

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) 327-5851
pppflorida@cfl.rr.com
<http://www.pppflorida.org>

April 21, 2011

Ms. Barbara Edwards
Director of the Disabled and Elderly Health Programs Group
Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
Attention: CMS-2337-P
P.O. Box 8016
Baltimore, MD 21244-8016

INCLUSION and COMMUNITY

(A commentary by Parents Planning Programs (PPP), Inc. on the position advanced by the National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD) in their letter of December 6, 2010 to the Centers for Medicare & Medicaid Services-2296-ANPRM re: the Home and Community Based Waiver.)

Our comments address the stated concerns of these organizations “about the potential use of Medicaid waiver funding that may support *segregated* rather than *integrated* housing for people with disabilities.” Their position assumes a definition of “community” that would apply to the Home and Community Based Waiver.

For those who want to close down government centers and send everyone out into the general “community,” the term “inclusion” is the Holy Grail. “Inclusion” should be the ultimate goal of every person with a developmental disability. ANY other lifestyle would be condemned as “segregated” or “institutional.”

A review the definition of the terms is critical. We agree, that the term, *segregation*, means set apart, shut off or isolated by force or rule, rather than by choice. The term, *integration*, (Webster), means “incorporation as equals into society” and carries the connotation of blending or uniting into a functioning or unified whole.

The fundamental question: What is “*community*”? How does it relate to *inclusion* and *integration*?

Webster defines “community” as “a unified body of individuals; people with common interests living in a particular area; fellowship; a social state or condition.” We contend that “community” is more than a place or a location. “Community” is defined not just by where people live, but how they interact.

“Community” has a more significant meaning to people with developmental disabilities when it reflects shared interests and responsibilities, opportunities for growth, recreation and social networking. To be a part of a “community” in this sense is essentially INCLUSION. It is a

condition of *belonging*. And if you don't belong, you're **not included**. You are instead, **excluded**.

The basic assumption of the organizations which claim to advocate for our disabled population is that unless people with developmental disabilities live among people without developmental disabilities, apart from their friends, they will lose their empowerment for economic self-sufficiency, self-determination, independence, productivity, integration and inclusion in all facets of "community" life. They argue that all people with developmental disabilities will *adapt* to the demands of "community" life and be able to compete in the job market, lead productive and fulfilling lives simply by virtue of their address.

In the state of Florida as in many other states, the word *inclusion* means that adults with special needs are forced to live in isolated settings like group homes, separated by a radius of 1000 feet, where there is little or no contact with neighbors. The residents are typically shuttled back and forth to their workshop settings where they do piecework like stuffing envelopes. This presumes that the residents are "out in the community" and thus *included*. In Supported Living arrangements, residents of apartment dwellings or even their own homes are dependent on their family members or paid companions to take them out for recreation, social events, shopping, etc. Their social and life-sustaining services are totally dependent on availability of these persons. Thus, when they are unavailable or don't show up, we too often see isolation, loneliness and abuse.

The term, *inclusion*, as used by the cited organizations, begs the question: Inclusion by whom and in what narrow concept of "community"? We believe that being included implies an invitation to join a group or participate in the activities of a group. Simply having free access to community facilities does not mean inclusion in the sense of acceptance and involvement.

On the other hand, the notion of "inclusion" as sharing and participating in the activities and responsibilities of a community, being invited to a neighborhood party, or living near neighbors and friends who care about each other, is the kind of "inclusion" that parents want for their family members when they will no longer be there for them.

Unfortunately, "inclusion" cannot be legislated or enforced. Neighbors can't be forced to ask a person with a developmental disability to hang out with them. A "community" of shared interests and interaction among people with vastly different interests and cognitive abilities is simply not realistic.

Yet, we have been told by policy makers that all people with developmental disabilities should live in the general "community" where they will be "included." We think this is **inclusion delusion**.

The many individuals we have known over the years have never been "included" in any social activities by any of their peers or neighbors.

We reject the paternalistic policies that would supersede the choice of individuals and their families. We hold that individuals and their families are the primary decision makers regarding where and with whom to live (DD Act, 42 U.S.C. par 6 15001 (c) (3) 2000).

We hold that "inclusion" should be a goal only if people can choose where they want to be included rather than where they are *forced* to be included.

We believe that “*forced inclusion*” does not promote adaptive behaviors, increase independence and productivity.

We hold that people with developmental disabilities should not be *coerced* into a “one size fits all” situation by the threat of losing vital supports:

[Rules] forcing them into the ‘normal’ world where they cannot compete, where they are not wanted in many situations or ‘mainstreamed’ into a neighborhood where the neighbors cannot understand them, might fear them and thus won’t interact with them, deny that kind of inclusion. Our family members with developmental disabilities need inclusion in situations and environments where they can be successful emotionally, socially, behaviorally, intellectually and even spiritually. -- David Clayman, M.D.

While the stated values of CMS include “*promoting initiative and choice in daily living,*” there exists an inherent contradiction: Home and Community Based Waiver funding would be denied to those who would benefit from choice of residential options.

We maintain that there is nothing in the design of creative residential *initiatives* that would deny or restrict personal control, privacy, development and opportunity. To the contrary, the fundamental goal of supportive residential options is to increase personal empowerment and opportunity for interaction in a broader setting.

We hold, therefore, that Medicaid waiver funding should be person-centered, choice-based, consumer-driven, cost-neutral and that the money follows the person, not some idealistic ideology.

Most of all we hold that “inclusion” must not *exclude* our citizens with developmental disabilities from the rights afforded to all other citizens. Inclusion is not based on inherently discriminatory distancing requirements which isolate and separate individuals from each other, set quotas, boundaries and density restrictions, a form of *de facto segregation*. “Inclusion” means that all citizens, including persons with developmental disabilities, share the same rights and privileges, specifically the right to live next to peers in a setting of choice – to seek a lifestyle which meets their needs if that is their choice.

Fortunately, the Florida legislators agree. On June 3, 2010, Governor Crist signed into law SB 1166 which affirms the right of our special needs citizens to live in a planned residential community of their choice in an environment supportive of their safety, preferences and needs, with the friends who meet their personal and meaningful need for “*inclusion*.”

Respectfully submitted,

Lila Klausman, Pres.

Parents Planning Programs (PPP), for the Developmentally Disabled of Florida, Inc.

Member, Family Care Council Area 7, Agency for Persons with Disabilities