



DOCUMENTATION IN SUPPORT OF AMENDING CHAPTER 419, EXEMPTING PLANNED RESIDENTIAL COMMUNITIES FROM THE THOUSAND FOOT RULE

MINUTES OF PPP MEETING WITH BOB MORIN, ADMINISTRATOR, AREA 7, APD 2/19/01

Luann Malark, parent, Titusville:

My point today is that families know best how to address the "housing" needs of their individuals and any intervention/funding by agencies should support those decisions. I realize that "cluster housing" is not acceptable by some, however, when it's my tax dollars being used to promote programs, it should be up to me how my son's needs are best met. Ideally, group homes in the community can be very beneficial for some and that idea should not be ignored. However, when others feel more comfortable with a planned community, their pleas should not be ignored either. Yes . . ."choice-based, family oriented and consumer driven" . . . is this a dream for some and a nightmare for others? Let all voices be heard.

Sue Cannon, parent and Education Specialist, Parent to Parent of Brevard:

I have a young child who is only seven. I don't know what the future holds for him, but when he gets to a stage where he needs to move out of the family home, I want options for him and I want him to have a say in making the decisions as to where he will live. He will need supervision, but he has to have options like all people have options, so this is very, very important to me. I don't know if he will be living in a congregate community, I don't know if he will be living in a group home, I don't know if he'll be able to live in an apartment with supports. But those options need to be made available and this is currently very difficult, so I'm backing this program for that reason.

Irene Burnett, Board of Directors, Cobblestone, Viera:

I absolutely agree with you that what we need is choices. And what is best for your child may not be best for somebody else's child. So what we really need is a lot of different programs on the community level so that parents can choose. This one rule that we're talking about, we're running up against just the same as you are. And obviously, we need to speak as one voice to our legislators. . . . I used to work for the department. I was the District Administrator for the four counties, Brevard, Osceola, Orange and Seminole Counties. That was before it was the Department of Children and Families. My biggest frustration the whole time was to try to get the DCF to understand what I saw as their job. DCF, in my opinion, is not there to say, No, you can't do something, but to look at local communities and say, What is the need and how can we help you to meet these needs? And they should be helping the local community to find waivers, help us with the legislators, do the things that are needed to be done. I was with HRS when they closed Sunland here. I know that whole picture where 'this is terrible and we're hurting these people.' Well, Sunland did some wonderful things for a lot of clients.

Myriam Brix, parent and member of PPP writes to Bob Morin, Administrator APD Area 7:

My husband and I attended the Parents Planning Programs (PPP) meeting on Feb. 19, 2001, in Melbourne, when you were the guest speaker. The big issue was congregate living. I would like to tell you why I am for it. My middle child, Bernadette, is mentally retarded. When my older daughter was about two years old, I began meeting with my neighbors every day. Since they also had small children, we went for walks to the park or got together for a cup of tea while the children played. Once Bernadette started to show signs of retardation, my children and I were excluded from the activities. When they saw us coming, they turned around and walked the opposite way. When I invited my neighbors' children to come and play in my backyard, they told me that their parents didn't want them to play with Bernadette because they may catch what she had. Nobody ever comes to my house to speak to Bernadette, to play a game of checkers or go for a walk. The community does not want our children living in their neighborhood. I went to many meetings in areas where a group home was going to be opened and I heard people say that they don't want to see those "funny" faces next door to them. They were also very concerned about their property value going down. Our children are very sensitive. They feel it when somebody looks at them with disdain. Why is the State against our ideas? We know what is best for our children. Why can't we have a special community for our special children, where they can be happy, safe, have friends, walk to each other's house by themselves, ride a bike, etc., without the fear of traffic? How wonderful it would be to have such a community!

(Cont'd.)

RESPONSE TO SUSAN DICKERSON OF APD WHO DEFENDS THE THOUSAND FOOT RULE

Mary O'Meara, parent and Director of DD Programs, Volusia Parks and Recreation 6/20/02:

There are many caring, hard working people who want to run these [group] homes and for whom it would be more efficient to have more than one within a reasonable proximity of one another. God forbid there should be such a rule pertaining to senior citizens in Florida! My street would be empty. Surely it would have been a better response from Ms. Dickerson if she replied, "The intent of the law may have had the best of interests in mind but we should ALL fight for legislative change to effect the wonderful changes/advancements that you want to make in your county." Sadly she chose to hide behind the law and do a dump and run.

