HCBS.

First, we must acknowledge that there are very few Medicaid funded assisted living programs (ALPs) that operate a special needs assisted living residence (SNALR), referenced in the STP as Special Needs Assisted Living Programs (SNALPs). LeadingAge NY provider members have attempted to operate SNALPs to provide low-income older adults with access to specialized services related to their dementia. Unfortunately, they have found that it was financially infeasible and administratively cumbersome. The Medicaid ALP rate does not support the level of services and the environmental modifications needed to provide the services that the state requires in the SNALR model. Additionally, the ALP and SNALR have two different sets of regulations, different processes and different mandated forms; making the operation of the program administratively complex and burdensome. These are issues that the state should address if they want to ensure that low-income older adults with Alzheimer’s disease and other dementias have options other than a nursing home. It would, however, be truly unfortunate and contrary to the intent of the Rule, if the HCBS Setting Rule were to operate as an insurmountable barrier to delivering specialized assisted living services to Medicaid beneficiaries with dementia, thereby forcing them receive care in nursing homes.

The STP indicates that if a facility is unable to comply with the rule, then, the Medicaid-HCBS funded resident would need to transfer into a compliant setting. We must stress that the SNALP is a rare and unique offering. If the state decides that they categorically do not meet the requirements of the federal rule, the only option left for this population will be nursing home care—which is counter to the objectives of the rule.

As a policy matter—and with the hope that the state will ultimately better fund and streamline a model to serve Medicaid eligible people with specialized needs due to dementia, we must officially object to the assertion that such a model could not be compliant with the federal rule. Further, as described below, federal guidance issued in 2016 contradicts the assertion in the STP.

CMS guidance dated Dec. 15, 2016, available [here](#), points to training, person centered care and a holistic assessment to understand one's wandering and exit seeking behaviors. Q2 specifically addresses the delayed egress issue:

“Q2: Can provider-controlled settings with Memory Care Units with controlled-egress comply with the new Medicaid HCBS settings rule? If so, what are the requirements for such settings?”

A2: Yes, but only if controlled-egress is addressed as a modification of the rules defining home and community-based settings, with the state ensuring that the provider complies with the requirements of 42 C.F.R. 441.301(c)(4)(F), 441.530(a)(vi)(F) and 441.710(a)(vi)(F). Any setting using controlled-egress should assess an individual that exhibits wandering (and the underlying conditions, diseases or disorders) and document the individual's choices about and need for safety measures in his or her person-centered care plan.”

The document goes on to address how the provider can make individual determinations and accommodations through person centered planning. It indicates that home and community-based settings should not restrict a participant within a setting, unless such restriction is documented in the person-centered plan, all less restrictive interventions have been exhausted, and such restriction is reassessed over time.

Additionally, a CMS sponsored webinar conducted on July 27, 2016, *entitled HCBS Rule and Wandering and Exit-seeking* featured a subject matter expert, Doug Pace, Director, Alzheimer's and Dementia Care, Alzheimer's Association. Mr. Pace stressed a reasonable balance of safety and autonomy for safety of residents. He indicated that while “...some features of residential life, such as controlled egress, may place some limitations on personal freedom...however denying Medicaid HCBS funding on this basis would only mean that residents are forced into more restrictive institutional settings that generally do not have the same PCC requirements or orientation.” In response to questions on this point CMS indicated that delayed egress could be an acceptable approach to ensuring safety – under the condition that individuals that do not need that level of restriction are able to access the community, and the service plan for those individuals that need that level of restriction is appropriately documents. It was also indicated that using a key pad to exit a community would be acceptable access to the community if they are giving code to appropriate residents. In other words, residents who do not need delayed egress would have a mechanism to come and go freely, bypassing the delayed egress. CMS also stressed that the person-centered service plan be appropriately documented and updated to reflect these specific needs and abilities of residents.

Given the CMS guidance on this issue, it seems that there *is* a way in which a SNALP could be compliant with the federal rule, and the state should not simply close the door on that option. Rather, the state should work

with these providers to ensure the proper measures are taken, consistent with the aforementioned CMS guidance. Further, the state should work with stakeholders to determine how we can serve *more* Medicaid-eligible people with special needs due to dementia in assisted living settings.

b. Ensuring a Shared Understanding of the Rule

The STP highlights the training that has been conducted regarding the rule, which occurred several years ago. There has been significant turnover in the field over the past two years, so we urge the Department to consider reissuing the training to the ACF/AL provider community. With the state now proposing regulatory changes, this too provides an opportunity to ensure that providers and surveyors have a shared understanding of the regulatory changes. While our members embrace the person centered approach and support resident autonomy, they continue to be concerned about how the survey process will evolve to recognize this. Ensuring that all parties have a common understanding of the expectations will help ensure success and address any obstacles early on.

