



December 19, 2014

Ms. Marilyn Tavenner,  
Administrator & Chief Operating Officer  
Centers for Medicare & Medicaid Services  
U.S. Department of Health and Human Services  
Room 445-G Hubert H. Humphrey Building  
200 Independence Avenue S.W.  
Washington, D.C. 20201

Via email

**RE: Compliance Concerns regarding HCBS Final Rule CMS-2249-F and CMS-2296-F**

Dear Administrator Tavenner:

The Coalition for Community Choice (CCC) is writing to thank you for your ongoing commitment to the integration of individuals with disabilities. We believe individuals with disabilities should have the broadest range of affordable and accessible housing options, and we encourage the formation of public-private partnerships to create local solutions for the national housing crisis.

CCC sent a letter dated March 4, 2014, to thank the Centers for Medicare & Medicaid Services (CMS) for the outcome-oriented criteria, mandated public comment, and authority of person-centered plans (PCP). The letter outlined our concerns and interest in providing input for the upcoming guidance publication. Currently, the CCC has more than 85 organizations and is growing. Our Coalition is dedicated to person-centered supports and life opportunities. We recognize innovative living arrangements that reflect individualized styles and choices for living that serves the unique interests, supports and services individuals with disabilities need to live as independently as possible.

Many CCC members expressed concerns with some states' interpretation and implementation of the Toolkit during their transition process based on the CMS issued Informational Bulletin dated March 20, 2014, entitled "Home and Community-Based Service (HCBS) 1915(c) Waiver and 1915(i) State Plan Amendment (SPA) Settings' Requirements Compliance Toolkit." State leaders cited the Toolkit document, *Guidance on Settings that Have the Effect of Isolating* as reason why HCBS funds cannot be used in settings such as farmsteads, live-work-play communities, and other congregate settings. Furthermore, there is concern that the congregate settings highlighted in the Toolkit will not be individually assessed if a state chooses to implement more restrictive setting criteria.

We are concerned about state-level confusion in the wake of this new Toolkit. We seek further CMS guidance to clarify the confusion that intentional living communities are permissible under HCBS funds so that our constituents can work with their state leadership to best serve the needs of individuals with intellectual and developmental disabilities (I/DD). The flexibility and person-centered intent of the Final Rule will lead to public-private innovations that are positive, long-term, desirable, and can help meet the growing demand.

We want to offer our support to you in your efforts to help states implement the Final Rule. Millions of Americans with disabilities are impacted. Self-advocates, parents, extended families and community leaders would like to be involved in solving a portion of the national housing issues within their counties and cities. As individuals with I/DD and families are planning, they want assurance that in 20 or 30 years, they will not fall through the cracks and be shuffled from place to place.

The Coalition for Community Choice strives to increase the supply of housing so that individuals can have more choice and control in housing opportunities. Many individuals should have a variety of housing locations and settings that meet their support needs, are affordable, and allow choice in living styles. HCBS regulations should not be used to restrict innovative living opportunities.

We ask that CMS consider three requests:

- 1) Please do not accept State Transition Plans that do not follow the intent of the Final Rule by including HCBS criteria that is neither outcome-oriented nor based on individual experience.
- 2) Provide further clarification to state leaders that congregate intentional living settings should not be dismissed as not meeting HCBS criteria.
- 3) Request that states publicly post all public comments as well as the state summary of public comment that will be sent to CMS to ensure accountability to stakeholders.

We appreciate your continued efforts to ensure quality settings and we look forward to working with you on these issues.

Sincerely,

*JaLynn Prince, President & Co-founder*

**Madison House Autism Foundation**

A public 501(c) 3 not-for-profit, national organization working to eliminate barriers and increase opportunities for adults on the autism spectrum.

cc. *Cindy Mann, Deputy Administrator & Director, CMS*  
*Ralph Lollar; Director, Division of Long Term Services and Supports, CMS*

*[Attached list of CCC signatories are listed alphabetically by state and last name]*

## NATIONAL ORGANIZATIONS

### 1. Agricultural Communities for Adults with Autism

*Gene Bensinger, Co-Founder*

A consortium of 35 established and developing provider organizations focused on sharing best practices and advocating for holistic, agricultural based employment and housing models for adults with autism.

### 2. College Living Experience

*Stephanie Martin, President*

Provides post-secondary supports to students with I/DD and on the autism spectrum. Dedicated to providing the highest quality of individualized services in the areas of academics, independent living, social skills, and career development.

