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LTO Ventures is a 501(c)(3)
non-profit company that develops
live/work/play communities for adults
with Autism Spectrum Disorder.

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December 5, 2012

Submitted via fax

The Honorable Darrell E. Issa, Chairman
Committee on Oversight and Government Reform
United States House of Representatives
2157 Rayburn House Office Building
Washington, DC 20515-6143

RE: Public Testimony for Hearing: "1 in 88: A Look into the Federal Response to Rising Rates of Autism"

Dear Chairman Issa:

Thank you for holding the hearing on November 29 to hear testimony from leading autism advocacy organizations and governmental entities. I look forward to the Committee holding more hearings on this issue, and I would be more than welcome to provide testimony at any future session.

I respectfully submit this document and all attachments into the public record for the November 29 hearing in three capacities:

- Founder, President & CEO of LTO Ventures, a 501(c)(3) non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorder ("ASD"). More at www.ltoventures.org.
- Chairperson of the Community Living & Employment Subcommittee for the Nevada Governor's Commission on Autism Spectrum Disorders.
- As an only parent of a teenage daughter with ASD. More on her story -- <http://bit.ly/w1M1ha>.

My testimony herein is specific to continuing efforts by the Centers for Medicare & Medicaid Services ("CMS"), including this year in its NPRM CMS-2249-P2, to improperly constrain the definition of a Home and Community-Based Setting.

Coupled with the authority CMS holds over the funding that provides the primary financial safety net for most disabled persons, the failure of CMS leadership to understand the primary directive of the *Olmstead* decision, or the concept of choice, or to hear the voices of the disabled, portends a potential regulatory injustice that will harm the lives of tens of thousands of disabled Americans.

The outcome of the rule-making process should not be to arbitrarily limit options and reduce choices. It should produce an outcome that expands choices, supports disabled Americans' right to choose, and removes barriers to innovation of and investment in residential settings desired by adults with Autism Spectrum Disorder and other disabilities. The outcome also should be consistent with the letter and spirit of the Americans with Disabilities Act and the *Olmstead* decision. Efforts by CMS since 2009 to redefine the characteristics of a Home and Community-Based Setting fail that test.

[continued]

We implore the Committee to use its authority to call upon CMS to cease-and-desist its efforts to impose its paternalistic bias on disabled Americans. We ask the Committee to encourage CMS to facilitate development of the broadest range of choices in residential settings to address the varied needs and desires of the Americans they are mandated to serve, and let the market decide which settings should prosper.

The attached documents describe in detail our analysis of the proposed rule-making and our argument for CMS to focus on outcomes that expand choices.

Sincerely,

A handwritten signature in black ink that reads "Mark L. Olson". The signature is fluid and cursive, with a long horizontal stroke at the end.

Mark L. Olson
President & CEO

Enclosures



June 28, 2012

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attn: CMS-2249-P2
Mail Stop C4-26-05
7500 Security Boulevard
Baltimore, MD 21244-1850

(via electronic submission)

RE: Comment on CMS-2249-P2

Dear Secretary Sebelius and Acting Administrator Tavenner:

I respectfully submit this letter with our public comments about CMS-2249-P2 in three capacities:

- Founder, President & CEO of LTO Ventures, a 501(c)(3) non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorder (“ASD”). More at – <http://wp.me/P1ZYZ5-u>.
- Chairperson of the Community Living & Employment Subcommittee for the Nevada Governor’s Commission on Autism Spectrum Disorders.
- Only parent of a teenage daughter with ASD. More on her story -- <http://wp.me/p1ZYZ5-3K>.

Our comments about the rule proposed under CMS-2249-P2 published May 3, 2012 in the *Federal Register* will be specific and detailed about the following sections:

- “Definition of Home and Community-Based Settings for the 1915(k) Community First Choice State Plan”
- § 441.530 “Home and Community-Based Setting”
- § 441.656 “State plan home and community-based services under the Act”

EXECUTIVE SUMMARY

We strongly opposed CMS’ last attempt to define Home and Community-Based Settings under NPRM CMS-2296-P as published April 15, 2011 in the *Federal Register*. To assist CMS in understanding the concerns it was receiving, we published an analysis of the public comments entitled “Choice v. *Olmstead*” documenting that the overarching issue is “choice” and who gets to make that choice.

