AUTISTIC SELF ADVOCACY NETWORK

POLICY BRIEF • SEPTEMBER 2014

# **Defining Community:** Implementing the new Medicaid Home and Community-Based Services rule

***Samantha Crane,*** *Autistic Self Advocacy Network*

## Introduction

In January 2014, the Centers for Medicare and Medicaid Services (CMS) issued a new rule defining the kinds of services that qualify for funding through Medicaid home and community-based services (HCBS) programs.[1]

The new rule seeks to improve quality of life for people with disabilities by ensuring that HCBS funding is used only for services in settings that are truly integrated, as opposed to those that replicate institutional environments in all but name. It focuses not only on the settings' physical placement within the community but also on the day-to-day experiences of residents, including the extent to which they can exercise autonomy, enjoy privacy, and pursue opportunities to work and socialize with the larger community. It also imposes specific rules on HCBS in provider-owned residential settings, including a list of personal and tenancy-related rights that providers in these settings must respect.

*The new rule seeks to improve quality of life for people with disabilities by ensuring that HCBS funding is used only for services that are truly integrated.*

States have up to five years, beginning in March 2014, to bring their existing HCBS programs into compliance with the new rule.[2] States with existing HCBS programs must submit transition plans detailing their plans for coming into compliance. These transition plans must be submitted by March 17, 2015, or when a state seeks to renew or amend its HCBS program, whichever comes earlier.[3]

CMS has advised states to approach the transition planning process in two steps: first, they must conduct an assessment of their current level of compliance with the new rule—including the consistency between the new rule and their own standards, regulations, and oversight process—and submit their findings to CMS.[4] In the likely scenario that the new rule differs in some way from the state's pre-existing standards for HCBS providers, states must submit a plan to CMS detailing the specific actions it will take to come into compliance. States may also conduct reviews of specific providers to determine whether any existing providers are already, in practice, complying with the new rule despite the absence of similar state requirements.

Several states have already submitted transition plans to CMS.[5] Because these transition plans were submitted only a few months after CMS issued its new rule, however, many of these plans are essentially "plans to plan" that have not yet identified which of its settings are out of compliance with the new rule. Instead, these plans are focused on developing a process to identify and remedy noncompliant settings. These "plans to plan" require states to submit updated, comprehensive transition plans after the

completion of this process.[6]

It is important that state administrators and advocates have a detailed, comprehensive understanding of how the new rule is likely to apply to different kinds of settings, even at the earliest stages of the transition planning process. Without such an understanding, states risk submitting incorrect or incomplete evaluations of their existing regulations and providers, leading to delays in the transition process. These delays can, in turn, result in states having insufficient time to implement smooth, cost-effective changes in service delivery to comply with the new rule.

This Guide for Administrators and Advocates provides guidance to professionals and advocates responsible for developing, implementing, and overseeing state transition plans. The Guide includes an overview of the new rule, discussion of how the new rule is likely to apply to certain kinds of settings, and suggested provisions to be included in states' transition plans. For additional information on the transition planning process in general, states may wish to consult CMS' recently-issued toolkit for alignment with the new rule.[7]

## History of HCBS

Since 1983, state Medicaid programs have had the option of offering home and community-based services as an alternative to institutional care for targeted groups of individuals with disabilities. These services typically include case management; homemaker services such as house-cleaning, meal preparation, and laundry; home health and personal care services; adult day health services; habilitation (both day and residential); and respite care. States can also provide other services, such as transportation and decision-making support services, as necessary to help people live in the community.

In 1999, the Supreme Court issued a landmark decision[8] finding that segregation of people with disabilities constituted discrimination under the Americans with Disabilities Act. The court's holding in that case, *Olmstead v. L.C.*, requires states that provide services to people with disabilities – including support with daily living – to provide these supports in the most integrated environment appropriate to their needs. Because many of these supports can be funded through HCBS waivers and state plan amendments, states have relied heavily on such programs in order to fulfill their obligations under *Olmstead*.

Activism by people with disabilities, the *Olmstead* decision, and availability of federal funding for Medicaid HCBS have enabled thousands of individuals with disabilities to move from congregate care facilities into home- and community-based settings over the past several decades.[9] This trend has increased quality of life for people with disabilities. Compared with those who live in larger congregate settings or institutions, people with disabilities who live in small, community-based settings have more friends, more opportunities to make choices about their lives, more opportunities to develop and maintain skills, and higher satisfaction with their living arrangements.[10]

Unfortunately, the Supreme Court's decision in Olmstead has not been fully implemented across the country. Although the United States Senate Health, Education, Labor, and Pensions Committee has found that "virtually all people with disabilities can live in their own apartment or house with adequate supports" and that "for virtually all people with disabilities, the most appropriate integrated setting is their own home," hundreds of thousands of people with disabilities under age 65 remain in nursing

*In 1999, the Supreme Court issued a landmark decision finding that segregation of people with disabilities constituted discrimination under the Americans with Disabilities Act.*

homes and institutions and many people with disabilities live in settings that, despite receiving funding through Medicaid HCBS programs, are nevertheless isolating in nature.[11]

The new rule defining HCBS is intended to promote integration of individuals with disabilities by ensuring that federal funding for Medicaid HCBS is provided in settings that are truly integrated. The new rule does not apply to long-term services and supports, such as nursing home placements, that do not receive Medicaid HCBS funding.

*Under the new rule, all HCBS must be delivered in settings that are truly integrated into the community.*

## Settings Requirements

The new rule defines home and community-based services largely in terms of the settings in which they are provided. These settings requirements apply equally to HCBS programs operated as waivers under § 1915(c) of the Social Security Act and HCBS provided as part of the State Plan under § 1915(i) or (k). This means that, if a state Medicaid program provides HCBS coverage through both a state plan and a 1915(c) waiver, it need only develop one compliance standard under which to evaluate both programs.

### In General

Under the new rule, all HCBS must be delivered in settings that are truly integrated into the community. Individuals must have "full access" to the greater community, including opportunities to seek competitive integrated employment, "engage in community life," control their own money and other resources, and receive services in the community.[12]

#### *1. Integration into the Community.*

The rule requires that individuals receiving HCBS have access to the greater community "to the same degree" as individuals who are not receiving HCBS. A setting that supports only occasional or scheduled forays into the greater community will not meet this standard, as this level of access is markedly lower than the degree to which individuals not receiving HCBS are able to access the community. On the other hand, rural or suburban settings may be considered community-based, even if they are distant from many public accommodations and community gathering places, so long as they enable individuals receiving HCBS to access the community to the same degree as their nondisabled neighbors.

According to the new rule, access to the community must include opportunities, to the same degree as individuals not receiving HCBS, to:

- Seek competitive integrated employment;[13]
- "Engage in community life";
- Control their own personal resources; and
- Receive services in the community.[14]

The rule does not contain exceptions for individuals with significant support needs, who may be presumed to be unable to work, control their own resources, or engage in community life. To ensure that such individuals have more than merely theoretical opportunities to access the broader community, the rule requires that the setting not only permit, but also "support" full access to the community. A facility that allows residents to leave at any time may not meet this standard unless individuals have access to trans-

portation and support with navigating the community.[15] Similarly, a setting will not be considered to "support" access to opportunities for competitive integrated employment if service recipients do not have access to transportation or supported employment services. Individuals may also need support, in the form of supported decision-making services or financial coaching, in order to control their personal resources.[16]

*A setting will not be considered to "support" access to opportunities for competitive integrated employment if service recipients do not have access to transportation or supported employment services.*

***2. Individual Choice.***

The new rule also requires that the individual be offered a choice of settings that includes non-disability specific settings and the option for a private unit. The options that the individual considered must be identified and documented in a person-centered service plan.

The options must also be "based on the individual's needs, preferences, and, for residential settings, resources available for room and board."[17] This requirement makes clear that merely listing options that are not based on an individual's needs, preferences, or resources would be insufficient to meet this standard. An individual cannot be said to have had the option of receiving services in a non-disability specific setting if that setting is unaffordable or in a location that is not consistent with the individual's needs or preferences.

It is also important to note that this requirement is in addition to all other requirements, including the integration requirement. A setting that is isolated and/or does not offer full access to the community cannot be considered "home and community-based" simply because the individual had the option of living in a non-disability specific setting. [18]

***3. Individual Rights.***

The setting must ensure individuals' rights to "privacy, dignity and respect, and freedom from coercion and restraint."[19] This component of the new rule is consistent with the input of self-advocates, who identified the absence of privacy and the use of coercion and restraint as a major factor determining whether a setting was "institutional" or community-based.[20] In residential settings, the right to privacy and dignity include the right to lock one's own bedroom or bathroom door, and the right to choose a private room or select a roommate.[21] Other standards, such as the integration, autonomy, and choice requirements, may also implicate individuals' rights to privacy, dignity, and respect.

***4. Optimizing Autonomy***

The setting must be one that "optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices." These choices may include "daily activities, physical environment, and with whom to interact."[22]

The rule's prohibition on "regimenting" individual choices should be understood as a caution against attempting to promote "choice" simply by requiring individuals to choose options from a predetermined list. Individuals should also not be required to adhere to rigid daily schedules if this is inconsistent with their priorities and preferences, even if they had some opportunity to set those schedules. Service users should have the opportunity – and the support they need – to fill their free time with activities of their own choosing, even if those activities were not included in a predetermined "menu" of options.

The prohibition on "regimenting" individuals' lives also applies to settings in which ser-

vice recipients' activities are tightly controlled by staff. This phenomenon is especially characteristic of large settings in which multiple people with disabilities receiving services are living; providers in these settings may experience incentives to impose stringent rules or routines for administrative convenience or to prevent conflicts among multiple service recipients.[23]

Individuals with disabilities within a setting should not generally be subject to rules or standards of behavior that are different or more restrictive than those applicable to nondisabled people in similar settings. For example, while it would not generally be appropriate to dictate to service recipients where they can go or what they should be doing at any given time during the day, a personal care aide may help ensure that an HCBS recipient arrives on time for important appointments and takes medications on time, and a job coach may redirect an HCBS recipient away from distractions while on the job.

