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May 16, 2011

Barack Obama
The President
White House
1600 Pennsylvania Avenue N.W.
Washington, D.C. 20500

Fax: 202-456-2461

Dear Mr. President,

We respectfully urge you to review efforts by the Centers for Medicare & Medicaid Services to define “Community” under the Proposed Regulation CMS-2296-P:
<http://www.gpo.gov/fdsys/pkg/FR-2011-04-15/pdf/2011-9116.pdf>

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 aging parents of a son with Down Syndrome and Autism, we see this situation as critical.

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

Our son’s condition seriously affects his ability to communicate and to function independently. On the fateful day we learned of his diagnosis, 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 Medicare Waiver services under the Home and Community Based Services (HCBS) Waiver, as an assisted living facility in 2007, authorized under Florida Statute 429.01

Bishop Grady Villas is a 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, each with a family room and kitchen. There is nursing supervision. At least half of the 48 residents are employed.

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Mark has never had this kind of “community” or “integration” before. While people in our neighborhood were polite to Mark, 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, shopping, etc. Their safety, social and life-sustaining services are totally dependent on availability of these persons. When they are unavailable or don’t show up, we too often see isolation, loneliness, neglect and abuse by other members of the “Community.”

The many individuals our organization, Parents Planning Programs (PPP), Inc., 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”? Simply having access to community facilities does not mean integration in the sense of acceptance and involvement.

We consider “Community” to be more than a place or location. We view “Community” as having a more significant meaning when it provides “integration” based on interaction, shared interests, responsibilities, opportunities for growth, recreation and socialization.

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.

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.

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.

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

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.

CMS inherently contradicts its stated values of “promoting initiative and choice in daily living” by denying appropriate residential choice, with sweeping generalizations and one-size-fits-all solutions.

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.

Please support the mission of families for our special needs sons and daughters to provide 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

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).

We thank you for your support of individual rights and to your service to our country.

Sincerely,

Lila Klausman, Pres.

Parents Planning Programs (PPP), for the Developmentally Disabled of Florida, Inc.

Cc: Kathleen Sebelius, Executive Director, HHS
Donald M. Berwick, Administrator, CMS
Laverdia Roach, Acting Exec. Dir., President’s Committee for People with Intellectual Disabilities
Cindy Mann, Director, Center for Medicaid & State Operations
Barbara Edwards, Director of the Disabled and Elderly Health Programs Group, CMS
Mary Sowers, Director, Disabled & Elderly Health Programs Group, CMS
Ralph Lollar, Director of Long Term Services and Supports, CMS
Arun Natarajan, Health Insurance Specialist, CMS
Henry Claypool, Director of Office on Disability
Kareem Dale, first Special Assistant to the President for Disability
Gov. Rick Scott, Florida
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Sen. Bill Nelson, Sen. Marco Rubio, Sen. Thad Altman, Rep. Bill Posey
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