



September 27, 2013

The Honorable Kathleen Sebelius
Secretary
U.S. Department of Health and Human Services
330 Independence Ave., SW
Washington, D.C. 20201

Marilyn Tavenner, Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
Room 445-G, Hubert H. Humphrey Building
200 Independence Avenue SW
Washington, DC 20201

Dear Secretary Sebelius and Administrator Tavenner,

Madison House Autism Foundation has been made aware of a letter dated September 3, 2013 from Dohn Hoyle, Executive Director/CEO of The Arc Michigan that expresses concern about the building of new group homes, the colocation of group homes, proposals for disability specific campuses with group homes, etc. We would like to provide a different perspective in concert with the organizations that have signed this letter.

In April 2013, more than 20 national experts serving those with autism and other intellectual/developmental disabilities (I/DD) met in roundtable forum, [Spectrum of Possibilities: Decreasing Barriers, Increasing Options](#), to consider housing options. Parents, autistic adults and others with I/DD are developing public-private partnerships to create local solutions that fit their specific support needs and wishes. Now, however, policy developed to protect and empower those with I/DD is creating barriers to appropriate housing.

Each person is entitled to the most integrated setting for that person's needs, determined on a case-by-case basis. Many autistic adults and others with I/DD are adversely affected by unstructured settings. These settings can be isolating, provide too little assistance and/or supervision, and are thus detrimental to the individual. In sharp contrast, an article is enclosed featuring a community festival in support of Benjamin's Hope, one of the very residential homes for autistic adults that Mr. Hoyle describes as segregated and isolating. Hundreds of community supporters attended the event, including "those . . . who shared [a] vision for a campus where

the developmentally disabled would feel as comfortable as those without and were driven to help” ([Holland Sentinel](#), Sept. 12, 2013).

The undersigned agree on and ask for your support for the following principles:

1. We understand that the *Olmstead v. L.C.* decision protects against involuntary placements and upholds one’s right to choice of residential placement, support services, and community. Yet, this important ruling is misinterpreted when used to exclude or limit residential options in cases where residents with I/DD voluntarily choose to live with self-determined lifestyles and desired support services or when used to exclude any residential setting modeled after communities.

2. We believe that any definition of “home” and/or “community,” which excludes specific settings, proximity of residences, limits number of residents with I/DD, etc. should be recognized as discrimination. An individual with I/DD has the right to choose a home and community appropriate to his or her support needs, a right which is given to the general population.

The number of people with autism and others with I/DD without residential programs is unprecedented and growing. Ideologically forced integration of individuals without regard to needs and preferences is inconsistent with the needs of the autistic community and other individuals with I/DD. More significantly, restricting choice violates the letter and intent of the *Olmstead* decision. We strongly urge you not to implement any policy that would create barriers to innovative housing models, discriminate against and limit individual choice, and/or further restrict already scarce residential opportunities and limited resources.

We would be happy to discuss our concerns and views with you and/or provide detailed information.

Sincerely yours,

JaLynn Prince, President and Co-Founder
Madison House Autism Foundation

A public 501 c 3 not-for-profit, national organization working to eliminate barriers and increase opportunities for the rapidly growing numbers of adults with autism.

(In alphabetical order by last name)

Cathy Purple Cherry, Principal
Purple Cherry Architects & Purposeful Architecture, Annapolis, MD
Purposeful Architecture is an architecture firm committed to creating spaces that foster thoughtful learning and living environments that inspire creativity and individuality in our children and adults with special needs.

Micki Edelsohn, Founder and Treasurer
Homes For Life Foundation, Wilmington, DE
A 501(c)(3) organization dedicated to raising funds to build safe and comfortable group homes for men and women with IDD.

and

Founder
Families Speaking UP
A grassroots movement of people with IDD, their families and caregivers advocating for a variety choices for ALL people with IDD

Laurie Nicoli, Board Member
Pat Swanson, Board Member

Luke & Betsy Farmer, Co-Founders
Promise in Brevard, West Melbourne, FL
A place where young adults with special needs can live a life full of opportunities and freedom never thought possible

Cheryl Felak, RN, BSN, Founder
Because We Care - Beyond Inclusion, Seattle, WA
Holistic care approach supporting 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

Mari-Anne Kehler, Director
FRED Conferences
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.

Jack Kosik, Executive Director
Noah's Ark of Central Florida, Lakeland, FL
Addressing the concerns of people with developmental and intellectual disabilities

Mark L. Olson, President & CEO
LTO, Henderson, NV
LTO Ventures is a 501(c)(3) non-profit company in Henderson, NV that develops live/work/play communities for adults with autism spectrum disorders.

Kathleen Miller, President
The Parent Hospital Association (PHA), CA
In support of the dedicated staff and management of the Sonoma Developmental Center, the Parent Hospital Association advocates for residents of SDC and others with developmental disabilities in Northern California.

Mark R. Klaus, President / CEO
Home of Guiding Hands (HGH), El Cajon, CA
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.

Ann S. Knighton, President
VOR
A national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

Carmen B. Pingree, Advisory Board
Carmen B. Pingree Center for Children with Autism, Salt Lake City, UT
Provides comprehensive treatment, education and related services for children with autism and their families

Neil J. Pollack, CEO/Executive Director
Anderson Center for Autism, Staatsburg, NY
Located in Staatsburg, NY, with additional adult homes situated throughout the community, Anderson Center for Autism, a not for profit organization, offers the highest quality year round day and residential programs to children and adults who have been diagnosed on the autism spectrum.

Denise D. Resnik

Founder and Board Chair of First Place AZ

A nonprofit dedicated to developing new housing options for adults with autism and related disorders.

Rose van Wier Hein, Founder/Executive Director,

Golden Heart Ranch®, Hermosa Beach, CA

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.

cc:

The Honorable Bill Huizenga, U.S. Member of Congress, House of Representatives

James K. Haveman, Director, Michigan Department of Community Health