

HCBS FINAL RULE: FREQUENTLY ASKED QUESTIONS

The Coalition for Community Choice (CCC) has created a Policy Brief to help self-advocates, families, service providers, and friends of those with intellectual/developmental disabilities (I/DD) understand the implications of the new Federal regulations regarding Home and Community Based (HCBS) waivers. For more information, please see the CCC Policy Brief, available on the CCC website: www.CoalitionForCommunityChoice.org

What is the purpose of the new federal HCBS regulations (Final Rule) released in January 2014?

According to the Center for Medicare & Medicaid Services (CMS) website, “The rule, as part of the Affordable Care Act, supports the Department of Health and Human Services’ Community Living Initiative. The initiative was launched in 2009 to develop and implement innovative strategies to increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living.”

The Final Rule also adds new person-centered planning requirements to ensure people with I/DD are living more self-directed lives, it allows states to combine multiple target populations such as the elderly or mental health challenges in one waiver, and it is intended to streamline waiver administration.

To see this information on the CMS website, use the following url:

<http://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-Releases/2014-Press-releases-items/2014-01-10-2.html>

How did CMS determine what would be in the Final Rule?

Several years ago, CMS released the proposed regulation change that defined what settings people with disabilities could use for their HCBS waivers. The proposed policy restricted housing and employment options, and many responded by demanding less restrictive definitions of “home and community”. Several rounds of public comment gave CMS lots of perspectives, the Op-Ed ‘Choice VS Olmstead’ offers a great summary of the different perspectives during that process:

<http://ltoventures.org/news/articlesop-ed/choice-v-olmstead/>

CMS released the federal Final Regulations in January 2014. Because of the work of many advocates around the country, CMS determined it was best to base the regulations around individual life experiences. The CMS HCBS Setting Fact Sheet states the intent of creating ‘outcome-oriented’ regulations within the Final Rule:

“In this final rule, CMS is moving away from defining home and community-based settings by “what they are not,” and toward defining them by the nature and quality of individuals’ experiences. The home and community-based setting provisions in this final rule establish a more outcome-oriented definition of home and community-based settings, rather than one based solely on a setting’s location, geography, or physical characteristics.”

To see this fact sheet on the Medicaid website, use the following url:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/HCBS-setting-fact-sheet.pdf>

Where can I find a copy of the Final Rule?

The HCBS Advocacy website has the links to the complete Final Rule, as well as many links to documents and webinars that talk about the Final Rule’s implementation. They can be found online at the following url:

<http://hcbśadvocacy.org/learn-about-the-new-rules/>

This document lists the specific requirements for meeting HCBS setting criteria:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Requirements-for-Home-and-Community-Settings.pdf>

Is my housing choice at risk?

Every state is interpreting the Final Rule and Guidance and making changes in their state policy accordingly. Some states are closely following the intent and regulations of the Final Rule which emphasize individual experiences, preferences, and self-determined choices as documented in their person-centered plan. Therefore, citizens in these states will have more choices of compliant home and community settings.

Some states are not closely following the intent of the Final Rule and are creating additional regulations not established in the Final Rule. For example, some states are creating policy that will not allow a single-family home to serve more than four HCBS participants. Other states are restricting the clustering of homes, and therefore restricting your choice to have neighbors that are also being supported by an HCBS waiver. If your choice in housing includes a semi-rural/rural home or agricultural community, this setting may be deemed “isolating” or “segregating” and not “integrated” enough to meet your states interpretation of the criteria for HCBS settings. It will be very important for you to prove that this setting is indeed your desired home and community.

How does the Final Rule differ from the guidance?

In March 2014, CMS offered further guidance that included a document called, "Guidance on settings that have the effect of isolating individual's receiving HCBS from the broader community." They cited several specific settings as examples, including farmsteads, gated/secured communities for people with disabilities, residential schools, and multiple settings that are co-located and operationally related.

To view this guidance online use the following url:

<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>

The final regulations were "outcome-oriented", but this guidance is misleading and not based on individual assessment of quality of life, the authority of individual's with I/DD self-determined choices, or current research.

