

356 Las Olas Drive
Melbourne Beach, FL 32951
(321) 724-8899



Parents Planning Programs (PPP)
for the Developmentally Disabled
of Florida, Inc.
a 501c(3) non profit corporation

fax (321) 724-8899
pppflorida@cfl.rr.com
<http://www.pppflorida.org>

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Tom Rice, MPA
Operations Review Specialist
Agency for Persons with Disabilities
4030 Esplanade Way, Suite 380
Tallahassee, FL 32399

Fax: (850) 488-4257

Dear Mr. Rice,

Thank you for your letter confirming APD's position on the Thousand Ft. Rule (Ch. 419.001 FS). It is because of this position that we are compelled to request from our legislators, an amendment to this statute to insure that it is not misapplied to meet APD's agenda. The fact remains that the needs of our DD population are not being met for reasons of safety, supports and services, and more meaningful opportunities for and better access to community inclusion.

Your next to final paragraph appears to hold a note of promise for a contract to Bishop Grady Villas to provide Residential Habilitation Treatment (RHT). If their application is not going to be denied again, this is good news. We will be in touch with them to learn if they have been so advised and to learn of the final outcome.

In the meantime, I would like to address some of the issues you raise:

First, we appreciate the strides the state has made under the Home and Community Based Waiver, to provide supports and encourage independence for our people with developmental disabilities. My own son, Mark, is a recipient of many services since he is still living with us. We agree with the purpose of the DD Waiver to foster the principles of self-determination. What we are concerned about is the denial of rights afforded to every citizen by the contradictory laws that prohibit CHOICE.

The issue of residential options has been a source of great concern to us as well as our families with whom we have been associated over the years. What has been an intolerable situation is the movement to rule out categorically under the guise of "community inclusion" and "self-determination," the same opportunities that you and I and other members of society are free to enjoy. We are not talking about "institutions" or "institutional settings." We are referring to the same kind of community that is the choice of seniors and other interest groups to set up a 55+ community or any other intentional community or Assisted Living Facility that is designed specifically to support individuals with developmental disabilities, to broaden their choices and their support services.

You refer in your letter to Florida's part in the trend to serve people with developmental disabilities in "less-restrictive" community settings. What could be more restrictive than living in isolated circumstances, either in one's own apartment or in a group home located in a neighborhood that more likely does not want them there. The Thousand Foot Rule is their answer to Not In My Back Yard (NIMBY). Story after story comes to us of people returning to their own families because of inadequate or unreliable in home supports or of abuse in group homes. What could be more restrictive than inability to walk safely in a gated community without fear of being molested or run down or confined to one's room because there is no transportation?

You state that “abundant research” demonstrates a high correlation between congregate living and its impedence to community inclusion and the realization of full potentials. (Incidentally, will you please forward some of the citations referred to in this “abundant research?”) The communities that we have researched show just the opposite. There is a high level of interaction with not only peers, but with the community at large as residents engage in supported employment, regular employment, participation in the life of the community, access to transportation, recreation, planned activities and community service – with the added bonus of SAFETY, the number one priority of every parent we have ever polled.

Residential communities nationwide have long been models which offer community involvement and inclusion, such as Lamb’s Farm in Illinois and the Camphill Communities of North America. Far from being isolated from the community at large, they interact with and invite the large communities to share their services and activities.

You refer to freedom of choice of an “array of options” in regard to residential options. Unfortunately, for our own son, like many others, supported living is out of the question – he is totally dependent on 24/7 care and supervision. Realistically, there are basically two primary options: Supported Living, where the bulk of Med Waiver funding is allocated, and community residential homes (group homes). It is no secret that ARC, for example, supports the down sizing of Intermediate Care Facilities (ICF’s). The agenda to close down the larger state facilities is also no secret. In regard to the latter, I am forwarding an editorial from the St. Pete Times, January 25, 2007, “Consult Families Before Evicting Retarded Resident.” I quote:

Opponents of congregate care are so serious that they filed a federal lawsuit to force “community integration.”

The result was the 2005 closure of Community of Landmark and the (expected) closure of Gulf Coast Center, Fort Myers in 2010. Families were not consulted. Thus, they have secured the introduction of two state bills, to assure that a family Advisory Council have a legitimate voice in the process.

It strikes me as alarming that families need to have a bill introduced to protect the rights of their loved ones. By your own admission, the state makes policies about where and with whom they may or may not live. As you state: “. . . the provision of such [residential] options must be in full compliance with existing law and administrative rule.” You mention “a variety of federal and state laws, administrative rules and various court orders against the use of large-scale institutional settings (under the premise of honoring personal choice.)” This strikes me as inherently contradictory to APD’s offer of “choice” and “self-determination.”

Regarding “large-scale institutional settings,” again the state is thinking in terms of a stereotype. This is exactly our point! We are involved with several organizations who have initiated or are planning communities of varying sizes and all have different ideas. We are excited about Bishop Grady Villas -- 48 beds -- because of the advantages it offers: close to the business district of St. Cloud, a beautifully designed arrangement of individual homes and community center, work facilities, ongoing social activities and programs including supported employment. Parents give rave reviews. Bishop Grady Villas is a beacon of light that should shine on the institutional mentality of institutional thinkers. Licensed and lauded by AHCA as an asset to the community, it is a designated Assisted Living Facility.

Attesting to the fact that this type of residential setting is the overwhelming choice of parents is the hundreds of applicants they have had. Unfortunately, the cost to individual families is prohibitive.

Regarding Residential Habilitation Treatment (RHT), a service provided by the Med Waiver, there is provision for facilities licensed by the state to apply. The service manual states that RHT can be provided in the beneficiaries place of residence, foster home or a licensed residential facility. This is exactly what we would like to see implemented for Bishop Grady Villas and other similar living arrangements!

It is also interesting to note that Chapter 409.221 (4) (e) 6, Consumer Directed Care, allows services to include Assisted Living Facilities.

Again, in reference to Ch 419.001, our point is that **this statute was intended for community residential homes (group homes) in residential neighborhoods, and not intended to prohibit the development of planned residential communities.**

We are not talking about “certain types of institutional settings.” We are talking about many types of innovative residential communities that ordinary citizens enjoy. We are talking about a human rights and constitutional issue – the right of self-determination and personal choice. The unjustified labeling and generalization of this concept as “institutional” eradicates choice and closes the door to the opportunities for creative residential services – a real tragedy!

Please rethink the definition of “institution,” and consider the concept of “community” in a way that respects flexible and innovative design and departs from the notion that one size fits all! Our special needs people are individuals. To serve individual needs we need to advocate for services that involve thinking outside the box. We need CHOICE!

Thank you for your response to this vital concern of our families and loved ones.

Sincerely,
Lila Klausman, President, Parents Planning Programs (PPP), Inc.
Associate member, Family Care Council, District 7
Board Member, Florida’s Voice on Mental Retardation (FVMR)

Cc: Senator Mike Haridopolos