*Individuals with disabilities within a setting should not generally be subject to rules or standards of behavior that are different or more restrictive than those applicable to nondisabled people in similar settings.*

Individuals must also have choice regarding with whom to interact. HCBS recipients must remain free to pursue relationships—including romantic relationships—with others in the community and/or with each other.[24] In residential settings, HCBS recipients must be allowed to have visitors, including overnight.[25] Supports for day activities must include supports for visiting friends, relatives, or significant others; these visits may also include overnight stays.

In order to give full meaning to the right to interact with others, individuals receiving HCBS services must have access to a full range of communication mediums, including a telephone, a computer, the internet, and, when necessary, an augmentative communication device. Individual rights to privacy, discussed above, will apply to individuals' communication with others and ability to access information through technology. Individuals with disabilities may need digital literacy training and supports in order to access these forms of communication. Measures to ensure safety, such as restrictions on access to certain internet sites, should be based on individualized needs assessments and developed with the participation and consent of the individual and his or her chosen supporters.

Some individuals may need support in order to exercise maximum autonomy. In such cases, support must be value-neutral and respectful of individuals' autonomy and right to take reasonable risks.[27] Support may take the form of assistance in understanding information and options or assistance with component tasks such as navigation to desired locations or assistance using the kitchen. HCBS recipients may also need communication supports, such as alternative or augmentative communication (AAC) in order to express their interests and preferences.

***5. Choice Regarding Services and Providers.***

Settings must "facilitate[e] individual choice regarding services and supports, and who provides them."[28] In general, HCBS recipients should not be required to accept unnecessary or unwanted services as a condition of being in a particular setting.

The person-centered planning process, discussed in further detail below, may serve an important role in implementing and enforcing individuals' right to choice. This process requires that HCBS recipients are offered a choice of services and providers that is consistent with their needs, preferences, and priorities. The process also imposes conflict-of-interest restrictions on service providers involved in the planning process in order to ensure that providers of planning services do not pressure HCBS recipients

to accept other services from the same provider.

Nevertheless, mere compliance with a planning process will not be sufficient to meet this standard unless the HCBS recipient is offered a meaningful choice of services and providers.[29]

## Implications for Transition Planning

- The preliminary transition plan should include a detailed comparison between existing state standards and the new rule.[30] States should not, however, assume that similarly worded standards in its own regulation are identical in effect to the new rule. For example, existing state regulations may include aspirational statements that individuals should have enjoy autonomy and access to the community, but these statements will not be sufficient to establish compliance with the general provisions of new rule unless they (1) encompass at least the same specific requirements discussed in the new rule (such as the requirement that individuals enjoy the same degree of access to the community as individuals not receiving HCBS or that integration be understood to include access to competitive integrated employment), and (2) are directly enforced.
- The transition plan should include a process for evaluating compliance among existing providers and any potential barriers to bringing providers into compliance. This process should not focus solely on self-reported compliance or analysis of providers' written policies, but should also include site-specific evaluations by neutral third parties and interviews with consumers receiving services and consumer advocacy and self-advocacy organizations.[31]
- Where possible, states should use data-driven methods to identify settings that are likely to isolate people with disabilities. The National Core Indicators (NCI) program—a collaboration between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Initiative—has published a comprehensive guide on how its data may be used to bring states into compliance with the new rule.[32] The Council on Quality and Leadership (CQL) has also published a resource for states on how its service recipient survey data can be used to determine compliance with the new rule.[33] Other sources of data may also be useful; Iowa's transition plan proposes use of Geographic Information System (GIS) data to identify potentially isolating settings.[34]
- Individuals receiving HCBS should not be required or encouraged to have a guardian or use a representative payee arrangement as a condition of accessing the setting. If an individual cannot meet his or her financial responsibilities to the provider without support – e.g., if the individual has a pattern of late or missed payments for room and/or board – the provider should explore arrangements such as automatic payments or financial coaching prior to suggesting a representative payee arrangement.
- Transportation must be included in the individual's person-centered service plan. In some situations, individuals may be able to use public transportation, walk, or drive their own vehicle. If not, the service plan should identify another reliable source of transportation services to and from the setting.
- HCBS providers should have in place effective policies to prevent use of practices that deprive individuals of their dignity and autonomy, such as the use of seclu-

*The preliminary transition plan should include a detailed comparison between existing state standards and the new rule.*

sion or restraints (including mechanical and chemical restraints). Agencies that regulate providers, such as licensing bodies or adult welfare services agencies, should establish a process for receiving and investigating complaints by services recipients. This process should include, but not be limited to, efforts to shield service recipients from retaliation or continued abuse, such as by assisting the individual in changing service providers or staff members. Other consumer rights oversight bodies that already exist in the state, such as human rights councils, ombudsmen for people with mental health and developmental disabilities, or developmental disability councils may also play a role in receiving, investigating, and addressing complaints.

- HCBS providers must abide by a set of standards intended to safeguard privacy, dignity, and respect, including but not limited to:
    - Compliance with HIPAA privacy standards, even if the provider is not a covered entity under HIPAA;[35]
    - Avoidance of visible branding or other markers on homes, vehicles, or activity groups or other visible markers that unnecessarily "mark" HCBS users as people with disabilities (especially as people with a particular disability);[36]
    - Robust standards to prohibit aversive behavioral interventions, seclusion, and restraint. The Keeping All Students Safe Act[37] and Minnesota's ban on seclusion and restraints[38] may serve as examples.
- The transition plan should include an effective system to conduct ongoing compliance enforcement, including both routine monitoring and investigation and resolution of individual complaints. This Guide includes a detailed discussion of the important elements of such an enforcement process on page 25.
- States should ensure that HCBS recipients have meaningful options through (1) a comprehensive analysis of available providers, their operational capacities, any restrictions that they place on eligibility to receive their services, and their regions of operations and (2) a robust person-centered planning process. States should ensure that services in non-disability-specific settings are available to all individuals, regardless of disability category or level of service need, throughout the state. States may identify specific regions or service types in which provider capacity needs to be increased.
- State transition plans should include plans to increase access to self-directed services, which allow service recipients and their chosen supporters to exercise control over hiring, firing, and supervising of direct services staff.[39]
- Direct service providers who are employed and supervised primarily by HCBS providers, rather than by the service recipients themselves, must receive training on the rights of individuals with disabilities, including rights to self-determination.[40] This training should specifically include training on helping people make informed decisions without restricting them to "pre-approved" lists of options.[41] The National Alliance for Direct Services Professionals (NADSP) is in the process of creating detailed training resources for professionals specifically aimed at ensuring compliance with the new rule.[42]

*HCBS providers must abide by a set of standards intended to safeguard privacy, dignity, and respect.*

## Presumptively excluded settings

Under the new rule, HCBS services cannot be provided on the grounds of a nursing facility, an institution for mental diseases (IMD), an intermediate care facility for individuals with intellectual disabilities (ICF), a hospital, or "any other locations that have qualities of an institutional setting."[43] Facilities that share the same buildings as, or are "directly adjacent" to the grounds of, such institutions are presumed to have the "qualities of an institutional setting," as are settings that "have the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS."[44]

*Under the new rule, HCBS services cannot be provided on the grounds of any "locations that have qualities of an institutional setting."*

CMS has issued detailed guidance explaining what it means for a setting to "have the effect of isolating individuals . . . from the broader community."[45] According to CMS, a site is particularly likely to have the effect of isolating people from the community if it either (1) was designed specifically for people with disabilities (or for people with a certain type of disability), or (2) is primarily populated by people with disabilities and staff members who provide services to them. As a result, the new rule not only presumptively prohibits use of HCBS funding for placements in institutional facilities, but also use of HCBS funding for services such as:

- Residential placements in "communities" or "villages" designed specifically for people with disabilities;
- Placement in a job setting that primarily employs people with disabilities and staff members who supervise and provide job coaching services to them;
- Center-based "adult day services," especially if located in a building that also houses a nursing home or hospital;
- Use of HCBS funding for placement in a residential school for children with disabilities or disability-related service needs;

According to CMS, these settings are particularly isolative if they are designed to provide multiple types of services (such as housing, medical care, and day activities) on-site to people with disabilities, if the people in the setting have limited interaction with the broader community and if staff at the settings use (or are authorized to use) interventions that are either characteristic of institutional settings or that have been discontinued in institutional settings (such as aversive interventions, seclusion and restraint). Size may also be an important factor; larger settings are more likely to isolate people with disabilities than smaller settings.[46] In nominally non-disability-specific settings, isolation of people with disabilities within the setting should also be considered.[47]

This guidance is not exhaustive, and state administrators should consider other ways in which a setting may isolate people from the broader community. For example, when it is clear from the address of a residential setting that it is a congregate setting for people with disabilities, residents may experience isolation or stigma when applying for jobs or participating in other activities that require them to provide their address.

### *Exceptions*

This rule is subject to limited exceptions. First, states can use HCBS funding to transition someone from an institutional setting into the community. For example, HCBS

funding could be used to pay a case manager to visit someone who is living in an IMD, to determine which services need to be in place in order for that person to move into the community.

Second, HCBS funding can be used to provide services during a temporary hospitalization, as long as the HCBS does not duplicate hospital services. For example, a person who is in the hospital following surgery may ask his or her case manager to come to the hospital in order to discuss potentially necessary post-surgery alterations to the service plan. This visit by the case manager can be funded through the HCBS program in which the individual is enrolled. On the other hand, HCBS funding may not be used to provide services such as changing bed linens or basic personal care, if the hospital also provides these services.

Finally, services in settings that are "presumed" not to be community-based—such as programs located adjacent to or in the same building as a nursing home, hospital, IMD, or ICF—may still receive HCBS funding if the Secretary of Health and Human Services decides that the setting "does not have the qualities of an institution and that the setting does have the qualities of home and community-based settings." Because the rule makes clear that integration into the community is a key feature of HCBS settings, merely making efforts to make these settings "home-like" and complying with CMS's requirements for provider-owned settings (discussed in further detail below) will not be enough to overcome the presumption that they are institutional in nature. Instead, the state will have to prove that the setting is truly integrated into the community. Examples could include:

- An individual chooses to live in an apartment building that is next door to a nursing home, where the individual's parents live. The majority of other tenants in the apartment building are people without disabilities, the building has no affiliation with the company that operates the nursing home, and the individual's HCBS service provider does not encourage or require recipients to live near the nursing home. HCBS funds can help provide independent living supports in the individual's home.
- In consultation with his or her job coach, an individual decides to volunteer at a local hospital. The individual may receive HCBS pre-vocational services funding in order to enable the job coach to accompany him or her on the volunteer placement.
- A child with a mobility impairment receives a scholarship to a private boarding school that does not specialize in serving children with disabilities, behavioral challenges, or other special educational needs. HCBS funds may be used to provide a personal care attendant to assist the child with daily activities while living in a dormitory alongside nondisabled peers.

