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Dear Ms. Harris and Mr. Lollar,

Thank you and your colleagues for your continued efforts to implement the HCBS settings rule. As you know, Justice in Aging works to protect the interests of low-income older Americans, focusing particularly on those who need assistance to remain living in the community. Consumer Voice is a national voice representing consumers in issues related to long-term care, and works to empower consumers to advocate for themselves. We write to express our strong support for the HCBS settings regulations, and to share our perspective on how those regulations can best be implemented for older persons who receive HCBS in day services centers.

We strongly support the requirement that states offer multiple settings, including individualized services provided at the home and in the community, as part of their HCBS programs. This letter, however, focuses on our recommendations for services provided through a day services center model for older adults.

As we discuss below, we support the adult day services model as one option for day services, but recognize that many programs have deficiencies in how they operate, including the unnecessary isolation of program participants. The HCBS regulations offer an opportunity to address these deficiencies, and we encourage CMS to decrease isolation by implementing the regulations in a rigorous way.

We also recognize that program participants, like all persons, value autonomy and choice, and we believe that these values should be taken into account in evaluating integration within the community. Program participants should have realistic opportunities to participate in activities outside of the center, and the extent of that participation should be based on the participant's preferences and choices.

Day Services Programs: Strengths and Weaknesses

Our recommendations are, of course, informed by our understanding of how day services centers currently operate. As we have experienced with our families, friends and clients, day services centers play an invaluable role in the aging services network. For many older persons, the availability of a day center is the difference between living at home, and moving into a nursing facility. The day center provides participants with access to both peers and service providers; without the center, they often would have little access to either.

That being said, we also see deficiencies in how many day centers currently operate. In too many programs, participants are limited almost exclusively to the particular center. They travel from home to

the day center and back again, with no realistic opportunity to experience other aspects of the community. Within the center, they have little choice of activities, and may have minimal ability even to choose where to go in the center at any one time.

Recommendations

Integration with the Community

As you know, the settings regulations require that the setting support “full access of individuals receiving Medicaid HCBS to the greater community.” This access must include “opportunities to ... engage in community life ... and receive services in the community, to the same degree of access as individuals not receiving Medicaid HCBS.”¹

Under these integration requirements, day center participants should not be limited to the day center and the grounds. The day center should facilitate participants’ ability to access the greater community, based on participants’ interests and preferences. This facilitation should include individual and group activities, and transportation, supervision, and other supports as necessary.

Access to the community must be real and not just theoretical. Thus, a center would not satisfy this requirement by providing participants with a list of community activities and a bus schedule. By definition, persons receiving HCBS coverage require assistance with certain activities of daily living, and many will benefit from transportation that is provided specifically for them and fellow participants. To facilitate integration with the community, programs must be willing and able to provide needed supports. The service planning process should be used to determine a participant’s preferences and the needed supports.

Currently, in many day centers, community access is facilitated mostly through visits to the center by community members —musicians, for example, or children’s groups. We recognize the value of these visits, but emphasize that they do not substitute for true community access. Regardless of frequency, visits to a center cannot give participants access to the community. Such access must include the opportunity to get out and into the community, and cannot be replaced solely by in-center activities.

Implementation of community access should honor a participant’s autonomy and choice. The regulations refer to “opportunities” to access the community, and an opportunity is not an obligation. Program participants will vary in their interests and desire to access community activities, and those individual factors should be recognized and honored in each individual service plan. Some participants will be eager to visit shopping centers on a regular basis, attend movies and concerts periodically, or value an occasional picnic in a park. At the same time there may be individuals who prefer to remain at the center and participate in individualized activities there.

In preparing these recommendations, we have considered the prevalence of dementia in day programs for older adults. We recommend that dementia be factored into the service planning process, but it cannot be a disqualifier for community access. Although a person with dementia may be less likely to want multiple community activities, he or she has a right to and could benefit from opportunities for community engagement.

¹ 42 C.F.R. § 441.301(c)(4)(i).

Put another way, a dementia diagnosis does not mean that the person's life should be restricted to just her home and the day center. For persons with dementia, just as much as anyone else, it would be dispiriting and inappropriate to live a life almost entirely within a few thousand walled-in square feet.