RESPONSES TO HILLARY BRAZZELL, APD, RE: PUBLIC RULE WORKSHOP, CH. 419, THE 1,000 FT. RULE

Sue Cannon, parent, Special Education Trainer 1/07/03:

Community living is not the way it used to be – An isolated home in a neighborhood of people that don't often interact is not my idea of inclusion. Inclusion to me is being an accepted member of a community. It is the job of the community to include -- not the job of the individual to have options narrowed in order to be included. Nor is it the job of government to ensure that individuals don't have particular options so that they can be included. Maybe I am too new at this to understand the ramifications of [the 1,000 ft. rule]. But it appears that by restricting options, the current rule is in essence taking away what it attempts to do – give individuals with disabilities choices, flexibility, control and responsibility in their decision making and in their lives. I plead with you to seriously consider the discrimination that this rule implies for our family members.

Eugene Klausman, parent, Treasurer, PPP 1/06/03:

The law with respect to the Thousand Foot Rule attempts to treat all persons with developmental disabilities as if there was no diversity among them. There is a tremendous gulf between those whose disability is barely noticeable and those who are totally immobile with not even an awareness of self. In the law there is the implicit demand that you must live our way, not the way you might desire. There is a total lack of awareness that for some, integration into a local community is simply neither possible nor desirable. Our son is incapable, for example, of speaking with you, has no concept of money, is unaware of dangers in the "community," e.g., traffic, predators, etc. He can't use public transportation and cannot exist by himself. The "compromise" that gave rise to the 1,000 ft. rule really comes about from the "communities" which want to exclude "that kind" from its midst. Separate them far enough apart and we will not have to notice them. The Florida Developmental Disabilities Council (FDDC) fact sheet is nothing more than an emotional and partisan statement of a position to the exclusion of all other positions.

Teina De Bakey, parent of resident of Gulf Stream DSI, scheduled to close in 2010 -- 1/06/03:

This is being done under the supposition of "inclusion" -- integrating the mentally disabled into a neighborhood. Unfortunately it does not take into consideration the compassion of the neighborhood! Can you imagine a [law] which prohibited more than 2 or 3 families of any given religion or race living more than 1,000 feet from each other? I think the very foundation of this law (besides being extremely hypocritical) is the fact that "they" are assuming these kids do not want to live with each other! It is such a fundamental right! I wonder if they have ever watched the Special Olympics.

Myriam Brix, parent, 1/08/03:

I support the PPP initiative to amend the 1,000 ft. rule and I respectfully ask for your support. There are several benefits to [a planned residential community.] Collocation [of group homes] allows better management of resources (resident supervision, security, etc.) as well opportunity for the residents to socialize. I would like my daughter to live in an environment in which she can go for a walk, ride a bicycle or play ball with friends free from danger.

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LETTERS TO FLORIDA LEGISLATORS REQUESTING AN AMENDMENT TO CHAPTER 419:

Jeannie Forthuber, parent and Co-Chair Family Care Council Area 7-- 12/06/07:

The Area Seven Family Care Council, is in support of an amendment to Ch. 419.001 to specify that the 1000 Foot Rule does not apply to licensed Assisted Living Facilities and other qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services. Chapter 419.001 represents the opposite of choice in the lives of individuals with developmental disabilities and their families. As the state of Florida has made an effort to encourage self-determination and independence, it is important that we do it in every aspect of their lives, not just where it's convenient. We do not deny the thousands of seniors in Florida a community to live, that is 55 years or older, as this is their choice. So why would we, and how can we rightfully deny the citizens of Florida who have developmental disabilities the right to live where they choose? Our council would like to request that you sponsor and introduce a bill during the 2008 legislative session that would exempt planned residential communities from Ch. 419.001, specifically the 1000 ft. rule. We ask that you support and advocate with your fellow legislators to make this happen.