Because these settings must be approved by the Secretary of HHS before states can use HCBS funding for placements, states should avoid infrastructural investments in settings near or in the same building as an institution until soliciting feedback from both the public and HHS. Moreover, such investments may be inadvisable even when they are not located near or on the grounds of an institution, as any structures built for the specific purpose of serving people with disabilities may be found not to be home and community-based settings.

*Services that are "presumed" not to be community-based may still receive HCBS funding if the Secretary of Health and Human Services decides that the setting "does not have the qualities of an institution"*

### *Implications for Transition Planning*

- HCBS funding will not be available for either residential or day placements in hospitals, nursing homes, adult homes,[51] ICFs, or IMDs.
- HCBS funding may be available to support transition out of institutional or other non-community-based settings. Services may include case management and counseling for the purpose of identifying alternate setting options that meet the individual's needs and priorities, financial planning, initial meetings with prospective care providers to ensure familiarity with the individual's needs upon transitioning out of the institution, and assistance with moving.
- Individuals who receive HCBS services may continue to receive these services through the HCBS program during temporary hospitalizations, provided that the hospital does not provide the same service. The state will consider the availability of hospital staff trained in meeting the individual's specific needs and able to communicate effectively with the individual before determining that the proposed service is duplicative of a hospital service.
- Services in settings adjacent to or sharing the same building or grounds as a nursing home, hospital, nursing home, adult home, ICF, or IMD will be presumed ineligible for HCBS funding unless non-disabled members of the community also routinely use the setting for the same purposes for which the individual with a disability is using the setting. Examples may include:
    - Living in scattered-site, non-disability-specific apartment buildings, or visiting non-disability-specific community attractions, located next door to an institution;
    - Volunteer or job placements in a hospital or nursing home that are consistent with the individual's interests and career goals and with the integration requirements generally applicable to non-residential services;
    - Routine doctor's visits, birthing classes, or visits to hospitalized friends or family;
    - Using services that a community hospital offers to the public at large, such as health and fitness classes; or
    - Attending a church fellowship that uses donated hospital space.
- If states propose to continue funding HCBS services by a provider that is located in one of the presumptively excluded settings, it must identify that provider in the transition plan and explain the basis for its belief that the provider qualifies for an exception. Providing evidence of site visits may be helpful.[52] Exceptions should not be granted based merely on the supposition that the settings are "home-like." Moreover, as noted above, exceptions should not be based on the finding that individuals chose the setting over other options. Although the new rule encourages individual choice, it does not permit states to use HCBS program funding for institutional placements merely because individuals had other options; these placements, if desired, must be funded through other programs. For example, a collection of single-family buildings on the grounds of an institution or closed institution will be presumed to be isolating and institutional in nature despite any architectural resemblance to single-family homes in the community. States that previously relied on this form of housing should make plans to replace it with

*HCBS funding may be available to support transition out of institutional or other non-community-based settings.*

single-family housing scattered throughout the community.

## Special Considerations for Residential Settings

The new rule's general requirements for home and community-based settings apply equally to residential and non-residential settings. The new rule, also, however, includes provisions addressing the special case of provider-owned residential settings. These provisions include numerous additional, specific requirements for HCBS provided in such settings. This special attention to provider-owned residential settings reflects the special risks that these settings pose to individual choice, autonomy, and integration into the community.

### *Taking into account self-advocate perspectives.*

In September 2010, the Autistic Self Advocacy Network (ASAN), Self-Advocates Becoming Empowered (SABE), and the National Youth Leadership Network (NYLN) asked 72 individuals with developmental disabilities attending a self-advocacy conference which features made a residential truly "integrated" into the community. Participants' responses focused on five key "dimensions":

- Physical size and structure;
- Respect for individual rights and self-determination;
- Qualities and attitudes of providers;
- Access to community life; and
- Meeting individuals' support and access needs.[53]

Consistent with the presumptions set forth in the new rule, participants overwhelmingly responded that "gated communities, farmsteads, and clusters of group homes," as well as other settings housing multiple unrelated individuals with disabilities who have not specifically chosen to live together, are not community-based settings. Participants noted that these settings typically deprive residents of opportunities to participate in community life and interact with nondisabled individuals who are not staff members.[54]

Participants expressed particular concern about arrangements in which the service provider and the housing provider were the same, especially when the residential service provider also acted as the provider of day services.[55] These settings are highly likely to be congregate and, due to the provider's dual role as service provider and landlord, there is a heightened risk that individuals living in these settings will face restrictions on their daily routine that are inconsistent with full integration into the community.

The new rule's requirements for provider-owned residential settings are largely parallel to the self-advocacy community's concerns. The framework set forth in *Keeping the Promise*, as well as the statements of self-advocates, is therefore a valuable tool for states hoping to understand how to apply the new rule to provider-owned settings.

### *States must offer scattered-site housing.*

Currently, individuals often receive HCBS in provider-owned residential settings. Under the new rule, however, HCBS recipients must be offered a realistic opportunity to receive HCBS in a non-disability specific setting, which by definition could not

*Other systems designed to support youth, including public schools and child welfare programs, should incorporate health care transition planning into their overall transition plans.*

be provider-owned.[56] State transition plans must include a realistic plan to expand their capacity to provide HCBS in non-provider owned settings, including in HCBS recipients' own homes or apartments. States should consider a broad array of options to accomplish this goal, including use of other streams of federal funding. Rental assistance programs, expansion of housing voucher availability targeted to people with disabilities, use of HUD affordable housing development funding to create accessible units in non-disability-specific projects, and other incentives can help expand access to scattered-site, non-provider owned housing for people with disabilities.[57]

*Scattered-site, supported housing is a proven alternative to provider-owned housing models.*

Scattered-site, supported housing is a proven alternative to provider-owned housing models. The scattered-site supported housing model allows individuals with disabilities to live in the community on the same terms as individuals without disabilities. Under this model, residential settings must be "embedded" in the community. Single-family residences must be located in a neighborhood where people without disabilities also live and must not be clustered together. Multi-family units must be in buildings that are populated primarily by people without disabilities. Although the scattered-site housing model does not preclude two or more individuals with disabilities from choosing to live together, any shared living arrangements must (1) be voluntary, and (2) take the form of private agreements among the cohabitants and the property owner—such as a shared lease or subletting arrangement—rather than an agreement between the individual cohabitants and the service provider.

Moreover, residences must not be linked to a specific service provider or level of services. Rather, the individual and his or her support team determine the type of services the individual will receive and who provides those services. Access to housing is not contingent on adherence to treatment, daily regimens, or lifestyle restrictions beyond those required of nondisabled tenants, and choice of service providers and types of services should be independent of housing choices.

When drafting transition plans, states should specifically ensure that scattered-site housing is available to individuals with high service needs. The United States Senate Health, Education, Labor, and Pensions Committee has found that "virtually all people with disabilities can live in their own apartment or house with adequate supports" and that "for virtually all people with disabilities, the most appropriate integrated setting is their own home."[58] Research has shown that, with the right supports, people with a wide variety of support needs – including persons with complex medical needs, people who have both developmental and psychiatric diagnoses, people with a history of involvement in the criminal justice system, and people who have spent many years in an institution – can live successfully in truly integrated community settings.[59]

Scattered-site housing is not only a required option under the new rule, but is also the best way to achieve compliance with the new rule's requirement that individuals be integrated into the community; have the opportunity to exercise choice regarding living arrangements, daily activities, and providers; and enjoy basic rights such as privacy, dignity, and respect. Data from the National Core Indicators project, shown below, illustrates this effect. For further information, see ASAN's Data Brief on housing settings.*

* URL to be added.

