



June 3, 2011

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attn: CMS-2296-P  
Mail Stop C4-26-05  
7500 Security Boulevard  
Baltimore, MD 21244-1850

(via overnight delivery)

RE: Comment on CMS-2296-P; Home and Community-Based Services (HCBS) Waiver

Dear Secretary Sebelius:

We respectfully submit this letter and comments on behalf of LTO Ventures and other developers and providers of residential settings for adults with autism and developmental disabilities across the U.S.

LTO Ventures is a non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorders (ASDs). Our community model provides a continuum of "person-centered" residential, employment and social-recreational options suited to the needs and desires of each individual within a master-planned, community-based, *Olmstead*-compatible campus (see *Executive Summary*).

LTO Ventures' model combines the best design, financial and operational elements of senior living, gated residential and master-planned communities, as well as college campuses, and mixed-use live-work environments. The design model is enhanced by best practices developed from research into supportive and sustainable residential options for adults with ASD. The financial model will eschew government and insurance funds and be self-sustaining through partnerships with for-profit businesses, donations, investments, grants and volunteers.

The proposed rule change for HCBS Settings, specifically the language of the proposed new paragraphs under § 441.301(b)(1), FAILS on all counts and, if implemented, will have a devastating negative impact on current and future housing for hundreds, if not thousands, of Americans with ASD.

**We strongly oppose the addition of paragraphs § 441.301(b)(1)(iv), (iv)(A), (iv)(B), and § 441.302(a)(5) as proposed because:**

- **They will create a regulatory precedent that could be used by organizations or persons to oppose innovation of and investment in new residential settings and models**
- **They will severely restrict choices of suitable residential settings, denying affected Americans the right to choose and exacerbating an already-critical housing shortage**
- **CMS fails to provide a legal or defensible standard for "integration," "segregation" or "meaningful access" at the same time it seeks to use these terms to determine eligibility**
- **CMS fails to establish a defensible correlation between physical structure type, resident density, setting size or location AND suitability of certain residential settings to serve the needs of affected Americans**



- **CMS exceeds and abuses its authority in seeking to regulate what settings do not qualify as home and community based settings**
- **CMS is mis-using the rule-making process to broadly litigate what it describes as “...isolated situations that have emerged where States and other stakeholders are expressing interest in using HCBS waivers to serve individuals in segregated settings or settings with a strong institutional nature.”**

The outcome of this rule-making process should not be to arbitrarily limit options and reduce choices. It should produce an outcome that **expands choices** and **removes barriers** to innovation and investment in residential settings desired by ASD and developmentally disabled adults. We encourage CMS to facilitate development of the broadest range of choices to address the varied needs and desires of the Americans they are meant to serve, and let the market decide what settings should prosper:

- Separate Funding for Services from Funding for Housing. HCBS Waiver funding for housing must be separated from funding for support services. Until that fundamental change is made in the program, CMS is failing to address the real concerns of affected individuals.
- Competitively Compensate Direct Care Professionals. The average hourly rate of pay for a licensed Direct Care professional in Nevada is \$8.50 per hour. These dedicated individuals are responsible for the care of often severely-affected persons, 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. This significantly increases the cost of care, and unnecessarily creates discontinuity and disruption that affects the quality of care of affected individuals.
- Encourage Housing Innovation. CMS should be creating opportunities for, and removing barriers to, development and construction of innovative new housing settings including, but not limited to: farmsteads, mixed-use campuses, urban redevelopment, and home clusters.
- Encourage Private Financing. 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 and accelerate development and availability of housing to reduce waiting lists, create jobs, improve pay and provide higher quality services.

Respectfully,

A handwritten signature in black ink that reads 'Mark L. Olson' with a long, sweeping underline.

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

Enclosures



## COMMENT ON CMS-2296-P

### Where the Proposed Rule § 441.301(b)(1)(iv) Fails, and Why

Removes Choice. The proposed rule fails because it will severely restrict choice and the right of affected individuals and their parents and caregivers to evaluate and choose the residential setting they decide is most appropriate. 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.

Incorrectly Links Right to Choose With Physical Structure or Setting. 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.” CMS even recognizes that a retirement community for older individuals is not an institution if certain conditions are met. There is no evidence of fact to directly correlate an individual’s right to “*choose whether or with whom they share a room...freedom of choice on daily living experiences such as meals, visitors, activities, and...individuals’ opportunities to pursue community activities*” with the physical structure or setting in which they choose to reside.

Quashes Innovation and Investment in New Housing. The proposed rule fails because it will quash development of innovative residential settings and have a chilling effect on investment in housing that otherwise could reduce or eliminate the waiting lists. A University of Minnesota study reported 122,870 people were on the waiting list 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. 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.

Lack of Understanding of “Community”. The proposed rule 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. The Supreme Court’s *Olmstead* decision did not define the term community because the Court intended to let individuals choose that for themselves. 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.*

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## COMMENT ON CMS-2296-P

### **Where the Proposed Rule § 441.301(b)(1)(iv) Fails, and Why** (continued)

Many individuals with Autism Spectrum Disorder (ASD) 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.

