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Statement to the ADD Forum, November 8, 2010

Some comments from parents and advocates:

"I have argued before that inclusion means to be "part of" an individual's own world and surroundings. Isolating my son, who is severely autistic, in a community (city) based group home, would deny him the safe and supportive community which would accept him with his challenges, provide him purposeful work and appropriate social contacts. In fact, a community based group home would be dangerous for my son who does not understand that going out at night and entering a neighbor's home is not only socially unacceptable, but puts him at risk of being killed. I am still stymied as to why the Florida Developmental Disabilities Council, continues to insist that planned residential communities means institutionalization. There are examples of residential communities such as Camp Hill in New York, which clearly are successful in providing a meaningful life for some of our special needs citizens."

David A. Clayman, MD  
President, AFDDAA  
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The following was addressed to an opponent of SB 1124 published in FFDDnews.com 3/30/09:  
Support SB 1124 or Hobson's Choice

I read with interest your objections to SB 1124. Am I right in assuming that you agree with the stated missions of organizations like the Advocacy Center and FDDC?

Advocacy Center: "To advance the quality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities . . ."

FDDC: "To facilitate the development of a comprehensive and cohesive public policy and governmental structure which: encourages choice and self-direction in the lives of persons with developmental disabilities . . . consumer- and family-directed . . . promote innovative initiatives . . ."

These organizations have taken a position where they neither support choice nor are willing to encourage innovation. It appears that you agree with them. I have high regard for the concept of choice, which receives so much lip service. As a practical matter, I have no objection whatsoever to the DD population who are capable and choose to live apart from their peers. Or do you only offer HOBSON'S CHOICE? \*\*

In my case, my son, who is incapable of communicating, would be overwhelmingly segregated" if forced to live in a community that shuns him. Case in point, he was once dropped off in error at our house while we were away, instead of his brother's. Not a single one of our neighbors, with whom I have friendly relations, made the slightest effort to contact anyone in the family to find out what he was doing there. One family in fact turned him out when he rang their doorbell. He was unable to voice his plight. I think many people would exert a greater effort over a lost dog, at least call Animal Control. Where was the safety net in this case? Not even a call to 911. His very life was in jeopardy. He needs, above all, a safe place to live in a community of his peers. An isolated apartment or group home just won't do! Physical integration is a myth for many at the bottom of the intellectual ladder and simply not a preference for many less dependent folks. Why the unbounded determination to force a foot into a shoe that doesn't fit? We could cite other heartbreaking stories of people who are never "included" in the community, where nobody from their apartment complex

responded to an invitation to a party, others who are never included in a neighborhood barbecue, or where a resident in an apartment complex was beaten up by his neighbors. There are so many of our family members who are innocent, who don't sense the dangers lurking at every street corner, or who are forced to live in low income housing where drugs and crime abound.

"Inclusionists" need a reality check. How many of our state advocates have children of their own? How many parents of young children are charmed into thinking that their child will be accepted and "included" in the neighborhood? How many children are shunned by kids in the neighborhood because one of them is "different"?

Is there a hidden agenda that I am unable to see? Is this all about money? From some comments on your "I Petition" web site, some folks think this initiative will cost millions of dollars. Let me assure you: The proposal for Planned Residential Communities is cost neutral. The state doesn't build group homes. The proposal will simply give another choice to residents of group homes isolated by the 1,000 ft. Rule. It will not change the distancing rule for those who wish to remain in existing neighborhoods. The entire initiative is family and consumer driven, not a government package. As a planned unit development, it will be subject to local zoning. It will not lock anyone into a ghetto. It will give voice to progress and creative private initiatives. It will provide safety, supports, services and meaningful inclusion. It will include other living arrangements such as Supported Living.

Under your alarmist banner of: "STOP DISCRIMINATION, ABUSE & SEGREGATION OF PEOPLE WITH DISABILITIES" –

1. You've turned around the meaning of "discrimination." Proximity, quotas, and density restrictions which you propose are discriminatory -- six beds no closer than 1,000 feet! No exceptions! Even AHCA recognized discrimination when they deleted the 10% Density Rule from the DD Handbook, as did the Administrative Code three years before.

2. Horror stories about abuse are not restricted to congregate living settings alone. Statistics abound with abuse in scattered group homes.

3. You are supporting segregation by the very fact that you champion isolation from friends and common interests with a "scatter" mentality. It seems obvious that you are not aware of the wonderful "inclusion" data of Bishop Grady Villas in St. Cloud. Yes, they do have programs on site, to their credit, but they also have 50% of their residents out in the community working either independently or in their Supported Employment program.

4. Constitutionality?

According to Federal PUBLIC LAW 105-402-OCT. 30, 2000 114STAT. 1677:

"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."

The option of a planned residential community which guarantees exemption from proximity rules must be available if that is what individuals with developmental disabilities and their families choose. Why are you offering only Hobson's Choice?

Eugene Klausman, Concerned Parent, Vice President, Parents Planning Programs (PPP), Inc.

