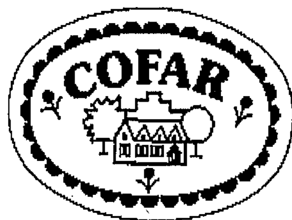

COFAR, Inc.

THE MASSACHUSETTS COALITION OF FAMILIES AND ADVOCATES

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VIA EMAIL (HCBSWAIVERS@MassMail.State.MA.US)

HCBS Waiver Unit
Executive Office of Health and Human Services
1 Ashburton Place, 11th Floor
Boston, MA 02108

November 10, 2014

Dear Sir or Madam:

We are commenting on the Massachusetts Department of Developmental Services (DDS) policy and transition plan regarding Home and Community Based Services (HCBS). These documents were developed by the state of Massachusetts pursuant to the HCBS Community Rule published on March 17, 2014, by the federal Centers for Medicare and Medicaid Services (CMS).

The DDS transition plan is identified as Attachment A of the Massachusetts Statewide HCBS Transition Plan, which is dated October 2014. The DDS policy is dated September 2, 2014.

Our main concern regarding the DDS HCBS policy and transition plan is that both of these documents are efforts by the government to decide what is in the best interest of persons with developmental disabilities with little or no concern given to the wishes and desires of the individuals themselves, their families, or their guardians.

CMS has stated in guidance concerning the HCBS Community Rule that farm-based residential programs isolate developmentally disabled people from the broader community. A similar statement by CMS is made about residential schools for the developmentally disabled, group homes on the grounds of a private developmental or Intermediate Care Facility (ICF), and group homes located in "close proximity" to each other.

But while the CMS Rule does not appear to ban those particular settings outright, DDS appears to be proposing to do just that. Under the policy, DDS states that it will not fund or support new residential settings such as farmsteads, "gated or secured communities," residential schools, settings that "congregate a large number of people with disabilities for significant shared programming and staff," or even new group homes with more than

five residents. Residents of "noncompliant programs" will be given "the opportunity to move to a compliant setting" or else face possible dis-enrollment from the HCBS program.

The placement of DDS clients in ever smaller and more dispersed settings is yet another in a long list of efforts to divert taxpayer money appropriated for the developmentally disabled into a grossly unregulated and opaque corporate operated service system.

It does not appear to matter that the participants may greatly enjoy living in a congregate setting such as a farm, for instance, or that they may derive many important skills from these programs that improve their self-care, receptive and expressive language, learning, mobility, self-direction, and capacity for independent living. It does not appear to matter either that families and guardians may value those skills highly and consequently value those programs themselves. It also does not appear to matter to DDS that thousands of people in Massachusetts are waiting for residential and other care options, and that eliminating potential options, as CMS and DDS are doing, is only going to make that situation worse.

In its guidance document, CMS criticized residential farm programs, in particular, because "an individual generally does not leave the farm to access HCBS or participate in community activities." The CMS guidance document said similar things about residential schools for people with developmental disabilities, and about other programs that "provide multiple types of services and activities on-site."

It is not clear what evidence CMS has to make the claims that people in farm-based and other congregate care programs are not provided with access to community activities. The federal agency's guidance offers no citations or backup information or studies to support its claims.

Even if it were true that residents in most residential programs providing "multiple services" are not regularly taken into the community, we believe it would make more sense to require that those programs periodically take participants into the community than to effectively ban the programs altogether. The approach taken by DDS, in particular, amounts to throwing the baby out with the bath water. CMS acknowledged that it received many comments about how valuable and therapeutic farm programs, in particular, are.

By the same token, CMS and DDS appear to be ignoring evidence that there is often little or no community integration by residents of small group homes or corporate-operated day programs (which comprise nearly 100 percent of all day programs in Massachusetts

for the developmentally disabled). Yet, as noted, even CMS is not willing to prohibit Medicaid funding for farm programs, residential schools, or multiple group home settings outright. In contrast to the Massachusetts DDS, CMS has stated that it will subject so-called isolating programs to "heightened scrutiny," which may result in continuing to fund them if a state makes the case that the settings do not have institutional qualities.

