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June 26, 2012

Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Attention: CMS-2249-P2  
Submitted electronically: <http://www.regulations.gov>

Dear Centers for Medicare and Medicaid Services,

As a parent and president of Parents Planning Programs (PPP) for the Developmentally Disabled of Florida, Inc., I appreciate the opportunity to comment on this critical situation.

We refer to CMS' Definition of Home and Community-Based Settings for the 1915(i) Community First Choice (CFC) State plan Option with the intention to apply these rules regarding settings to all Medicaid Home and Community Based Services (HCBS) programs, including Medicaid 1915(c) HCBS Waivers, with potential for impact beyond the scope of the 1915(i) and CFC rules.

Fundamental Premises Advanced by CMS Concerning Community Based Settings  
for Delivery of Services to Persons with Intellectual Disabilities

**1. CMS proposes that the "community" as defined in its most narrow sense, is the "setting" most appropriate for an entire spectrum of people with intellectual disabilities including the more dependent and severely impaired, for those who do not have a family to live with at home, or for those whose abilities are declining due to advancing age.**

*The setting is integrated in, and facilitates the individual's full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources and receive services in the community, like individuals without disabilities . . . (Pp. 67, 84,)*

Comment

To have the ability to access the general community is very different from being forced to live in a community "setting" that is not only unwilling, but unable to provide resources for safety, supports, interaction, social integration and employment in competitive settings. The proposal assumes that all persons with intellectual disabilities are able to communicate, integrate socially, live independently, and have the intellectual capacity for self-determination. The broader arguments follow that all people with intellectual disabilities will be able to compete in the job market, lead productive and fulfilling lives and be included in a community of shared interests simply by virtue of their location in the community.

To forcibly subject persons with an intellectual disability to live in the community "setting" where they are unable to communicate their basic needs, who are unaware of danger, who have no basic skills for requirements of daily living, and who are at the mercy of a supported living assistant or

Companion who may not show up, is nevertheless expected to live in “competitive integrated settings, engage in community life, control personal resources and receive services in the community, in the same manner as individuals without disabilities.” ([i] p. 151(*emphasis added*)).

CMS proposes that the denial of HCBS Waiver is a just penalty for disabled persons who do not live in a “community” setting although it subjects them to abuse, neglect, molestation and isolation.

To assume that location will enforce the goals of integration -- social interaction, productivity and competitive employment -- is in our opinion, absurd and uninformed, by all accounts of families who have had their loved ones shunned, isolated and abused by the very “community” that CMS champions.

*“[My daughter] can’t live alone in a scattered site apartment because she doesn’t know how to cross a street safely, or how to avoid neighbors who might bully, exploit, or abuse her.”*  
(Mark L. Olson)

<http://blog.autismspeaks.org/2012/01/04/autisms-fly-over-population/>

## **2. CMS denies the choice of a “disability specific housing complex” (Pp. 150, 153): Choice is not an option.**

### Comment

This policy discriminates grievously against a class of citizens by denying basic civil rights to which all citizens are entitled: the right to choose a residential setting that is safe, supportive and which provides a quality of life that meets needs-based criteria.

To specifically disqualify for HCBS Waiver funding the choice of a “disability-specific housing complex,” in favor of one-size-fits-all solutions, ignores the intent of a zoning classification, Planned Unit Development, available to the general population:

Sec. 62-1441 Planned Unit Development Encouraged. Florida Statute par 163.3202 (3)

*The purpose of a planned unit development is to encourage the development of planned residential neighborhoods and communities that provide a full range of residence types, as well as industrial, commercial and institutional land uses. It is recognized that only through ingenuity, imagination and flexibility can residential developments be produced which are in keeping with the intent of this subdivision while departing from the strict application of conventional use and dimension requirements of other zoning districts and article VII of this chapter, pertaining to subdivisions.*

As a result of this incentive, we see the growth of “new urbanism” and the popularity of intentional communities such as senior communities, golf communities, veterans communities, religious communities, deed restricted communities, co-housing, etc., which address individual needs and preferences.

Choice of location should not be a reason for disqualifying people for the services to which they are otherwise entitled.

CMS limits choice to what it determines is best for an individual, regardless of the complexities of the individual’s condition. Therefore, choice is not an option, regardless of how they say it is.

We hold that recipients, not CMS, should be allowed to choose the most appropriate residential setting. Choice, not coercion, is paramount.

**3. CMS advances the notion that accessibility of supportive community resources and opportunities for social interaction with peers is not an issue: The “community” is accessible to everyone and the only appropriate resource.**

Comment

Florida passed legislation in 2010 (F.S. 419.001) which would allow planned residential communities for people with developmental disabilities to include amenities and resources otherwise inaccessible or unavailable.

“Settings” which provide accessible opportunities for employment, learning, interactive arrangements with the broader community and recreation, where one can play and ride a bike safely, are innovative alternatives to institutionalization. Typical of existing successful interactive opportunities provided by Camphill Communities, Lamb’s Farm, e.g., are: hospitality businesses, gift shops, coffee shops, amusement parks, bakeries, internships with local businesses.

In addition, this legislation allows the inclusion of group homes in closer proximity than 1,000 feet, thus addressing the isolation and segregation of residents living in group homes in the general community. Despite their claim that a “disability-specific housing complex” would be a setting isolated from the larger community (Pp. 70-71), CMS turns a blind eye to de facto segregation via the Thousand Foot Rule.

