

# Choice v. Olmstead

*The Debate over Community Living, Proposed HCBS Waiver Changes, and the Impact on Housing for Adults with Autism Spectrum Disorders*

*What 338 Public Comments Tell Us About Who is on Which Side and the Issues*

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A deadly serious debate is raging within the disability community over proposed changes to the Medicaid Home and Community-based Services (HCBS) Waiver and what qualifies as community living. A reading the 338 public comments<sup>1</sup> submitted in response to the proposed changes reveals that the debate is fundamentally about “choice” versus “*Olmstead*,” with the primary line of demarcation being what each side believes about the terms “home” and “community.” And about who gets to make that choice.

At stake is nothing less than the future of essential residential and supportive services for hundreds of thousands of adults with Autism Spectrum Disorder (ASD) as well as adults with intellectual, developmental and other disabilities (ID/DD).

The regulation changes that the Centers for Medicare & Medicaid Services (CMS) is proposing would do three things: 1) provide for consolidation of multiple target groups under a single waiver; 2) more narrowly define what constitutes a “home and community-based” setting where waiver participants may receive services; and, 3) establish new requirements for person-centered planning.

This article will focus on efforts to redefine HCBS settings and community living.

## **WHO IS ON WHICH SIDE**

The 338 comment submissions are split fairly evenly. On the side of “choice” are primarily the disabled individuals served by the waiver, parents, caregivers, providers and state Medicaid agencies.

*“Allow us as parents to try to make the ‘right’ choices for our sons and daughters and don’t limit us to our choices based on some other advocates beliefs that what they are saying is more important or they know better than ‘us parents’ to make recommendations and choices for our disabled sons or daughters.” -- Peter and Dru Barnett, Mason, OH; parents of an 18 year old daughter with autism<sup>2</sup>.*

*“...we are concerned that your efforts to improve the waiver program might actually have the unintended consequence of reducing choice...”* -- Rose M. Hughes, Executive Director, Montana Health Care Association<sup>3</sup>.

*“Based on their collective experience, the Commenting States believe that Proposed Section 441.301(b)(1)(iv) is likely to limit recipients’ choices without meaningfully advancing the goal of community integration.”* – Agencies and officials responsible for administering the Medicaid program in 14 states, AK, CA, HI, IL, LA, ME, MD, MI, MO, NV, RI, TN, WA and WI (Commenting States)<sup>4</sup>

On the “*Olmstead*” side are primarily CMS itself and disability advocacy organizations, including the Protection & Advocacy/Client Assistance Programs (P&A/CAP) Network which has special federal and state authorities to advocate for people with disabilities.

*“...we seek to ensure that Medicaid is providing needed strategies for States in their efforts to meet their obligations under the Americans with Disabilities Act (ADA) and Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999). In the *Olmstead* decision, the Court affirmed a State’s obligations to serve individuals in the most integrated setting appropriate to their needs.”* – Donald M. Berwick, Administrator, CMS<sup>5</sup>.

*“By definitively stating what environments are not a home or community setting, CMS will help ensure that the intent behind HCBS waivers is fulfilled by providing services in the most integrated settings. Clarifying that building smaller homes on the grounds of institutions and creating disability specific housing complexes or communities are not considered home or community will help end recent troubling attempts to use 1915c waiver funds to create these inherently non-integrated settings.”* -- Elizabeth Priaux, Senior Disability Legal Specialist, National Disability Rights Network<sup>6</sup>.