- Our public comment can be found at: <http://www.regulations.gov/>, keyword CMS-2296-P; document ID: CMS-2009-0071-1662
- “Choice v. *Olmstead*” can be read in HTML and PDF formats at <http://wp.me/P1ZYZ5-1D>. We have enclosed a copy with this letter.



Comment on CMS-2249-P2 / Page 2

Interestingly, 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) – also opposed CMS’ last attempt:

“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.”

What is most disconcerting about CMS’ latest attempt (CMS-2249-P2) to define the characteristics of a home and community-based setting is that for all the public comment it received and stakeholder meetings it says it held, the leadership at US HHS and CMS (Secretary Sebelius and Acting Administrator Tavenner) appear to have learned very little.

Coupled with the authority CMS holds over the funding that provides the primary financial safety net for most disabled persons, the failure of CMS leadership to understand the primary directive of the *Olmstead* decision, or the concept of choice, or to hear the voices of the disabled portends a potential regulatory injustice that will harm the lives of tens of thousands of disabled Americans.

The outcome of the rule-making process should not be to arbitrarily limit options and reduce choices. It should produce an outcome that expands choices, supports disabled Americans’ right to choose, and removes barriers to innovation of and investment in residential settings desired by adults with Autism Spectrum Disorder and other disabilities.

We implore CMS to cease-and-desist its efforts to impose its bias on disabled Americans and instead we encourage CMS to facilitate development of the broadest range of choices in residential settings to address the varied needs and desires of the Americans they are mandated to serve, and let the market decide which settings prosper.

OUR ARGUMENT

We strongly oppose language proposed in CMS-2249-P2 to establish specific characteristics that settings must NOT exhibit to be approved as eligible sites for delivery of home and community-based services for the following reasons:

Proposed Rule Denies Choice, Fails *Olmstead*

The rule will arbitrarily and severely restrict choices of suitable residential settings, denying disabled Americans the right to choose what they consider most appropriate and most integrated from all available alternatives. If the proposed rule is enacted as proposed, state Medicaid agencies have estimated a loss of up to 25% of available settings, exacerbating a critical housing shortage that has worsened by more than 60 percent since the *Olmstead* decision. By codifying in this rule what CMS decides is NOT a community-based setting, CMS is taking away the right of these individuals to live in the setting of their choosing.



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“Choice” advocates consistently argue for an all-inclusive position in order that the consumers of these services and their families and care teams should be the ones to decide, or considered more broadly, to let the market decide. From CMS’ last attempt to arbitrarily exclude settings (CMS-2296-P) we heard from many disabled Americans and their provider agencies about what “choice” means to them, and should mean to CMS and US HHS:

“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.

“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.

“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).

We are especially disheartened to read in NPRM CMS-2249-P2 that CMS’ acknowledges and explicitly dismisses the above and similar concerns voiced by disabled Americans, their families and caregivers:

[CMS]: *“Some commenters stated that if an individual or his or her family ‘chooses’ a residence, it is therefore a ‘home and community-based’ setting. We disagree, as individuals can and do choose to receive services in institutional settings.”*

[LTO Ventures’ rebuttal]: CMS’ declares in this single sentence that: 1) it shall be the final arbiter of choice and reserves the right to overrule the will of the disabled Americans it exists to serve; 2) it shall interpret and selectively implement *Olmstead* as it so chooses even if the regulations it proposes are in direct conflict with the ruling itself.

Justice Ginsburg, in announcing the judgment and delivering the opinion of the Supreme Court in *Olmstead* wrote: *“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.



