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Dear Advocacy Center Addressees,

This is in response to the comments posted by the Advocacy Center on August 21, 2009 on the Medicaid Program: Home and Community Based (HCBS) Waivers, CMS – 2296-ANPRM.

Under the title: ANPRM: H.B. Home and Community Based Characteristics, you state:

Historically, state level policy-making has not been fully successful at preventing HCBS waiver dollars from supporting individuals in settings that, due to their characteristics, are not community based. Specifically, many individuals with developmental disabilities reside in institution-like settings where the providers are reimbursed for HCBS waiver services. In years past, Florida asserted that its DD HCBS waiver system lacked sufficient provider capacity to support these individuals in home and community based residences. Recently, bills* have been filed in the Florida Legislature seeking to remove the few safeguards now in place to prevent further expansion of this problem. Proposals have also been made to build developments for people with developmental disabilities, some of whom would receive services through an HCBS waiver. ⁽⁴⁾ . . . The Advocacy Center supports the overall intent of the proposed rules and commends CMS' goals of removing barriers to person-centered, needs-based home and community based services.

<http://www.regulations.gov/search/Regs/home.html#docketDetail?R=CMS-2009-0071> Comment # 100

We were shocked, but not surprised at the Advocacy Center's sweeping generalizations, labels and attempts to destroy the legislative and real initiatives taken by families and people with developmental disabilities to provide supportive residential alternatives to the discriminatory distancing, quota and density rule contained in Ch. 419.001 F.S. (Thousand Ft. Rule -- six residents separated by 1,000 ft.) in violation of the true concept of "integration." This Rule actually supports de facto "segregation."

The Advocacy Center's support of the former 10% Density Rule is testimony to its policy of forcing individuals to scatter widely throughout an area. AHCA thought differently and recognized its violation of individuals' civil rights to choose where and with whom people want to live. It was finally deleted from the DD Services and Limitations Handbook in 2008 under protest from the Advocacy Center.

The Advocacy Center refers to "person-centered" home and community based services. We call it "choice," the same choice afforded to all other citizens to live in a residence of their choice, next to or among their friends if they wish, the choice to receive Residential Habilitation services they are entitled to in a setting of their choice in a community in which they feel comfortable, that fits their own, individual sense of what a community is and should be.

Rather than honest inquiry, the Advocacy Center supported "alarm" tactics of the Florida Development Disability Council (FDDC) to oppose legislation allowing for exemption of community residential homes from the Thousand Foot Rule if they are contained in a planned residential community.

There are specific restrictions on the use of HHS and ADD grant funds to influence the enactment of legislation and related activities that are applicable to nonprofit organizations, (Section 503 of Publ. L. 106-554 the Consolidated Appropriations Act, 2001 Web Page: <http://www.access.gpo.gov>). The requirements of OMB Circular A-122, Attachment B, Paragraph 25 state:

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 feelings than on objective factual conclusions.

The Advocacy Center's position is in direct conflict with Federal Law, particularly 114 STAT.1680 Section 503 of Pub. Law 106-402, which states:

Individuals with developmental disabilities and their families are the primary decision makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options, and play decision making roles in policies and programs that affect the lives of such individuals and their families . . .

Regarding INCLUSION, this Federal Law also states that individuals with developmental disabilities shall "have interdependent friendships and relationships with other persons [and] live free of . . . violations of their legal and human rights."

Effectively, the Advocacy Center is seeking to limit available options, prevent a wider spectrum of options from becoming available, and restrict individuals' choice and freedom to choose. Additionally, the voices of concerned families around the state are being drowned out by the Advocacy Center's so-called advocacy against them.

The Advocacy Center comments:

1. "Historically, state level policy-making has not been fully successful at preventing HCBS waiver dollars from supporting individuals in settings that, due to their characteristics, are not community based."

The Advocacy Center is referring to a term, "community based," which has many definitions, particularly when it refers to residential settings. Statewide zoning ordinances encourage planned unit developments.¹

This recognizes that "community" is an ever expanding zoning phenomenon. As populations grow, so do geographical communities. Planned unit developments may be deed restricted subdivisions, intentional communities, retirement communities, religious communities, golf communities, 55+ communities, veterans communities, assisted living facilities, etc.

Besides having a geographical connotation, "community" has a more significant meaning when people consider where they want to live based on shared interests, safety, meaningful activities, opportunities to learn, amenities, supports, social events, as well as opportunities for employment and access to transportation, stores, libraries, theatres, gyms, amusement parks, etc. This is particularly important for the more dependent population with developmental disabilities, those with substantial or multiple cognitive impairments, who no longer can rely on their immediate family to be there for them forever "at home."

The Advocacy Center's position seems to ignore that residents of isolated and scattered group homes are seldom, if ever, in any true sense "included" in the community in any social events or shared interests. People with intellectual disabilities frequently are at best avoided, are never invited to neighbors' homes, or offered companionship. At worst, they are targets of violent crime, theft, and abuse. Although Supported Living arrangements may be working for some Med Waiver recipients, particularly those who are on the higher end of the cognitive spectrum of developmental disabilities, we have seen many cases of isolation, deteriorating living situations and abuse for those who are more substantially cognitively impaired. We have met several families who have had to take their adult children back home. So-called "community based" isolated group homes and Supported Living arrangements have been disastrous for some, with documentation of robbery and physical abuse, but mostly loneliness. In the state of Oregon, a study found that one in five developmentally disabled clients had been abused in group homes since the closing of the Fairview Institution in the year 2000.²

Without neighbors who offer friendship and shared interests -- social or recreational activities -- or willingness to offer a helping hand, there is no "community." There is isolation.

