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**Parents Planning Programs (PPP)**  
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April 22, 2008

Governor Charlie Crist  
Office of the Governor  
State of Florida  
The Capitol  
400 South Monroe Street  
Tallahassee, FL 32399-0001

Att: Warren Davis

Dear Governor Crist,

On February 28, 2008 you designated the Advocacy Center as the governor protection and advocacy system for the State of Florida. We would like to ask your help in obtaining a financial report from the Advocacy Center and to consider our objections to their position as advocates for our citizens with developmental disabilities.

My husband wrote to Sylvia Smith Esq., a lobbyist for the Advocacy Center: "Try as I may, I have been unable to find your annual report, including income and its sources and expenses, salaries and stipends. I believe that this information is part of the public record." To date we have been ignored.

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 – all funded with our tax dollars.

We call into question how the Advocacy Center justifies its position on the issues facing our citizens with developmental disabilities. It appears that its officers and lobbyists never solicit any input from the disabled, their families and guardians, although they claim to be the "client assistance program with funding, responsibility, and authority under eight federal programs to protect the rights of Floridians with disabilities."

The most recent criticism of the Advocacy Center comes from a dozen or more grass roots advocacy organizations as well as individuals and families of people with developmental disabilities because of its position to retain an obsolete 10% Density Rule in the Medicaid Developmental Disabilities Waiver Services Coverage and Limitations Handbook (incorporated into the Florida Administrative Code 59G-13.080 by reference). This rule was taken from the Florida Administrative Code 65B-11.005 which was deleted in 2003 for lack of statutory authority:

Recipients in Supported Living live in homes . . . 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. The recipients' homes shall be scattered, noncontiguous, and dispersed throughout the area.

On March 19<sup>th</sup> after the Public Hearing on March 3<sup>rd</sup>, Pam Kyllonen of AHCA announced to the Joint Administrative Procedures Committee that the two references to this rule had been deleted from the Handbook -- a major victory for our advocates.

Particularly vocal at this hearing were two families and two residents of Noah's Nest in Lakeland which were denied a Supported Living coach by the Agency for Persons with Disabilities because their three houses are in a cluster, and therefore, violate the 10% Density Rule.

The Advocacy Center apparently agrees with this punishment. Their statement on March 17<sup>th</sup> argues that the 10% Density Rule should be retained because they must have policies in place to ensure "physical integration," otherwise waiver dollars would not be used for their intended purpose.

We understand that the Home and Community Based Waiver (HCBW) was intended as an alternative to institutionalization and was not intended to require people with disabilities to live apart from each other in a vigorously controlled quota system in order to enforce "physical integration." We feel that this over-correction is a violation of basic civil rights where our most vulnerable citizens are isolated from their friends and supports -- another form of "segregation."

For a better insight into the outrage and discrimination that families and our own people with disabilities feel, you might take a look at comments in FFDDnews.com in various articles about the Advocacy Center and the 10% Density Rule. We're also sending a DVD from Amanda and Daniel.

Ironically, at the Public Hearing, an attorney from the Advocacy Center mentioned that the 10% Density Rule sounded unconstitutional. But the greatest irony of all is that the Advocacy Center's stated mission is "to advance the quality of life, dignity, equality, self-determination, and freedom of choice of persons with disabilities."

We question how a quota system protects and advocates while it mandates where and with whom our citizens with developmental disabilities may or may not live. To deny people the right to live next to friends and to access services in a less costly and more efficient way for their mutual supports and safety is against every principle of self-determination and choice available to the general population.

From our perspective, 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. They do not need our tax dollars to achieve that purpose.

My husband adds: "I find it staggering to think that my tax dollars are being used by the Advocacy Center to promote a philosophy at an extremely opposite pole from just about every parent's wishes with whom I have discussed the subject. . . Why the unbounded determination to force a foot into a shoe that doesn't fit?"

Among the dozens of protests referenced, the following are quotes about the Advocacy Center:

"You ask, 'Does the Advocacy Center speak for you?' I am certain that many of our members would shout, "NO!! The Advocacy Center time and again takes positions that are counter to choice and family input - all while being funded by the federal government - YOUR tax dollars. Its position on the 10% Density Rule is just more of the same. See, <http://www.vor.net/FamilyTestimonials.htm> and, specific to Florida, <http://www.vor.net/FLTestimonial.htm>, for more examples." -- Tamie Hopp, Gov't. Relations/Advocacy VOR

“I called the advocacy center for help when the school board tried to kick our son out of school (change his placement to home hospital, yet he is well enough to go out to theme parks, movies, etc). They offered no assistance whatsoever in spite of my calling repeatedly for legal advice. Useless organization.” -- Mary V., Family Care Council Area 7

“In 25 years we have never seen the Advocacy Center on the correct side of any issue. They work against families and their loved ones. It is time for this agency to be abolished! The Federal Gov't should NOT reauthorize their funding.” -- David Engels, DSI Supporters, Inc.

We urge you as governor to encourage expansion of choice in living arrangements which ensure safety, socialization and support by putting an end to rules which discriminate.

For now, our question is how does this agency justify the use of our tax dollars and assume moral and government authority under the guise of advocacy and protection, while working against the most sensitive needs of our disabled citizens?

Thank you for responding to our letters in the past. We look forward to hearing from you.

Sincerely,

Lila Klausman, Pres.  
Parents Planning Program (PPP), Inc  
Associate Member, Family Care Council Area 7

Encl: State of Florida Office of the Governor Executive Order Number 08-34  
DVD Amanda and Daniel

CC: Warren Davis, Office of Citizen Services  
Bryan F. Vaughan, Executive Director, Governor's Commission on Disabilities  
Gary Weston, Executive Director, Advocacy Center  
Family Care Council, Area 7