States must not base their assessment of settings on the guidance, but focus their assessment and regulations on the Final Rule.

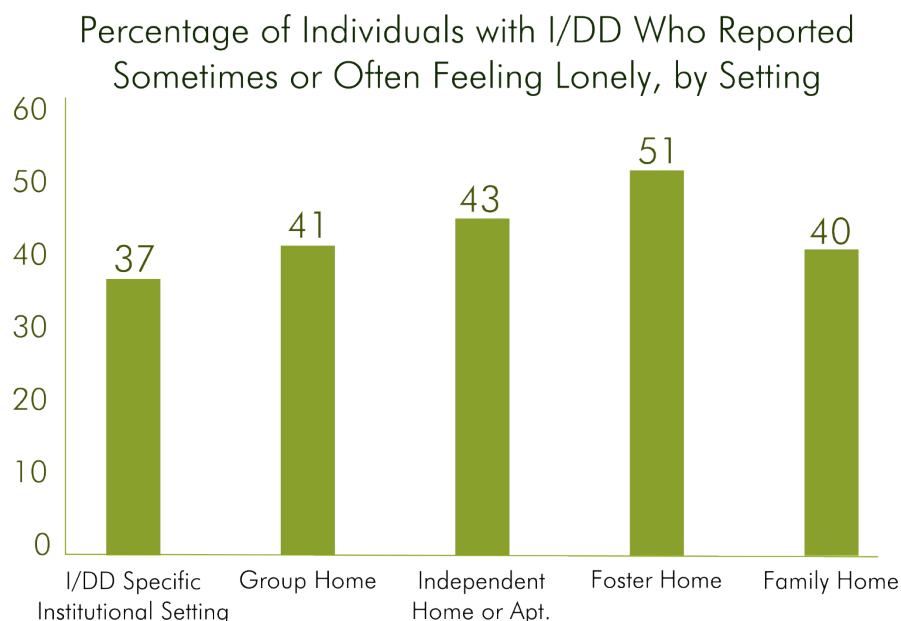
Why does the guidance label these settings as isolating?

Historically, individuals with disabilities were forcefully and involuntarily segregated or isolated in large congregate settings. These institutions were dehumanizing and offered virtually no individualized supports or privacy. These individuals had no control over their life choices and were not given opportunities to be part of the broader community.

This must NEVER happen again.

The theory behind deinstitutionalization was this: if people are placed in smaller settings, scattered within community neighborhoods, they will become integrated into the broader community. Legislation in more recent years has given people with disabilities protection against forced segregation and discrimination as well as the right to accommodations within the least restrictive environment.

However, research now shows that regardless of the an individual's geographic location, about 40% of people with I/DD report feeling lonely. Furthermore, people who live with their peers feel less lonely than those who live in their own apartment, family home or foster home:



National Core Indicators. (2012). National Association of State Directors of Developmental Disabilities Services and Human Services Research Institute.

Despite this research and many examples across the country, CMS continues to demonstrate a bias against settings where people with disabilities find friendships, benefits from living together with peers, and access their services and amenities "under one roof."

To view some of these housing examples, please visit the Autism Housing Network at the following url:

<http://www.autismhousingnetwork.org/housing/>

The burden is now on states, with input from advocates (self-advocates, families, and providers), to prove that these congregate settings should not be restricted from using HCBS funding. As protected by the American with Disabilities Act, Developmental Disabilities Bill of Rights, and the Olmstead Decision, individuals with disabilities have the human and civil right to be supported in a setting of their choice, and not forced into choosing from a limited menu of options.

Does the Olmstead Decision denounce congregate settings?

No. The Supreme Court Olmstead Decision ruled that involuntary segregation, unjustified isolation, and institutionalization are discrimination and that individuals with disabilities have the right to live in the most integrated setting.

Unfortunately, the Olmstead Decision has been misinterpreted and heralded as a mandate for integration of all persons in “home and community” settings typical to those without disabilities.

