



## **A Place Of Her Own (Part II)**

### **The 2014 CMS Home and Community-Based Settings Rule**

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*This is the second in a series of three articles exploring the challenges, options and effects of new regulations on community-based living for individuals with disabilities. The author is both a special needs attorney and father to Kathryn, who has autism. The first installment ([link to first installment](#)) describes family concerns as they investigate residential opportunities for Kathryn and summarizes types of living arrangements. The opinions reflected in this article are those of the author.*

In early 2014, the Centers for Medicare and Medicaid Services (CMS) introduced new regulations under the Home and Community-Based Services (HCBS) waiver programs. Ever since, families, disability advocacy organizations and many state Medicaid agencies have been struggling with their implications for independent housing choices for adults with special needs. If your family is like ours and everyone acknowledges that your adult child with special needs will need certain support services in order to live independently, you are likely to find that your options have been reduced.

At their core, these regulations limit the availability of HCBS waiver services based upon the independent living arrangement. CMS claims that the purpose of the rules is to ensure that HCBS services are administered in a person-centered manner and in an integrated setting with full access to the benefits of community living – as opposed to a setting deemed to be institutional or isolating. As a parent and a special needs attorney, I find that the purposes behind these regulations seem in conflict with each other. I applaud the requirement that HCBS services be based on person-centered planning, a focus which has been too long in coming. On the other hand, I am troubled by the limitations inherent in the rules detailing what constitutes integration in the greater community. I wonder whether those rules are too limiting with respect to residential choices and needs. By limiting an individual's access to HCBS waiver services, which are often absolutely necessary for many individuals with special needs to live independently, don't we also reduce that person's housing options?

In Georgia, the state Medicaid agency understands the rule to require that:

- the individual with special needs be fully included in, be part of and be given full access to the greater community, including employment in integrated settings and the ability to engage fully in integrated community life activities,
- the residential setting be selected by the individual, with family input, from more than one option,
- the individual be supported with services chosen by the individual,
- the individual's residential setting ensures privacy, dignity and respect, and
- the residential setting never requires an individual to do something he/she does not want to do or keeps the individual from doing something he/she wants to do.

The federal regulations are specific concerning which settings will be deemed to be institutional:

- if located in a building that is also a publicly or privately operated facility providing inpatient institutional treatment;
- if located in a building, on the grounds of, or immediately adjacent to a public institution;
- if they have the effect of isolating individuals receiving waiver services from the "broader community" of individuals not receiving such services.

Here's what they consider to be *isolating*:

- settings designed to provide all-inclusive services onsite to those with special needs, including, housing, day services, medical, behavioral and therapeutic services and/or recreational and social activities;
- setting which allow participants/residents only limited interaction with the broader community; and
- settings which use or authorize interventions/restrictions which are unacceptable in Medicaid settings, and more often found in institutional settings (e.g. seclusion).

Based on these guidelines, CMS specifically opines that the following residential settings are *isolating*:

- farmstead or disability-specific farm communities,
- gated/secured "communities" for people with disabilities,
- residential schools, and

- multiple settings that are co-located and operationally related.

Yet elsewhere, CMS's written guidance recognizes that settings that are specifically designed for, or primarily serve, individuals with special needs, using onsite staff, *are not necessarily isolating*. That written guidance further muddies the issue by asserting that communities which resemble Continuing Care Retirement Communities (CCRCs), which are designed to allow couples to age in place together, regardless of the level of care needed, do not raise the same isolation concerns as other living arrangements since they typically include a mix of residents who do and do not receive waiver services.

New CMS privacy regulations for sleeping or living units will likely also require changes in how many states operate group homes. More specifically:

- individual units must have locking doors;
- residents must have a choice of roommates (if rooms are shared);
- residents must have the freedom to furnish and decorate their rooms as they wish and that right must be guaranteed in the lease or other legal document;
- residents must have the ability, freedom and support to choose their own schedules and activities, including access to food;
- residents must have the ability to have visitors of their own choosing at any time; and
- providers must ensure that the accommodations are physically accessible to those choosing to reside there.

Modifying any of these individual dictates requires supporting documentation, as further described in the regulations.

These new rules leave me very conflicted in my different roles as an advisor to families with adult children having special needs, as an advocate for disability organizations (of which I am a member and/or sit on the board) and, finally, as Kathryn's father. On one hand, I firmly believe that individuals with special needs deserve choices, especially the dignity to decide on their own living arrangements. But while the opinions and choices of the individual with special needs should matter most, it should be made in consultation with the family, based on the individual's and the family's experiences and beliefs. Individuals who are able to and/or want to live in the *greater community* should absolutely be allowed the opportunity to do so. However, I object to being forced by the government to use a specific residential setting for Kathryn if she believes, and her mother and I agree, that a

different living arrangement would better suit her needs and provide her a better, more productive life.

Contrary to the apparent “one size fits all” rationale of CMS’s settings rule, my personal experience is that different individuals with special needs require different types of residential options. In the autism community, there is much truth in the saying that “if you have met a person with autism, you have met only one person with autism;” making broad general pronouncements about the residential needs difficult and often in error. It has been my further experience as a special needs attorney that individuals with other I/DD disabilities also have unique needs with respect to structured and supportive residential settings. It, therefore, bothers me greatly to unilaterally limit the residential options for individuals with special needs in the manner that the settings rule appears to do.

An article that appeared in *The Atlantic*—Amy Lutz’s “Who Decides Where Autistic Adults Live?”—illustrates the adverse effects of this one-size-fits-all approach. It details the frustration and disappointment of several individuals and their families when, after the individuals had finally established successful living situations, they had to relocate because waiver services were denied them. I wish CMS had given greater consideration to the fact that transitions can be very difficult for those with any type of special need.

I favor the freedom of true choice for Kathryn. To dictate that group homes in traditional neighborhoods or their functional equivalent are the only proper residential settings for those with special needs ignores the fundamental underpinning of person-centered planning — the concept of choice. I respectfully disagree that all institutions or semi-segregated living arrangements are inherently bad or inappropriate for everyone with a disability. Some members of our community find peace and acceptance in non-traditional residential settings. On the other hand, even living in the family home in a traditional neighborhood can bring anxiety and isolation when surrounded by neighbors who reject all attempts to reach out and develop relationships. The residential settings categorically rejected by CMS are sometimes the only ones that work for certain individuals with special needs and their families. Let’s hope that the contradictions inherent in these regulations are recognized soon, before other choices in living arrangements disappear entirely.

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