Donna Rauber, sister and Co-Chair Family Care Council Area 7-- 3/09/07:

Many families, especially elderly Parents, live with the ongoing fear of what will happen to my loved one when I'm no longer here. Many adult children with developmental disabilities continue to live at home with family. It's becoming more difficult for parents as they age to care for their loved ones. The answer for many families would be a residential community similar to retirement communities where their loved one could live and provide a permanent living arrangement until his/her death. A perfect example of one is Bishop Grady Villas in St. Cloud. Currently families of BGV residents private pay for them to live there. Most families don't have the financial means to do this. BGV would like to open enrollment to individuals who require assistance with daily needs but when they applied to become a Medicaid Waiver Provider asking for residential habilitation services they were denied by APD citing the 1000 ft. rule as their reason. Families would like your help in actively sponsoring or supporting an amendment to Chapter 419 which would exempt residential communities from abiding by the 1000 ft. rule.

Donna also writes:

Attached you'll find a December 16th, 2005 article published in the Cincinnati Inquirer. An Ohio provider is looking to create a Life Care Center very similar to what we are calling a residential community. They hired Proctor and Gamble to do a market research on the subject to determine if there truly was an interest within the state for this type of residential housing. P& G was absolutely amazed when they received a 100% response to their inquiries. They were overwhelmed by the number of people wanting to be part of the project. (This reminds me of our housing survey from years past and how many mentioned they too wanted to get involved.) I asked if within the state agencies this type of community was being viewed as "institutional" and he advised, yes. However he did say they have talked with the Agency on Aging and the MR/DD Agency (our APD) and they are both very interested in learning more about their plans. After the article appeared in the paper they received phone calls from all over the nation. Currently they are a very large provider of residential services. Their website address is: www.rhcorp.org.

Lori Brothers, Administrator of Bishop Grady Villas, St. Cloud, 3/01/07:

As an Administrator of an Assisted Living Facility for developmentally disabled adults with a diagnosis of mental retardation, I personally support an amendment to Chapter 419 exempting Assisted Living Facilities from the Thousand Foot rule. I believe applying that rule to such facilities is a misuse of it and eliminates another option for those seeking a safe and nurturing environment for those seeking assistance in everyday living skills, job skills, employment, and other developmental, social, emotional, and spiritual support. I hope that you will make this one of your priorities and I invite you to visit Bishop Grady Villas in St. Cloud, Florida. Our residents would love to meet you and tell you about their successes. You would be very proud of them.

Dr. David Clayman, parent and founder of AFDDAA, urges members to write to legislators 3/10/07:

As the parent of a teenager (young adult) with autism, I am greatly concerned regarding the availability of a safe and nurturing environment for my child who requires assistance in everyday living skills, job skills, and employment, as well as developmental, social, emotional, and spiritual support. I personally support an amendment to Chapter 419 exempting planned residential communities from the Thousand Foot rule, an action that will make available the option of group homes while preserving state financial support.

(Cont'd.)

Lois Smith, parent and member of the Family Care Council Area 7-- 3/10/07:

As the parent of a forty year old daughter with severe multiple developmental disabilities, I would greatly appreciate your support in amending Chapter 419.001. My daughter is an only child and the supports we offer her will one day be gone. It is in her best interest and her right to be allowed to live where she chooses. Without an amendment to Ch. 419, this choice is denied her. The developmentally disabled population is the only one impacted in this way. An example of what amending Ch. 419 would provide, is Bishop Grady Villas in St. Cloud. APD denied licensing of this facility based on the 1,000 ft. rule found in Ch. 419. Across the state, parents are realizing APD has no plan in place for the aging and permanent placements of individuals with developmental disabilities. It has taken the forethought of concerned parents and guardians to address this situation. In my opinion, by disallowing planned communities, APD has been greatly remiss by denying choice and a solution to this issue.

Donna Tobias, parent and member of PPP 3/10/07:

My family and I support measures that would amend Ch. 419.001 - the Thousand Foot Rule. By supporting an amendment to Ch.419, you will be enabling disabled persons to live with dignity and have a level of self-sufficiency. This type of community would allow for a support system that could focus directly on the needs of the individual residents. As the parent of an autistic person, I would like him to have access to a safe environment and yet have the independence and skills to take care of his own needs, when I am no longer able to take care of him. The day will come where we won't be here to do that. A community aimed directly at supporting the most nearly "normal" living environment is best and right. As Ch. 419 is currently enforced, these persons are being denied their basic rights. A change in the Thousand Foot Rule benefits society. These communities will help them achieve some independence and in many cases help them find gainful employment so they will be less dependent on government services. Our family members should have the same protections as everyone else, under the Fair Housing Act and within Ch. 419.