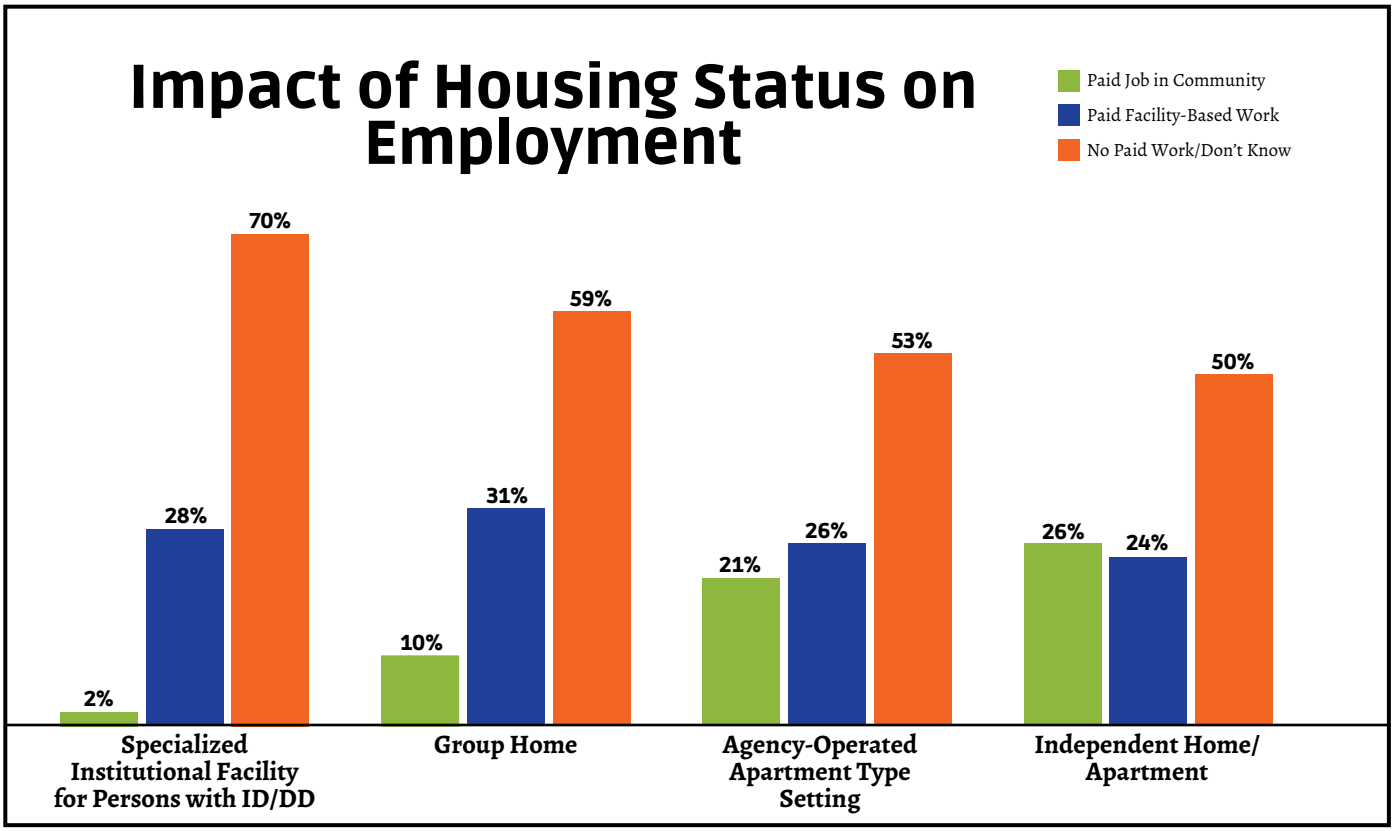


**Figure 1.** Source: National Core Indicators, http://www.nationalcoreindicators.org/charts

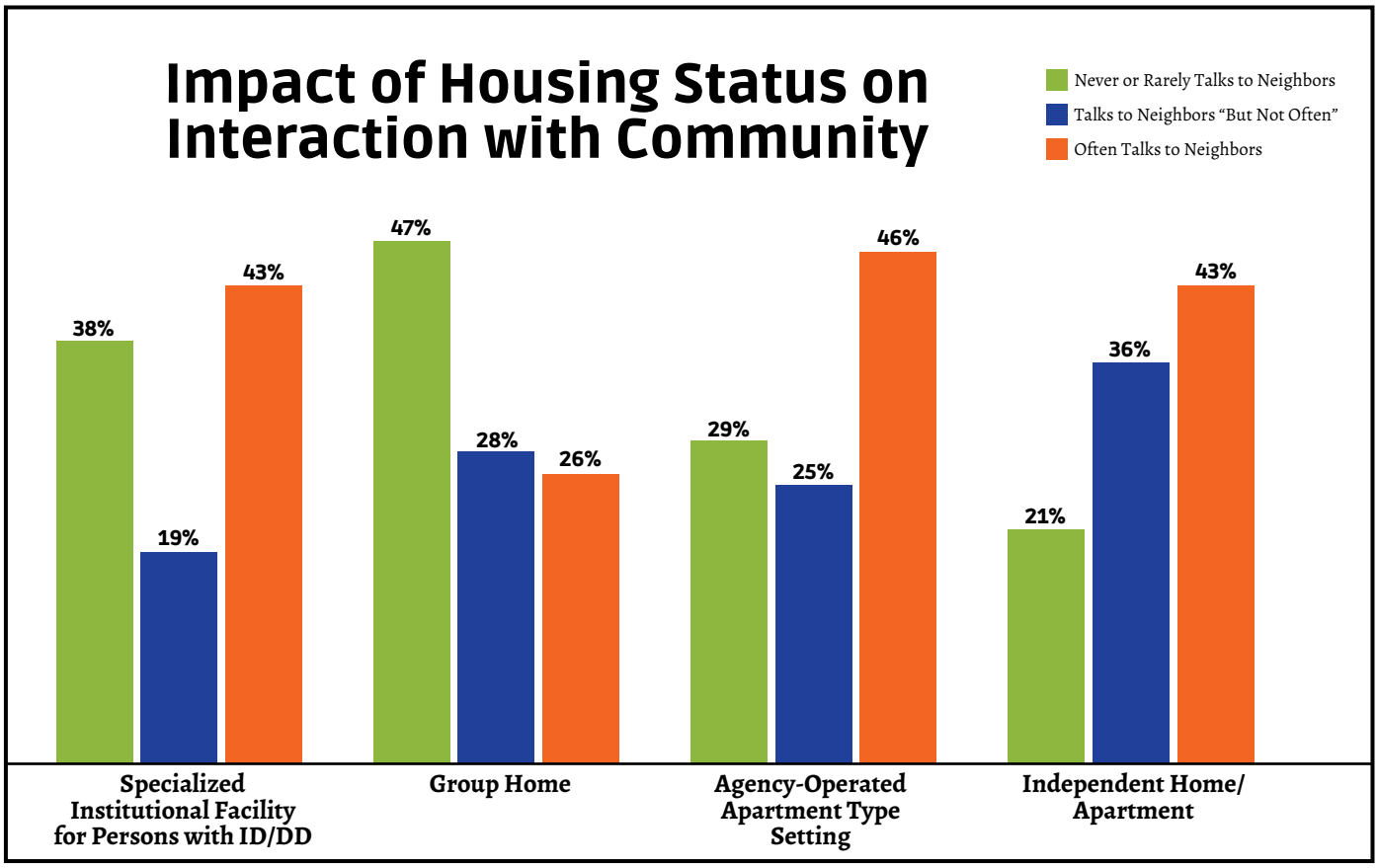


**Figure 2.** Source: National Core Indicators, http://www.nationalcoreindicators.org/charts

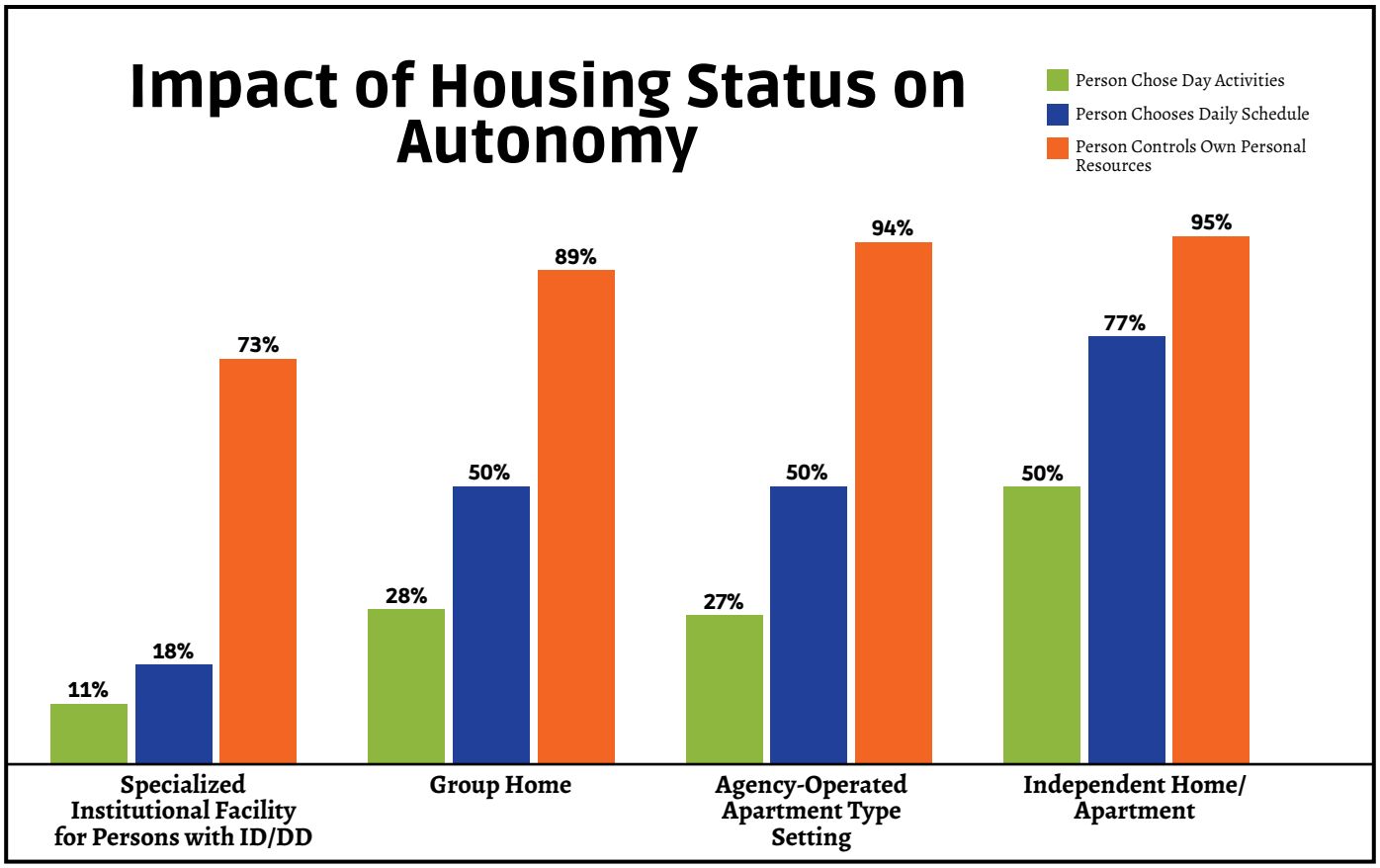


**Figure 3.** Source: National Core Indicators, http://www.nationalcoreindicators.org/charts

Scattered-site housing also provides, overall, a more cost-effective means of serving people with disabilities than congregate settings such as group homes.[60] Cost savings result from higher flexibility in service levels and lower costs of facilities in comparison to group homes. Congregate environments, such as gated communities, group homes, and institutions, are associated with high fixed costs and limited flexibility due to the need to maintain buildings, staff, food service, and other such ongoing expenses. It may be difficult or impossible to reduce staff hours when residents acquire skills and need fewer services, or to reduce the size or number of buildings if residents move out.[61] The difficulty of adjusting service levels to an individual's changing needs can also result in unnecessary and costly transfers from one housing provider to another.