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"We emphasize that nothing in the Americans with Disabilities Act or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187

The plurality opinion in *Olmstead* stated: *"Each disabled person is entitled to treatment in the most integrated setting possible for that person – recognizing on a case-by-case basis, that setting may be an institution."* 119 S. Ct. at 2189

Secretary Sebelius and Acting Administrator Tavenner in the subsequent paragraph then attempted to defend their position, but in fact unreasonably expanded their definition of institution beyond the scope of *Olmstead*:

[CMS]: *"In addition, this reasoning is especially suspect in situations where an individual may not be given the option of receiving services in a variety of settings outside of an institution (for example, in their own home or apartment or, depending on the service, in a competitive employment situation), but rather is offered services only in a provider-owned or operated congregate setting."*

[LTO Ventures rebuttal]: In this sentence, CMS states that any provider-owned or operated congregate setting equates to an institution. But more importantly, CMS suggests that if the individual is given the option of receiving services in a variety of settings and thereafter freely chooses to receive those services in a provider-owned or operated congregate setting, the individual's reasoning and choice is suspect.

We are grateful that CMS acknowledges that it appears to have read the compelling and well-documented pleas from the disabled Americans they exist to serve, but we are greatly disturbed that CMS appears to be so locked into its own bias and misinterpretation of *Olmstead*:

[CMS]: *"We received a range of responses as to whether disability-specific congregate settings are appropriate settings for delivery of HCBS. Some individuals and organizations are articulate about their right to live with anyone of their choosing, including those with disabilities...In addition, some commenters stated that community can be defined in many ways, and therefore that home and community-based could include integration into a community of peers; that is, in a disability-specific congregate or campus setting that includes a rich array of supports and activities within the setting of care. We acknowledge the importance of peer relationships but we do not agree that a community of one's peers is the same as 'community based' in terms of settings in which HCBS is delivered."*

[LTO Ventures rebuttal]: In the *Olmstead* majority 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.



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The proposed CMS rule fails because CMS does not understand the concept of “community.” Community is what individuals decide for themselves, not what CMS, the P&A Network, or a vocal minority group of stakeholders decide. A simple lookup online at Merriam Webster Online (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 disabilities, for example, prefer to live, work and socialize with and around other individuals with disabilities because they feel more comfortable and accepted. Of course, many individuals with disabilities prefer to live, work and socialize with and around non-disabled individuals. “Community” is what each individual decides for himself or herself, not what CMS dictates.

What CMS fails to understand is that its pursuit of “all available alternatives” and “most integrated settings” does not equate to restricting choice to fewer settings.

CMS’ Argument is Self-Contradictory

In several places in 42 CFR Part 441 as proposed in CMS-2249-P2, CMS’ argument includes conflicting language that expressly includes the individual’s right to choose the setting in which they desire to reside, then in several places expressly excludes all alternative settings other than those determined by the Secretary to be eligible under a rebuttable presumption. See detail below.

This is no different than if the Secretary invited a disabled American to go to the ice cream shoppe for a treat and then explained that the person was free to choose any flavor ice cream provided the person chose vanilla.

CMS includes the individual’s right to choose without limitation:

- [p. 26400] §441.530(a)(1)(ii) *The setting is selected by the individual from among all available alternatives and is identified in the person-centered service plan.*
- [p. 26400] §441.530(a)(1)(iv) *Individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented.*
- [p. 26400] §441.530(a)(1)(v) *Individual choice regarding services and supports, and who provides them, is facilitated.*

CMS excludes the individual’s right to choose as overruled by the Secretary:

- [p. 26401] §441.530(a)(2)(v) *Any other locations that have qualities of an institutional setting, as determined by the Secretary. The Secretary will apply a rebuttable presumption that a setting is not a home and community-based setting...*



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CMS' Argument is Self-Contradictory *(continued)*

The same contradictory language in §441.530 also can be found in §441.656 as proposed.

Dangerous Precedent That Quashes Innovation and Investment

The rule will create a dangerous regulatory precedent that could be used by organizations or persons to oppose innovation of and investment in new residential settings and models for persons with Autism Spectrum Disorder and other disabilities. The proposed rule fails because it will have a chilling effect on investment in housing that otherwise could reduce or eliminate the waiting lists.