David and Leni Engels, parents and Board Members DSI Supporters 3/10/07:

We need an amendment to 419.001 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services. All of us are permitted to choose where we live. Why does Florida discriminate against the disabled dictating to this community where they can and cannot live? This is a basic violation of this group's civil rights. Please understand the DD community is only demanding what all others today already enjoy, choice! Thanks for your attention, and for committing yourself to correcting a wrong that has caused great hardship for 1000's and 1000's of families.

Brett Calder, parent and member Brevard Buddy Walk 3/10/07:

Please note our support for an amendment to Ch. 419.001 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services. Without this change, kids like my daughter Lee (10 years old, photo attached) will be denied fair opportunities as a result of unintended consequences of a rule.

Ed Carraway, grandfather and Pres. DSI Supporters 3/11/07:

Please note our support for an amendment to Ch. 419.001 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services. My 29 year-old grand daughter wants to live in a community of homes made just for the disabled where staff is available. She has many seizures so you can see why such a community is so very necessary.

Carol Russotto, sister, Deerfield Beach 3/11/07:

As our parents become unable to care for their children later in life, we want our brothers and sisters to have a loving environment and a place they can continue to call home. It shouldn't be so difficult to ensure that our loved ones have a place to go. We have a very dedicated group of parents who have taken it on themselves to see that this becomes not just a dream, but also a reality. They are spending countless hours doing what they can to remove these unnecessary obstacles. With your support I see a better road ahead for my little brother. (Cont'd.)

Rob Holl, parent and Member Family Care Council Area 7 – 3/12/07:

I am extremely pleased to hear of your help in the effort to amend Ch. 419.001. My wife and I, at this very moment, are wrestling with where our developmentally disabled daughter will live in the near future. In large part, this question is made more difficult by too few options to consider. The 'thousand foot rule' should not apply to qualified planned residential communities aimed toward serving folks with developmental disabilities. By eliminating this obstacle, a new range of opportunities would be made available. This additional support would go a long way to easing my family's transition concerns, as well as, a great many other families.

Eugenie Amalfitano, sister, Secretary PPP 3/12/07:

I hope you will support an amendment to Ch. 419 which would grant an exemption to the Thousand Foot Rule to allow for planned, congregate residential communities designed to accommodate those with special needs, particularly the developmentally disabled. This would broaden the support services and residential options available to the more severely handicapped people with developmental disabilities. For some, living in a group home that is isolated, far away from other such group homes, is not appropriate, safe, or desirable. My brother is among the severely handicapped, with both Down Syndrome and autism. We recognize that the existing Thousand Foot Rule serves to prevent an overconcentration of group homes in an "existing" community. However, "new", planned communities that are specifically designed to serve the needs of this special population, are desperately needed. My brother deserves to live in a community where he will be supervised and protected, and where services can be provided in a cost-effective way. We hope he will be able to live among friends, caregivers, and others with special needs, in a community that can provide a needed social outlet as well as a supportive safety-net. We hope you will take a proactive role in bringing this dream to fruition.

Maryann Sarra, parent and Member Family Care Council Area 7 -- 3/12/07:

Please support amending chapter 419.001. We as the parents of an adult with autism would not be afraid to die if we knew that our son had the opportunity to live where he chooses. People with developmental disabilities should have the same freedom in housing that everyone else enjoys. I hope that you will be successful in ending this injustice.