### 3. The Daniel Jordan Fiddle Foundation

*Linda Walder Fiddle, Esq., Founder & President*

Develop, advocate for, and fund Signature Programs that create innovative blueprints for grassroots organizations and service providers to develop their own programs for the diverse population of adults living with ASD.

### 4. Families Speaking UP

*Teesie Bonk, Micki Edelson, Co-Founders*

A grassroots movement of people with IDD, their families and caregivers advocating for a variety choices for ALL people with IDD.

### 5. FRED Conference

*Mari-Anne Kehler, Executive Director*

While originally focused on agricultural communities as a solution to the growing challenge for living options, FRED has grown into a movement to advance the ability for special needs adults to live with real purpose regardless of the housing options.

### 6. IMPACT Autism

*Diana O'Brien, Founder & Chairman*

IMPACT Autism seeks to change the world for people living with autism through life management solutions that help overcome the educational, emotional and social challenges of autism through each life stage. Our driving vision of the future is to build communities where every child and adult with autism can be an enriched, engaged, healthy and productive citizen in a safe vibrant environment.

### 7. VOR, Speaking Out for People with Intellectual Disabilities

*Tamie Hopp, Director of Government Relations & Advocacy*

In developing principles that reflect individual differences, VOR rejects a "broad brush" approach to rights and principles which apply to most individuals with disabilities, but not all.

## ARIZONA

### **8. Chapel Haven West, Inc.**

*Michael P. Storz, President*

Chapel Haven West serves those on the autism spectrum and those with mild developmental disabilities, teaching them to live independent and productive lives in a residential transitional program.

### **9. First Place**

*Denise Resnik, Founder & Board Chair*

First Place represents home for individuals who live there, peace of mind for family and friends who come and go, and an inspiring and enriching environment for those who work and learn there. It represents a new residential prototype for adults with autism and related disorders and individuals without disorders, that aspires to be an international model.

### **10. Toscana Properties**

*Alex J. Krem, President*

A 24 unit apartment complex in Phoenix that fosters independent living in a caring, supportive environment for its residents.

## CALIFORNIA

### **11. Autism Society of the San Francisco Bay Area**

*Jill Escher, President*

Autism Society San Francisco Bay Area advocates on behalf of the more than 12,000 autism families in the SF Bay Area region, focusing on the urgent need to expand housing, day program, and support options for the burgeoning population of young adults with autism and significant functional limitations.

### **12. Big Wave Group**

*Jeff Peck, President*

Big Wave Project, El Granada aims to create an inclusive and interactive community of people and businesses; provide a purposeful, independent life for individuals with developmental disabilities through affordable housing, meaningful employment, and supportive community; benefit the Coastside and the environment.

### **13. Camping Unlimited**

*Alex J. Krem, Interim Executive Director, Treasurer, & Member of the Board*

Established in 1957, Camping Unlimited provides recreational activities for over 5,000 special needs children and adults for 10 weeks in summer and every weekend of the year.

### **14. Casa de Amma**

*Aaron Vorell, Executive Director*

Casa de Amma believes adults with special needs can and should be productive, contributing members of their community. Our supported living environment provides every opportunity for life long learning and achieving personal potential.

### **15. Costanoa Commons**

*Heidi Cartan, Founder & Executive Director*

Inspired by the L'Arche communities, Costanoa Commons is a non-profit organization working to create a life-long community for adults with disabilities, located on an urban farm where meaningful employment is available in our aquaponics greenhouse and on our organic farm.

### **16. Golden Heart Ranch**

*Rose Van Wier Hein, Executive Director & Founder*

GHR is dedicated to building an intentional residential community where special needs young adults can live, learn, and work side-by-side in a harmonious and caring environment that is emotionally and physically safe.

### **17. Home of Guiding Hands**

*Mark Klaus, Executive Director*

A 501(c)(3) nonprofit public benefit corporation that provides quality support and training services to individuals with developmental disabilities. As an industry leader for more than 45 years, HGH is dedicated to providing innovative services that meet and exceed the needs of people with developmental disabilities.

### **18. Life Services Alternatives, Inc.**

*Dana Hooper, Executive Director*

Provides exceptional community-based living experiences and services for people with special needs through licensed, community-based homes and individual programs.