Many states have already been legally required to develop scattered-site housing options. The Department of Justice - which is tasked with enforcing *Olmstead* - has taken the position that "congregate settings populated exclusively or primarily with individuals with disabilities" are segregated settings and thus inconsistent with *Olmstead*'s integration requirements.[62] Settlements and consent decrees arising out of the Department of Justice's *Olmstead* enforcement actions typically include requirements to develop scattered-site community housing options.[63] Similarly, the United States Senate Health, Education, Labor, and Pensions Committee found that people with disabilities must have access to "scattered-site" community housing as opposed to merely group homes or multi-unit complexes that are primarily for people with disabilities.[64]

Scattered-site housing developments also enable states to take advantage of federal funding that is not available for congregate housing developments. The Department of Housing and Urban Development restricts states from using funding to finance development of congregate residential settings for people with disabilities, except where specifically authorized by statute. HUD funding is, however, available for scattered-site housing developments for the purpose of creating integrated community housing options for people with disabilities. These units, unlike most other HUD-funded projects, can be preferentially offered to people with disabilities. In fact, HUD has issued guidance explicitly encouraging states to use HUD funding for this purpose.[65]

## Special Standards for Provider-Owned Residential Settings

Although the new rule does not completely prohibit delivery of HCBS in provider-owned residential settings, it includes a detailed list of standards that these settings must meet in order to qualify for HCBS funding. These standards are best understood as a detailed explanation of the way in which the general settings standards should apply to the special case of provider-owned settings. They serve as an acknowledgment that, as noted by the self-advocates surveyed by ASAN, SABE, and NYLN, provider-owned settings are particularly likely to present barriers to the integration and self-determination goals of HCBS. For example, when the provider owns the house where service recipients live, it may adopt policies that regiment residents' daily lives or restrict their right to privacy in the interest of (real or perceived) administrative efficiency.

*Although the new rule does not completely prohibit delivery of HCBS in provider-owned residential settings, it includes a detailed list of standards that these settings must meet in order to qualify for HCBS funding.*

When individuals receive HCBS in a provider-owned residential setting, the new rule requires that:

- Individuals retain at least the same rights and responsibilities as tenants under state's landlord-tenant law;
- Individuals enjoy privacy in their sleeping or living units. Individuals must be able to lock their own doors, with only "appropriate staff" having extra keys to the doors. Individuals who choose to have roommates[66] must be offered a choice of roommate. Individuals must be able to furnish and decorate their sleeping or living units within the provisions of the lease or other agreement.
- Individuals have the "freedom and support to control their own schedules and activities, and access to food at any time" (emphasis added);
- Individuals are able to have visitors of their choosing at any time; and
- The setting must be physically accessible to the individual.[67]

Unsurprisingly, these rules closely mirror and elaborate on the general standards for home and community-based settings discussed above.

With the exception of the requirement that the setting be physically accessible—which cannot be modified—the new rule permits individualized modifications to these requirements. For example, a resident of a provider-owned setting who needs support to comply with medical dietary restrictions may need supervision when selecting or accessing food. These modifications must be individualized, rather than applied to all residents of a home. Moreover, they must be based on the specific needs of the individual rather than the convenience of staff. To ensure that the modifications are based on actual individual needs, the new rule requires that they be documented in the individual's person-centered service plan.[68]

### *Recommendations for Transition Plans*

- Provider-owned residential settings that receive HCBS funding must comply with the standards of the new rule with respect to all residents, even if they do not receive HCBS funding for all residents. A provider-owned setting that has the characteristics of an institution with respect to some residents will necessarily have those characteristics with respect to all residents.[69]

- States should amend their landlord-tenant statutes such that residents of HCBS provider-owned settings (with the exception of time-limited respite care settings) qualify as tenants. Although this is the preferred option, as an alternative, states should develop a "model residency agreement" to be used by all provider-owned residential settings. At a minimum, this agreement should ensure that residents enjoy:

    - Protections against eviction, including the same due process procedures that the state offers to tenants; and

    - Enforceable rights to a habitable and secure dwelling place, free from unreasonable interruption by the property owner. If tenants in the state are legally entitled to withhold rent or place rent into an escrow account when the premises do not meet habitability standards, service recipients should enjoy similar rights. Housing providers should not be permitted to act as an individual's representative payee for Social Security or other benefits payments, as this practice effectively enables landlords to directly access tenant funds and may interfere with tenants' remedies under the lease agreement. In the event that the housing provider does act as the representative payee, they must be required to deposit all benefits in an account controlled by the tenant (and/or by his or her chosen representative), from which the tenant may make rent payments.[70]

States should ensure that any state-, county- or municipality-sponsored tenant advocacy or assistance programs must also serve individuals who live in HCBS provider-owned settings.

*States should ensure that any state-, county- or municipality-sponsored tenant advocacy or assistance programs must also serve individuals who live in HCBS provider-owned settings.*

- The transition plan should include standards to determine when it is "appropriate" for a staff member to have a key to the individual's living unit. These standards should closely mirror any existing State laws and regulations governing landlords' maintenance and use of spare keys to tenants' units.

- The transition plan should ensure that all provider-owned settings offer the option of a private room, at a rate that is affordable to individuals receiving SSI.

- General restrictions on furnishings and decorations must be consistent with those typically seen in residential leases (e.g., restrictions on water-beds, furniture that presents a fire hazard, or drilling holes into ceilings and walls).

- Residents of provider-owned settings must have the option of receiving day services from another provider. Providers must not adopt policies such as universal wake-up times, mealtimes, or curfews that restrict residents' daily activities.

- Provider-owned settings cannot impose a single "menu" on all residents. Residents who are interested in buying their own groceries must be allowed to do so and must have access to food-storage areas, including a refrigerator and freezer, and to a kitchen area.[71] Residents who need support to comply with dietary restrictions should be entitled to support with grocery shopping and/or selecting a menu. Where necessary, providers must offer support in using kitchen facilities, at any time, to individuals who may not otherwise be able to use them safely. When the provider serves some individuals with food allergies or other medical dietary restrictions, it may not impose this restriction on all residents but may

instead be required to provide separate food-storage areas or kitchen equipment in order to prevent cross-contamination, and may impose restrictions on bringing outside food into the affected individual's sleeping and living areas.

- Individuals should enjoy the same rights to visitors—including overnight visitors—as those traditionally enjoyed by tenants. As in the case of traditional tenancy arrangements, the provider may limit prolonged visits only to the extent necessary to ensure that the visitor does not become a legal resident, or in response to behavior by the guest that violates the terms of the lease. The transition plan should specifically articulate the contexts in which providers may limit visits, which in turn must be consistent with the provisions in traditional lease agreements and applicable landlord/tenant laws in the state.
- The transition plan should clearly explain, in detail, the information that the state Medicaid agency will obtain before approving an entity to provide home and community-based services. CMS has published a sample set of exploratory questions for residential providers online.[72]

*The transition plan should clearly explain, in detail, the information that the state Medicaid agency will obtain before approving an entity to provide home and community-based services.*

## Special Considerations for Non-Residential Settings

HCBS delivered in non-residential settings may include:

- Adult day services (also known as "adult day care");
- Habilitation services, including both home-based services designed to help people gain skills in activities of daily living;
- "Pre-vocational" services to prepare individuals for paid or unpaid employment;
- Educational services;
- Supported employment services; and
- Personal care attendant services delivered while the individual is outside the home.

This guide will focus in particular on settings in which individuals receive pre-employment, supported employment, or recreational day services, as these often account for several hours of individual's daily schedules. As in the case of residential HCBS, non-residential HCBS can have the effect of isolating individuals from the community when they use congregate and/or center-based service delivery models. When individuals spend their days in congregate, disability-specific settings, they miss out on opportunities to fully participate in community life.

### *Background on CMS Guidance*

When it issued the new rule in January, CMS announced that it would issue more detailed guidance on the rule's application to non-residential settings.[73] As of August 2014, CMS had not yet issued this guidance. In the meantime, many states that have submitted transition plans to CMS have deferred transition planning with respect to non-residential settings, citing the need for additional guidance.[74]

Nevertheless, CMS has announced that it would not grant extensions to states that deferred planning on non-residential services while awaiting further guidance. As a result, it is extremely important that states develop transition plans with respect to non-residential services even in the absence of detailed guidance from CMS. Transition plans should take into account all existing sources of guidance on which kinds of non-residential services are considered integrated, including (1) the general settings standards included in the new rule, which apply to both residential and non-residential settings;[75] (2) other past guidance from CMS; and (3) positions taken by the Department of Justice in *Olmstead* enforcement actions, including the provisions of any settlement agreements and consent decrees arising out of such actions.

*Like residential HCBS, HCBS in non-residential settings must foster integration into the community and individual choice, rights, and autonomy.*

### *Applying General Settings Requirements to Non-Residential Services*

The general settings requirements apply equally to non-residential and residential services. Like residential HCBS, HCBS in non-residential settings must foster integration into the community and individual choice, rights, and autonomy. As noted in further detail starting at page 23, they must also be chosen through a person-centered planning process.

**1. Integration into the Community.**

Non-residential service settings must be integrated into the community. As with residential settings, they must offer individuals the opportunity to:

- Seek competitive, integrated employment;
- Engage in community life;
- Control personal resources; and
- Receive services in the community.

These settings must provide access to these opportunities "to the same degree of access as individuals not receiving Medicaid HCBS."[76] As a result, recreational and employment activities that typically do not involve extensive interactions with others—such as working from home, working in non-disability-specific rural settings, or solitary recreational activities—may be considered HCBS so long as they offer the same degree of access to the community as the access enjoyed by nondisabled individuals engaged in similar activities.

As in the case of residential HCBS, all non-residential HCBS settings must provide opportunities to engage in competitive, integrated employment.[77] Although the rule does not require individuals to seek employment, the rule does not contain any provisions allowing individuals to waive the *opportunity* to seek competitive integrated employment.[78] Non-residential settings that fail to offer opportunities for competitive integrated employment are therefore not home and community-based, even if the service recipient is not actively seeking employment.

