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September 30, 2009

Debra Dowds  
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Dear Debra and FDDC Members,

This is in response to the comments posted by Debra Dowds, Executive Director of FDDC on August 19, 2009 on the Medicaid Program: Home and Community Based (HCBS)Waivers, CMS – 2296-ANPRM.

When you announced the formation of a Work Group beginning July 24, 2009 to study alternative residential options for people with developmental disabilities, we were hopeful that the FDDC would welcome the opportunity to learn about Planned Residential Communities. We hoped that you would approach the issue with an open mind, in view of the many grassroots initiatives for planned residential communities and family concerns about the limited residential options currently available in Florida.

We discover, with dismay, that the FDDC's comments to CMS were in direct conflict with the Work Group's promise of fair and unbiased representation of both sides of the issue. It now appears that the Council's position was a *fait accompli*, while adopting the appearance of fairness, even before the Work Group had completed three more scheduled meetings.

We question why the Council reverted to the lobbying propaganda displayed in FDDC's March Alert relative to HB 371<sup>(1)</sup> as well as Susan Gold's letter in May charging use of Med Waiver funds to rebuild segregated "institutions." Instead of encouraging honest inquiry among your Council members, you authorized alarm tactics in violation of compliance with Section 503 of Pub. L. 106-402,<sup>(2)</sup> and, as a nonprofit organization, the requirements of OMB Circular A-122, Attachment B, Paragraph 25.<sup>(3)</sup>

In the Work Group meeting of July 24, members agreed to avoid those emotionally charged, "hot button" terms like "institution," or "inclusion" unless they were defined.<sup>(4)</sup> The term "segregation" was another label to be avoided as individual groups discussed case studies prepared by the facilitator to identify family concerns, such as safety issues and loneliness.

The statement to CMS using these inflammatory terms was made in spite of the fact that neither you or apparently any of the Council members had yet visited a planned residential community or spoken to representatives of successful established communities, or had yet heard the presentations in support of planned residential communities on August 25<sup>th</sup> (JimWhittaker of Arc, Carl Penxa of Loveland Center, Susan Thiele of Earth Serve Village and Simone Tetrault of Statewide Coalition of Residential Options). The FDDC summarily disregarded the many letters that families and I had personally sent, telling stories of their loved ones and their choice for planned residential communities.

**Essentially, we find that the FDDC and Advocacy Center are proposing to deny Residential Habilitation services to those who are entitled to receive them based on their choice of a location where they may be served.**

To be more specific, the statements made in the FDDC's posted comments to CMS – 2296-ANPRM, raise serious concerns as to the validity of their federal and state authorization "to educate, advise or inform federal, state and local policymakers" (Sections 125(a)(5)(J). 143(a)(2)(L). 153(a)(1), and 161(2)(D)(iii).

In the spirit of fair play, and to represent both sides of an issue before coming to consensus, we as members of the Work Group are asking you to reconsider and revise the FDDC's statements to CMS, and to provide answers to our questions at the next Work Group meeting scheduled for October 15, 2009.

The FDDC's comments re: CMS – 2296-ANPRM state:

**1. "One of our main purposes is developing the capacity for and sustaining the growth of, inclusive communities and self directed services and supports for individuals with developmental disabilities."**

a) There appears to be a serious discrimination issue hidden in the FDDC's marketing of "inclusive communities."

Is the FDDC's definition of "inclusive communities" based on the discriminatory distancing requirement that you have always supported (1,000 ft. rule contained in Ch. 419.001), which isolates and forces residents of group homes to be effectively segregated from each other under the guise of "inclusion"? How can the FDDC justify *de facto* segregation in disregard of Civil Rights?

b) Can the FDDC explain why a person with developmental disabilities should not be allowed to *self direct* to live in a group home other than in a location that has distancing, boundary and quota restrictions (six residents per 1,000 feet)?

c) Was the FDDC aware that since March of 2008, there is no longer a 10% Density Rule requiring residents in the Supported Living program to "scatter" – contrary to the boundary and quota restrictions in the Thousand Foot Rule as it applies to group homes?

