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Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-2296-P
P.O. Box 8016
Baltimore, Md. 21244-1850

Submitted electronically: <http://www.regulations.gov>

Dear Centers for Medicare and Medicaid Services,

As a parent and as president of Parents Planning Programs (PPP) for the Developmentally Disabled of Florida, Inc., I appreciate the opportunity to comment on this Critical Situation.

We respectfully request that the Centers for Medicare & Medicaid Services carefully consider the definition of “Community” under the Proposed Regulation CMS-2296-P.

Proposals being considered will rule out residential choice for our most vulnerable citizens with intellectual disabilities in the name of “integration” and service in the “least restrictive environment.” As the number of aging parents grows, we see this situation as critical.

By buying into this new proposal, CMS has lost sight of individuals. In one broad stroke it will wipe out 60 years of innovative and meaningful residential options for our most challenged citizens with intellectual disabilities, with one-size-fits-all solutions.

Alternative Residential Solutions

Our son’s condition seriously affects his ability to communicate and to function independently. On the fateful day we learned of his diagnosis of Down Syndrome and Autism, my first question was: What happens forty years from now?

Happily, that question was answered when Mark was accepted at Bishop Grady Villas (BGV) in September of 2010 at forty-three years of age. Our prayers were answered and our hard work paid off. Through the Catholic Diocese of Orlando and the support of our Family Care Council Area 7 of the Agency for Persons with Disabilities, BGV was fully licensed as a provider of Medicaid Waiver services under the Home and Community Based Services (HCBS) Waiver, as an assisted living facility in 2007, authorized under Florida Statute 429.01

In contrast to government owned and administered “institutions,” Bishop Grady Villas is a privately owned community-based subdivision of eleven acres in the heart of St. Cloud, Fl., facilitating residents’ access to broader community resources. For Mark, this is the “least restrictive environment” he has ever known, providing him a rich social life and freedom of movement in safety. He can now ride his adult tricycle on the grounds. Transportation is

readily available to the gym, bowling, swimming, shopping, library, movies, community theatre, picnics on the lake, local Disney attractions, and his volunteer activities at the local adult center. On site activities are posted on a daily calendar of events -- arts and crafts, cooking class, etc. There is a wood shop, plant nursery, a community center with computers, TV, pool table, and day training with staff and volunteers to teach safety, communication skills, aerobics, e.g. Additionally, there are six beautiful homes with private rooms and bath, each home with a family room and kitchen. There is nursing supervision. At least half of the 48 residents are employed.

Integration

Mark has never had this kind of “integration” before. While living with us, people in our neighborhood were polite to Mark, but he was never invited to hang out with the kids on the block or ever invited to a party, or neighborhood barbecue. While attending the local sheltered workshop, where Mark stuffed and unstuffed envelopes or did other sorting tasks, he was never engaged in the community in any sort of “integrated” way. On the few occasions when he received respite at a group home, he was shuttled back and forth to the workshop and became a couch potato the rest of the time. However, he was out in the community and thus, by current definition, he was “integrated.”

In the state of Florida as in many other states, the word “integration” means that adults with special needs live in isolated settings like group homes, separated by a radius of 1000 feet. This amounts to a condition of *de facto segregation*, where there is little or no contact with neighbors.

Likewise, in Supported Living arrangements, people living in their own homes or apartments are dependent on their family members, or paid companions to take them out for recreation, social events, medical appointments, etc. Their **safety**, social and life-sustaining services are totally dependent on availability of these persons who are frequently unavailable or don't show up.

Loneliness is also a major issue in the lives of our more dependent people, as well as the fundamental issue of safety, where they are often victims of molestation, neglect and abuse by other members of the “community.”

The many individuals our organization has served in recreational activities over a dozen years, have never been “integrated” in any social sense of *belonging* by any of their “peers” or neighbors. Our folks do not belong; rather they are shunned.

The term, “integration,” as used in the proposed rulemaking, begs the question: Integrated with whom and in what narrow concept of “Community”?

“The goal of such waivers is to integrate people into the social mainstream with equal opportunities and the chance to make choices.”

Simply having access to community facilities does not mean integration in the sense of acceptance and involvement in the social mainstream. “Integration” according to Webster is “incorporation as equals into society,” and, therefore, should afford equal rights and opportunities for our population with intellectual disabilities. Unfortunately, our people's

handicapping condition prevents them from having equal opportunities in the “community.” Now they will also be denied equal rights to live in a community of choice.