Choice

The regulations require that an HCBS setting be selected by the person from among options that include non-disability specific settings. The settings options must be identified in the service plan, and be based on the person's needs and preferences.² We note that a state has related obligations to encourage and facilitate services provided in non-disability specific settings, as a person's choice will be meaningful only if the requisite options exist. The state's transition plan should explain what the state will do to ensure that HCBS are reasonably available in non-disability specific settings.

In the context of non-residential services, Medicaid-funded HCBS must include both home-based services and day center services (and each must offer access to the community). Also, the HCBS system must offer a sufficient number of day centers in each region in a state, so that a person has a meaningful choice among centers, including those that are located in non-disability specific community locations, such as community centers or senior centers.

In another facet of choice, a state's HCBS services should be coordinated so that a person has the ability to mix service options. For example, an HCBS recipient should not necessarily have to choose between day center services and home-based services: a good service plan might well provide for day center services on Monday, Wednesday and Friday, and home-based services on Tuesday and Thursday. Further, participating in day center services should not be a requirement or expectation of a particular assisted living facility or other residential setting.

Regarding non-disability specific settings, the state should encourage providers to locate day centers within settings that provide services to non-disabled persons. Examples of such an arrangement would be a day center within or adjacent to a senior center, community center, or church. A state's plans to facilitate such programs should be set forth in the state's transition plan.

Finally, day services programs must offer a meaningful choice of services. Programs should provide streamlined access to supportive services in a frequency and quality to meet participants' needs. These services should address participants' individual needs and preferences, as chosen by each participant. A participant's choices can be exercised both through the service planning process, and through choices made by him or her in the course of a day or week.

Privacy, Dignity and Respect

Under the regulations, a setting must ensure a participant's rights of privacy, dignity, and respect.³ Thus, private information should be discussed privately with the participant, out of earshot of other participants and service providers. Likewise, private information should not be visibly posted within a center.

² 42 C.F.R. § 441.301(c)(4)(ii).

³ 42 C.F.R. § 441.301(c)(4)(iii).

Dignity and respect must include recognition of needs and preferences that are specific to individuals or to identifiable groups of individuals. Services must be provided in a culturally competent way, with options that meet the needs of diverse populations such as limited-English-proficient older adults.

Freedom from Coercion and Restraint

The federal regulations require that participants be free from coercion and restraint.⁴ Under this clear requirement, day centers should not use chemical or physical restraints. CMS has recognized the inappropriateness of restraints in institutional settings,⁵ and certainly should not condone their use in HCBS settings, particularly given the unambiguous language of the HCBS settings regulations.

Consistent with a no-restraints policy, a center should not restrict a participant to a single room or area within a center. Such a limitation would be overly institutional and with no legitimate logistical justification.

As discussed above, we recognize the high percentage of individuals with dementia in adult day centers, and believe that centers should have authority to prevent a participant from leaving the center, but only under limited circumstances. This authority should be tightly defined, and should not be justified solely by a diagnosis of a dementia. A balance must be struck — a center should be able to restrict a participant with limited capacity who otherwise might wander off to likely injury, but this authority must be limited only to those participants whose significantly limited mental capacity prevents them from travelling independently, as determined through the service planning process. Any limitations on a participants' ability to leave a center must be based on a specific assessed need and set forth in an individual, person-centered service plan. Any such limitations on a participant's ability to leave a setting must be justified under the same process used under the HCBS regulations to allow modification of the requirements applicable to provider-owned or controlled residential settings.⁶

Furthermore, limitations on leaving should be implemented in a non-institutional manner. As much as possible, centers should rely on staff monitoring and redirecting of individuals, rather than on (for example) a blaring alarm. If an electronic system is used, it should be unobtrusive to other participants and visitors.

Most importantly, service provision for persons with dementia should not focus exclusively on preventing some participants from leaving the setting. Day center staff must be trained in dementia and dementia care, and understand the best ways to speak and interact with persons who have dementia. Good dementia care relies on extensive knowledge of a participant's needs, routines and preferences, likes/dislikes, stressors, and measures that bring comfort; personal relationships fostered by consistent

⁴ 42 C.F.R. § 441.301(c)(4)(iii).

