April 10, 2018

Dear Secretary Azar, Administrator Verma and Mr. Lynch:

We are writing in response to the alarming demands for an expanded process of heightened scrutiny submitted by the Center for Public Representation and the National Health Law Program on behalf of twenty organizations (henceforth referred to as “the HCBS Advocacy Coalition”) determined to force all adults with intellectual and developmental disabilities (I/DD) into small, dispersed residential and vocational settings — whether or not those are appropriate or even desired by waiver recipients.

We applaud CMS’ desire to support adults with I/DD in community settings, and completely agree that those who want to live and work in the greater community should receive whatever services they require to succeed. However, the campaign to solely fund small, dispersed, “integrated” settings is just as dangerous, paternalistic, and ideological as the forcible institutionalization of the mid-20th century to which it responds. We reiterate, because this one point should be sufficient to end this debate, that this is an ideological crusade rather than an evidence-based agenda: although the aforementioned advocates have long maintained that “studies” show that small, dispersed settings are best for adults with I/DD, an independent review of the literature by Dr. David Mandell, ScD., Director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, found that, although “decisions about [residential] care may have the most profound effect on well-being and happiness...our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data.”¹

Not only is there no scientific evidence behind the one-size-fits-all model of residential and vocational supports, but the lack of more intensive, structured settings for our most

¹ David Mandell, “A house is not a home: The Great Residential Divide in Autism Care,” *Autism* 2, no. 7 (2017), 811.
impaired adults has resulted in catastrophic consequences. Mandell notes that “today, media exposés of abuses in community settings rival those of psychiatric hospitals a generation before.” Recent investigations of group homes in New York, Chicago and Philadelphia found rampant abuse and neglect in small, dispersed settings that, as Mandell reports, “often are not up for the task of caring for individuals with more profound impairments.” Undoubtedly, it was his fear of exactly these outcomes that motivated Justice Anthony Kennedy to warn, in his concurring opinion to the 1999 Olmstead decision, “It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision.”

But this debate isn’t just about those with the most severe intellectual and developmental disabilities. Many Americans choose to live with peers in retirement, religious and ethnic communities – there’s even an “adult dorm” in Syracuse for lonely Millennials. It is only when adults with I/DD choose to live and work with their peers that opponents claim these settings are “isolating” and “segregating” – resulting in the heartbreaking irony that adults with I/DD represent the only population in this country denied the civil right to decide where and with whom they live, and that this outcome is largely due to the influence of groups allegedly concerned with preserving the rights of the disabled. It is the height of arrogance for the HCBS Advocacy Coalition to insist it knows what’s best, even as applications pile up for new projects like First Place in Arizona, which consists of 55 apartments for adults with autism, and the 97-unit The Arc Jacksonville Village in Florida. We encourage you to visit these communities, as well as others all over the country whose names and contact information we would be happy to provide.

On a practical level, the more elaborate process of heightened scrutiny demanded by the HCBS Advocacy Coalition would devour the time and funding of already stretched

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2 Mandell, 810.


6 Mandell, 810.


agencies. Almost two hundred thousand individuals with I/DD were on waiting lists for Medicaid long-term supports and services as of June 2015. We need to foster a creative environment in which adults with I/DD and their families are encouraged to work with providers to develop the environments they want. What we absolutely do not need is a landscape dominated by even more bureaucratic obstacles.

Importantly, this vision is very much in line with the Final Rule as it was originally articulated by CMS. It acknowledged that regulations should be more “outcome-oriented…rather than based solely on a setting’s location, geography, or physical characteristics.” Secretary Price and Administrator Verma similarly emphasized the need for choice in their March 14, 2017 letter to the states’ governors, in which they expressed their commitment “to a new era for the federal and state Medicaid partnership where states have more freedom to design programs that meet the spectrum of diverse needs of their Medicaid population.” They noted that the states “are in the best position to assess the unique needs of their respective Medicaid-eligible populations and to drive reforms that result in better health outcomes.”

It is in line with these priorities as articulated by your own agency – as well as by the ADA and the Olmstead decision – that we ask you to retrace the contradictory guidance that stigmatized farmsteads, gated communities, clustered housing and, more generally, all disability-specific settings as “isolating.” Not only does Federal law support the right of choice, but the concept of person-centered planning on which our system of service delivery is based mandates that these important decisions be made exclusively by waiver recipients and their families, from the most expansive range of home and workplace settings possible.

We look forward to participating in this critical conversation. Correspondence may be addressed to Amy Lutz via email at amy@easifoundation.org or by mail to EASI Foundation, P.O. Box 351, Villanova, PA 19085.

Best,

Together for Choice (NV)
Autism Science Foundation (NY)
ACCSES (DC)
VOR (IL)
Autism New Jersey (NJ)
Madison House Autism Foundation (MD)

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9 University of Minnesota Supporting Individuals and Families Information Systems Project (FISP): https://fisp.umn.edu/chart-gallery/waiting


11 CMS “Guidance on Settings that have the Effect of Isolating Individuals Receiving HCBS from the Broader Community,” https://www.medicaid.gov/medicaid/hcbs/downloads/settings-that-isolate.pdf
EASI Foundation: Ending Aggression and Self-Injury in the Developmentally Disabled (PA)
Bergen County United Way (NJ)
Advocates for Community Choice (MO)
Special Moms Network LLC (NY)
First Place AZ (AZ)
Casa de Amma (CA)
Citizens for Choice in Housing and DD Services (NJ)
Point Rider (TX)
Camping Unlimited for the Developmentally Disabled (CA)
Families Speaking Up (DE)
Homes for Life Foundation (DE)
Parles Rekem, LLP (NJ)
Elevare Community (CA)
Sunflower Hill (CA)
Benjamin’s Hope (MI)
Noah Homes (CA)
Kansas Neurological Institute (KNI) Parent Guardian Group (KS)
Glennwood House (CA)
OASIS (NJ)
Keeping Individuals with Intellectual Disabilities Safe (KIIDS) (PA)
Safe Haven Farms (OH)
Peacehaven Farm (NC)
Ability Network of Delaware (DE)
The DD News Blog (MI)
Osprey Village (SC)
New York City Family Advocacy and Information Resource (NYC FAIR) (NY)
Blue Spruce Community (CO)
Opportunity Village (NV)
Life Services Alternatives (CA)
The Arc Jacksonville (FL)
Rusty’s Morning Star Ranch (AZ)
29 Acres (TX)
Langton Green (MD)
Marbridge Foundation (TX)
Farmsteads of New England (NH)
Eastern New York Developmental Disabilities Advocates (ENNYDA) (NY)
Live Oak Living Community (TX)
The Daniel Jordan Fiddle Foundation (NJ)
The Camphill School (PA)
Good Works Farm (OH)
Sweetwater Spectrum (CA)
Ohio Coalition for Person-Centered Planning (OH)
Misericordia Home (IL)
Jessa’s Place (WV)
New England Communities (MA)
Long Island Advocacy Network for the Developmentally Disabled, Inc. (NY)
John M. Migton Foundation (NJ)
Good Shepherd Manor (IL)
Crotched Mountain Foundation (NH)
Families & Friends of Care Facility Residents (FF-CFR) (AR)
Olympic Peninsula Special Needs Housing (OPSNH) (WA)
Murray Parents’ Association (NJ)
Eternity Enterprises and Consulting (VA)
Vanguard Landing (VA)
Southbury Training School (CT)
Their Rights, Expert Witness and Consultation Services (TREWACS) (VA)
Triform Camphill Community (NY)
LTO Ventures (OH)
Developmental Disabilities Advocates of Western New York Family Committee (DDAWNY) (NY)