II. Managed Long Term Care (MLTC)

We are concerned that the STP and Person-Centered Service Planning process (PCSP) unfairly raise expectations concerning the ability and responsibility of MLTC plans to make available integrated and accessible housing. As noted in the STP, nearly all MLTC enrollees live in private homes with family or friends. And, according to the STP, "[t]he HCBS recipients' own home or the home of a family, friend, neighbor or relative are presumed to be compliant." The private homes occupied by MLTC enrollees provide varying levels privacy, physical accessibility and access to the community. Further, the beneficiary's choice of alternative living arrangements may be limited by a variety of factors, including income, the location of informal caregivers, and the availability of affordable housing in their community. The STP and the associated PCSP template and guidance require MLTC plans to assess the residence of each MLTC enrollee for privacy, physical accessibility, and access to the community, among other features.

While we agree that accessible housing, fully-integrated with the community, and offering the desired level of privacy is important to the quality of life of MLTC enrollees, the PCSP process should not create the unrealistic impression that MLTC plans have the responsibility or resources to locate and pay for alternative housing for their enrollees. It must be acknowledged that Medicaid does not pay for housing. If the resident's home environment does not entirely comport with the standards set forth in the STP and PCSP guidance, and the resident would like to move to a more integrated home or a home with more privacy, the MLTC premium covers (and the contract requires) only the identification of this goal in the PCSP and the provision of care management services to refer the enrollee to organizations that can assist with obtaining alternative housing and to coordinate with the services of those organizations. The PCSP process should not unrealistically raise enrollee expectations about the role of the MLTC plans in housing; nor should MLTC plans that are unable to arrange for more desirable housing be deemed in violation of PCSP and care management requirements.

III. Social Adult Day Care (SADC)

The STP indicates Social Adult Day Care programs (SADCs) are coming into compliance with the Rule with the assistance of managed long term care plans. Their training, policy development and operational changes focus on full implementation of person-centered care and care planning, ensuring an individual's rights of privacy, dignity, respect and freedom from coercion and restraint, optimizing individual initiative, autonomy and independence in making life choice, supporting integration in and access to the greater community, and staff training to facilitate these requirements.

A few aspects of the Rule have been difficult to fully operationalize. SADCs were hit hard by the pandemic, and over one-third of programs continue to be closed due to staffing challenges. These challenges continue to be an issue for open programs as they strive to provide more frequent community and individual outings for SADC participants. Ensuring access to individual and group outings requires additional staff and additional transportation resources, all of which are at additional expense to the program operating at a limited Medicaid rate. Further, infection control due to rising rates of COVID, RSV, and flu in the community also hampers community integration as programs seek to ensure participants health and safety.

For SADC programs undergoing heightened scrutiny, LeadingAge New York urges the State to look to operationalizing person-centered service planning and community integration as the priorities which ensure their compliance with the Rule.

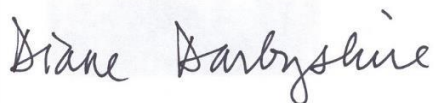
To note, SADC programs, in and of themselves, afford engagement in the broader community for their participants, who are both Medicaid and non-Medicaid individuals. A participant's time in the SADC program -often limited in duration to a few days a week-is sometimes the only opportunity for them to receive needed socialization and personal care. Given these unique factors, we urge the State and CMS to consider ways in which SADC programs might have a meaningful role in facilitating access to the community that are not solely conducted by the SADC program.

SADC programs are a critical option on the continuum of HCBS services. Significant health care workforce shortages will require many options other than home care to be available to older individuals and this setting is important to both SADC participants and their families and caregivers at home. The State must ensure SADC program compliance to stay viable and open in all geographic areas of the state so that individuals can choose this HCBS option.

Conclusion

Again, LeadingAge NY appreciates the opportunity to comment on the STP, and we look forward to continued work with DOH on this endeavor. Do not hesitate to reach out with any questions.

Sincerely,



Diane Darbyshire, LCSW
Vice President for Advocacy and Public Policy