A University of Minnesota study reported 115,062 people were on the waiting list in 2010 for Medicaid-eligible residential services for intellectually and developmentally disabled persons. This is an increase of more than 60% over the 71,922 people on the same waiting lists in 2000, the first year after the Supreme Court *Olmstead* decision.

In many states, the length of time eligible individuals have languished on waiting lists exceeds ten years. In March 2011, a federal class action lawsuit seeking relief for more than 19,000 Florida residents on waiting lists alleges failure by the state to provide community-based services to eligible residents constitutes a violation of the Americans with Disabilities Act and other laws.

Ambiguous, Unenforceable Terminology

CMS fails to provide a legal or defensible standard for the some of the most problematic and ambiguous terminology in the rule including, but not limited to “all available alternatives,” “integrated in,” “full access to,” “the greater community,” “physical environment,” and “controlled residential setting” at the same time that it seeks to use these terms to determine eligibility and restrict choice.

The proposed rule will deny Medicaid funds from persons and settings based expressly upon these terms, resulting in substantial damages to the health and welfare of individuals, and the sustainability of otherwise eligible facilities. As a result, the proposed rule is unenforceable and so ambiguous that it will result in millions of dollars of unnecessary litigation.

Unsubstantiated Correlation

CMS again fails to establish a defensible, evidence-based, legal correlation between physical structure type, resident density, setting size or location AND suitability of certain included or excluded residential settings to serve the needs of disabled Americans.

Non-disabled individuals are free to choose to live in any physical housing structure or setting they desire. For example, a condominium tower housing hundreds of residents with a primary entrance point, common areas, and common tenant services is not considered an “institution.”



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Unsubstantiated Correlation *(continued)*

The proposed rule fails because CMS is attempting to legislate human behavior and provider practices by excluding certain settings. CMS has failed to provide evidence that the number of persons in a setting directly correlates to desegregation and/or abuse. There is not a single objective study that proves that four (4) or fewer unrelated persons in a setting is not segregated and is suitable as a home and community based setting, and that five (5) or more unrelated persons in a setting is segregated and is not suitable as a home and community based setting.

Moreover, there is no defensible evidence that the exact same home and community-based services funded by CMS and desired by otherwise eligible individual recipients provided in an individually owned or leased single family home or apartment cannot be provided in any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or a disability-specific housing complex.

CMS Seeks to Establish a Separate Class of HCBS Recipient

CMS's efforts and proposed language seek to establish a separate class of HCBS funding recipient based on their choice of setting by deeming the same person eligible for funding in CMS-approved setting, yet ineligible in a setting not CMS approved.

Abuse of Process

CMS again is abusing the rule-making process to broadly litigate what it describes as compliance with respect to the Community First Choice State plan option for the Affordable Care Act when, in fact, there is no requirement to do so. Perhaps the greatest travesty in the entire process of developing these proposed rules is that they divert attention and resources from the most pressing issues affecting persons with intellectual or developmental disabilities.

Proposed Rule Fails Affordable Care Act, Deficit Reduction Act

Contrary to CMS' claims in the preamble of CMS-2249-P2, CMS' proposed language that establishes what specific qualities are NOT home and community-based settings is in direct conflict with the Patient Protection and Affordable Care Act of 2010 ("PPACA"), the Community First Choice State plan option under PPACA, and the Deficit Reduction Act of 2005 as it relates to:

- strengthening consumer-controlled choice of services and supports
- supporting individuals with disabilities right to choose
- improving long-term care for the nation's disabled
- addressing long-term services and supports in a comprehensive way that guarantees disabled individuals the care they need
- supporting individual choice and self-directed services.

Proposed Rule Fails Social Security Act

CMS' proposed rule also is non-compliant with §1902(a)(23) of the Social Security Act regarding free choice of providers.