When determining whether a non-residential setting offers adequate opportunities to participate in competitive integrated employment, states should focus not only on the setting's explicit policies (such as a policy to "encourage" or "permit" individuals to seek employment), but also the actual track record of the provider and/or other providers who use the same model.

For example, although many "sheltered workshops" offer Medicaid HCBS-funded "pre-vocational" services that are nominally intended to help individuals develop job skills that may translate to competitive integrated employment at a later date, no more than five percent of those who work in sheltered workshops ever achieve competitive integrated employment.[78] In contrast, supported employment services that are provided in integrated workplaces have high success rates.[79]

Pre-vocational services funding should instead be used to fund services that help individuals with disabilities "develop the work skills needed to succeed in competitive, integrated employment."[80] Pre-vocational services funding could, for example, be used to assist an individual in an integrated volunteer placement or unpaid internship. They could also be used to provide coaching services – such as financial or time-management coaching – that take place in the individual's home or in the settings where the individual is expected to practice these new skills (such as local banks or public transportation systems).

Other factors that may influence individuals' access to opportunities for competitive employment may include:

- **Access to interviews and networking opportunities:** during day activities, do HCBS recipients have meaningful opportunities to interact with members of the community other than volunteers or staff members? Do they have the opportunity and support to gain experience through volunteering, respond to notices of job openings, and attend job interviews?
- **Access to transportation:** do HCBS recipients have reliable access to transportation for the purpose of attending job interviews and arrive at work on time every day?
- **Access to job coaching and supports:** do HCBS recipients have access to supported employment and job coaching services to help them identify career skills and interests and meet workplace expectations?
- **Access to communication supports:** do HCBS recipients have the ability to communicate using their preferred form of communication, which may include alternative and augmentative communication (AAC) technologies? Do they have access to forms of communication and information that may be helpful during a job search, including a telephone, email, and internet?
- **Flexibility of schedule:** can people with disabilities make modifications to their daily services schedule as necessary to attend work?

Non-residential service settings must also provide individuals with opportunities to control their own personal resources. In the context of supported employment or pre-employment services, HCBS recipients must have the opportunity and support to make their own decisions regarding the wages they earn. As in the case of residential services, service providers should avoid acting as a representative payee or requiring service recipients to have a representative payee. Instead, individuals should have access to financial decision-making supports, which may include benefits counseling, assistance in creating a bank account, setting a budget, and/or setting up automatic payments for important bills.

*Non-residential service settings must also provide individuals with opportunities to control their own personal resources.*

Finally, non-residential services must offer individuals maximum opportunities to participate in community life. Individuals must have opportunities to engage in community life on their own terms and should not be restricted to a limited selection of occupational or recreational activities that service providers choose to offer.

**"Whether we work in sheltered workshops, enclaves, or day habilitation centers, vocational segregation of us from people without disabilities does not count as community living. It is not gainful employment if we do not have the opportunity to make money at the same levels as other people who work in our community. We lose an important aspect of community life if we spend our time only around people with disabilities, in day habilitation centers, and are not able to be included in our broader communities."**

***- Keeping the Promise at 14.***

*Individuals must have opportunities to engage in community life on their own terms and should not be restricted to a limited selection of occupational or recreational activities that service providers choose to offer.*

**2. Individual Choice.**

The new rule also requires that the individual be offered a choice of settings that includes non-disability specific settings. In the context of non-residential services, disability-specific settings would include not only center-based workshops or day programs but also work placements in disability-specific "enclaves" and "work crews," and day services in the form of large congregate outings into the community.

**3. Individual Rights.**

The setting must ensure individuals' rights to "privacy, dignity and respect, and freedom from coercion and restraint."[81] As in the case of residential settings, service providers should ensure that HCBS recipients in day settings are not subject to demeaning or abusive treatment such as seclusion or restraint.

**4. Optimizing Autonomy**

The setting must be one that "optimizes, but does not regiment, individual initiative, autonomy, and independence in making life choices." These choices may include "daily activities, physical environment, and with whom to interact."[82]

The general explanation of this standard on page 4 of this guide should apply straightforwardly to most recreational day services. Employment contexts, however, present a special case in that many people, with and without disabilities, are subject to some degree of supervision and limitations on autonomy while on the job. Employees may be required to arrive at work at a specific time every day and must follow instructions from supervisors. Supported employment services should qualify as home and community-based services even if the workplace setting imposes rules for employees that would be considered unduly restrictive in non-employment contexts. Again, the critical question is whether HCBS recipients have the same opportunities to exercise autonomy and choose their daily activities as non-disabled individuals in the same or similar settings.

**5. Choice Regarding Services and Providers.**

Settings must "facilitate[e] individual choice regarding services and supports, and who provides them."[83] HCBS recipients should have the opportunity to decide who provides their non-residential services and supports. Individuals should not be required to accept employment or day services from the same entity that provides their residential services—even if they live in a provider-owned or controlled setting. Additionally, an individual's ability to remain in a particular workplace or volunteer position should not be tied to their acceptance of supported employment or pre-employment services from a particular provider.

*HCBS recipients should have the opportunity to decide who provides their non-residential services and supports.*

### *Automatically Excluded Settings*

The new rule's presumption that certain settings are not home or community-based—such as the grounds of a hospital or nursing home—applies to non-residential services as well as to residential services. As noted on page 9 of this guide, exceptions may be made when non-disabled members of the community also routinely use the setting for the same purposes for which the individual with a disability is using the setting. For example, an HCBS recipient may receive supported employment services while working as a receptionist at a hospital, provided that non-disabled people in the community also hold similar jobs at the hospital.

### *Guidance from CMS, Department of Justice, and Other Statutes*

State administrators should also base policies on non-residential settings on other guidance from CMS and DOJ, setting forth integration requirements for day and employment services.

Already in 2011, CMS issued an informational bulletin explaining that "All individuals, regardless of disability and age, can work – and work optimally with opportunity, training, and support that build on each person's strengths and interests."[84] States should ensure that non-residential services do not deny employment opportunities to individuals with significant service needs based on the perception that they are "too disabled" to work.

The Department of Justice has brought enforcement actions against Virginia and Rhode Island, alleging among other things that the states had violated *Olmstead* by failing to offer integrated day services to Medicaid recipients. In both cases, states were required to develop integrated day services, including supported employment, for Medicaid-eligible people with disabilities.[85] State administrators should look to the services listed in these settlement agreements as a minimum standard for compliance with the new rule.

Finally, state administrators should ensure that employment services providers are compliant with the Workforce Opportunity and Innovation Act (WIOA). WIOA amended the Rehabilitation Act of 1978 by adding Section 511, which restricts the situations in which individuals may work for less than the minimum wage.[86] It is critical, however, to understand that Section 511 sets standards for the kinds of subminimum wage employment arrangements that can operate, not which kinds of subminimum wage settings can *receive federal or state funding*. As a result, states cannot treat compliance with Section 511 as sufficient to establish compliance either with the new rule or *Olmstead*. Where the new rule and *Olmstead* impose standards that are stricter than Section 511, the stricter standards must also be met.

For example, a state may not use HCBS funding for placements in disability-specific, sub-minimum wage workshops that have the effect of isolating individuals from the community or that do not maximize individuals' opportunities for competitive integrated employment. The vast majority of existing sub-minimum wage employers would not meet the criteria of the new rule and would therefore be ineligible for HCBS funding, regardless of their compliance with Section 511. Similarly, under *Olmstead* a state that provides employment services must ensure that these services are offered in the most integrated setting appropriate to individuals' needs. An workplace's compliance with the procedural protections contained in Section 511—such as providing individual counseling regarding alternative employment options—cannot transform it from a segregated setting to an integrated one.

*Compliance with the new rule will require ongoing monitoring and enforcement.*

## Enforcement

Because the definition of home and community-based settings does not merely focus on the structural qualities of the setting but also on the ongoing experiences of service recipients, compliance with the new rule will require ongoing monitoring and enforcement. Accordingly, state transition plans should include strategies to enforce the new rule not only when licensing or approving providers, but throughout the course of a provider's operations.

Enforcement efforts, like the rule itself, should primarily focus on the actual experiences of service recipients. This should take the form of active monitoring and periodic surveys of service recipients across providers, combined with a robust process for investigating and resolving individual complaints.

In order to be effective, states must recognize that people with disabilities may face barriers to communicating their complaints or concerns. These barriers may take the form of either active interference by providers—as in the case where a residential service provider denies a person with a disability access to the telephone and/or accessible information on how to file a complaint—or denial of communication and other supports that people with disabilities may need in order to understand their rights and navigate the complaints process. States should mitigate these potential barriers by, at a minimum:

- Ensuring that all HCBS recipients receive clear, accessible information about their rights under the new rule through their preferred form of communication. This information should be provided during the person-centered planning process, at subsequent periodic intervals, and upon request;
- Training all enforcement personnel regarding the supports that may be necessary to assist individuals with disabilities in understanding their rights and communicating complaints, including communication supports; and
- Ensuring that HCBS provider-owned settings post information about HCBS recipients' rights in a prominent location.
- Providing individuals receiving HCBS, particularly those receiving it in provider-controlled settings, with an effective and accessible mechanism to file complaints, request investigations and otherwise take actions to enforce their rights under the regulation.

Many HCBS providers, such as home health practitioners and group homes, require state licensure in order to provide services. Existing licensing boards may offer an extra avenue for enforcement activities. As a result, some advocates have suggested that states incorporate HCBS settings requirements into their provider licensing standards.[87] Nevertheless, it is critical that States also conduct enforcement efforts outside of the licensing context, as many HCBS providers do not require state licensure.[88] Multiple other agencies should be involved in enforcement, including adult welfare agencies, the state Medicaid agency, human rights councils, disability ombudsmen, or developmental disability councils.