Community

“Community” carries the connotation of “fellowship, a social state or condition, an interacting population, people with common interests living in a particular area” (Webster). We consider “Community” to be more than a place or location. “Community” is defined not just by where people live, but how they interact. “Community” has a more significant meaning when it provides “integration” based on shared interests, responsibilities, opportunities for growth, recreation, socialization and supports. This is particularly important for the more dependent population with intellectual disabilities, those with substantial or multiple cognitive impairments, who can no longer rely on their immediate family to be there for them forever “at home.”

The term, “community” is an ever expanding phenomenon known as “new urbanism” – with a variety of residential zoning classifications including “planned unit developments” encouraged by statewide zoning ordinances. These may be deed restricted subdivisions, intentional communities, retirement communities, 55+ communities, veterans communities, religious communities, golf communities, etc. In 2010, legislation was passed via Florida Statute 419.001 for “planned residential communities” for people with developmental disabilities.

Mark is now, for the first time in his life, an integrated member of his community and engages in a variety of challenging as well as recreational activities in the general community – which he would otherwise be unable to do in his own apartment or an isolated group home.

Policy Makers as “Advocates” Supersede Families and Choice

For our federally funded “advocacy” agencies, like the National Association of Councils on Developmental Disabilities (NACDD), the National Disability Rights Network (NDRN), and the Association of University Centers on Disabilities (AUCD), to act as policy makers and deny Waiver funding to our loved ones because of the location in which they choose to live, makes a mockery of a person-centered approach. To expect people of vastly different cognitive abilities to interact based on shared interests is simply unrealistic. To label planned communities “segregated institutions” as if shut off by force, is blatantly uninformed. Our own Florida Developmental Disability Council and Disability Rights Network with whom we have been involved in a Work Group over five sessions this past year, had never visited a planned community such as the widely acclaimed Lamb’s Farm in Illinois, Camphill or L’Arche Communities in the U.S. and abroad.

Creative Initiatives Facilitating Integration

The success of these creative initiatives and our own Bishop Grady Villas is that they were conceived as interactive arrangements with the broader community – through hospitality businesses, gift shops, coffee shops, amusement park, craft studios, organic farming, baking industries, the arts, for example, as well as developing apprenticeships and employment opportunities with local businesses, even setting up housing for their more independent residents.

Forced “Integration” and “Segregation”

The federal agencies’ policy of forced integration is not protecting the disabled from forced segregation. Rather, their policy is forcing them to “integrate” based on the paternalistic idea that it knows best where the disabled should choose to live. The tyranny of federally funded public policy over democratic values has become apparent – Our way or no way! This is an inherent contradiction to their stated values of “promoting initiative and choice in daily living” while denying appropriate residential choice based on sweeping generalizations.

Our plea to the CMS: Support Waiver funding that is person-centered, choice-based, consumer-driven where **money follows the person**, not some extremist agenda of forced integration.

Discrimination

We believe that policies advanced by federally funded agencies must not discriminate by denying our citizens with intellectual disabilities the constitutional rights afforded to all other citizens to live in a setting of choice, regardless of diagnosis, specifically the right to live in their most integrated setting, to seek stability and a lifestyle appropriate to their needs, without fear of losing services.

Choice as Paramount to Freedom and Independence.

We believe that “integration” assumes that all citizens, including persons with intellectual disabilities, share the same rights and privileges, specifically the right to live next to peers in a community of choice – to seek a lifestyle which meets their needs if that is their choice, and that choice is fundamental to person-centered planning. Policy makers authorized to educate, advise and inform have abused their authority by assuming the right to limit choice. They have violated their role as a “source of information and advice in helping legislators and other policymakers to identify and evaluate the available alternatives for meeting the needs of individuals with developmental disabilities.” (ADD-PI-01-1)

Please support the mission of families for our special needs sons and daughters to expand, not stifle, alternate residential options which:

- provide **safety**, supports, socialization
- facilitate access to community resources and employment
- guard individual rights and welfare
- recognize the vast range of individual intellectual disabilities
- permit choice
- direct Waiver funding to follow the person
- recognize **families** as decision makers:

Please renounce an ideology that allows federally funded agencies to dictate policy in preference to families as primary decision makers regarding where and with whom to live (Developmental Disabilities Act, 42 U.S.C. par 6 15001 (c) (3) 2000).

Lila Klausman, Pres.

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