

ADVOCACY CENTER ARGUES TO KEEP 10% DENSITY RULE
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Pam Kyllonen at AHCA reported to the Joint Administrative Procedures Committee on March 19, 2008, that all references to the 10% Density Rule had been deleted from the Medicaid Developmental Disabilities Waiver Services Coverage and Limitations Handbook, soon to be referenced as FAC 59G-13.083. This was a major victory for scores of advocates and organizations that have been opposing this obsolete rule deleted from Florida's Administrative Code in 2003 for lack of statutory authority.

The Advocacy Center was not happy about this decision. On March 17, the last designated date for public comment, they issued a statement opposing the deletion of the 10% Density provisions, claiming authority as "Florida's official Governor-designated protection and advocacy agency and client assistance program with funding, responsibility, and authority under eight federal programs to protect the rights of Floridians with disabilities." They protested that their "substantial interests would be affected by the department's proposed action."

According to their published description, the Advocacy Center has a staff of approximately 63 (including 13 attorneys, 5 paralegals, 16 advocates, 21 other advocacy specialist and outreach service staff and 13 administrative/support staff). Their stated mission is "to advance the equality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities. . . ."

Their rationale: "The DD HCBS Waiver program exists to provide services and supports in integrated community living situations. The Agency for Health Care Administration and the Agency for Persons with Disabilities must have policies in place to ensure *physical* integration or ensuring that waiver dollars are being used for their intended purpose will be impossible. The absence of density limitations would open the floodgates to individuals with developmental disabilities being heavily clustered in apartment complexes and other developments in contravention of integration, inclusion and true community living."

REMARKS

They review the 10% Density Rule language: "Recipients in supported living live in homes occupied by no more than two other recipients with developmental disabilities and in areas in which residences of persons with disabilities account for no more than 10 percent of the houses or 10 percent of the units in an apartment complex, unless otherwise waived by APD." However, they have chosen to omit an essential component of the 10% Density Rule: "**The recipients' homes shall be scattered, noncontiguous, and dispersed throughout the area.**"

Our take on the Advocacy Center is that they flagrantly contradict their own stated mission: "to advance the equality of life, dignity, equality, self-determination and

freedom of choice.” Instead, they are using our federally funded tax dollars to advance their own “special interests.” In direct conflict with their avowed mission, they use a lobbyist, Sylvia Smith, Esq., to advocate their policy of discrimination.

Their statement: “ The DD HCBS Waiver program exists to provide services and supports in integrated community living situations to ensure that waiver dollars are being used for their intended purpose” – is a **stretch**. More accurately stated, the waiver program was intended as an alternative to institutionalization.

The idea of requiring a density rule to “protect” citizens’ right to live in physical proximity with non-disabled people is ludicrous! They already have that right.

The inherent contradiction of their claim to “protect” and “advocate” becomes obvious as they would support the penalty imposed by APD on Noah’s Nest, to deny a Supported Living Coach because they violate the Density Rule.

How does a quota system which mandates where and with whom our citizens with developmental disabilities may or may not live “protect” and “advocate” for them? How is this consistent with choice and self-determination?

We find the phrases “would open the floodgates,” “heavily clustered in contravention of integration, “inclusion and true community living” ironic as well as offensive. While they object to “clusters,” they nevertheless recognize that this is a preference. They neglect to define “integration, inclusion and true community living.” Apparently, they think that these values are enforceable by law.

Our definition of integration, inclusion and true community living is involvement in community life, purposeful occupation wherever appropriate, social activity, supports, and above all, safety. A visit to Camphill Communities, Lambs Farm, or our own Bishop Grady Villas in St. Cloud would make converts of those who harbor a “physical integration” mentality. These organizations represent a variety of models that may include family style living arrangements as well as physical integration with the community at large.

PUBLIC HEARING

The presentations at the March 3, 2008 public hearing in Tallahassee addressed the obsolete 10% Density Rule contained in the Medicaid Developmental Disabilities Waiver Services Coverage and Limitations Handbook slated for incorporation into Florida Administrative Code 59G-13.083.

Major players at AHCA and APD heard speakers. Families, providers and recipients of Supported Living services spoke enthusiastically about the benefits of living in Noah’s Nest, a cluster of three houses in Lakeland. Advocates in support of this kind of living arrangement objected to the discrimination and bias of the outdated rule.

Among the arguments for deletion of the 10% Density Rule were:

It was removed from the Florida Administrative Code in 2003.

“There is lack of statutory authority -- F.S. 409.906 (13) is vague and ambiguous. It is unconstitutional because it discriminates against persons with disabilities, challenging their residential choices and their freedom to associate under the U.S. and Florida constitutions.” (Florida’s Voice on Developmental Disabilities).

It denies choice and self-determination.