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US District Court Rules for Choice

CMS's efforts and proposed language are in direct conflict with a recent federal court ruling about patient's rights to receive the appropriate care of their choice. In the civil action No. 3:12cv59-JAG between the United States of America as plaintiff and the Commonwealth of Virginia as defendant, heard in the US District Court for the Eastern District of Virginia, a group of residents of Virginia's state-run Training Centers, which are congregate care facilities, petitioned the Court to be allowed to continue to reside at the Training Centers despite the federal government's efforts to close them.

In a May 9, 2012 ruling by US District Judge John A. Gibney, Jr., the Court stated:

"Furthermore, the Petitioners have a significant, protectable interest in receiving appropriate care of their choice and protecting their rights under the ADA. *See Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 602 (1999) ("Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.")

"In short, the Petitioners have a federally protected right, under *Olmstead* and the ADA, to receive the appropriate care of their choice."

The issues in this case and ruling are clear. The primary issue at stake is the quality of care provided the residents, not the characteristics of the setting. The residents have clearly stated that the quality of care they desire to receive and be funded by Medicaid can be provided and they desire it to be provided in their Training Center setting. The other issue the Court affirmed is choice and the right of individuals eligible to receive Medicaid funding to receive it in the setting of their choice.

Ignores Decades of Medical Findings, Treatments, and Supports

The proposed rule fails because it ignores overwhelming evidence that programs, treatments and supports designed expressly around an individual's diagnosis – Autism Spectrum Disorder (ASD), in this example – can be the most effective solution for Medicaid-eligible individuals.

The prevalence of ASD is now 1 in 88 children. More than 1.5 million people in the U.S. are diagnosed with ASD. In the next 10-15 years, more than 500,000 children under age 22 will reach adulthood and many will require housing. Diagnostic tools and physician training designed expressly to identify ASD at an earlier age have enabled parents and doctors to begin evidence-based early intervention treatments earlier and improve odds of recovery. Thirty states now have passed autism insurance mandates to force insurers to pay for testing and treatments designed to benefit children and young adults with ASD.

Two extraordinary reports published in the Fall of 2009 -- the result of six years of research and study by Southwest Autism Research & Resource Center, the Urban Land Institute, Pivotal Foundation, and Arizona State University – concluded that residential solutions designed expressly for individuals with ASD offered the best opportunity to address the housing needs and lifelong care concerns of affected individuals who choose those settings. The *Opening Doors* report, and its sister *Full Spectrum Housing* report can be accessed at: <http://autismcenter.org/openingdoors.aspx>.



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Fails to Recognize Impact on Successful Settings

Thousands of non-profit organizations currently providing, and planning to provide, innovative, compassionate residential solutions for disabled Americans will be significantly impacted by the proposed rule. In many cases, these residential services providers could be forced to close, displacing thousands of disabled individuals into settings unprepared and unsuitable for them. Many of these non-profit organizations derive the majority of their operational funding via HCBS. Declaring their business model non-compliant would have an immediate and devastating impact on the availability of residences for the individuals they serve.

RECOMMENDATIONS

We reiterate our earlier statement that the outcome of the rule-making process should not be to arbitrarily limit options and reduce choices. It should produce an outcome that expands choices, supports disabled Americans' right to choose, and removes barriers to innovation of and investment in residential settings desired by adults with Autism Spectrum Disorder and other disabilities. We implore CMS to cease-and-desist its efforts to impose its bias on disabled Americans and instead we encourage CMS to let the market decide which settings prosper.