⁵ See, e.g., CMS National Partnership to Improve Dementia Care in Nursing Homes (initiative to reduce use of antipsychotic medications in nursing facilities); CMS Surveyor's Guideline to 42 C.F.R. §483.13(a), Appendix PP to CMS State Operations Manual. The guidelines state: "Falls do not ... warrant[] the use of a physical restraint. Although restraints have been traditionally used as a falls prevention approach, they have major, serious drawbacks and can contribute to serious injuries. There is no evidence that the use of physical restraints, including but not limited to side rails, will prevent or reduce falls. Additionally, falls that occur while a person is physically restrained often result in more severe injuries (e.g., strangulation, entrapment)."

⁶ 42 C.F.R. § 441.301(c)(4)(vi)(F).

assignment; and activities (such as music) that engage participants. A setting should be staffed at a level that allows for the individualized attention that participants with dementia require.

In many cases, the fact that a participant has dementia may require that a particular activity be modified rather than abandoned. For example, a participant's inability to walk unsupervised does not mean that he or she must be restricted to the center. Instead, the participant should receive the supervision necessary to allow him or her to walk around the block, or to attend some particular activity identified in the service plan.

Optimizing Autonomy and Independence in Making Choices

Under the HCBS regulations, a setting must optimize, but not regiment, a participant's individual initiative, autonomy and independence in making choices. These choices include daily activities and with whom to interact.⁷

For these rights to be effectuated, participants must have meaningful choices of activities and with whom they wish to interact. The participant must make those choices himself or herself, unless lacking capacity to make the particular decision. To facilitate choices, the center should support the participant in expressing preferences and making as many decisions as possible. If a participant lacks capacity to make decisions, the center should work with family and those who know the participant well to make decisions consistent with the participant's demonstrated preferences.

Adult day center activities must include options for both group activities and individual activities — each have their benefits and limitations — and those activities should take the participants' interests and preferences into account. Through the service planning process and otherwise, the center should take all necessary steps to identify each participant's interests and preferences, and to facilitate activities consistent with such interests and preferences. To the extent reasonable, a center must provide all necessary supports to enable each participant to participate meaningfully in the activities of his or her choice.

Choice Regarding Services and Supports, and Who Provides Them

The HCBS regulations also require that a setting facilitate choice regarding services and supports, and who provides them.⁸ As discussed above, the service planning process is essential in determining appropriate services and supports. The planning process should be led by the participant whenever possible, and he or she must be provided with all necessary information and support.⁹ Through this planning process, the center should take all necessary steps to identify each participant's interests and preferences, and to facilitate activities consistent with such interests and preferences.

To be useful, service plans should always be up-to-date. Centers on a regular basis should support participants in updating service plans and modifying preferences.

Staffing

⁷ 42 C.F.R. § 441.301(c)(4)(iv).

⁸ 42 C.F.R. § 441.301(c)(4)(v).

⁹ 42 C.F.R. § 441.301(c)(1)(ii).

The HCBS regulations have raised the bar for HCBS services. Proper implementation will require providers to increase the level of supports provided, and the individualization of services. Each of these will likely require increased staffing levels.

States and CMS must require adequate staffing; without realistic staffing levels, a center will be unable to provide the individualized care envisioned by the HCBS regulations, including but not limited to the ability to provide supports for participants' community activities.

In accord, states and CMS must set provider reimbursement rates at an adequate level. The HCBS regulations envision a system in which services often are not provided on a group basis, and in which participants are able to pursue individual activities with facility-provided supports. As CMS pursues the worthy goal of individualized services, it must take steps to ensure that reimbursement levels are sufficient to support the required level of service.

Again, we appreciate the sustained efforts of everyone at the Centers for Medicare & Medicaid Services and the Administration for Community Living to ensure that older adults and persons with disabilities can receive high quality, person-centered home and community based services with full access to the greater community. If you have any questions, please do not hesitate to contact us. At Justice in Aging, Jennifer Goldberg can be reached at jgoldberg@justiceinaging.org, and at Consumer Voice, Robyn Grant can be reached at rgrant@theconsumervoice.org.

Sincerely yours,

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