Granting enforcement authority to multiple agencies allows for a variety of investigation and enforcement options. Individuals whose rights to integration, dignity, or autonomy are violated should have access to meaningful remedies even if it cannot be proven that the violation was intentional or due to the kinds of systematic deficiencies that would justify revocation of the provider's license or authorization to provide services. As a result, remedies should range from enhanced oversight, fines, and/or individual relief in response to isolated instances of noncompliance to revocation of a provider's license or authorization to provide HCBS services in the case of persistent noncompliance.

## Person-Centered Planning

The new rule requires that all recipients of HCBS – whether through the State Plan under § 1915(i) or through a § 1915(c) waiver –receive person-centered planning to determine which services will be covered and in which settings HCBS recipients will receive those services.[89] Unlike the settings requirements, the new rule does not provide a "transition period" for coming into compliance with the person-centered planning requirements and does not require that states address compliance with the person-centered planning requirements in their transition plans. Nevertheless, because person-centered planning is closely tied to individuals' choice of setting, states should keep this process in mind when developing their transition plans.[90]

*The new rule requires that all recipients of HCBS receive person-centered planning to determine which services will be covered and in which settings HCBS recipients will receive those services.*

The new rule requires that:

- Individuals receiving HCBS and their chosen representatives must play a leading role in the person-centered planning process;
- The planning process must include participants chosen by the individual receiving HCBS;
- Individuals receive all necessary information *and support* necessary to direct the process and make informed choices, including information in "plain language" and language that is accessible to people with limited English proficiency;
- The planning process is "timely" and occurs "at times and locations of convenience to the individual";
- The process "reflects cultural considerations of the individual";
- The process includes "strategies for solving conflict or disagreement";

- The process includes "clear conflict-of-interest guidelines for all planning participants." It must also restrict participation of individuals or organizations that provide HCBS to the individual from developing the person-centered service plan or providing case management, unless the State shows that that entity is the *only* willing and qualified entity in the individual's geographic area. In such situations, the state must create conflict-of-interest protections that must be accepted by CMS and must provide individuals with a "clear and accessible" alternative dispute resolution process.
- The process allows the individual to make "informed choices . . . regarding which services to receive and from whom";
- The process allows the individual to request changes or updates to the plan "as needed" and must involve review of the plan at least every 12 months or whenever the individual's "circumstances or needs change significantly"; and
- The service plan must include a record of alternative home and community-based settings that the individual considered.

*The plan must be accessible and understandable to the individual receiving HCBS, and the individual must agree to the plan.*

The new rule also includes specific elements that must be included in the final service plan, including the individual's strengths and preferences, goals and desired outcomes, the setting in which the person will receive services, and the provider(s) of those services. The plan must be accessible and understandable to the individual receiving HCBS, and the individual must agree to the plan. Goals and desired outcomes should "incorporate consumers' preferences, and should not be limited to clinical concerns."[91]

Following the person-centered planning process should not be viewed as sufficient to establish substantive compliance with the settings requirements in the new rule. Such focus on procedure over substantive results has historically resulted in isolation of individuals with disabilities, especially when individuals were offered only a limited number of options during the planning process.[92] Moreover, although the new rule allows the person-centered plan to include some modifications to the standards for provider-owned residential settings, the general settings rules do not include any provision for exceptions—even if they are included in the person-centered plan.

States are advised to test the format of their proposed person-centered planning process with groups of consumers in order to ensure compliance with the new rule's requirement that the plan be understandable to the consumer.[93] If states have already adopted person-centered planning as part of their HCBS programs, they should survey existing beneficiaries on whether they found the process, and their plans, to be accessible and understandable.

## Other resources

- Centers for Medicare and Medicaid Services, *Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements at* 2 (2014), available at **http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Statewide-Transition-Plan-Toolkit-.pdf**

- Centers for Medicare and Medicaid Services, *CMCS Informational Bulletin:, Updates to the § 1915(c) Waiver Instructions and Technical Guide Regarding Employment and Employment Related Services* (2011), available at **https://www.cms.gov/CMCSBulletins/downloads/CIB-9-16-11.pdf**

- United States Senate Health, Education, Labor, and Pensions Committee, *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*, at 34-35 (July 18, 2013) (hereinafter "Separate and Unequal"), available at **http://www.harkin.senate.gov/documents/pdf/OlmsteadReport.pdf**

- Eric Carlson, National Senior Citizens Law Center, *Just Like Home: An Advocate's Guide for State Transitions under the New Medicaid HCBS Rules* p. 15 (2014), available at **http://www.nsclc.org/wp-content/uploads/2014/06/Just-Like-Home_-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf**

- Autistic Self Advocacy Network, *Keeping the Promise: Self Advocates Defining the Meaning of Community Living* pp. 6-7 (2012), available at **http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf**

- Elizabeth Pell, National Core Indicators, *NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurance, Practical Tools for States* (2014), available at **http://www.nationalcoreindicators.org/upload/files/HCBS_Reqmts_and_CMS_Assurances_Crosswalk_with_NCI_May_2014_FINAL.pdf**

- Kerri Melda & Drew Smith, Council on Quality and Leadership, *Evidence to Support New CMS/HCBS Reporting Requirements Using CQL Basic Assurances® Data and CQL Personal Outcome Measures® Data©* (2014), available at **http://thecouncil.org/uploadedFiles/Resources/Tools/crosswalk%20pdf.pdf**

- National Council on Disability, *Deinstitutionalization Toolkit: Community InDetail* at 13-14 (2012), available at **http://www.ncd.gov/publications/2012/DIToolkit/Community/inDetail/**

# Endnotes

1 *See* 79 Fed. Reg. 2947 (Jan. 16, 2014).

2 *Id.* at 2948, 2979.

3 42 C.F.R. §§ 441.301(c)(6)(ii), 441.710(a)(3)(ii).

4 Centers for Medicare and Medicaid Services, *Statewide Transition Plan Toolkit for Alignment with the Home and Community-Based Services (HCBS) Final Regulation's Setting Requirements* at 2 (2014) (hereinafter "*CMS Transition Plan Toolkit*"), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Statewide-Transition-Plan-Toolkit-.pdf.

5 For a full compilation of state transition plans, see http://HCBSAdvocacy.org.

6 *See, e.g., Indiana Preliminary Transition Plan for Assessing DDRS' HCBS Setting Compliance* (July 7, 2014), available at http://www.in.gov/fssa/files/HCBS_Transition_Plan_FINAL_7_3_2014.pdf.

7 *CMS Transition Plan Toolkit* at 3-7.

8 Olmstead v. L.C., 527 U.S. 581 (1999).

9 United States Senate Health, Education, Labor, and Pensions Committee, *Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act*, at 34-35 (July 18, 2013) (hereinafter "Separate and Unequal"), available at http://www.harkin.senate.gov/documents/pdf/OlmsteadReport.pdf

10 National Council on Disability, *Deinstitutionalization Toolkit: Community InDetail* at 13-14 (2012), available at http://www.ncd.gov/publications/2012/DIToolkit/Community/inDetail/ (citing Kozma, A., J. Mansell, and J. Beadle-Brown, *Outcomes in Different Residential Settings for People with Intellectual Disability: A Systematic Review*, 114 American Journal of Intellectual and Developmental Disabilities 193–222 (2009)

11 *Separate and Unequal* at 3-4; Autistic Self Advocacy Network, *Keeping the Promise: Self Advocates Defining the Meaning of Community Living* pp. 6-7 (2012) (hereinafter "*Keeping the Promise*"), available at http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf.

12 42 C.F.R. §§ 441.301(c)(4)(i), 441.530(a)(1)(i), 441.710(a)(1)(i).

13 This requirement does not force individuals who receive HCBS to seek employment, but it does require that all working-aged individuals have the opportunity and support necessary to do so. *See* Eric Carlson, National Senior Citizens Law Center, *Just Like Home: An Advocate's Guide for State Transitions under the New Medicaid HCBS Rules* p. 15 (2014), available at http://www.nsclc.org/wp-content/uploads/2014/06/Just-Like-Home_-An-Advocates-Guide-for-State-Transitions-Under-the-New-Medicaid-HCBS-Rules.pdf (hereinafter *"Just Like Home"*).

14 *Id.*

15 *See, e.g., Keeping the Promise* at 13, *Just Like Home* at 15.

16 To learn more about supported decision-making, *see* Quality Trust for Individuals with Disabilities, The Council on Quality and Leadership & Burton Blatt Institute Syracuse University, *Supported Decision Making: An Agenda for Action* (2014), available at http://bbi.syr.edu/news_events/news/2014/02/Supported%20Decision%20Making-2014.pdf.

17 42 C.F.R. §§ 441.301(c)(4)(ii), 441.530(a)(1)(ii), 441.710(a)(1)(ii).

18 *Just Like Home* at 16.

19 42 C.F.R. §§ 441.301(c)(4)(iii), 441.530(a)(1)(iii), 441.710(a)(1)(iii).

20 *See Keeping the Promise* pp. 6-7.

21 *Id.*; 42 C.F.R. §§ 441.301(c)(4)(ii), 441.530(a)(1)(ii), 441.710(a)(1)(ii). See also 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi) (referring to provider-owned or controlled residential settings).

22 42 C.F.R. §§ 441.301(c)(4)(iv), 441.530(a)(1)(iv), 441.710(a)(1)(iv).

23 *See Keeping the Promise* pp. 7-8.

24 *See Keeping the Promise* p. 8 (2012).

25 This right may be subordinated to the rights of others in the setting when such limitations would also normally apply to people without disabilities. For example, a service recipient who opts to live with a roommate may not have an overnight guest in his or her room over the voiced objection of the roommate. This right may also be subject to time limitations intended to prevent the visitor from claiming rights as a legal occupant.

26 *Keeping the Promise* p. 17.

27 *See Keeping the Promise* p. 9.

28 42 C.F.R. e C.F.R. (c)(4)(v), 441.530(a)(1)(v), 441.710(a)(1)(v).

29 *Keeping the Promise* at 3.

30 *CMS Transition Plan Toolkit* at 2.

31 *Id.* at 2-3.

32 See Elizabeth Pell, National Core Indicators, *NCI Performance Indicators: Evidence for New HCBS Requirements and Revised HCBS Assurance, Practical Tools for States* (2014), available at http://www.nationalcoreindicators.org/upload/files/HCBS_Reqmts_and_CMS_Assurances_Crosswalk_with_NCI_May_2014_FINAL.pdf.