### **19. Moving Forward Towards Independence**

*Don Fann, Executive Director*

Moving Forward is a unique residential community of adults with developmental and learning disabilities, autism, and other neurological conditions that trains and supports residents to live independently as fully as possible.

### **20. Peak Partners LLC**

*Mark Jackson, President*

A real estate investment and consulting company that is committed to creating high-quality, comprehensive living solutions for adults with developmental disabilities in small, integrated shared-housing settings.

### **21. Reid's Gift, Inc.**

*Molly K. Rearick, Founder & Director*

We believe everyone has the right to a high quality of life. We strive to grow and support independence, fulfillment, and community engagement for individuals with developmental disabilities.

### **22. Sunflower Hill**

*Susan Houghton, Executive Director*

Seeking to change the paradigm of institutional and home living options by creating a sustainable, supportive and intentional community for individuals with special needs that is akin to senior living.

**23. Vine Village, Inc.**

*Saenen Kerson, Assistant Director*

Located on a beautiful 25-acre ranch, our residential and art/country day programs are designed to meet each individual's needs for a balance between support and independence. Our programs emphasize personal development, social interaction, independence and the security of knowing he or she is accepted and valued.

**COLORADO**

**24. Promise Ranch Therapeutic Riding**

*Mark Scheuneman, Executive Director & President of the Board*

Proudly provide therapeutic riding, equine assisted activities, and hippotherapy to individuals who have physical and developmental disabilities.

**25. Rooster Ranch**

*Blair Wyles, Founder*

Rooster Ranch is a place where people of all abilities will find their foundation, explore budding interests, and grow into an interdependent community.

**26. Sundance Therapy LLC**

*Jeffrey Galloway, President*

Offering Occupational Therapy with focus on Animal Assisted Therapy, Hippotherapy, Sensory Integration, Mindfulness.

**27. Tall Tales Ranch**

*Susan Mooney, Co-Founder*

Tall Tales Ranch is dedicated to providing a life sharing community where both people with and without disabilities can live in a supportive, cooperative environment that honors their individuality, celebrates their uniqueness and helps them to reach their full potential.

**CONNECTICUT**

**28. Chapel Haven, Inc.**

*Michael P. Storz, President*

Residential transition program serving those with autism, Asperger's, and other adults with developmental disabilities.

**DISTRICT OF COLUMBIA**

**29. M&L Special Needs Planning, LLC**

*Maedi Tanham Carney, Certified Financial Planner*

Educate families in an emphatic, methodical, non-threatening way by providing workshops and creating financial security with comprehensive special needs life plans and government benefit counseling.

## DELAWARE

### **30. Homes for Life**

*Micki Edelson, Founder*

Homes for Life is constructing and furnishing homes for men and women with intellectual/developmental disabilities.

## FLORIDA

### **31. Adonis Autism**

*Terry Kays, President*

Adonis Autism will strive to enhance the quality of life for people living with autism by providing resources, activities, information, advocacy and support to those who love someone living with autism.

### **32. The Arc Jacksonville**

*Jim Whittaker, President & CEO*

Together we unlock potential for achievement at home, at work, and at play. The Arc Jacksonville believes we all have the right to be in community and to make personal decisions about how we live, learn, work and play.

### **33. The Loveland Center**

*Carl Penxa Jr., President & CEO*

It is the Loveland Center's mission to help adults with developmental disabilities live their lives to the fullest. Loveland Center's vision is to become a leading innovator in providing services to adults with developmental disabilities.

### **34. Mariposa Village**

*Deborah Lawrence, Director*

Mariposa Village is an active non-profit organization working to create solutions to the limited affordable housing, recreational and vocational opportunities for persons with developmental disabilities in South Florida.

### **35. Noah's Ark of Central Florida**

*Jack Kosik, Executive Director & Co-Founder*

Noah's Ark was founded in 1997. Their first homes at Noah's Nest in Lakeland were constructed between 2002 and 2007 with a community planned for opening in late 2015. There are currently 16 residents living independently with the support of their fellow residents, family and friends. They all enjoy an active lifestyle and most importantly, continue to develop all of the skills needed to ensure independent living.

**36. OCA - Opportunity, Community, Ability**

*Chuck Carter, President*

It is OCA's goal that every individual that walks through our doors will have an Opportunity, in or out of the Community, to maximize their Ability.