The Supreme Court Justices were very clear that this ruling must not restrict options, nor sway funding in a way that puts individuals at risk:

Justice Ginsburg, in announcing the judgment and delivering the opinion of the Supreme Court in Olmstead wrote: “Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, the States’ need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States’ obligation to administer services with an even hand.”

Supreme Court Justice Kennedy noted in his concurring opinion regarding the Olmstead Decision, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

President Obama, in a June 22, 2009 White House press release commemorating the 10th anniversary of the landmark Supreme Court decision said: “The Olmstead ruling was a critical step forward for our nation, articulating one of the most fundamental rights of Americans with disabilities: Having the choice to live independently.”

Many of the congregate housing options that exist or are being developed offer much needed affordable and accessible housing for those with I/DD to live self-directed and more independent lives.

Is there additionally funding to pay for the changes providers will need to make?

No.

This is a key concern for states that are inserting additional rules and restrictions within policy that are not outcome-oriented, such as maximum limits to the number of residents that can be served in a setting, restricted setting locations based on access to public transit, etc.

Less than 3% of adults with I/DD are supported in a home of their own. Policy must not restrict housing choices even further, nor put providers at risk of going out of business. Please see and share this video, which describes the lack of growth in housing options over the past decade:

<https://www.youtube.com/watch?v=3KvIUSzNXSQ>

Is every HCBS waiver participant required to have a person-centered plan?

YES! This is a very important element of the Final Rule as it gives the individual with I/DD more authority and leadership for the direction of their life.

It also offers the opportunity to document why certain accommodations are needed that may not meet criteria for HCBS settings. It is imperative that individuals with I/DD lead this process to the extent possible and that their choices and support needs are well documented.

For more information, see the ACL guidance on Person-Centered Planning and Self-Direction, released by the Administration on Community Living (ACL) June 2014:

<http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf>

Does the Final Rule only apply to residential options?

No. See this webinar hosted by the Department of Labor on the implication of HCBS Final Rule on non-residential settings:

<https://www.youtube.com/watch?v=h70-DmMNoEg>

How can I be an advocate?

State regulations and policy must not be more restrictive than the Federal standard as clearly outlined in the Final Rule. Following the intent of the Final Rule, state regulations and policy should be outcome-oriented and based on the decisions of individuals with I/DD as documented in their person-centered planning process.

You can use the step-by-step CCC Action Alert for easy instructions on how to contact Developmental Disability Administration and Medicaid leaders in your state to ensure your voice is heard. Please use the following url to view it online:

http://www.autismhousingnetwork.org/wp-content/uploads/2013/12/CCC_ActionAlert_1.pdf

Additionally, every state is now required to send in a Transition Plan to inform CMS of how they will meet the new criteria of the Final Rule. The Final Rule mandates that states receive public comment on drafts of all state waivers and the transition plan for a minimum of 30 days. See the CMS Statewide Transition Plan Toolkit for more information:

<http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Statewide-Transition-Plan-Toolkit-.pdf>

You should also continue to check the HCBS Advocacy website for periods of public comment in your state:
<http://hcbsadvocacy.org/>

Should I contact my State Representatives?

YES! Your Representatives may not be aware that the housing choices of those with I/DD are at risk. Make an appointment for an in person visit, or write a letter informing them of your concerns. Your story and opinion about the future of housing choices is VERY VALUABLE to them. See this list of CCC Talking Points, which may also be of interest:

http://www.autismhousingnetwork.org/wp-content/uploads/2013/12/CCC_Talking_Points_FINALSHORT_Jan-2014.pdf

How can I connect with the CCC online?

For statistics or help on what to discuss, please contact the National Coordinator of the CCC:
Dkameka@MadisonHouseAutism.org

See the CCC Take Action! Page for more information:
<http://www.AutismHousingNetwork.org/advocacy/take-action/>

Join and/or connect with others in the Coalition for Community Choice:
<http://www.CoalitionForCommunityChoice.org>

Like our CCC Facebook page for updates:
<https://www.facebook.com/CoalitionForCommunityChoice>



Coalition for Community Choice | Winter 2014
www.CoalitionForCommunityChoice.org