\*\*There is a story that this comes from a Mr. Hobson who rented out horses and gave his customers no choice as to their mount. Thomas Hobson (1545–1631), was a real historical figure and he ran a thriving carriage and horse rental business in Cambridge, England, around the turn of the 17th century. Hobson rented horses mainly to Cambridge University students but refused to rent them out other than in their correct order. The choice his customers were given was 'this or none,' i.e. Hobson's Choice.

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“Should people have the right to choose a setting that violates some people’s understanding of “normal” or “community” or “inclusion”? By developing this work group, the FDDC set themselves up as the

arbitrators of this issue. There has to be a level of trust in the FDDC. This trust appears to have been violated.”

Richard Stimson, Special Gatherings, Melbourne Beach FL

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“I’ve found the comments submitted to CMS to be appalling and in direct contradiction to the spirit and the intent of the work group’s efforts of trying to really understand each other’s points of view and to reach a consensus. In my opinion, the comments that were submitted to CMS have severely undermined, and possibly destroyed, the effectiveness of the Work group. The comments certainly breached the public trust. I now believe that the FDDC’s efforts in sponsoring the Work Group are purely self-serving and with a hidden agenda.”

Jack Kosik, Father, Guardian and Advocate for Brittany, Co Founder of Noah’s Ark

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“When did the FDDC become the entity that develops standards for the DD Community? You really need to take a step back and look at what reality is before taking a position. I think the Council is being very one sided in its approach and continuing to do so will do nothing more than alienate more families to the point of having to take sides against the Council. Ironic, considering you are supposed to be representing the very people that you are potentially harming by taking these positions.”

Ven Sequenzia, President, Autism Society of America, Florida Chapter

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“State DD Councils are not permitted to use their positions to oppose choice by people with disabilities and their families and chosen advocates. Public Law states that the person with DD and their families are the primary decision makers. Many state DD agencies put that part of the Law aside. They believe their decisions prevail. There needs to be an HHS audit of how DD Act programs are working and whether they are **respecting family choice.**”

Lucille Pavinski, Parent, Boca Raton, FL

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“Nothing in FDDC’s federal charter” mandates or even allows FDDC to pursue “community integration” (as they define it) for *all* people with developmental disabilities. The FDDC receives public funds to represent *all* people with developmental disabilities. Instead, it operates in pursuit of an ideology that results in the disenfranchisement of one segment of their constituency because of where this group of people and their families choose to receive residential care. FDDC’s ideology has also contributed to a regrettable chasm between families of people with developmental disabilities. This ideology and related activities are contrary to common sense and law.

Tamie Hopp, Representative VOR

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Message from Sen. Thad Altman, Oct. 6, 2010, Crown Plaza hotel, Melbourne Beach, FL:

“I want to thank all who have worked hard on the bill for Planned Residential Communities (SB 1166). This is an opportunity for parents to have a choice to put their children in an environment that’s best suited for them. We live in a country that’s all about freedom and choice, and when you have freedom, choice, competition, the cream rises to the top and this is all about those American values – by providing an opportunity for those people with developmental disabilities to work and live in a way that they choose to work and live.”

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Some Comments from Parents Planning Programs (PPP), Inc.

We respectfully request that the ADD investigate National Developmental Disability Councils, National Disability Rights Network and University Centers for Excellence, in Developmental Disabilities, supported by our tax dollars that are taking action in violation of federal law as expressed in ADD PI-01-1.

1. The Florida Developmental Disability Council (FDDC), for example, claims: “We Speak for You.” However, the FDDC does not speak for those who have been declared incompetent by the courts, have no possibility of leading independent lives or being “included” by the general community. The one size fits all solution ignores the needs of more challenged individuals.
2. The FDDC’s banner of “Inclusion Now” supports an inherently contradictory and discriminating position by
  - giving tacit approval to the 1,000 foot distancing requirement for community residential (group) homes as defined in F.S. 419.001 – a form of exclusion and segregation by setting boundaries and quotas
  - promoting forced “integration” as a requirement. (There is no study to support a mandate for “inclusion” that explains exactly how integration in the sense of social interaction may be achieved under these circumstances. 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.)
  - denying equal opportunity enjoyed by all citizens to live where and with whom they prefer
  - violating the Bill of Rights for people with disabilities – the right to determine one’s own future and make one’s own life choices (#15)
  - contradicting Public Law – that 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
  - denying the rights of our special needs citizens to be “included” among *all* citizens to live in close proximity to their friends in an environment supportive of their preferences and needs
  - claiming that a planned residential community is not “community based” but an “institution”
  - misleading the public to believe that planned residential communities are using Med Waiver funding to build “institutions” or using Med Waiver funding intended for community based services
  - failing to acknowledge that government centers (“institutions”) and ICF/DD’s are government owned and operated entitlements as opposed to privately supported, unique, choice-based creative initiatives
  - ignoring the fact that Med Waiver money follows the person authorized to receive services; it does not build group homes or communities

Unless the FDDC posts a revised position already sent to CMS on August 19, 2009, we consider the \$40,000 of our tax money that they have spent on a Work Group (over five sessions from July to November 2009) to study planned residential communities, then they have misspent and misled the ADD and the families that gave them their time and trust.

Sincerely,

Lila Klausman, Pres.  
Parents Planning Programs (PPP), Inc.