Embracing the Problem: Choice vs. Government Policy

Since the deplorable condition and confinement of residents of state owned and operated "institutions" of fifty years ago, notably the infamous Willowbrook exposed by Giraldo Rivera in the 70's, the movement to provide a more humane and community based setting for people with developmental disabilities has developed under the guise of advocacy and protection. Federally funded councils and agencies, waving the banner of "inclusion" and "integration" have taken up the cause to another extreme, viewing any form of congregate living as "institution" and "segregation."

There are, however, two existing residential alternatives both involving "segregation":

1. The large government owned and operated institutional campuses (Sunland of Mariana and Tacachale in, FL, for example) as well as public and private Intermediate Care Facilities which are their own communities, designed solely for residents with developmental disabilities, providing residential settings, programs and supports appropriate for safety, health and activities of daily living.
2. Community residential homes (group homes), commonly housing six residents, isolated from other group homes in the community by a distancing requirement known as the "Thousand Foot Rule." The effect of this rule contained in F.S. 419.001 is a quota, density and distancing restriction: 6 residents with developmental disabilities separated by 1,000 feet.

Until 2008, there was a specific segregating rule in existence, the 10% Density Rule, which stipulated that people in the Supported Living Arrangements program could occupy no more than 10 % of the homes in the smallest geographical area (city block, deed restricted community, mobile home park, etc.) and that they had to be "scattered" and non contiguous. People with developmental disabilities could not occupy two apartments that were next to each other. The Agency for Health Care Administration (AHCA) agreed that this was discriminatory and so the Florida Administrative Code deleted this rule in 2003. It took a massive effort on the part of advocates for civil rights to have this rule abolished from the Medicaid DD Services and Limitations Handbook over the protests of the Agency for Developmental Disabilities, the Florida Developmental Disability Council (FDDC) and the Advocacy Center (Now National Disability Rights Network, NDRN). As of March 2008, there is no more 10% Density Rule.

We still, however, have the discriminatory Thousand Foot Rule on the books which has historically been supported by the federally funded FDDC, the NDRN and the Florida Center for Inclusive Communities (FCIC) at the Mailman Center of Miami, to ostensibly enforce "integration" or "inclusion."

Realistically, we know of no rule which can force a neighborhood to "include" people living on their block in their social circle. We have story after story of our people with developmental disabilities who have been ignored, excluded from neighborhood functions and social gatherings. We realize that the term, "community" embraces more than just a place where people live, but is intrinsically bound to shared interests and privileges, and above all, equal status. Because of real estate interests and the phenomenon known as the Not In My Back Yard (NIMBY) syndrome, we have tried to work around the Thousand Foot Rule by introducing legislation to exempt Community Residential Homes (group homes) from this restriction if the group homes were part of a planned residential community designed for people with special needs. S.B. 1166 was finally signed into law on June 3, 2010 by Gov. Charlie Crist.

The introduction of the idea of a privately funded residential community which would allow group homes to exist without distancing requirements, created a furor among "inclusionists" who viewed it as a return to the dreaded "institutions." A frantic Alert and alarm was widely circulated by the FDDC to warn of return to "institutions." Emotionally charged lobbying techniques warned of sweeping changes in policy and claimed that Medicaid Waiver funded intended for Home and Community Based services

would now be use to fund "institutions." Attempts were made by FDDC to substitute Supported Living Arrangements for community residential homes in the proposed legislation.

Despite the clarity of the proposed legislation to limit Med Waiver funding to group homes for Residential Habilitation services, subject to local zoning in a "planned unit development," the "big lie" continued. A letter by the chair of the FDDC was widely circulated alleging:

- Institutional care
- Totally segregated setting
- Loss of control, choice of activities, inclusion, productivity, participation in the full community
- Use of funds designed to avoid institutionalization

Contrary to FDDC's claims:

1. **Med Waiver funding would not be used except to reimburse group homes for Residential Habilitation services for eligible recipients. This is not about robbing Peter to pay Paul. The initiative is entirely cost neutral.**
2. **Planned residential communities are not government funded and administered "institutions" like Sunland. They are privately owned, uniquely individual designs driven by families and consumers in order to provide safety, supports, socialization and amenties.**
3. **They would be subject to local zoning.**
4. **The concept of "inclusion" will not be based on a discriminatory distancing rule which isolates and segregates individuals from each other and sets quotas and density restrictions.**
5. **While providing a safe environment, services, supports, and socially meaningful inclusion, they encourage independent employment and interaction with the community at large as well as a variety of residential options including Supported Living and family homes.**

We strenuously object to any federally funded agency or government supported policy that restricts the rights of people with disabilities who wish to live in planned communities of their choice like other citizens. We also believe that the current FDDC and state agencies should respect innovation and be sensitive to the various needs of individuals who would be at extreme risk to health and safety in the quest for "independence." We do not believe the FDDC or any other federally funded agency has the right to dictate what is best for individuals with development disabilities or to require its stamp of approval on residential *design.* CHOICE of individuals and their families is the ultimate determiner.

In conclusion, we hope that the FDDC will prove their stated commitment to principles of civil rights:

- Respect the right to make such essential decisions as where to live, with whom to live, where to work and with whom, and how and where to spend their time
- Assure consumer and family directed services
- Support individual initiatives
- Recognize individuals as the primary decision makers in the management of their lives
- Encourage meaningful relationships with friends, peers, families and fellow citizens

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Other documentation is contained on our web site which spans the last ten years. Featured videos: Amanda and Daniel's Story and Letters, a compendium of heartfelt statements in support of planned residential communities. http://www.pppflorida.org/

Documentation in support of elimination of 10% Density Rule:
http://pppflorida.org/misc_docs/09Feb13/ADVOCACY%20CENTER%20%20NEW%20VERSION%20ARGUES%20TO%20KEEP%2010%20PER%20CENT%20DE%85.pdf