1. **Expand Choice, Encourage Housing Innovation.** CMS should be focused on expanding opportunities for, and removing barriers to, development and construction of innovative new housing settings including, but not limited to: disability-optimized mixed-use campuses, farmsteads, home clusters, and disability-optimized urban redevelopment projects.
2. **Focus on the Person, Not the Setting.** We strongly urge CMS and US HHS to cease-and-desist their counter-productive efforts focused on defining what an eligible setting is NOT. We urge CMS and US HHS instead to focus their efforts and resources on programs such as Money Follows the Person to ensure that disabled Americans receive the federal and state funding for which they are eligible based on their disability rather than as determined by the setting in which they choose to live.
3. **Competitively Compensate Direct Care Professionals.** The average hourly rate of pay for a licensed Direct Care professional in Nevada is \$8.50. These dedicated professionals are responsible for the care and quality of life of disabled Americans, yet they are paid less than a high school student working at Starbucks. Staff turnover at facilities in Nevada is more than 50 percent annually. More and better trained care professionals are needed to meet the growing demand, but this can only happen if Medicaid compensates them at a competitive rate.
4. **Encourage Private Financing and Public-Private Partnerships.** CMS should be expanding opportunities for, and removing barriers to, development of and access to private financing and public-private partnerships that would offset, complement or replace public funding. Doing so would accelerate development and availability of residential settings that would reduce waiting lists, create jobs, improve pay and provide higher-quality services.



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5. **Eliminate Specific Language.** At a minimum, the language contained in this entire paragraph must be eliminated from this and future CMS efforts to revise Medicaid regulations related to residential settings, for all the reasons stated in this letter and comments:

Any other locations that have qualities of an institutional setting, as determined by the Secretary. The Secretary will apply a rebuttable presumption that a setting is not a home and community-based setting, and engage in heightened scrutiny, for any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex.

One last thought. On p. 26382 you include the remark "...we have facilitated and participated in multiple stakeholder discussions related to this issue." I have not been part of such discussions in the past, thus I would like to volunteer myself, in any or all the capacities under which I submit these comments, to participate in future stakeholder discussions.

Respectfully,

A handwritten signature in black ink that reads "Mark L. Olson". The signature is fluid and cursive, with a long horizontal stroke at the end.

Mark L. Olson
President & CEO
molson@ltoventures.org

Enclosure

- "Choice v. *Olmstead*"

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

Mark L. Olson

Chairperson, Community Living Subcommittee, Nevada Commission on Autism Spectrum Disorders; President & CEO, LTO Ventures (www.ltoventures.org); and, parent of a 16 year old daughter with Autism.

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 comments¹ 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 autism².

“...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 Association³.

“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)⁴

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, CMS⁵.

“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 Network⁶.

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 2010⁷:

“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* decision⁸.

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 laws⁹.

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 ASD¹⁰, and more than 500,000 of those individuals will reach adulthood by 2024¹¹. 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)¹².

“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 Association¹³.

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.* case¹⁴ 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*¹⁵.

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 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 independently¹⁶.”*

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) 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 Missouri¹⁷.

“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 Network¹⁸.

“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)¹⁹.

“*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 Disabilities²⁰.

“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 Texas²¹.

“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 Network²².

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, IL²³.

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 proposed²⁴.

- 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. Our public comment can be found at: 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. Our public comment can be found at: www.regulations.gov, keyword CMS-2296-P; document ID: CMS-2009-0071-1662.

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- ¹ 338 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.
- ² Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0867
- ³ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0684
- ⁴ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1401
- ⁵ *Federal Register*, Vol. 76, No. 73; April 15, 2011, p. 21312
- ⁶ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0962
- ⁷ <http://www.ncd.gov/publications/2010/Jan192010>, p. 89
- ⁸ 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
- ⁹ Disability Scoop website, "Medicaid Waiver Waiting List Triggers Federal Lawsuit," March 29, 2011; <http://www.disabilityscoop.com/2011/03/29/medicaid-waiver-lawsuit/12716/>
- ¹⁰ Centers for Disease Control and Prevention website; <http://cdc.gov/ncbddd/autism/data.html>
- ¹¹ Centers for Disease Control and Prevention, *Morbidity and Mortality Weekly Report*, February 9, 2007
- ¹² Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1452
- ¹³ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0890
- ¹⁴ 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.
- ¹⁵ *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
- ¹⁶ 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
- ¹⁷ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0354
- ¹⁸ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1286
- ¹⁹ Ibid 12
- ²⁰ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0986
- ²¹ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-0432
- ²² Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1476
- ²³ Regulations.gov website (www.regulations.gov), keyword CMS-2296-P; document ID: CMS-2009-0071-1261
- ²⁴ Ibid 5, p.21317