

## Subject: FDDC Focus Group -- Facts or Opinions?

To: Florida Developmental Disability Council (FDDC) Sent by e-mail  
April 9, 2010

Dear Council Members,

My husband and I attended the FDDC Focus Group in Orlando on April 6, facilitated by Allison Chase. The chairperson of the Family Care Council Area 7 and her husband, and another parent were also present. Allison handed out a list of questions from the FDDC asking what our people with developmental disabilities require to improve their quality of life and other questions regarding current services, technologies and supports. After looking at the questions, one dad asked if we could hold them for the moment and get right to more pertinent questions:

Why isn't the FDDC supporting what our families want for their kids?

Why is the FDDC so opposed to innovation and change?

Why hadn't the Council Members represented at the staged Work Groups to study Residential Options ever visited one of the many Planned Residential Communities around the country?

Why had Debra Dowds addressed the CMS -2296-ANPRM with FDDC established policies even after the Work Groups had begun?

Why were we not consulted about their subsequent proposed amendments to SB 1166?

Why does the FDDC under the leadership of Debra Dowds, employ people like Michael Capps who is also president of APSE and claims that SB1166

"opens the doors to state funded institutions under the name of 'Choice' ... a bill which authorizes facilities which have virtually no constraints, . . .effectively allows them to become institutions regardless of what they are called, [that] the bill can take community service dollars away from people served in a traditional group and foster home(s) . . . and underscores the danger inherent in creating institutions. . . Ask [legislators] to vote against SB 1166 because it promotes the development of institutions and discriminates against people with developmental disabilities."? (See attachment below from APSE.)

Why does the FDDC support untruths, misinformation, fear tactics, inflammatory disparaging terms and unsupported conclusions based on vested interests? (Sunrise Corporation, owner of many group and foster homes, hired Kingsley Ross, a professional lobbyist, to frame this language.)

Why does the FDDC keep reinforcing the notion that Medicaid Waiver funding will be used in Planned Residential Communities, implying that the state funds will establish these communities?

The Fact

The government does not build or maintain group homes or in any way pay for the construction or maintenance of a planned residential community.

The Fact

The Medicaid Waiver funding follows the person to receive Residential Habilitation Services in a group home of choice.

The next hour and a half was an outpouring of outrage and disbelief that the FDDC is staging a contest with families.

I referred to the latest FDDC bulletin concerning SB 1166 to address the unsupported opinions, distorted facts, inflammatory and disparaging terms and conclusions based on strong emotional feelings rather than on objective factual conclusions (a violation of Sec. 503 of Publ. L. 106-554 the Consolidated Appropriations Act, 2001.  
<http://www.acf.hhs.gov/programs/add/instructions/PI011.html>

The following FDDC statements are addressed:

1. *"Currently there are licensing requirements for group homes that are 1000 feet from each other, but there are no specific criteria for these group homes, when they are beside each other in a planned Residential Community."*

The Fact

This is a non issue and an unsupported opinion:

Florida Administrative Code 65G-2.012 Group Home Facility Standards, provides seven pages of regulations specifying safety and other criteria. Nowhere in this document is there reference to separate rules for group homes based on location. Furthermore, there is no statutory authority that specifies licensing rules for any location other than the 1000 foot distancing requirement in the community at large. However F.S. 419.001 specifies that local zoning be notified of the location of the home before licensing can be authorized.

2. *"DD/HCBS Medicaid Waiver funding is used to provide assistance to individuals with developmental disabilities who want to waive their right to institutional living and to live in a family home or home in the community."*

The Fact

Equating Planned Residential Communities to "institutional living" is use of inflammatory and disparaging terms and a completely unsupported opinion of the intent of a Planned Unit Development, that is, to provide for innovative and creative alternatives to the isolation of group homes and also in many cases, of Supported Living arrangements. Family homes and homes in the community will be encouraged in a Planned Unit Development. The definition of "community" is not confined to location, but embodies the essential elements of social

interaction and shared interests. It is not a hospital or a nursing home or a government owned and operated "facility." It is a local zoning approved Planned Unit Development. The Planned Unit Development zoning provision recognizes that "community" is an ever expanding zoning phenomenon. As populations grow, so do geographical communities as exemplified in the increasingly popular "new urbanism." Planned unit developments may be deed restricted subdivisions, intentional communities, retirement communities, religious communities, golf communities, 55+ communities, veterans communities, assisted living facilities, etc. The following definition applies:

Florida Statute par 4 163.3202(3) -- Planned Unit Developments Encouraged. "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 of conventional use and dimension requirements of other zoning districts and article VII of this chapter, pertaining to subdivisions."

3. *"Provides for housing options only - no workshops or day training provided on-site."*

#### The Fact

This is a policy-directed dictum rather than an informed assessment of diverse person-centered needs: Activities, amenities and services are an intrinsic part of the popularity of planned residential communities. Creative design will appeal to the residents who choose to live there. They exist precisely because people (seniors or otherwise) may not have the level of independence or resourcefulness to create their own daily activities or to access to the general community freely. The success of initiatives like Camphill Communities, Lamb's Farm and our own Bishop Grady Villas inspires many new possibilities. In addition to the unique and varied opportunities and supports these communities offer within as well as outside the community -- in agriculture, business apprenticeships, supported employment, retail ventures, restaurants, hospitality centers, recreational attractions, etc. -- there is a large potential for true belonging and broader community interaction. Meaningful work may be an inherent part of the design, e.g., organic farming, studios for wood working, book binding, stained glass, music, crafts, gym, campus classes of choice, etc. There are far more resourceful programs than workshops or day training programs.