It proliferates a quota system (no more than 10%) -- another form of exclusion.

It isolates people with developmental disabilities from friends under the mandate to “scatter.”

It stifles innovative and creative solutions to residential alternatives.

It exposes our most vulnerable citizens to abuse and molestation in unsafe neighborhoods while denying essential supports.

It discriminates against the only minority that is told where they may or may not live based on a measuring tape and a calculator.

It assumes automatic “integration” by forcing disabled citizens to live in physical proximity with non-disabled residents.

Pam Kyllonen of AHCA made available a collection of letters and e-mails:

Regarding ***enforced integration*** Ann Millan, chairperson of Tampa Family Care Council, states in a letter to Gov. Crist: “My daughter has been in her own condo for over five years. This Christmas she had an Open House for her neighbors (12 families) in her quad. She was so excited planning the event. NONE OF HER NEIGHBORS CAME TO HER OPEN HOUSE. NONE!” Ann continues: “I could have used the story about when her smoke detector went off in her condo and NOBODY came to help her OR call the fire department.”

The Family Care Council, Area 7: “F.A.C. 59G-13.083 not be adopted until such time as the Handbook is revised to remove the obsolete density rule language. The quota system established in this 10% Density Rule is a violation of civil rights and the Americans with Disabilities Fair Housing Act.”

Regarding choice, Dennis Bartholomew, Executive Director of The Sun Up Center for the Developmentally Disabled: “On behalf of those I serve I ask that you carefully consider how the Density rule, if it remains in place, will adversely affect the citizens of Florida with developmental disabilities. The Density rule undermines the basic civil rights of the individual to choose where and how they will live.”

Rev. Richard Stimson, minister of 300 persons at Special Gatherings, and brother: “I do think the 10% rule came from good motives of not wanting to have ‘Retarded Ghettos.’ That being said, I do not think it has served us well. There are two fundamental problems with the 10% rule. The first problem is that of ‘Choice.’ APD has advocated that ‘Choice’ is one of the most important issues in delivering services to mentally challenged persons. In fact APD teaches against imposing one’s moral or philosophical views on mentally challenged persons. The 10% rule comes from a philosophical view that it is

bad for mentally challenged persons to live in cloister situations. Imposing a philosophical view is not the role of government or the purpose of an administrative rule. APD may not like the choice but it is a choice. The second concern is one of safety. It is my view that safety should be a greater concern to APD. I used to serve on the Local Advocacy Council (LAC). The LAC went to all of the law enforcement agencies in Central Brevard County and asked them to identify all unsafe areas. The vast majority of those living in supportive living lived within those dangerous areas. Please allow Choice and Safety to be more important than a philosophical view.”

Jim Gerhauser of the Family Liaison Project in Melbourne: “The Density Rule subverts the individual’s right to housing of choice, undermines self-determination and will erode basic civil rights we all pay so dearly for now.”

Theresa Mitchell, President of Brevard Buddy Walk: “Back in 2003 the Density Rule became obsolete when F.A.C. 65B-11.005 was amended to remove the Density Rule as a requirement for Supported Living. I object to this dated language and reference to old rules and consider it a violation of civil rights.”

Michael Allen, parent and Security Financial Management: “The Density Rule needs to be deleted from the Handbook It is unfair and limits individuals with disabilities ability to live a fulfilling life.”

Donna Tobias, parent: “We do not discriminate against any other segment of the population of people receiving services, so WHY is there a very concerted effort to discriminate against people in supported living situations? This is very offensive. It doesn’t allow for the people who choose to live in a supportive community to have the Pursuit of Happiness and the right to choose safety and socialization with persons like themselves. It boggles the mind as to how the most needy of our citizens can face so much discrimination by a government agency.”

Kathy Buerrose, President of Independence Heights in Boca Raton: “The 10% Density Rule is in direct conflict with the requirements RFP from the Florida Housing Finance corporation. Florida Housing is making available \$13 million from the SAIL (Federal Funds) program as loans for construction or rehabilitation of housing for special needs populations. When building for people with disabilities, in order to qualify, they must commit to rent not less than 80% of the units to people with disabilities. Florida Housing and Finance Corporation (FHFC) will provide help to build housing for people with DD but Florida’s APD will not let them live there.”

Lois Smith, parent and member of Family Care Council Area 7: “The best residential choice for my daughter (her needs are intensive) would be in a planned community of her true peers. However, based on the language contained in the Med Waiver Home and Community Based Service Handbook, this preferred “choice” is denied to her. To deny the rights of my daughter and others to live where they choose is unthinkable.”