## **HOW THE CMS HCBS WAIVER RULE IMPACTS HOUSING**

To understand the scope and significance of changes to the definition of HCBS settings under Medicaid, check out this paragraph from the National Council on Disability report “*The State of Housing in America in the 21st Century: A Disability Perspective*” published January 2010<sup>7</sup>:

*“Most housing and supportive services that people with disabilities require to live as independently as possible exist in large measure because federal, State and local housing policies dictate specific goals and allocate annual funding. Private and nonprofit organizations that develop and manage or operate housing or provide supportive services are dependent to a significant degree upon a combination of these public resources, as well as on certain private sources of funding that vary regionally. Consequently, any discussion of promising housing practices must acknowledge the extent to which public policy drives the development of projects as well as the influence of effective disability advocacy on both policies and final projects. Many...promising housing policies and practices illustrate the extent to which these factors are inseparable.”*

Medicaid is the primary funding safety net for hundreds of thousands of persons with disabilities. To be clear, under the HCBS waiver Medicaid pays only for services, not room and board. However, CMS requires those services be provided in a CMS-approved setting. This is where the debate really starts to heat up.

The side for “choice” argues that funding for services should not be tied to a CMS-approved setting because if the recipient is worthy of services, they should be worthy of services wherever they receive them. The side argues further that if CMS is successful at narrowing the type of setting it considers “home and community-based” (i.e. “eligible”), fewer settings will be eligible as places to receive Medicaid-paid services, and existing Medicaid clients will be forced to seek new settings or lose services. They estimate that as many as 25 percent of existing eligible residential settings would no longer meet the proposed new CMS criteria, and would force tens of thousands of ID/DD/ASD individuals out of their residences.

Moreover, the “choice” side argues that narrowing the definition of an eligible setting would have a chilling effect on innovation in housing models and financing mechanisms, public and private, would severely impact the development of residences suitable for the tens of thousands of ID/DD/ASD adults who need them, and would balloon already bloated waiting lists nationwide.

The side for “*Olmstead*” argues that only living situations that closely or exactly mirror those of “typical” persons fulfill the intention of the Supreme Court and the Americans with Disabilities Act, and that federal and state funding under HCBS waivers should only be used for such settings.

Moreover, they have co-opted the lexicon of the debate – “institution,” “home,” “community” – to attempt to codify their more restrictive position and starve the efforts of those who want the freedom to choose.

This is a classic case of the federal government and its surrogate advocates forgetting “who the customer is,” and it could not be happening at a worse time.

## **THE ID/DD/ASD HOUSING SITUATION IS DETERIORATING**

Almost 123,000 people were on waiting lists in 2009 for Medicaid-eligible residential services for intellectually and developmentally disabled persons. This is an increase of almost 71% over the 71,922 people on the same waiting lists in 2000, the first year after the Supreme Court *Olmstead* decision<sup>8</sup>.

In many states, the length of time eligible individuals have languished on waiting lists exceeds ten years. The housing crisis for ID/DD/ASD adults has become so severe that in March 2011 a federal class action lawsuit was filed seeking relief for more than 19,000 Florida residents on waiting lists alleging that failure by the state to provide community-based services to eligible residents constitutes a violation of the Americans with Disabilities Act and other laws<sup>9</sup>.

And it is projected to get much worse...

The Centers for Disease Control and Prevention estimate that 730,000 individuals under 22 years of age have an ASD<sup>10</sup>, and more than 500,000 of those individuals will reach adulthood by 2024<sup>11</sup>. It is estimated that 70-85 percent of adults with ASD live with their parents or a family member until they can no longer support them. At that point, the most common recourse for these adults is emergency placement in nursing homes, group homes, or supported/assisted living arrangements.

*“The current fiscal environment is not a time to discourage innovation in either design or service delivery.” -- A four-state alliance for ASD’s Adult Community Housing and Living and The Autistic Global Initiative (AGI)<sup>12</sup>.*

*“To arbitrarily create limited access, prevent true patient choice and purposefully interrupt the concept of a ‘continuum of care complex’ is simply bad public policy.” -- Jesse W. Samples, Executive Director, Tennessee Health Care Association<sup>13</sup>.*

## **WASN’T THE OLMSTEAD RULING A GOOD THING?**

Of course. Everyone can agree that the kind of involuntary segregation that existed at the state-run institution in Georgia at issue in the *Olmstead v. L.C.* case<sup>14</sup> was bad. But so too is the kind of institutional abuse that the *New York Times* uncovered in March 2011 among the 2,000 state-run group homes which were supposed to be the solution for de-institutionalizing its state-run facilities per *Olmstead*<sup>15</sup>.