**37. Osprey Village CoHousing Community**

*Debby Lasik, Co-Founder*

We are a group of parents of persons with disabilities creating a multi-generational diverse co-housing community.

**38. Parents Planning Programs (PPP), Inc.**

*Lila Klausman, President*

An organization formed by parents seeking to prepare for the future of their loved ones who have developmental disabilities in Florida.

**39. Promise in Brevard**

*Betsy Farmer, Co-Founders*

A place where young adults with special needs can live a life full of opportunities and freedom never thought possible

**ILLINOIS**

**40. Misericordia Heart of Mercy**

*Sister Rosemary Connelly, Executive Director*

Through a spectrum of residential options on its 31-acre Chicago campus and in the community, and with a wide variety of programs, Misericordia offers a community of care that maximizes potential for persons with mild to profound developmental disabilities.

**MASSACHUSETTS**

**41. Cape Cod Village**

*Bob Jones, President*

To meet the ongoing residential and community living needs of adults on the autism spectrum.

**42. New England Communities, Inc.**

*Marc Slotnick, President*

A housing development firm dedicated to the creation and preservation of affordable housing for those with disabilities and the elderly.

**MARYLAND**

**43. Purposeful Architecture**

*Cathy Purple Cherry, Principal*

Purposeful Architecture projects a unique sensitivity to the world of special needs and fully understands the methods, programs and environments that most successfully support this incredible group of individuals.



## MICHIGAN

### **44. AACORN Farm (Autism Agricultural Community Option for Residential Need)**

*Catherine Pinto, Board President*

AACORN Farm strives to provide a dynamic experience for adults with autism or developmental disabilities. This agricultural community supports our 'farmers' in reaching their full potential through meaningful interactions, work, and leisure activities.

### **45. Benjamin's Hope**

*Krista Mason, Executive Director*

Benjamin's Hope is a first of its kind community model designed to address the multifaceted needs of individuals and families affected by autism and developmental disability.

### **46. The DD News Blog**

*Jill Barker, Author & Editor*

The DD News Blog supports choice and the availability of a full range of services and settings to meet the diverse needs of people with developmental disabilities.

### **47. Special Dreams Farm**

*Larry Collette, President*

Special Dreams Farm is a full time skill building program specifically for developmentally disabled adults emphasizing socialization, exercise, and fresh air on 31 beautiful acres.

## MISSISSIPPI

### **48. The Baddour Center**

*Parke Pepper, Executive Director*

A non-profit residential community serving adults with I/DD. The Center is committed to providing programs, supports and services for the purpose of promoting maximum growth and empowering residents to make decisions and choices which lead to personal satisfaction and quality of life.

## NEW HAMPSHIRE

### **49. Farmsteads of New England, Inc.**

*Deborah DeScenza, Founder & Executive Director*

Farmsteads of New England, Inc. was created to provide a farming environment that is conducive to a meaningful and satisfying life for people who have autism and other developmental disabilities and who are seeking a holistic lifestyle that supports their vocational, recreational, and residential needs.

### **50. The Lukas Community**

*David Spears, Executive Director*

A shared living residential community for adults with IDD. Lukas provides a caring, therapeutic environment in which each person is recognized as a unique human being with dignity, freedom and purpose.

## NEW JERSEY

### **51. Bergen County's United Way**

*Thomas Toronto, President*

Affordable housing developers specializing in building supportive housing for people with developmental disabilities with a particular focus on purpose built housing for people on the autism spectrum.

### **52. Parles Rekem, LLP**

*Lisa Parles, Esq.*

Parles Rekem, LLP is a New Jersey based law firm representing children and adults with special needs and their families.

### **53. Supportive Initiatives for Brothers and Sisters in New Jersey (SIBS NJ)**

*Kara Sellix, President & Co-Founder*

Comprised and organized by siblings and sibling supporters, SIBS NJ seeks to help siblings connect with one another and to the resources they need to help them and their siblings with disabilities live full, meaningful lives.

## NEVADA

### **54. LTO Ventures**

*Mark Olson, Founder, President & CEO*

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

## NEW YORK

### **55. SustainAbility Services, Inc.**

*Wendy Kaplan, Executive Director*

SustainAbility Services is a non-profit organization that works on the staffing, residential and employment needs of adults with autism and other IDD. One of our projects has been to create a thriving organic vegetable farm which we plan to expand to give more residential options to people, with and without autism or other developmental disabilities, who love to farm.