**2. "The FDDC has a deep concern over the increased use of segregated communities to provide housing and other services for people with developmental disabilities."**

a) Does the FDDC also share our "deep concern" about policies of federally funded Councils, supported by our tax dollars to the tune of millions of dollars a year,<sup>(5)</sup> which are in direct conflict with grassroots initiatives to expand choice of residential options?

b) Does the FDDC share our "deep concern" about our loved ones who will not have their families forever and who will require supports similar to the frail and elderly – who may face nursing homes, a different kind of "institution" as their only alternative?

c) Which communities are you referring to that are "segregating" their residents? What means are they using to segregate?

d) Does the FDDC know of any planned communities that do not encourage and provide programs to assist residents to gain employment in the general community and to use the resources of the community – gym, library, restaurants, movies, shopping malls, etc.?

e) Does the FDDC define "community" solely as a location without recognizing the need for neighbors who are willing to offer friendship and a helping hand?

f) Does the FDDC recognize that, 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, shopping, libraries, theatres, gyms, amusement parks, transportation, etc.?

g) Does the FDDC recognize that this is particularly important for our more dependent population with developmental disabilities particularly those with substantial or multiple cognitive impairments who no longer can rely on their immediate family to be there for them forever "at home"?

h) Does the FDDC recognize that the term "community," is an ever expanding zoning phenomenon as populations grow – all with varying community based zoning classifications including "planned unit developments"? Statewide zoning ordinances encourage planned unit developments. These may be deed restricted subdivisions, intentional communities, retirement communities, golf communities, religious communities, 55+ communities, veterans communities, etc., classified as residential.

**3. "Many of these proposed communities have all the features of an institutional setting."**

a) What are the documented "features of an institution" besides the FDDC's allegation of "segregated" that you object to?

b) What is the FDDC's rationale for considering them objectionable?

c) Are you aware that the Olmstead Decision supports the rights of residents who are in need of these services?

**4. ". . . we do not consider communities that only contain people with disabilities and paid staff members to be community-integrated."**

a) Does the FDDC consider isolated group homes with paid staff members to be community-integrated? Or Supported Living arrangements with live-in supports to be community-integrated?

b) Does the FDDC consider that paid staff may be employed precisely for the purpose of increasing independence, offering friendship and enabling residents to gain access to the general community?

c) How does the FDDC respond to the dozens of stories that we have sent you or to those that were collected for a Work Group assignment where people are shunned by the community while living in Supported Living arrangements or their own family homes? The standard rule is that they are avoided, are never invited to neighbors' homes, and in one particularly poignant case, were summarily ignored when they sent party invitations to their neighbors?

d) Has the FDDC considered the Not-In-My-Back-Yard (NIMBY) syndrome when you assume that isolated group homes will automatically be "included"?

e) What data have you collected from any isolated group home or Supported Living arrangement that they are truly "community integrated"? What are the criteria?

**5. "The Council supports non-segregated community developments that enhance socialization and other inclusive living opportunities."**

a) How do scattered group homes and Supported Living arrangements specifically "enhance socialization"?

b) Is it just by allowing them to locate in a residential neighborhood, public apartment complex or on the block in their own home?

**6. "The FDDC offers itself as a partner in the process of developing standards for community living."**

a) Would these "standards" rule out choice over where our family members may want to live or what families prefer for their loved ones?

- b) Why did the FDDC try to substitute "Supported Living" for "community residential homes" (group homes) in the FDDC's proposed amendment to SB 1124 in the last legislative session?
- c) Does the FDDC believe that Supported Living arrangements are the answer for all people with developmental disabilities regardless of their degree of dependence -- that one size fits all?
- d) Does the FDDC agree with families that our more dependent family members have different requirements in terms of support than our more independent ones?

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We would appreciate an answer to our questions. Our trust will be measured by the proven sincerity of the FDDC in serving families who have struggled for many years to develop innovative and reasonable alternatives to the limited residential options currently available.

Sincerely,  
Lila Klausman, Pres.  
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- (1) HB 371 / SB 1124 to amend Ch. 419.001 would exempt APD licensed community residential homes (group homes) of six or fewer residents from the distancing requirement of one thousand feet if located within a planned residential community approved by local government as a planned unit development with amenities designed to serve residents who have developmental disabilities.
- (2) "Individuals with developmental disabilities and their families are the primary decisionmakers 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 . . ."
- (3) "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.  
Grantees advising legislators and others concerning adoption of legislation should approach the task in a balanced way, discussing the advantages and disadvantages of the legislation and comparing it with other proposals that may also be under consideration. A nonpartisan approach to informing legislators does not require that grantees be neutral about outcomes for individuals with developmental disabilities. Rather, grantees would have to demonstrate an unbiased attitude when considering alternatives for meeting the needs of such persons"
- (4) <http://www.fddc.org/sites/default/files/file/news/Alternative%20Residential%20Options%20-%20Meeting%20Notes%207-24-09.pdf>
- (5) Grants for year 2008 -- \$3,850,681  
Grants for year 2007 -- \$3,853,348