We see "community" as more than a **location**. Furthermore, location should not be a reason for disqualifying people for the services to which they are otherwise entitled.

2. "Specifically, many individuals with developmental disabilities reside in institution-like settings where the providers are reimbursed for HCBS waiver services."

This allegation was unsubstantiated in the Advocacy Center's comments. We know of no such case. Specifically, which documented "institution-like" settings is the Advocacy Center referring to? Please state what features the Advocacy Center objects to and why.

3. "In years past, Florida asserted that its DD HCBS waiver system lacked sufficient provider capacity to support these individuals in home and community based residences."

In more recent years, the HCBS waiver system in Florida has been very successful in increasing and providing supports through the Supported Living program, Residential Habilitation in community residential homes (group homes), and other living arrangements such as family home rather than facilities owned and administered by the state. However, efforts to evict residents from state facilities, such as Gulf Coast, without family notification and consent has been met with strong objections by families who initiated legislation to prevent such action.

The Olmstead Decision recognizes that some individuals are better served in settings such as Gulf Coast.

4. "Recently, bills* have been filed in the Florida Legislature seeking to remove the few safeguards now in place to prevent further expansion of this problem."

(*The Advocacy Center's reference to SB 1124 was incorrect.)³

Regarding the "few safeguards" now in place to prevent further expansion of this "problem," does the Advocacy Center consider distancing restrictions a "safeguard"? Did it also consider the 10% Density Rule a safeguard, mandating that homes had to be "scattered"?

Does the Advocacy Center wish to limit all funding for people with developmental disabilities to be directed solely to Supported Living arrangements? Does the Advocacy Center seek to deny funding altogether to the large number of Floridians with developmental disabilities, for whom Supported Living is not an appropriate program but who do not wish to live in a state facility?

5. "Proposals have been made to build developments for people with developmental disabilities, some of whom would receive services through an HCBS waiver."

Once again, individuals' choice of community or location should never be a reason for disqualifying them for the services to which they are otherwise eligible, currently receiving, or entitled. Furthermore, planned unit developments are community based, subject to local zoning and may be classified as residential. HCBS Waiver funding would not be accessed for the actual construction and maintenance of residential development.

6. "The Advocacy Center supports the overall intent of the proposed rules and commends CMS' goals of removing barriers to person-centered, needs-based home and community based services."

Is the Advocacy Center removing "barriers" by setting policies which dictate where and with whom our citizens with developmental disabilities may or may not live?

How would limiting an individual's choice be consistent with "person-centered" and "needs-based"?

In conclusion, as the concerned parents of people with developmental disabilities:

- we see an individual's choice of community or location as paramount, and feel that a person's choice must outweigh the supercilious attempts by the Advocacy Center to mandate their notion of "inclusion" at all costs by forcing individuals to scatter throughout a wider geographical area.
- we have deep concerns that the Advocacy Center, a massive federally funded organization with a staff of 63 including 13 attorneys⁴, would subvert the wishes of individuals or their families, that federally funded state agencies should serve as surrogates to act as primary decision makers.
- we object to any agency which claims the right to supersede these individuals and their families and to recommend policies which violate fair and unbiased representation.
- we recommend that the Advocacy Center consider a more thoughtful definition of "integration," "inclusion" and true "community living." From our perspective, we see our people shunned, isolated, and frequently abused or neglected.
- we maintain that physical proximity does not take precedence over socialization, safety and belonging or guarantee inclusion and integration.
- we see the Advocacy Center's notion of integration and inclusion as discriminatory, an insidious type of exclusion -- no more than six persons with developmental disabilities per 1,000 feet.
- we reject the Advocacy Center's paternalistic idea that it knows best what lifestyle is best for people with developmental disabilities.
- we disagree with the Advocacy Center's position which "ensures the protection of and advocacy for" persons with disabilities by limiting choice.
- we consider the Advocacy's comments an attack on personal freedom and self-determination.
- we urge the Advocacy Center to join the ranks of more enlightened advocates who encourage and are developing innovative, humane and supportive living arrangements in the interests of "true community living."

Unless the Advocacy Center reverses its position in support of de facto segregation rather than choice of expanded residential options, we consider its position discriminatory and will continue our efforts to take appropriate action.

Sincerely,

Lila Klausman, Pres.
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Cc: Gov. Charlie Crist
Bryan Vaughan, Director, Governor's Commission on Disabilities
Henry Claypool, Director Office on Disability, U.S. Department of Health and Human Services
Roosevelt Freeman, Regional Manager, Department of Health and Human Services Office for Civil Rights
FDDC et al.

¹ Sec. 62-1441 Planned Unit Development

Florida Statute par 163.3202(3) – Planned Unit Development Encouraged
Sec.62-1442. Same—Purpose and intent.

The planned unit development is a concept which encourages and permits variation in development by allowing deviation in lot size, bulk or type of dwellings, density, lot coverage and open space from that required in any one residential zoning classification under this article. 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.

² <http://blog.oregonlive.com/oregonianextra/2007/11/grouphomes.html>
http://blog.oregonlive.com/oregonianextra/2007/11/graphic_sincefairview.html

³Line 52 (f) "Planned residential community" means a local government-approved, planned unit development having amenities that are designed to serve residents who have developmental disabilities and may ~~consist of~~ contain two or more community residential homes, licensed by the Agency for Persons with Disabilities, which are contiguous to one another.)

⁴In the report of 9/30/07 the Advocacy Center received significant Federal funds of \$2,310,900 from U.S. Department of Health and Human Services, U.S. Social Security Administration and the U.S. Department of Education to cover expenses for Developmental Disabilities.