## OHIO

### **56. Autism Society of Northwest Ohio**

*Linell Weinberg, Executive Director*

We provide support, education, and advocacy to individuals, parents, family members, and professionals affected by autism across the lifespan and the entire autism spectrum in 12 counties in Northwest Ohio. Our mission is to improve the lives of all affected by autism.

**57. Bittersweet Farms**

*Vicki Obee, Executive Director*

The mission of Bittersweet, Inc. is to positively impact the lives of individuals with autism and those whose lives they touch.

**58. Good Works Farm, Inc.**

*Nancy Bernotaitis, Executive Director*

Good Works Farm is to provide an environment where adults with autism can learn, work, grow and become a vital member of a community, where they are respected and treated with dignity.

**59. Safe Haven Farms**

*Dennis Rogers, President & Co-Founder*

Safe Haven Farms offers an integrated day vocational and residential setting where each individual is part of a close-knit supportive farm family. Their participation in the therapeutic cycle of farm life fosters self-sufficiency, independence, and a sense of achievement. There are significant opportunities to learn new skills and develop friendships with their housemates, staff, and neighbors.

**60. Stepping Stones**

*Sam Allen, Director Programs & Operations*

Stepping Stones provides year round recreation and leisure programs for individuals with autism. Specifically, the agency provides weekend respites, summer day camps, weekend day programs and educational programs.

**PENNSYLVANIA**

**61. EASI Foundation**

*Amy Lutz, President*

EASI Foundation, Ending Aggression and Self Injury in the Developmentally Disabled, supports autistic individuals with dangerous behaviors and their families by cultivating an online resource guide, connecting caregivers, and educating parents and providers.

**62. Juniper Hill Farms**

*Diane Belnavis, Executive Director*

Juniper Hill Farms is a model of independent living for adults on the autism spectrum. We are just guys renting in the community, on a small farm with lots of animals... and fields of sunflowers in the summer.

**SOUTH CAROLINA**

**63. Osprey Village**

*David Green, Director of Development & Operations*

Working to develop a "neighborhood with a purpose" to be an integral part of an intentional, inclusive community where adults with developmental disabilities can live as independently as possible alongside seniors, families, volunteers, and staff in service of one another.

## TENNESSEE

### 64. Brightstone

*Brenda Hauk, Executive Director*

Provides a comprehensive work, social support, and future residential community for adults with special needs, expanding their potential and helping them to develop mentally, physically, socially, emotionally, and spiritually.

## TEXAS

### 65. Autism Treatment Center

*Anna Hundley, Executive Director*

The Autism Treatment Center provides lifetime services and supports for adults with autism.

### 66. Down Home Ranch

*Jerry Horton, Co-Founder & Executive Director*

With 32 Ranchers plus about 30 staff and staff family members living on the Ranch, Down Home Ranch is a working farm and ranch, caring for 330 rolling, forested acres of the Post Oak Savannah in Central Texas.

### 67. The Marbridge Foundation

*Scott McAvoy, Vice President of Operations*

Our vibrant community provides residential care to more than 240 adults with intellectual disabilities. Unlike group homes for mentally challenged adults, our 170-acre campus consists of three interconnected communities where we provide varying levels of care from skilled nursing and physical rehabilitation services, to assisted living, to semi-independent care.

### 68. New Danville

*Kathy Sanders, Founder & President*

A master-planned, integrated community where adults with intellectual, developmental and/or physical disabilities can Live, Learn, Work and Grow socially, spiritually and emotionally with their non-disabled peers in a caring environment.

### 69. Therapeutic Communities, LLC

*David Seaton, Founder & CEO*

Nestled on 8 beautiful, tree-covered acres, LiveOak Therapeutic Communities is a small residential program offering person-centered support for adults living with brain injuries and other cognitive disabilities.

## WASHINGTON

### 70. Because We Care - Beyond Inclusion

*Cheryl Felak, Founder*

We support a continuum of care which looks at individual, family and community strengths to promote health, safety, relationships and quality of life for people with intellectual disabilities.

**71. Lakeland Village Associates**

*Bonnie Sullivan, President*

Lakeland Village Associates' purpose is to provide appropriate, comprehensive, quality services that meet individual needs, honor human and legal rights, and promote independence and self-management in personalized home-like environments.