

POLICY BRIEF: HCBS FINAL RULE

HISTORY OF FUNDING

The Center for Medicare & Medicaid Services (CMS) is the primary source of funding for long-term support services (LTSS) for individuals with intellectual/developmental disabilities (I/DD) and the elderly. In 1980, an advocacy breakthrough gave individuals more flexibility in where they could be supported. Medicaid established "home and community-based waivers" (HCBS) to "waive" the original requirement of institutional care for less restrictive settings, therefore individuals with I/DD could be supported in their family home or another setting of their choice.

Presently, individuals living in group homes, supported living arrangements, intentional communities, and farmsteads may receive LTSS funding by virtue of HCBS waivers. This could change.

FINAL REGULATION OVERVIEW

On January 10, 2014, CMS released new federal regulations and criteria for residential and vocational settings that use HCBS funding. A setting is eligible for HCBS funding if it meets the new outcome-oriented criteria (see next section) and is integrated in, and supports full access to, the greater community.

Additionally, as part of a person-centered planning process, all HCBS waiver recipients must self-direct, to the extent possible, the documentation of current support needs, necessary changes to the plan, and future life goals.

States must demonstrate to CMS that their HCBS Waiver and State Plan settings remain eligible for HCBS funding or how they will be transitioned to conform to the new criteria by March 2015. This must be done with public input, therefore it is very important they hear your voice.

CRITERIA for COMMUNITY

The Final Rule requires that all HCBS settings meet certain requirements:

- *is integrated in, and supports full access to, the greater community*
- *selected by the individual from among setting options*
- *ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint*
- *optimizes autonomy and independence in making life choices*
- *facilitates choice regarding services and providers*

The Final Rule defines additional criteria for provider owned or controlled settings, which include:

- *individuals have a lease or other legally enforceable agreement*
- *the home is physically accessible*
- *individuals have a private, locking room with choice of roommates and décor*
- *the right to visitors at any time and the right to food at any time*

Additionally, the Final Rule requires all HCBS participants to have a person-centered plan that ensures individualized health, support, and long-term services. This plan must support any modifications to HCBS criteria (e.g., locked food; locked home to prevent elopement) with documentation that less restrictive solutions have been tried.

THE HOUSING SHORTAGE FACED by INDIVIDUALS with I/DD

Restrictive regulations may make it difficult to develop new housing options that could provide meaningful choice to individuals with I/DD. This is problematic at a time when there is insufficient housing to meet this population's needs.

- 4,902,835 adults with I/DD in the USA
- 1,389,611 individuals supported in an out-of-home residential setting
- 852,923 individuals living with a caregiver 60 years old or older
- 244,195 additional residential placements funded from 1994-2011

ADVOCACY CHALLENGES AND OPPORTUNITIES

Although CMS supports “meaningful choice” among all available residential options, the bias against congregate settings that offer friendships and benefits from living together and accessing services and amenities as a group remains.

It will be up to community choice advocates to (1) urge states to secure HCBS funding for an array of settings to meet the diverse needs of the I/DD community and (2) raise awareness of the dire lack of housing, employment, and support service options currently available and ask how will your state meet the need (3) urge states to follow the outcome-oriented intent of the Final Rule as they revise state policy and regulations, therefore not including any language that could restrict home and community choices for those with I/DD.

CMS Guidance to States

CMS has sent additional guidance to each state's I/DD agency. Unfortunately, this guidance was not outcome-oriented nor based on research. It unfairly concluded that congregate settings “tend to isolate” and specifically mentioned higher scrutiny was needed for farmsteads, disability specific communities, residential schools, and settings where people access multiple supports such as residential and vocational services. It is up to you to tell your state leaders that these settings should not be presumed as isolating, and that individuals with I/DD have the right to be supported in any setting they consider home and community.

PUBLIC COMMENT PERIODS

In order to receive HCBS funding, states must apply to CMS for every waiver and submit a general state transition plan. These applications are required by the Final Rule to undergo a 30-day period of public comment. It is incumbent upon stakeholders to provide information and insight that help states develop strong applications. You can view your state deadlines at www.HCBSAdvocacy.org.

Contact Your State Representatives

A continuous relationship with your state Representative is vital. Share with your representative that you are part of the Coalition for Community Choice, a national network to advance housing options, and you want to help your state create a more sustainable and empowering future, but that policy may be creating barriers to public-private partnerships and housing choices for those with I/DD. For statistics in your state and more advocacy tools, contact DKameka@MadisonHouseAutism.org.

Share Your Story

There is a dearth of housing options, and it is time to raise awareness in your community! If you would like to tell people about a successful home and community you have chosen, please contact DKameka@MadisonHouseAutism.org for a toolkit to share your story.

CONCLUSION

The new regulation provides both challenges and opportunities for community choice advocates – self advocates, families, providers and organizations who support an array of residential, day, vocational and service options for individuals with I/DD.

It is up to advocates to ensure that the human and civil right of individuals with I/DD to be supported in a home and community of their choice is protected.

Go to www.CoalitionForCommunityChoice.org for resources to be an advocate in your state!

ABOUT THE CCC

The Coalition for Community Choice (CCC) is a national grassroots collaboration of individuals with disabilities, their families and friends, disability rights advocates, professionals, educators, and providers to advance the principle that policy should increase options and decrease barriers to housing and employment choices. Community can be experienced in all residential settings. CCC was created to:

- *promote and defend the rights of individuals with intellectual and developmental disabilities (I/DD) and autism to choose their home and community residential settings from the broadest range of options*
- *educate federal and state governments on innovative Olmstead-compliant housing alternatives to “one size fits all” approaches*
- *preserve access to essential, publicly-funded services and supports in these settings*

To learn more or to be included as a listed supporter of CCC please contact the CCC National Coordinator, Desiree Kameka, at: DKameka@MadisonHouseAutism.org