Also overlooked is the unintended isolation and segregation that exists today for tens of thousands of ID/DD/ASD individuals who are trapped in their parents’ homes with nothing to do because of a lack of housing, employment and social-recreational choices, and the funds to pay for them.

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.”* 119 S. Ct. at 2185.

President Obama, in a June 22, 2009 White House press release commemorating the 10<sup>th</sup> 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<sup>16</sup>.”*

## **THE HEART OF THE PROBLEM**

So where is the problem? The “choice” and “*Olmstead*” sides have significantly different views about what is a “home” and what is a “community.” And they wildly differ on who has the right to make the “choice.” Nature and disability advocacy abhor a vacuum, so considerable energy, time and resources have been devoted by each side to defining what a “home and community” setting should be...and not be. And to arguing who gets to decide what is and isn’t a suitable setting.

In its opinion, the Supreme Court used the terms “home” seven times and “community” 80 times, but never defined those terms. The Supreme Court did not define these terms because it intended individuals to be served by these benefits decide that for themselves.

The proposed CMS HCBS waiver rule change fails in attempting to establish that a setting is not integrated in the community because CMS fails to understand the concept of “community.” Community is what individuals decide for themselves, not what CMS or a vocal minority group of stakeholders decide. A simple lookup online at Merriam Webster Online ([www.m-w.com](http://www.m-w.com)) produces the following definition:

*“community”: a unified body of individuals: as people with common interests living in a particular area; an interacting population of various kinds of individuals in a common location; and, a group of people with a common characteristic or interest living together within a larger society.*

Many individuals with ASD, for example, prefer to live, work and socialize with and around other individuals with ASD because they feel more comfortable and accepted. Of course, many individuals with ASD or other developmental disabilities prefer to live, work and socialize with and around non-disabled individuals. “Community” is what each individual decides for himself, not what CMS dictates.

What the “*Olmstead*” side fails to understand is that its pursuit of a “less restrictive setting” and “setting that is least restrictive” does not equate to, nor is it served by, restricting choice to less and fewer settings.

### **CHOICE. WHO GETS TO DECIDE.**

Both sides claim to be devoted supporters of “choice,” yet the two sides have strikingly different ideas about what “choice” means and who gets to decide. Here’s where *Olmstead* and each sides’ definitions of “home” and “community” collide.

“Choice” advocates consistently argue an all-inclusive position that the consumers of these services and their families and care team should be the ones to decide, or considered more broadly, to let the market decide.

*“First, it is our understanding that the ultimate goal of CMS is to give individuals personal choice regarding their homes and activities. The ‘choice’ for a number of our residents and their families is a campus home. Family members cite such reasons as security, proximity to friends and specialized activities, closer oversight by senior staff and overall safety as their reasons for desiring their loved ones remain in a campus setting.” -- Cindy Clark, provider of residential services to individuals with developmental disabilities in Missouri<sup>17</sup>.*

*“Consumer choice as to where an individual wants to live, receive services and work should be the primary driver of the development and the implementation of a person-centered service plan and the determination of housing possibilities and non-residential settings for services.” -- Meg Cooch, Director of Policy and Advocacy, Lutheran Services in America Disability Network<sup>18</sup>.*

*“Choice should rest with the waiver recipient and not be dictated by policy. In keeping with the ideals of a person-centered approach, a broad menu of options must be available, similar to the processes that took place under ‘Money Follows the Person.’ Some people may wish to live with those who have the same diagnosis; some may not. This should be their decision, in consultation with their families and/or closest allies.” – A four-state alliance for ASD’s Adult Community Housing and Living and The Autistic Global Initiative (AGI)<sup>19</sup>.*

“*Olmstead*” advocates, however, consistently argue for choice, but clearly delineate that by “choice” they mean only those settings that they deem suitable according to their exclusive interpretation of “home” and “community.” Alarming, this means they also go out of their way to condemn some of the most innovative, person-centered settings existing and planned.

