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**Parents Planning Programs (PPP)**  
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## GERALDO AT LARGE – THE WAITING LIST

Original Message to: [atlarge@foxnews.com](mailto:atlarge@foxnews.com)  
Dec. 28, 2008

Dear Geraldo and Fox News,

Thank you for bringing the plight of people with developmental disabilities to the public on December 27th.

While the focus of Geraldo's show was an anti-institution program featuring the ARC-US, we need to bring into focus other more current issues. We agree with Robin Sims of VOR, interviewed by Geraldo, that one size does not fit all:

- 1) There are Medicaid licensed facilities which provide great care and a wonderfully, integrated environment.
- 2) Most community facilities don't have the staff, supports and funding to safely care for medically fragile residents.
- 3) Cost of care is lower for the severely disabled in facilities than in the community.

We are parents of a 42 year old son who has Down Syndrome and autism. Like all other aging parents, we are haunted by the prospect of what will happen to our son when we are gone.

For a very long time, we have been looking for a suitable residence for him. We were very enthusiastic about communities we had visited in New York, Pennsylvania, California and Illinois among which were Camphill Communities and Lamb's Farm and a more recent community established by the Diocese of Orlando in Florida, Bishop Grady Villas. In these communities we saw meaningful inclusion in a least restrictive environment -- involvement in community life, purposeful occupation, social activity and above all, safety.

When we came to Florida about thirteen years ago, we started an organization called Parents Planning Programs for the Developmentally Disabled of Florida, a 501 (c) 3 Corporation. We had hoped to bring this concept to Florida. We invited Camphill people to talk to parents and held meetings with administrators of the state's Agency for People with Disabilities (APD). We were told by these administrators that what we had in mind was an "institution" and would be denied Med Waiver funding.

The mindset has not changed in all this time.

We have met several families through our networking who are also interested in building special needs communities for their adult children who are lost in the general community. These efforts have been frustrated by the "rules" like Florida's statute, Chapter 419, which requires group homes to be separated by a distance of 1,000 feet. APD interprets this Thousand Foot Rule to say that a special needs community is against the law!

We have approached our legislators to amend Chapter 419 to exempt planned residential communities for people with developmental disabilities from the Thousand Foot Rule. At present a bill is being prepared by two of our legislators.

Please understand that APD's determination to block our efforts is fierce. It took three years to finally take down the discriminatory 10% Density Rule contained in the Medicaid Developmental Disabilities Services Handbook which stipulated that recipients of Supported Living services could not live next to a friend in another apartment or house, but must be scattered and account for no more than 10% of the area!

As our children approach adulthood, they can no longer depend on the supports of parents and families to survive on their own. They need friends and a supportive environment. Although the Supported Living arrangements may be working for some adults, we have seen many cases of isolation and deteriorating living situations. We have a collection of letters from parents who say their adult children are never "included" by neighbors, as well as stories of abuse, and vulnerability in low cost housing.

We need residential alternatives and choice! We urge you, Geraldo and Fox News to take the time to visit some of the fantastic communities that we have seen and to make these the highlight of another show about our people with special needs.

Sincerely,  
Lila Klausman, Pres.  
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