33 Kerri Melda & Drew Smith, Council on Quality and Leadership, *Evidence to Support New CMS/HCBS Reporting Requirements Using CQL Basic Assurances® Data and CQL Personal Outcome Measures® Data©* (2014), available at http://thecouncil.org/uploadedFiles/Resources/Tools/crosswalk%20pdf.pdf.

34 Iowa Department of Human Services, *HCBS Settings: State Home and Community Based Services (HCBS) Setting Transition Plan Due 7/31/2014* p. 1, available at https://dhs.iowa.gov/sites/default/files/HBCS%20Settings%20Transition%20Plan%204-28-2014.pdf

35 *See* 45 C.F.R. § 164.502.

36 *Keeping the Promise* at 10.

37 H.R. 1893, 113th Cong. (2013).

38 Minn. Stat. 245D.06(5), (8).

39 *Keeping the Promise* at 12.

40 *Keeping the Promise* at 12.

41 *Keeping the Promise* at 16.

42 *See* NADSP, Webinar: Preparing Direct Support Professionals in CMS's Expectation to Provide People with Disabilities with "Informed Choice" (Sept. 5, 2014), available at http://www.nysacra.org/nysacra/pdf/PREPARING_DIRECT_SUPPORT_PROFESSIONALS.wmv. To learn more, visit www.nadsp.org.

43 42 C.F.R. §§ 441.301(c)(5), 441.530(a)(2), 441.710(a)(2).

44 *Id.* This position is not new. In 2010, CMS rejected Missouri's petition to amend its HCBS waiver because the proposal would have used waiver funds to place individuals into "residential units clustered on the grounds of a large State¬operated institution." CMS found that this setting was "segregated from and with restricted access to the larger community" and therefore not an appropriate use of waiver funds. *See* Letter from Donald Berwick, Administrator, Centers for Medicare & Medicaid Services, to Ronald Levy, Director of Missouri Department of Social Services (Aug. 2, 2010), available at http://www.arkdisabilityrights.org/doc/2010/20100802cms_modss1915c-disapproval.pdf.

45 *See* Centers for Medicare and Medicaid Services, *Guidance on Settings that Have The Effect of Isolating Individuals Receiving HCBS from the Broader Community* (2014), at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf.

46 *See* Autistic Self Advocacy Network, *Keeping the Promise: Self Advocates Defining the Meaning of Community Living* 7 (2012), available at http://autisticadvocacy.org/wp-content/uploads/2012/02/KeepingthePromise-SelfAdvocatesDefiningtheMeaningofCommunity.pdf

47 *Just Like Home* at 10-11.

48 *See Keeping the Promise* at 10.

49 79 Fed. Reg. 2,948, 2,951, 2,954-55, 2,967, 2,971 (Jan. 16, 2014).

50 *Just Like Home* at 6-7 (noting that the criteria for overcoming this presumption should be "more stringent and/or detailed than the basic standards" applicable to HCBS settings).

51 Although these settings were not mentioned by name in the regulations, the federal government has taken the position that these settings are isolating and institutional in nature. As a result, they would be considered to "have the qualities of an institutional setting." *See* Settlement Agreement, *United States v. O'Toole et al.*, Civ. Action No. CV-13-4166 (E.D.N.Y. Jul. 23, 2013), available at http://www.bazelon.org/portals/0/In%20Court/Current%20Cases/Current%20Cases/DAI/Court%20Documents/7.23.13DAI%20settlement%20(1).pdf.

52 *CMS Transition Plan Toolkit* at 3.

53 *Keeping the Promise* at 4.

54 *Keeping the Promise* at 6-7.

55 *Keeping the Promise* at 16.

56 42 C.F.R. §§ 441.301(c)(4)(ii), 441.530(a)(1)(ii), 441.710(a)(1)(ii).

57 According to HUD guidance, states are allowed to use HUD funding to develop scattered-site housing specifically for the purpose of promoting community integration of people with disabilities. As noted below, this can serve as a valuable source of funding that is not available for congregate housing projects. United States Department of Housing and Urban Development, *Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of Olmstead*, p. 7 (2013), available at http://portal.hud.gov/hudportal/documents/huddoc?id=OlmsteadGuidnc060413.pdf.

58 *Separate and Unequal* pp. 4, 34.

59 *Community inDETAIL* p. 19.

60 National Council on Disability, *Deinstitutionalization: Unfinished Business, Companion Paper to Unfinished Business Toolkit* p. 43 (2012), available at http://www.ncd.gov/publications/2012/Sept192012/. For the purposes of its report, National Council on Disability considered all facilities of four or more people who did not choose to live together to be institutions.

61 National Council on Disability, *Deinstitutionalization: Unfinished Business, Companion Paper to Unfinished Business Toolkit* p. 43 (2012), available at http://www.ncd.gov/publications/2012/Sept192012/. For the purposes of its report, National Council on Disability considered all facilities of four or more people who did not choose to live together to be institutions.

62 United States Department of Justice, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and* Olmstead v. L.C., p. 3, available at http://www.ada.gov/olmstead/q&a_olmstead.pdf.

63 *See*, e.g., Settlement Agreement, *United States v. O'Toole et al.*, Civ. Action No. CV-13-4166 at 6 (E.D.N.Y. Jul. 23, 2013), available at http://www.bazelon.org/portals/0/In%20Court/Current%20Cases/Current%20Cases/DAI/Court%20Documents/7.23.13DAI%20settlement%20(1).pdf; Settlement Agreement, *United States v. Virginia*, Civ. Action No. 3:12cv059-JAG at 12 (E.D. Va. Aug. 23 2012), available at http://www.ada.gov/olmstead/olmstead_cases_list2.htm#va; Settlement Agreement, *United States v. North Carolina*, Civ. Action No. 5:12-cv-557 at 6 (E.D.N.C. 2012), available at http://www.ada.gov/olmstead/olmstead_cases_list2.htm#NC.

64 *Separate and Unequal* pp. 4, 14-16.

65 United States Department of Housing and Urban Development, *Statement of the Department of Housing and Urban Development on the Role of Housing in Accomplishing the Goals of* Olmstead, p. 7 (2013), available at http://portal.hud.gov/hudportal/documents/huddoc?id=OlmsteadGuidnc060413.pdf.

66 The new rule's requirement that individuals have the option of a private unit applies to provider-owned settings as well as non-provider owned settings. 42 C.F.R. §§ 441.301(c)(4)(ii), 441.530(a)(1)(ii), 441.710(a)(1)(ii).

67 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi).

68 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi).

69 *See Just Like Home* at 18.

70 As noted in further detail above, providers who act as both representative payees and creditors without this type of safeguard would also potentially be violation of the new rule's requirement that HCBS recipients have the opportunity to control their own personal resources. When a provider that assists an HCBS recipient with financial matters is also receiving regular payments from that same recipient, that provider faces a significant conflict of interest that necessarily interferes with the goal of promoting financial autonomy.

71 When the residential services provider also provides assistance with daily activities, it must provide assistance with grocery shopping and other food-selection activities.

72 Centers for Medicare and Medicaid Services, *Exploratory Questions to Assist States in Assessment of Residential Settings* (2014), available at http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Exploratory-questions-re-settings-characteristics.pdf.

73 79 Fed. Reg. at 2960.

74 *See, e.g.*, Oregon Department of Human Services News Release, Public notice and comment on Transition Plans for Community-Based Settings in Support Services, Comprehensive and Children's Model Waivers (May 8, 2014), available at http://hcbsadvocacy.files.wordpress.com/2014/05/oregon-public-comment-on-transition-plan.pdf.

75 See 79 Fed. Reg. at 2960.

76 42 C.F.R. §§ 441.301(c)(4)(i), 441.530(a)(1)(i), 441.710(a)(1)(i).

77 This absence of exceptions is in contrast with the rule's provisions regarding services in provider-owned residential settings. *See* 42 C.F.R. §§ 441.301(c)(4)(vi), 441.530(a)(1)(vi), 441.710(a)(1)(vi).

78 NDRN, *Beyond Segregated and Exploited*, p. 18. *See also* National Disability Rights Network, *Segregated and Exploited: A Call to Action!* (2011), available at http://www.ndrn.org/images/Documents/Resources/Publications/Reports/Segregated-and-Exploited.pdf.

79 *Id.* See also National Disability Rights Network, *Beyond Segregated and Exploited.*

80 NDRN, *Beyond Segregated and Exploited*, p. 17.

81 42 C.F.R. §§ 441.301(c)(4)(iii), 441.530(a)(1)(iii), 441.710(a)(1)(iii).

82 42 C.F.R. §§ 441.301(c)(4)(iv), 441.530(a)(1)(iv), 441.710(a)(1)(iv).

83 42 C.F.R. §§ 441.301(c)(4)(v), 441.530(a)(1)(v), 441.710(a)(1)(v).

84 CMCS Bulletin "Updates to the § 1915(c) Waiver Instructions and Technical Guide regarding employment and employment related services" (2011), https://www.cms.gov/CMCSBulletins/downloads/CIB-9-16-11.pdf.

85 *See* Consent Decree, *United States v. Rhode Island*, Civ. Action No. 1:14-cv-00175 (D.R.I. Apr. 8, 2014), available at http://www.ada.gov/olmstead/olmstead_cases_list2.htm#ri-state; Settlement Agreement, *United States v. Virginia*, Civ. Action No. 3:12CV059 – (E.D. Va. Aug. 23, 2012), available at http://www.ada.gov/olmstead/olmstead_cases_list2.htm#va.

86 Workforce Innovation and Opportunity Act, Pub. L. No. 113-128 § 458(a) (2014) (amending Title V of the Rehabilitation Act).

87 *Just Like Home* at 14.

88 For example, many states permit individuals to hire and train their own personal care assistants, who may include friends or

family members. This system provides HCBS recipients with needed flexibility and autonomy.

89 42 C.F.R. §§ 441.301(c), 441.725(a).

90 *Just Like Home* at 22.

91 *Just Like Home* at 25.

92 *Keeping the Promise* at 3.

93 *Just Like Home* at 25.