*“These rules appear to strengthen HCBS by providing better specificity and guidance about what is and is not a home and what constitutes true community integration and participation...we would like to emphasize...the value and importance of setting out standards for community living that address not only the physical facility in which a person lives but the ability of an individual to exercise choice and control in their lives, and the recognition that the use of waiver services is intended to support those community living arrangements not congregate settings that exist in the community.” – Marilyn Sword, Executive Director, Idaho Council on Developmental Disabilities<sup>20</sup>.*

*“We strongly support having choice regarding where one lives and who provides the services, without having those housing and services inextricably connected. In Texas we have also had providers/organizations...seek to create HCBS funding mechanisms for their self sustaining ‘master planned’ congregate campuses, ranches, neighborhoods or gated communities that we strongly believe continue to separate and segregate individuals with developmental disabilities. Please clearly disallow these living arrangements in the final regulations.” – Susan Murphree, Senior Policy Specialist, Disability Rights Texas<sup>21</sup>.*

*“People should have the freedom to choose whether to live in a rural, urban or suburban community. Gated communities, farmsteads, and clusters of group homes – even those that include both people with and without disabilities – are not in the community. A large congregate care facility is not a home in the community.” – Joint comment from Autistic Self Advocacy Network, Self-Advocates Becoming Empowered and National Youth Leadership Network<sup>22</sup>.*

## WHAT WE SHOULD LEARN FROM THE PUBLIC COMMENTS

This debate should produce an outcome that **expands inventory and choices** and **removes barriers to innovation and investment** in residential settings desired by adults with autism and intellectual, developmental and other disabilities. CMS should adopt policies and regulations that facilitate development of the broadest range of choices to address the varied needs and desires of the disabled Americans they are mandated to serve, and let the market decide what settings should prosper.

*“Individuals with disabilities deserve an array of residential options. CMS should be encouraging the development of additional residential options instead of restricting them.”*  
-- Charles Steck, IL<sup>23</sup>.

More specifically:

- HCBS Waiver Changes. CMS must not add paragraphs § 441.301(b)(1)(iv), (iv)(A), (iv)(B), and § 441.302(a)(5) as proposed<sup>24</sup>.

- Separate Funding for Services from Housing. HCBS Waiver funding for support services must be separated from residential setting requirements. Persons eligible to receive services funding are worthy of that funding and those services regardless of the setting. Choice should mean waiver funding recipients have the freedom to choose their services, providers and settings.
- Encourage Housing Model Innovation. Autism is a spectrum of disability that demands a spectrum of choices determined by the individuals affected. CMS should be creating opportunities for, and removing barriers to, development and construction of innovative new intentional housing settings including, but not limited to: agricultural communities, mixed-use campuses, urban redevelopment, co-housing projects, disability-specific communities, and home clusters.
- Encourage Financing/Funding Innovation. CMS should be creating opportunities for, and removing barriers to, development of and access to private and public-private financing that would offset, complement or replace public funding (i.e. Medicaid) and accelerate development and availability of housing to reduce waiting lists, create jobs, improve pay and provide higher quality services.
- Vote with Your Wallet and Your Feet. ID/DD/ASD individuals eligible for waiver-funded services, parents, caregivers, and providers can have the most impact by supporting the residential settings of their choosing. Many providers of housing options for ID/DD/ASD adults depend to some degree on charitable contributions and donations. Volunteer your time and services. Let these providers know that you support their efforts and inquire about how you can help.
- Be Informed. Make Your Voice Heard. The rule-making process is a lengthy process open to the public, but CMS is a government agency that must answer to Congress for its funding. The comment period for the most recent part of the rule-making is past, but any new steps or decisions will be published in the *Federal Register*. Subscribe to organizations such as *DisabilityScoop.com* or Autism Speaks to receive emails with news about developments with Medicaid and the waiver. Write your representatives and tell them your story and your position. Tell your Medicaid gateway agencies about your preferences for residential settings.

