

Subject: Florida Development Disabilities Council Leadership and CMS-2296-ANPRM
From: Tito Balducci <balduct1@gmail.com>
Date: Thu. 20 Jan 2011
To: Mary.Sowers@cms.hhs.gov

Mary Sowers
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-1850

Dear Ms. Sowers,

It is utterly frustrating to hear the head of the Florida Disabilities Council (FDDC) Ms. Debra Dowds" (FDDC) is still referring to "planned residential communities as "segregated rather than integrated housing for people with disabilities."

My daughter lives in a "planned, integrated residential community" in Upstate New York. There, integration is not an abstract construct, but a way of life. Thus, it is imperative that bureaucratic organizations stop reciting their safe, divisive and outdated orthodoxies and begin representing the wider range of views on how to provide services and meet all the needs present in the disabilities spectrum.

As a supporter of the "One-Thousand-Foot Rule" in the State of Florida, Ms. Dowds clearly confuses Isolation with integration and thus, perpetuates the status of limited choices, one that stigmatizes those that don't fit the "cookie cutter" solutions supported by her leadership in the Florida Developmental Disabilities Council. This is leadership grounded in a bygone era -- pre-internet and with limited access to information.

The concepts of "planned residential community" and integration need not be mutually exclusive -- a point dismissed by Ms. Dowds. It is time for change, it is time for innovative, pragmatic solutions, and above all, it is time for new leadership!

Sincerely,

Tito and Mary Ellen Balducci

2402 Miranda Ave,

Tallahassee, FL 32304

Dear Ms. Sowers and Ms. Poisal,

I am writing to contribute my ideas and opinions about Home and Community based waiver funding. I am a parent of a 17-year-old son with moderate developmental disabilities. I have been involved somewhat in the state of Florida in the discussion regarding residential options for the last couple of years. I am in touch with many parents around the state who agree that we need innovation.

I participated in a work group for this purpose in Tallahassee and learned there that the abuse rate occurring in group homes in this state is at 90%. Yet, our leadership has no new ideas, no innovations and to my knowledge Florida is 49th in the nation for funding for developmental disabilities. It seems our "advocates" have spent most of their time in the last number of years trying to prevent successful legislation that allows people with developmental disabilities to live in intentional communities. I have witnessed a national trend against congregate living, mostly as a consequence of (and a continual reference to) the Olmstead decision. In our state, innovation in the form of unique, privately run intentional communities, has been labeled as institutional living, which is nothing more than a deceptive and misleading campaign to further their political agenda. I don't think you would find any parent or advocate for persons with developmental disabilities proposing institutions.

Please let me leave you with just one important thought. It is common for individuals to project their own ideas and predilections on those who cannot speak for themselves. The idea that being successful means that one lives in the community in the same way that everyone else is a projection on their part. In reality, persons with developmental disabilities in the state of Florida live in substandard housing, in isolation, and under emotionally, sometimes, physically, sometimes sexually abusive and other exploitive situations. According to our policy makers, this is ok as long as they don't live communally.

Let me ask you: Imagine that you are not able to use the phone on your own or drive a vehicle. Would you prefer to live in an isolated group home where you were at the mercy of the underpaid support staff to facilitate your friendships and socialization or would you prefer to be in a community where you could walk a few paces to the next home to be with friends? You could have many amenities that one finds in any gated community, and the safety of restricted traffic and security gate. In Florida, the retirement capital of the nation, this is a common residential choice. Which one would you choose?

Without Home and Community Based Waiver funding, you would have no choice.

Thanks for "listening". Please support "Choice".

Respectfully submitted,
Susan Thiele
Gainesville, Florida
(2/6/11)

February 11, 2011

Centers for Medicare & Medicaid Services
Attention: Mary Sowers and Ms. Poisal
Department of Health and Human Services
CMS-2296-ANPRM
Baltimore, MD 21244

Dear Mrs. Sowers and Ms Poisal,

It appears you have responded to letters from the NACDD, NDRN and AUCD addressing concerns over segregated rather than integrated housing for persons with intellectual disabilities. The writers have apparently based their comments and arguments on a school of thought having no practical significance, rather than from the perspective of a parent of a child with intellectual disabilities in the real world.