Overreaching CMS' Authority. CMS is far overreaching its authority to codify that a particular setting is eligible in one physical location, but ineligible if on the grounds of, or immediately adjacent to, a different physical location. Individuals must be free to choose the setting they desire, irrespective of the location of that setting.

Attempts to Legislate Behavior by Restricting Places Where Behavior Can Occur. 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 of fact of the following:

- The number of persons in a setting directly correlates to desegregation and/or abuse. There is not one single study that proves that four (4) or fewer unrelated persons in a setting is not segregated and is a home and community based setting and that five (5) or more unrelated persons in a setting is segregated and is not a home or community based setting.
- Fails to adequately define the legal standard for "integration," "segregation," and "meaningful access." What constitutes HCBS-compliant integration in the community? What constitutes meaningful access? 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.

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, in this example – can be the most effective solution for Medicaid-eligible individuals.

The prevalence of ASD is now 1 in 110 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. Twenty-five states now have passed autism insurance mandates to force insurers to pay for testing and treatments designed expressly to benefit children and young adults with ASD.

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## COMMENT ON CMS-2296-P

### **Where the Proposed Rule § 441.301(b)(1)(iv) Fails, and Why** (continued)

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>.

Fails to Recognize Impact on Successful Settings. The determination by CMS, and related certification by the Secretary, not to prepare an analysis for the Regulatory Flexibility Act is profoundly erroneous. Thousands of non-profit organizations currently providing, and planning to provide, innovative, compassionate residential solutions for developmentally disabled individuals will be significantly impacted by the proposed rule. In many cases, these residential services providers could be forced to close, displacing thousands of developmentally disabled individuals into settings unprepared and unsuitable for them. Many of these non-profit organizations derive the majority of their operational funding via the HCBS Waiver. Declaring their business model non-compliant would have an immediate and devastating impact on the availability of residences for the individuals they serve.

Fails to Address the Real Issues. 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.



## EXECUTIVE SUMMARY

LTO Ventures is a non-profit company that develops live/work/play communities for adults with Autism Spectrum Disorders (ASDs) and related developmental disabilities. Our community model combines a continuum of “person-centered” residential, employment and social-recreational options suited to the needs and desires of each individual within a master-planned, community-based, *Olmstead*-compatible campus.

Existing community-integrated living arrangements such as group homes and supported residential settings provide appropriate housing, but in numbers severely lag the surging demand. Moreover, they offer no solution for the staggering lack of meaningful employment and social-recreational options available to ASD/DD adults. Chronic funding issues resulting from dependence on Medicaid, SSI and other government sources compound the shortfall.

LTO Ventures’ model combines the best design, financial and operational elements of senior living, gated residential and master-planned communities, as well as college campuses, and mixed-use live-work environments. The design model is enhanced by best practices developed from research into supportive and sustainable residential options for adults with ASD/DD. The financial model will eschew government and insurance funds and be self-sustaining through partnerships with for-profit businesses, donations, investments, grants and volunteers.

### PROBLEM

The United States is on the verge of a crisis as more than 800,000 children identified with ASD enter adulthood, including an estimated 500,000 by 2020. Residential, employment and social services and settings already lag demand so severely that this new generation of special needs Americans threatens to overwhelm public and private resources. The problem is worsening as the prevalence of ASD is 1 in 110 children and is “a continuing urgent public health concern” according to the U.S. Centers for Disease Control and Prevention.

- Live:** An estimated 122,870 persons are on waiting lists for residential services. 70% of adults with ASD live with parents or a family member until they can no longer support them. Residential settings provided by state and non-state agencies have grown significantly in the last 30 years, but not fast enough to meet the demand. ASD adults unable to find appropriate residential services often end up in nursing homes or mental hospitals ill-equipped to address their unique needs.
- Work:** Unemployment among ASD adults exceeds 90% and the average salary for employed adults averages \$4,824 annually. Most jobs are low-skill/low-pay positions, and may be part of programs paying sub-minimum wage (e.g. FLSA 14c). Many ASD adults want to work full time and can hold jobs given proper supports, but state vocational rehabilitation programs are underfunded and poorly designed.
- Play:** Social-recreational opportunities are severely limited by transportation, program availability, staff availability, hours of operation, and funding.
- Money:** The primary source is federal and state funding through Medicaid. States typically bear a matching load for room, board and specialized services, and may adjust placement rates based on available funds. The result is extensive waiting lists, low staff pay and turnover greater than 50% annually. The average wage for direct service staff providing primary care for an ASD adult in a group home is \$8.50-9.50 an hour.

### LTO VENTURES SOLUTION

LTO Ventures is developing a repeatable model for communities that will: 1) offer least restrictive housing with appropriate opportunity for interaction with the non-disabled community; 2) offer onsite employment to 100% of residents at minimum wage or better; 3) offer onsite social-recreational programs convenient to residents; and, 4) be financially and operationally self-sustaining and independent of government and insurance money.