Kathleen Savarese, parent, provider and member PPP 3/14/07:

I have a 29 year-old daughter who is hearing and visually impaired and has developmental disabilities. Although she has numerous life challenges she has also been a taxpayer in the State of Florida for 8 years. Since the day she was born, my husband and I have been concerned about where she would live. Her every day life issues can still be handled as long as we, her parents are still alive. I have wondered why the agencies who support individuals with disabilities appear always to be against the direction that families think would be a safe inclusive environment. Florida is filled with communities for the senior citizens 55 and over. In THEIR communities they have friendships, services, recreation and security. In addition to the senior communities, the prestigious places to live in Florida are in gated communities. In our opinion the Thousand Foot Rule is in direct violation of the Freedom of Choice granted to every citizen of United States by our Federal Government via Section 504 of the Federal Fair Housing Act. To deny individuals who have disabilities their choice of where to live is prejudicial and discriminatory. Please help us correct this injustice.

Ann Millan, parent and Chair of Family Care Council, Tampa 3/14/07:

I understand the scope of the many concerns regarding the purpose of the 1,000 foot rule, however, the need for variances and exceptions in statute is paramount for individuals with developmental disabilities. A rule such as this does not allow for individual choice and needs to be reviewed. Many individuals cannot afford or do not want supported living and their only option should not be a group home. I understand the concern of repeating any institutional setting site; however, there are some really exciting options developing in Florida that need full support of the legislature. Bishop Grady Villas (ST. Cloud) is one and another is Noah's Ark (Lakeland). I have been to Bishop Grady Villas and have seen the presentation on Noah's Ark. Both are outstanding. Many of the individuals with developmental disabilities walk to work and are included in the community. Shopping is also within walking distance. I request these planned residential communities be approved based on the fact they are "in and part" of the community. Individuals with developmental disabilities are not being isolated "from" the community. An amendment to Ch. 419.001 should specify that the Thousand Foot Rule does not apply to qualified planned residential communities, within access to city limits, designed to include individuals with developmental disabilities as part of the community and to serve the needs and broaden their support services. (Cont'd.)

Betty Kay Clements, parent and Pres. Family Care Council of Florida 3/14/07:

I am writing in reference to your consideration of an amendment to Ch. 419.01 that would support small residential communities for individuals with developmental disabilities. My husband and I, along with many other elderly parents, are concerned about the future of our daughter who is 45 years old and has a developmental disability. Having visited Bishop Grady Villas in St. Cloud, it was possible to envision her thriving in such an environment. It resembles closely the retirement communities throughout Florida that provide opportunities for working, shopping and socializing in the neighborhoods of the community. Noah's Ark is a similar community in Lakeland, Florida. Both communities expand the spectrum of choice for our individuals with developmental disabilities. Visiting Bishop Grady Villas, we saw not a "secluded" environment, but one that offers the "inclusion" that Florida initiatives for individuals with developmental disabilities support. The cost of such an arrangement is prohibitive to many of us. Since BGV is ineligible to become a Medicaid Provider due to the Thousand Foot Rule, this is not a choice that my daughter or many others have available to them now. Please consider actively sponsoring or supporting an amendment to Chapter 419 with language that would include: An amendment to Ch. 419.001 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities, within access to city limits, designed to serve the needs of people with developmental disabilities and broaden their support services.

Sally Holloway, President, Professional Providers of Florida 3/15/07:

Please note my support for an amendment to Ch. 419.001 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services. Without this change, people who are served by Medwaiver will be denied fair opportunities as a result of unintended consequences of a rule.

Patricia Beeber, parent 3/15/07:

We are concerned that Daniel will not be able to live in a safe, secure, and stable residential environment where he can receive the maximum opportunities to develop healthy relationships, as well as have people in his life who can provide him with a "family" type lifestyle into his elder years. We understand the concern the legislature has had in monitoring and correcting the abusive conditions in the past "institutions," as well as the concerns some citizens have of creating large clusters of housing for special needs in established neighborhoods. However, in trying to avoid these concerns, there is another type of serious restriction disallowing the licensing of appropriate living communities such as the Bishop Grady Villas in St. Cloud, Noah's Ark in Lakeland, and Cobblestones in Melbourne. It must be noted that the legislature has made room for other special communities, based on age, as well as gated communities available to other restricted classes of people. In supporting an amendment to Florida Statute §419.001, clearly stating that communities such as Bishop Grady Villas do not fall under the "Thousand Foot Rule," you will be working effectively to remove this barrier to your constituents like Daniel, who are in need of similar communities. Daniel would not be safe in a residence such as an apartment due to his inability to understand basic safety issues and the type of support he needs.

