Applying the New Federal HCBS Rules to Adult Day Centers: What You Can Do

Background on New HCBS Rules

States currently are revising their Medicaid programs to comply with new federal regulations on home and community-based services (HCBS). These regulations require that HCBS be provided in settings that truly are non-institutional – for example, that program beneficiaries not be segregated from the greater community, and have choice in where they live and how services are provided.

All states must come into compliance by March 2019. Currently, most states are developing transition plans that describe how the state will move into compliance. A state's transition plan must be approved by the federal government. States can only submit plans to the federal government after the state has solicited and considered comments from in-state stakeholders.

Older Americans have much at stake. One important issue is how the new regulations will affect adult day centers. What should "access to the community" and "choice" mean for persons receiving adult day services?

Recommendations for Adult Day Centers

Justice in Aging and the National Consumer Voice for Quality Long-Term Care (Consumer Voice) recently provided the federal government with recommendations on how the HCBS regulations should be applied to adult day centers for older adults. Those recommendations are <u>available here</u>.

We encourage you as a consumer, family member, caregiver or advocate to give these issues some thought, and to advocate for the best options in your state. Let your state Medicaid program know how you want the HCBS regulations to be applied to adult day centers. The federal government will set some standards, but also will leave many decisions to individual states. States will set differing policies for their adult day centers, which makes it all the more important that state Medicaid programs hear now from consumers and their representatives.

To help you think about these issues, Justice in Aging and Consumer Voice offer the guidance below, which is adapted from the recommendations we submitted to the federal government. We encourage all interested persons to think through and talk about the most important issues for your community, and then to make recommendations to your state Medicaid program.

To find out more about your state's process, go to <u>www.HCBSAdvocacy.org</u> and click on your state on the map. To reach your state Medicaid program, go to <u>www.medicaid.gov/about-us/contact-us/contact-us.</u> <u>html</u> and enter your state where it says, "Contact your State Medicaid Agency."

Community Access

The regulations require that a day center must support "full access" by program participants to the greater community.

Recommendations:

- The new HCBS regulations can lead to improvement in adult day services. The adult day services model is an important option for older Americans, but some programs have deficiencies in how they operate, including the unnecessary isolation of program participants. The HCBS regulations offer an opportunity to address these deficiencies.
- **Program participants should have realistic opportunities to participate in activities outside of the center**. The extent of that participation should be based on the person's preferences and choices.
- The day center should facilitate participants' ability to access the greater community. This facilitation should include individual and group activities, and transportation, supervision, personal assistance, and other supports as necessary. Access to the community must be real and not just theoretical. For example, a center would not satisfy this requirement by providing participants with a list of community activities and a bus schedule.
- Visits to the center by others are not sufficient. In many day centers, community access currently is facilitated mostly through visits to the center by community members —musicians, for example, or children's groups. These visits are valuable, but they do not substitute for true community access.
- **Implementation of community access should honor a participant's autonomy and choice**. 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 travel outside the center; others may prefer to remain at the center and participate in individualized activities.
- A participant's dementia or other cognitive limitation should be taken into account, but should not be an automatic disqualifier. 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. 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 a day center must facilitate choices regarding services and who provides them. The center also must optimize a participant's autonomy and independence in making choices about daily activities and with whom to interact.

Recommendations:

• For non-residential services, Medicaid programs should include home-based services, integrated day programs, and day center services. Each of these service types must facilitate access to the community.

- A Medicaid program should offer a sufficient number of day centers in each region in a state.
- State Medicaid programs 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 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.
- **Day centers must offer a meaningful choice of services**. Both group activities and individual activities should be made available. The center should take participants' interests and preferences into account, and must provide the supports necessary for each participant to engage meaningfully in the activities of his or her choice.
- A participant should be able to make choices through the service planning process, and through routine decisions made during the course of a day or week.
- As required by federal service planning regulations, the service planning process should be led by the program participant whenever possible. The day center must provide the participant with necessary information and support.
- Centers should support participants in regularly updating service plans and modifying preferences.

Privacy, Dignity & Respect

The regulations require that a day center must ensure a participant's rights of privacy, dignity, and respect.

Recommendations:

- Private information should be discussed privately with the participant, out of earshot of other participants and service providers.
- Private information should not be visibly posted within a center.
- To support participants' dignity, services must be provided in a culturally competent way. Centers must provide options that meet the needs of diverse populations such as limited-English-proficient older adults.

Dementia Care, and Freedom from Coercion and Restraint

The regulations require that participants must be free from coercion and restraint.

Recommendations:

• When caring for program participants with dementia, centers should look for ways to modify an activity, rather than assuming too quickly that the activity is impossible for the participant.

- Service provision for persons with dementia should not focus exclusively or excessively 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. A center should be staffed at a level that allows for the individualized attention that participants with dementia require.
- Day centers should not physically restrain residents, or use chemical restraints such as antipsychotic medications. The federal government has recognized the inappropriateness of physical and chemical restraints in institutional settings such as nursing facilities, so such restraints certainly should not be used in non-institutional settings such as adult day centers.
- A center should not restrict a participant to a single room or area within a center. Such a limitation would be overly institutional and have no legitimate logistical justification.
- Given the prevalence of dementia among program participants, 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 dementia diagnosis. Restrictions should not be applied across the board to all participants and must be based on a specific assessed need and set forth in an individual, person-centered service plan.

Any limitations on leaving the center 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, who should retain freedom of movement.

Staffing

To fully implement the HCBS regulations, a center's staffing levels must be adequate to provide individualized attention.

Recommendations:

- State Medicaid programs must require adequate staffing levels.
- State Medicaid programs must set provider reimbursement rates at a level that is adequate to support required staffing levels, and that recognize a center's obligation to facilitate and support participants in going into the community.

Where can I find more information?

Both Justice in Aging and the National Consumer Voice for Quality Long-Term Care have more information for advocates who want to be involved as states make policy changes. We are creating a series of Advocacy Guides on different parts of the rule. Justice in Aging has published a guide to the rule and a guide to transition plans. Also, you can learn more from HCBSAdvocacy.org, a website designed specifically for advocates for persons with disabilities and older adults. This site has a toolkit for advocates who want to work on the rule. The federal government has posted information on the rule —including state-specific information on states' current processes—on the HCBS page of Medicaid.gov.