### **Community Living Subcommittee, Nevada Commission on Autism Spectrum Disorders**

The mission of the Subcommittee is to assess and advise the Commission on a modern approach to a variety of residential living situations for the Autism Spectrum Disorders (“ASD”) population in Nevada. For more information, visit: [www.facebook.com/NVAutismCommission.CommunityLivingSubcommittee](https://www.facebook.com/NVAutismCommission.CommunityLivingSubcommittee). Our public comment can be found at: [www.regulations.gov](http://www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1595.

### **LTO Ventures**

LTO Ventures is a 501(c)(3) non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorders (ASDs) and related developmental disabilities. For more information, visit: [www.ltoventures.org](http://www.ltoventures.org). Our public comment can be found at: [www.regulations.gov](http://www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1662.

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- <sup>1</sup> 338 public comments submitted in response to the Notice of Proposed Rulemaking published April 15, 2011 by the Centers for Medicare & Medicaid Services (CMS) in the *Federal Register* and available to the public under keyword CMS-2296-P through [www.regulations.gov](http://www.regulations.gov).
- <sup>2</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0867
- <sup>3</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0684
- <sup>4</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-1401
- <sup>5</sup> *Federal Register*, Vol. 76, No. 73; April 15, 2011, p. 21312
- <sup>6</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0962
- <sup>7</sup> <http://www.ncd.gov/publications/2010/Jan192010> , p. 89
- <sup>8</sup> University of Minnesota, Research and Training Center on Community Living; *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009*; K. Charlie Lakin, Sheryl Larson, Patricia Salmi and Amanda Webster. p. 37
- <sup>9</sup> Disability Scoop website, "Medicaid Waiver Waiting List Triggers Federal Lawsuit," March 29, 2011; <http://www.disabilityscoop.com/2011/03/29/medicaid-waiver-lawsuit/12716/>
- <sup>10</sup> Centers for Disease Control and Prevention website; <http://cdc.gov/ncbddd/autism/data.html>
- <sup>11</sup> Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report*, February 9, 2007
- <sup>12</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-1452
- <sup>13</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0890
- <sup>14</sup> Multiple sources including: <http://caselaw.lp.findlaw.com/scripts/getcase.pl?court=us&vol=527&invol=581>; also [http://en.wikipedia.org/wiki/Olmstead\\_v.\\_L.C.](http://en.wikipedia.org/wiki/Olmstead_v._L.C.)
- <sup>15</sup> *New York Times*, "At State-Run Homes, Abuse and Impunity", March 11, 2011; [http://www.nytimes.com/2011/03/13/nyregion/13homes.html?\\_r=3&pagewanted=1&hp](http://www.nytimes.com/2011/03/13/nyregion/13homes.html?_r=3&pagewanted=1&hp)
- <sup>16</sup> The White House, Office of the Press Secretary, press release, June 22, 2009: [http://www.whitehouse.gov/the\\_press\\_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities](http://www.whitehouse.gov/the_press_office/President-Obama-Commemorates-Anniversary-of-Olmstead-and-Announces-New-Initiatives-to-Assist-Americans-with-Disabilities)
- <sup>17</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0354
- <sup>18</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-1286
- <sup>19</sup> Ibid 12
- <sup>20</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0986
- <sup>21</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-0432
- <sup>22</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-1476
- <sup>23</sup> Regulations.gov website ([www.regulations.gov](http://www.regulations.gov)), keyword CMS-2296-P; document ID: CMS-2009-0071-1261
- <sup>24</sup> Ibid 5, p.21317