Betsy Farmer, Executive Director of Brevard Business Leadership Network: “My Luke is an amazing young man that was mainstreamed his entire time in public school, received his black belt in Tae Kwon Do at 15, got his first job and drivers permit at 17 and has been working for over 5 years. Luke very much wants to live on his own but right now his only options would be to live in a group home with a small number of roommates that he does not know or live in an apartment/condo in the community where he would not be safe and because of the 10% density rule have VERY FEW friends of his cognitive level to interact with. I have a number of friends who have chosen that option for their loved ones and the isolation has caused them to become very depressed. Like the retirees choose to live together because they have like interests, our sons and daughters with disabilities have a right to that same life style.”

David Engles of DSI Supporters, Inc.: “Perhaps we should restrict how many Christians and Jews and Muslims can live in one area, so that under Mike Dunn’s explanation ‘The recipient’s home must be scattered, noncontiguous, and dispersed throughout that area. This allows individuals with developmental disabilities to live in the same neighborhoods, without creating a barrier to integration into the community.’ I made this point to illustrate how absurd this logic is.”

Sue Cannon, parent and parent trainer: “I am moving onto retirement age and think that the kind of supports that I need, as well as the lifestyle that I want, would best be available for me in a retirement community. I will be fully involved in my community, an active member with activities, as well as the needed supports necessary as I age. I will be among friends who understand the issues and challenges I face as I grow older, and who will be available for me as needed. My son, on the other hand, has no such choice. He is currently 14 years old, and if things continue as they are now, he will have no choice at all. It has already been decided for him that he must live a certain way – to the exclusion of a community that may provide him with the necessary supports that he needs, and away from the friends that have shared interests. The ugly head of bias and discrimination is reared again.”

Kathy Savarese, parent and provider: “I have many family members who enjoy living in local communities where they can be with others the same age, who have similar leisure and social activities, feel safe and see friends as they walk or ride bicycles close to their homes! Why is this American promise being taken from those who have a disability? Why is this population being TOLD what they can’t do?”

Eugenie Amalfitano, sister, to Mike Dunn at APD: “If an individual with a disability chooses to live near another person or persons with a disability, that is their right – no amount of hiding behind a “community inclusion” façade will convince me otherwise. It is not up to you or anyone else in this state to tell people that they must scatter, like mice. Is that what you really think of them? What proof do you have that forcing these people to live in isolated, scattered arrangements creates true inclusion? What studies have you done? What percentage of the severely disabled residents living in this arrangement has ever been invited by a non-disabled neighbor to watch the Super Bowl, go to a movie, attend a picnic? I think you need to go back to the drawing board and find a more

humane way to comply with the statutory definition of supported living that allows people with disabilities to live near one another if that is their choice.

A DVD was played to feature two Med Waiver recipients:

Amanda Pivinski: “I do not want to live in an institution. I do not want to live in a group home. I want to live in a home with roommates in a community that I choose and near people who will be friends. Don’t you? Do not take away my choice. Do not take away my rights as a citizen. That 10% rule to deny supported living coaches is dangerous. It takes away my rights. It isolates me. I am 21. I am a citizen. I vote. The government should protect my rights, not take them away. Do the right thing. Delete the 10% rule.”

Daniel Tobias: “I am 24 years old. I worked very hard to graduate from a regular high school and to reach a lot of goals. I am autistic in the moderate range and probably will always have to live with my parents or with people who will help me. My friend Amanda wrote to tell you that she wants the freedom to choose where she lives and to be able to live near her friends. I want to have the right to make that choice also. I also want to be able to live where I know that I will feel safe. Have you ever had people make fun of you, threaten you with harm, or deny you a job, because you think differently or don’t have the same thought skill? If the 10% density rule isn’t changed, I won’t have the right to choose who I want to live near or safety.”

FINAL COMMENT

Please see other comments posted on FFDDnews.com – “APD’s Mike Dunn Denies Discrimination in the 10% Density Rule.” Dr. David Clayman’s eloquent insight into unsound underpinnings of the Rule really wraps it up:

“What is inclusion? Inclusion in what? Included how and for what purpose? For my developmentally disabled son, I want inclusion to mean included in a purposeful and meaningful life, full of emotions, dignity and opportunity. The 10% density denies that kind of inclusion by forcing him into the ‘Normal’ world where he cannot compete, where he is not wanted in many situations. We recognize seniors right to live in a manner that fulfills their desires. Why should my son have to live in a normal, ‘mainstream’ neighborhood where the neighbors cannot understand him, might fear him, and thus won’t interact with him? Why should he be in a job situation where an employer cannot afford his low productivity and where his chance of holding a job is less than seven percent. Our children, teenagers and young adults with developmental disabilities need inclusion in situations and environments where they can be successful, emotionally, socially, behaviorally, intellectually and even spiritually. Clinging to the 10% density rule denies these special citizens their rights to liberty and pursuit of happiness.”

Source: Parents Planning Programs (PPP), Inc.