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Response to the Comments Posted by Debra Dowds of FDDC on August 19, 2009 on the Medicaid Program Home and Community Based (HCBS) Waivers, CMS – 2296-ANPRM):

"State DD councils are not permitted to use their positions to oppose choice by people with disabilities and their families and chosen advocates. Public Law states that the person with DD and their families are the primary decision makers. Many state DD agencies put that part of the Law aside. They believe their decisions prevail. Period. There needs to be an HHS audit of how DD Act programs are working and whether they are **respecting family choice**. . . . Just as an example, they recently spoon fed propaganda to state legislators to get them to withdraw a Bill which would have given families a choice, simply another choice of where to live, in planned residential communities specially developed for people with DD. . . . The FDDC operates under the banner of WE SPEAK FOR YOU. . . . There is a tidal wave of need approaching us . . . current policies alone cannot provide solutions. There are parents and self-advocates who can increase the availability of real choices, yet their views are disrespected, are regularly opposed by DD agencies. How have these agencies usurped the rights of the vey people they are charged to represent and advocate for?"

Lucille Pavinski, Parent, Boca Raton, FL

"I have been following the workgroup on Planned Communities. I am a big supporter of choice and have questioned why we are even having this workgroup. It concerns me that advocates would want to limit choice through public policy. . . . I have been functioning under the assumption we had this workgroup to suggest a position to be adopted by FDDC. In your letter dated August 19, 2009 the second bullet under section B suggests that the FDDC already has a position. Why do we have a workgroup if we have already taken a position? Is there a position that has been adopted by the FDDC? If the FDDC has not taken a position and has a workgroup studying this issue, how can you go on record for the FDDC taking a position? As you know, there are two principles in play here. One is choice and one is inclusion. Should people have the right to choose a setting that violates some people's understanding of "normal" or "community" or "inclusion"? By developing this workgroup the FDDC set themselves up as the arbitrators of this issue. There has to be a level of trust in you and the FDDC. This trust appears to have been violated."

Richard Stimson, Special Gatherings, Melbourne Beach FL

"It is such a shame that the organization that is supposed to **"advocate and promote meaningful participation in all aspects of life for Floridians with developmental disabilities"** is promoting such a narrow definition of what it means for meaningful participation. I see meaningful participation as the ability to choose your own activities, friends and lifestyle. I see meaningful participation as the assurance that the right supports will be in place as naturally as possible to allow these choices. Personally, I am appalled that the FDDC is so closed minded on their opinion of planned residential communities for individuals with developmental disabilities. I question the behind the scenes agenda when there is such a closed mind/attitude at an organization."

Sue Cannon, Parent, Melbourne, FL

Cont'd.

Response to Comments, cont'd.

"I've found the comments submitted to CMS to be appalling and in direct contradiction to the spirit and the intent of the work group's efforts of trying to really understand each other's points of view and to reach a consensus. In my opinion, the comments that were submitted to CMS have severely undermined, and possibly destroyed, the effectiveness of the Work Group. The comments certainly breached the public trust. I now believe that the FDDC's efforts in sponsoring the Work Group are purely self-serving and with a hidden agenda."

Jack Kosik, Father, Guardian and Advocate for Brittany, Co Founder of Noah's Ark

"When did FDDC become the entity that develops standards for the DD Community? Please forgive me, but there are many issues that the DD Community has with FDDC positions, including the planned residential communities legislation. The only reason that FDDC is doing the work group is because you had many families communicate their support of these types of communities and challenged the FDDC position. Forgive me, but FDDC does not speak for everyone in the DD Community and You need to have a more open dialogue and open mind to what the community wants, vs. what bureaucrats feel is what is needed. . . . I lived in Florida since 1967. I know some of the DD Council members personally, for many years and I must say I am surprised at the tone and the position that the Council is taking when it comes to these issues. You really need to step back and look at what reality is, before taking a position. I think that the Council is being very one sided in its approach and continuing to do so will do nothing more than alienate more families to the point of having to take sides against the council. Ironic, considering you are supposed to be representing the very people that you are potentially harming by taking these positions."

Ven Sequenzia, President, Autism Society of America, Florida Chapter

"I agree entirely with Jack Kosik's points of concern. I strongly suggest that a significant portion of the October 15, 2009 FDDC Work Group Meeting be devoted to addressing the comments posted by the FDDC on August 19, 2009 on the Medicaid program: Home and Community Based (HCBS) Waivers, CMS_2296-ANPRM. As you know, for consensus to be reached (the decision-making method you selected for the Work Group), there must be identifiable **common ground** upon which consensus can be built. CMS_2296-ANPRM has **shattered** the consensus we had hoped to achieve with your office. As implemented, the Work Group lacks clear objectives that are embraced by all followed by meeting agendas and presentations that align with those objectives. It is only through substantive, relevant activities designed to open minds and expand viewpoints that common ground can be reached."

Tito Balducci, Parent, Tallahassee, FL

Lila Klausman, Pres
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