Our legislative efforts to expand residential alternatives have been met with vehement protests by federally funded "advocacy" agencies, supported by millions of our tax dollars in their quest to stifle any form of congregate living. At the same time, they are perfectly satisfied with density rules, quota systems and defacto segregation. We refuse to accept a prison of a different kind for those who will be sentenced to a life in a "community" where a person is essentially isolated.

**4. CMS assumes that individuals receiving services are capable of and have the availability of resources, the ability to make and execute life choices and find social acceptance in the “community.”**

*Home and community-based settings shall have all of the following qualities . . . as indicated in their person-centered service plan: (iv) Individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented. (Article 441.656, iv, Pp. 151-2).*

Comment

This assumes that persons with intellectual disabilities have the intellectual capacity and wherewithal to plan and follow their own schedule independently.

It rules out a campus setting while conveying the notion that a person assigned to a group home without a back yard chooses the least restricted physical environment.

It assumes that the regimentation of isolation and loneliness is not possible for those who are located in a “community” because they will be “integrated.”

It implies that integration in the social sense is enforceable or will happen automatically.

## **5. CMS condones the use of inflammatory labels.**

### Comment

Residential settings that have “*qualities of an institutional setting*” (p. 149) is a label that conveys the idea that housing complexes are government owned and operated facilities. Failure to make the distinction between a government facility and a free enterprise, privately owned residential community is in direct opposition to ADD PI-01-1 prohibiting federally funded agencies the use of inflammatory language that is biased and inaccurate:

*Using a nonpartisan approach, grantees would be free to advocate a particular position or viewpoint so long as there is sufficiently full and fair exposition of the pertinent facts to enable the policy maker to form an independent opinion or conclusion. In such an analysis, a grantee would refrain from presenting unsupported opinions, distorted facts, inflammatory and disparaging terms, or conclusions based more on strong emotional feeling than on objective factual conclusions.*

The term “institution” carries the connotation of a lock down facility, with a regimented lifestyle and restrictions on personal freedoms. This is a blatant example of misinformation and uninformed propaganda without any substantiation by reference to any existing intentional residential community or housing complex.

It is interesting to note that the Florida Developmental Disability Council (FDDC) in its advisory capacity to CMS, had never visited any of the successful intentional communities such as Lambs Farm or Camphill before it issued its statements to CMS in 2010 and before it completed its 5 session Work Group to study planned residential communities. In its alerts to stop legislation allowing planned residential communities, it claimed that this legislation would create “institutions.”

## **6. CMS promotes the ideology that their “policy” rather than individual choice is the ultimate determiner and basis of person-centered planning in all aspects of daily living.**

### Comment

The inherent contradiction between policy and person-centered planning becomes evident when one considers that person-centered planning would be achievable only in an approved “community” setting. Our position is that **choice, not policy**, is the basis of person-centered planning.

## **7. CMS proposes that Med Waiver funding should follow CMS policy rather than the person authorized for residential services.**

### Comment

The claim by federally funded agencies like the FDDC that Med Waiver funding would be “used” in these communities, and be considered a “*loss of funding intended to support individuals who want to live in the broader community.*” (March 24, 2010 Planned Residential Communities Announcement) conveys the notion that HCBS Waiver funding would be accessed for the actual construction and maintenance of residential development. In other words, it would rob Peter to

pay Paul. We wish to emphasize that Med Waiver funding for Residential Habilitation and other services by providers comes *via the person* authorized for that service.

### Summary

CMS appears to have concerns for the requirements of provider-owned residential settings such as privacy, freedom to furnish, entertain, use locks, have accessibility, etc. (p. 152) while ignoring the discriminatory “exclusion” position it has espoused.

We urge CMS to reconsider support of federally funded agencies whose policies restrict choice under the assumption that *we know what’s best for you*.

While housing complexes that contain intentional or planned communities may not always completely meet all the unique needs of every resident, they will provide the degree of safety, social integration, interaction, accessible training opportunities and recreational activities which the general community cannot provide.

Community residential designs may not always be all things to all people – disabled and nondisabled, especially if they must sacrifice their own intention to mimic the general community or abide by quotas, distancing requirements, rules and regulations under the mandate of CMS’ unauthorized “law.”

Choice rather than coercion is the determiner that will safeguard individual freedom. By denying appropriate residential choice for our more severely challenged persons with intellectual disabilities, CMS will violate the most fundamental rights of freedom and self-determination guaranteed by the DD Act which expressly requires recognition of individuals and their families as the “primary decision makers” regarding residential services, other supports, and policies. (Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. article 15001 (c)(3)).

For CMS to act as policy makers for people with intellectual disabilities and deny Waiver funding because of the location in which they choose to live, makes a mockery of a person-centered approach. To expect people of vastly different cognitive abilities to interact based on shared interests is simply unrealistic. To label planned communities “segregated institutions” as if shut off by force is blatantly uninformed. To make allegations without substantiation is serving an agenda rather than individuals.

We urge CMS to reshape extremist attitudes and eliminate stereotypes about their notion of “community.” We hope that CMS will join the ranks of more enlightened advocates who encourage and are developing innovative, humane and supportive living arrangements which enhance the quality of life in the interests of true “community” living.

Where does choice end, and coercion begin?

Respectfully submitted,  
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Parent of Mark