4. *"Provides special safety features"*

#### The Fact

This mandate overlooks the fact that safety is precisely why many people choose to live in a planned community. Vulnerability is far more likely in the general community where residents of group homes cannot walk about or recreate freely, access the general community, or receive the benefit of oversight by caregivers and other families who may choose to live in the community. The targeting of "safety features" is already addressed in the Florida Administrative Code relative to group homes. The FDDC has not addressed safety issues in the general community, where abuses, particularly in Supported Living arrangements in unsafe

neighborhoods are rampant.

5. *"Includes residents who are both individuals with disabilities and individuals without disabilities in a sufficient mix so as not to create a segregated community."*

#### The Fact

A mandated quota of disabled to non disabled individuals is a density issue and discriminatory. In 2009, AHCA decreed that the provision of the 10% Density Rule be removed from the Medicaid Developmental Disabilities Services and Limitations Handbook and was deleted from the Florida Administrative Code in 2003. In contrast, the 1000 foot rule does not allow for a "sufficient mix" of disabled to non disabled. Rather, it isolates and segregates residents of group homes by boundaries and quotas (six residents per 1000 feet).

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, theaters, 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." Legislation requiring a quota system mandating a mixed population cannot enforce "integration." A community of interests and social connections can best be developed among those who can associate freely with their peers and neighbors in an atmosphere of mutual support. The distancing requirement, supported by the FDDC in the general community creates isolation. The FDDC has never answered the question of how "integration" and "enhanced socialization" can occur under these circumstances.

The Fact Incidentally, a spacing of 1000 feet between group homes means one group home in a plot of land of 72 acres, a circle with a radius of 1000 feet.

In conclusion:

- We urge the FDDC to revisit their mission to advocate for people, not policies.
- We have deep concerns that the FDDC, a Federally funded organization (almost four million dollars a year), would subvert the wishes of individuals or their families and insist on serving as surrogates to act as primary decision makers.
- We object to any agency which claims the right to supersede individuals and their families and to recommend policies which violate fair and unbiased representation.
- We recommend that the FDDC 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 see the FDDC's notion of integration and inclusion as discriminatory, an insidious type of exclusion -- no more than six persons with developmental disabilities per 1000 feet.

- We reject the FDDC's paternalistic idea that it knows best what lifestyle is best for people with developmental disabilities.
- We disagree with the FDDC's position which claims to be "person-centered" by limiting choice and self-determination.
- We urge the FDDC 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."
- We maintain that forced inclusion does not take precedence over socialization, safety and belonging.
- We see an individual's choice of community or location as paramount, and feel that this choice must outweigh the FDDC's choice to mandate their notion of "inclusion" via the 1000 foot rule at all costs.
- We hold the definition of "inclusion" that gives people with developmental disabilities the same right to live in a planned residential community as all other citizens.

Sincerely,

Lila Klausman, Pres.  
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Cc: Gov. Charlie Crist  
Bryan Vaughan, Director, Governor's Commission on Disabilities  
Allison Chase, Facilitator  
Debra Dowds, Director, FDDC

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## Message from [Florida APSE](#)

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Below is information relating to the "DD Villages Bill". Please take action on this NOW. I have attached a link to each of the Committee Members. If for some reason the links do not work go to [www.flsenate.gov](http://www.flsenate.gov) and follow the links The Committee on Children, Families and Elder Affairs

Please act now!

Mike Capps, President

Florida APSE

Action Alert 5 – SB 1166

By Kingsley Ross

SB 1166 is scheduled to be heard in the Senate Children, Families and Elders Affairs Committee tomorrow morning, Friday March 26. As currently worded, the bill (and its companion HB 645) opens the door to private state funded institutions under the name of "Choice" by changing the siting requirements for group homes. HB 645 was heard this morning and passed its first committee of reference.

Background:

- The bill authorizes facilities, called planned residential communities, which have virtually no constraints placed on them in terms of what services they will provide onsite or how many people will live or be served there. This effectively allows them to become institutions regardless of what they are called.
- The bill can take community service dollars away from people served in a traditional group and foster homes because supporters want to get operating funds from the same budget item.
- An amendment supported by cities is being offered by the sponsor that would set a NIMBY (not in my back yard) precedent by not allowing these facilities in any area of less than 10 acres. This essentially bans these "communities" from urban areas. In effect, the amendment "red lines" these "communities into more rural areas of Florida and underscores the danger inherent in creating institutions.

Action Needed:

Please call or email members of the Senate Children, Families and Elders Affairs Committee. Ask them to vote against SB 1166 because it promotes the development of institutions and discriminates against people with developmental disabilities. It is extremely important that the legislature hear that not all advocates approve of this bill.

- Chair: [Senator Ronda Storms \(R\)](#)
- Vice Chair: [Senator Nan H. Rich \(D\)](#)
  
- [Senator Nancy C. Detert \(R\)](#)
- [Senator Alex Diaz de la Portilla \(R\)](#)
- [Senator Rudy Garcia \(R\)](#)
- [Senator Anthony C. "Tony" Hill, Sr. \(D\)](#)
- [Senator Charlie Justice \(D\)](#)
- [Senator Stephen R. Wise \(R\)](#)

Michael Capps, Chapter President

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