Theresa Mitchell, parent and President, Families Exploring Down Syndrome of Brevard, Inc. 3/16/07:

I am another parent of a child with developmental disabilities who supports an amendment to Ch. 419.001. While my child is very young, I am very appreciative of the efforts of people who are paving the way for a brighter future for my Annie. We are asking for an amendment to Ch. 419 to specify that the Thousand Foot Rule does not apply to qualified planned residential communities designed to serve the needs of people with developmental disabilities and broaden their support services.

Jack Green, Executive Director, Sun Up of Indian River, Inc. 3/27/07:

Sun Up of Indian River Inc., is a 501 (C) 3 not for profit organization, located in Indian River County. Organized by a group of parents in 1994, we have worked to build an intentional community that will meet residential needs of adults with developmental disabilities. Our ten acre site already has a 9,000 square foot Education and Activities building where we provide educational, social and recreational opportunities for 60 adults on a regular basis (Our current client mailing list is 162). It is our intent to build nine structures that will house up to six people each. You can look at our proposed plan on our website, www.sunupofir.org. Because of the 1,000 foot rule, only families who have sufficient private funding would be able to participate or Sun Up would need to fundraise an enormous
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amount to make the programs viable. Neither option appears reasonable. I understand it was apparently not the intent of the Legislature to prohibit the development of residential communities, but only to prevent an over concentration of community residential (group) homes in a residential area. This was the rationale for the Thousand Foot Rule contained in Ch. 419.001 FS. In the face of an historical philosophical bias against congregate living arrangements by the Agency for Persons with Disabilities, Sun Up of Indian River unanimously supports an amendment to Ch. 419 to exempt planned residential communities from the Thousand Foot Rule. There have been many organizations which have been frustrated in their attempts to launch creative and innovative planned residential communities based on miscommunication, misunderstanding, and misapplication of the Thousand Foot Rule. Another more deliberate attempt at prohibiting congregate living arrangements was the 10% density rule, previously part of the Agency's Administrative Code. Fortunately, that has recently disappeared. Please introduce or support an amendment to Ch. 419 that exempts from the Thousand Foot rule, a residential community specifically designed to serve the needs of people with developmental disabilities. In the interests of our family members who have been the object of discrimination for so many years, we feel this issue of the Thousand Foot Rule should leave no room for misinterpretation or misapplication.

REVIEW OF PPP's POSITION 1/01/09

Since January, 2000 our organization has been networking with families and other organizations such as the Family Care Council, Area 7, who express their preference for planned residential communities for their family members with developmental disabilities. The distancing requirement for community residential homes (group homes) under Ch. 419 specifies that they be separated by a minimum of one thousand feet. This is commonly known as the Thousand Foot Rule. The stated intent of the rule is to prevent an "over concentration" of group homes that would affect the character of the area. However, since planned residential communities would exist as a separate entity apart from an established residential area, they would not affect the character of any neighborhood.

The Agency for Persons with Disabilities (APD) is using this rule to deny licensing of group homes in any sort of congregate living arrangement and to label all such designs as "institutions." In the face of an historical philosophical bias against congregate living arrangements, APD is not only in conflict with the ADA, which recognizes the right of choice of individuals and their families, but they are obstructing the development of private initiatives for people with special needs. Planned residential communities would provide meaningful inclusion in a least restrictive environment, involvement in community life, purposeful occupation, social activity and above all, safety. Additionally, APD is using the 1,000 foot rule to deny our disabled citizens the same equal opportunities afforded to all other Americans to live in their community of choice.

Our organization was successful in getting Bishop Grady Villas in St. Cloud licensed by APD for Med Waiver services because they were initially licensed as an Assisted Living Facility. However, there are grassroots initiatives which failed because of the 1,000 foot rule, e.g., Cobblestones in Melbourne. We are concerned that without this amendment, others in the planning stages will fail, such as Noah's Landing in Lakeland, and Sun Up of Indian River County. Through our efforts, APD's 10% Density Rule was recently eliminated, Now our remaining objective requires an amendment to Ch. 419 exempting planned residential communities from the Thousand Foot Rule.

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