The arguments assume that all persons with disabilities are able to communicate, integrate socially, live independently, and have the capacity for self-determination. The arguments follow that they will be able to compete in the job market, lead productive and fulfilling lives and be integrated in a community of shared interests simply by virtue of their location in the community. Any other residential alternative such as a planned community of choice is deemed "segregation" or "institutional living." Nothing could be further from the truth. These arguments are the classic one-size-fits-all.

When living with us in a "community" for over 40 years, our son was never accepted by his peers. He was shunned by people his age living in the community. Community, as defined by the writers, is nonsensical. Intellectual Disabilities cover an extraordinary range of capability. To those who have the ability to sustain socially fulfilling, safe and productive lives in a community defined by "location," I give my support. However, I refuse to accept a prison of a different kind for those who will be sentenced to a life in a "community" of isolation.

I urge the CMS to stand behind its stated values that include "promoting initiative and choice in daily living." That choice is the same choice that all citizens enjoy, to share the same rights and privileges, specifically the right to live next to peers in a setting of choice, - to seek a lifestyle in a planned community with the same social recreational, educational and employment opportunities in a safe environment.

Thank you for listening.



Eugene F. Klausman
Parent and Advocate

Subject: CMS 2296 P: KEY ISSUES
From: Lucille Pivinski <JLACP@aol.com>
Date: Wed, 4 May 2011
CC: <eklausman@cfl.rr.com>

It is time to acknowledge and support a broader definition of "community"; a definition that respects individual views of what is meaningful, desired and preferred.

CMS 2296 P is going in exactly the wrong direction by endorsing and enforcing the exclusion of entire "settings" out of hand as places where people may live and receive supports through the waiver. The settings excluded are in fact, by law, alternatives to "institutional" placements; yet those who live there would be denied home and community based supports.

Some key issues are (in my opinion):

* **Choice** is fundamental to person-centered planning. Restrictions based on "arbitrary indicators" (*government speak for quotas, distancing, and density restrictions*) are inconsistent with the primary goal of person-centered planning, which is to deliver real control over ones own life to persons with ID/DD. Just because someone w/ ID/DD needs waiver supports does not give license to "others" to control their lives. They need not trade their freedom for supports.

* Forcing individuals to **forego choices** they would otherwise freely make by threatening them with the loss of life-enabling waiver supports is **coercion**. CMS should resist the hijacking of rulemaking by the radical one-size-fits-all, we know-better-than-you-do, agenda advocates who are clear in their intent to impose (by "financial" force) their views of "community", "inclusion" and "integration" on all others.

* The focus should be on **meaningful** inclusion, **meaningful** integration, and true **respect** for individuals' desires, **preferences and needs**. Artificial inclusion and artificial integration is more than meaningless....it is detrimental to the individuals on whom it is imposed. What some people define as "integration", other people may experience as isolation and neglect. Whose life is it anyway?

We ask that CMS reassess 2296 P and return to the primary purpose of the Medicaid HCBS waiver, which is to support **individuals** not agendas.

We ask that CMS reassess 2296 P and remove the threat of coercion implicit in excluding "out of hand" some non-institutional settings that individuals with ID/DD might consider and select if they were free of the threat of losing the life-enabling supports they would otherwise be entitled to.

Subject: Rebuttal to NACDD, NDRN and UCD view on segregation of DD persons

From: David Clayman <daclayman@pol.net>

Date: Thu, 20 Jan 2011 22:58:17 -0500 (EST)

To: Mary Sowers <Mary.Sowers@cms.hhs.gov>

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

Dear Ms. Sowers

I am writing in rebuttal to a position taken by the National Association of Councils on Developmental Disabilities, the National Disabilities Rights Network, and the Association of University Centers on Disabilities, whereby they express concern over the use of Medicaid Waiver funding for what they assert to be segregated housing. As a professional and a parent of a young man who is developmentally disabled, I am one of many parents and professionals working to create communities that will address the needs of our children, allowing them to live in a setting that will truly provide inclusion. The organizations above, despite their fancy names, either do not or refuse to understand that inclusion means to be a part of and function within a given community. The placement of a disabled individual in a "normal" environment, where he or she cannot function, will only result in that disabled person being segregated from that community. If my son chooses to live in a community with others like him and where there is the appropriate support, he can become an active member and be included in his community.

I strongly disapprove of the above political organizations presuming to know my son's abilities and disabilities, and further, I strongly disagree with their narrow view of what it means to be included.

Most sincerely,

David A. Clayman, MD