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### Key Facts & Market Data:

**122,870**

Number of people on waiting lists for ID/DD residential services

**800,000**

Number of Americans diagnosed with ASD who are aged 0-21

**90%+**

Rate of unemployment among adults with ASD

**\$4,824**

Average annual salary earned by an employed adult with ASD

**\$8.50-9.50**

Average hourly wage for residential direct care staff in a group home.

**50%**

Average annual staff turnover for residential direct care staff serving ASD adults

**75%**

Percentage of autistic individuals who become institutionalized as adults or are unable to live independently.

**90%**

Percentage of costs of caring for a person with ASD in adult services.

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## EXECUTIVE SUMMARY (page 2)

### SOLUTION (continued from p. 1)

Our communities will be designed to be safe and secure and accommodate hundreds of residents in a single campus, creating innovative residential settings faster than group homes can be brought online. Each community will provide:

- Residential options that include a continuum of care from individual and shared apartments to group homes to multi-unit buildings. Residents will be evaluated and matched to a domicile based on desired setting, living skills, medical need and financial resources. Residents will have the opportunity to transition to more independent settings within the community, and each community will accommodate the needs of aging residents.
- Employment options onsite that match the abilities of residents and pay market wages. Residents also will be free to pursue off-campus employment. Buildings integrated with the campus will house for-profit and non-profit businesses in partnership with existing employers as well as created by resident and outside entrepreneurs. These businesses will contribute to the revenues of the community and the wages will enable the residents to pay rent, purchase services and have discretionary income.
- Social-recreational options onsite that range from therapy and exercise rooms, pool, gym, TV and movie room, music and art rooms, café, bowling, and a meeting facility. Residents also will be free to pursue social and recreational activities off-site.

Communities will be vehicle-free, access-managed campuses that engage in outreach to involve the non-disabled community while providing ingress/egress control to guard against wandering or elopement and ensure the safety and security of residents and staff. Each community will be located near population centers that provide an ample paid and volunteer staffing pool, transportation, retail businesses and professional services.

### COMPETITION

The role of states as residential service providers has dramatically declined in the wake of the landmark 1999 *Olmstead v. L.C.* U.S. Supreme Court decision and the Community Choice Act of 2009. States accelerated the deinstitutionalization of persons out of large state-run facilities into homes, apartments, and community-based settings, mostly supported and/or operated by private providers, primarily funded through Medicaid. These settings typically include:

- Small Intermediate Care Facility-Developmentally Disabled (ICF-DD) – Community-based residences similar to group homes serving up to six persons, providing facility-based programs. Funding for the facility and support services stay with the facility, not the person.
- Group Homes – Community-based residences typically serving up to four persons and providing varying levels of support services based on the needs of residents.
- Self-Owned or Family Homes – Typically community-based residences serving one or two persons and owned or leased by the resident or family member. Private organizations provide varying levels of support services based on the needs of residents.
- Agricultural Communities/Farmsteads – Supported living arrangements in single-family homes or multi-unit dwellings serving four or more persons in farm or agricultural settings.
- Developmental Homes – Community-based private residences serving up to four persons where residents are integrated into family settings similar to foster care.
- Nursing homes/mental hospitals – when no other options are available.

### MARKETING / SALES

LTO Ventures plans to attract new residents through referrals from state regional centers, school districts, and autism advocacy/support groups, as well as online and offline marketing, public relations, events and word of mouth.

### FINANCIALS / FUNDING

LTO Ventures presently is raising funds to be used for: market/model research; board recruitment; engaging legal and accounting non-profit professionals; consulting a planner/architect; filings/licenses/fees; 501(c)(3) application; website development; marketing materials; and next-round fundraising.

### Leadership



**Mark L. Olson**  
*President & CEO*

Mark is father to a teenage daughter with autism. After a successful 25-year marketing and business development career in New York and Silicon Valley with F500 leaders and venture-funded startups, he founded LTO Ventures to serve adults with ASD. He chairs the Community Living Subcommittee for the Nevada Autism Commission, and is a graduate of the University of Kansas. For more, visit:

[www.linkedin.com/in/marklolson](http://www.linkedin.com/in/marklolson)



**Kimberly M. Breiting**  
*Director*

Kim is a lawyer focused on ASD, special needs and education. She began as a behavior therapist for ASD children and added a law degree to tackle issues facing special needs families. Kim has served as a public defender and brings her legal acumen to advocate LTO Ventures' vision. She graduated magna cum laude from Florida State University and cum laude from Seattle University School of Law.

### Board of Directors / Advisors

LTO Ventures is actively recruiting board members and advisors with proven track records and expertise in: nonprofit law and accounting; residential design and development; autism services; finance; land acquisition; and, fundraising.

### MILESTONES

Preliminary community model.....	Jun
501(c)(3) application.....	Jul
Advisory Committees filled.....	Aug
Board of Directors filled.....	Sep
Funding round.....	Oct

### Autism Spectrum Disorders

The technical term that refers to a group of developmental disorders including: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), Asperger's Syndrome, Rett's disorder and childhood disintegrative disorder.