CMS, in fact, specifically rejected the idea of banning group homes with more than a set number of residents. In responses posted on the Federal Register to public comments on the proposed regulation, CMS stated that it had previously proposed defining institutional care based on the number of residents living in a facility, but that:

> ...we were persuaded by public comments that this was not a useful or appropriate way to differentiate between institutional and home and community-based care. As a result, we have now determined not to include or exclude specific kinds of facilities from qualifying as HCBS settings **based on the number of residents in that facility** (our emphasis).

CMS also noted on the same Federal Register site that the goal of its new Medicaid regulation:

> ... is **not to take services from individuals, or make individuals move from a location where they have always lived...** The goal of this regulation is to **widen the door of opportunity** for individuals receiving Medicaid HCBS... **to have a choice in how, when, and where they receive services**; and to remove unnecessary barriers and controls (our emphasis).

It is evident from the language of the DDS policy and from DDS's own actions over the past several years that the choices of individuals and their families and guardians are simply ignored. For instance, only corporate provider-run settings are routinely offered by DDS as options for people seeking residential care despite the fact that there are state-operated group homes and intermediate care facilities (ICFs) available for those people.

Federal law requires Massachusetts to offer the choice of all available services and settings to intellectually disabled people, not act as an agent for the more than three hundred (300) companies that contract with DDS annually and who also pay their executives exorbitant sums of taxpayer money.

We agree with the VOR, a national advocacy organization for persons with developmental disabilities, which contends that the CMS HCBS Rule "continues to demonstrate an ideological bias against disabled people who find friendships and benefits from living together and accessing services and amenities 'under one roof.'" VOR further suggests that:

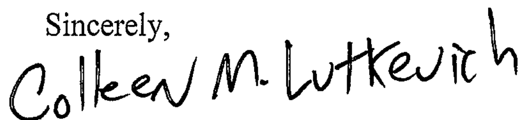
> ...if CMS determines some settings to be too 'institutional'... it is likely that states will realize higher costs to accommodate transitions to likely smaller, scattered settings where economies of scale will not be realized. Quality of care and access to specialized services may also be affected, exacting an untold cost on affected individuals.

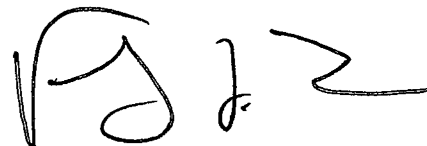
The reality is that the vulnerable people receiving DDS supports and services are just as likely to be "institutionalized" in a corporate group home as they are at a nursing home, ICF, hospital or foster care. What makes a program inclusive is long-serving direct care staff, good food, safe and comfortable surroundings, and, if possible, loving family and friends. This occurs under all kinds of roofs so long as there is a vigilant executive branch of government protecting people, listening to their families, and providing oversight that roots out waste, fraud and abuse. Regrettably, this type of oversight and transparency is lacking in Massachusetts, and the only proffered solution, like this new DDS policy, is one that leads to more contracts pouring more money into the same handful of executive pockets.

As has been the case for more than thirty years, COFAR remains concerned about cutting publicly funded programs and diverting that funding to DDS corporations, who are being encouraged to operate more and more widely dispersed, and smaller, group homes. We urge DDS to reconsider its policy of prohibiting specific programs from consideration for HCBS funding and of evicting and dis-enrolling individuals who choose to participate in those programs.

Thank you for your consideration.

Sincerely,





Colleen M. Lutkevich
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President

cc: Center for Medicare and Medicaid - VIA EMAIL
Massachusetts Congressional Delegation - VIA EMAIL
Governor Elect Charlie Baker - VIA EMAIL
Massachusetts Secretary of Health and Human Services - VIA EMAIL
Secretary of Administration and Finance - VIA EMAIL
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Joint Committee on Housing - VIA EMAIL
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