



January 24, 2012

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

Fax: 202-456-2461

Dear Mr. President,

Thank you for responding to our letter of May 16, 2011 concerning a request for your review of the very controversial Proposed Regulation CMS-2296-P regarding residential CHOICE.

While we applaud your actions to fund opportunities for education and employment of people with disabilities via educational and vocational rehabilitation programs, we are requesting further expansion of programs for a very ignored segment of our more intellectually disabled population in favor of higher functioning individuals.

In a review of your letter of July 27, 2011, our Board noted the major theme of “independence.”:

“We must ensure all Americans have equal access to opportunities and can live independently without discrimination.”

“I launched the ‘Year of Community Living’ to bring agencies together to improve access to housing, community support, and independent living arrangements.”

“The Recovery Act also provides an additional \$140 million to support independent living centers.”

We recognize that our intellectually disabled citizens should strive towards the goal of independence; however, we as parents and professionals in the field, believe that “independent living” involves many aspects of daily living skills. Among these are the ability to:

- Communicate verbally – use the telephone, ask questions, respond appropriately, read and write, articulate needs, hurts, desires
- Call for help if lost, threatened, bullied, exploited or abused
- Understand dangerous situations – crossing a street, unsafe places
- Attend to basic hygiene and household tasks – use appliances, prepare nutritious food, clean dwelling
- Understand money transactions
- Read common signs and traffic signals
- Seek and qualify for employment
- Manage time – set the alarm clock, follow daily schedule
- Use public transportation

I would like to quote a commentary regarding his daughter's status on "independence" from Mark L. Olson, (Nevada Commission on Autism Spectrum Disorders, Chairperson, Community Living & Employment Subcommittee):

She can't live alone in a scattered site apartment because she doesn't know how to cross a street safely, or how to avoid neighbors who might bully, exploit, or abuse her. It's a ludicrous notion to expect her neighbors to be her "it takes a village" safety net. . . . She can feed herself, but she cannot use a stove or microwave to prepare a hot meal. . . . She cannot speak, read or write. She will never be able to pursue competitive employment on the open market, but that doesn't mean she can't earn a minimum or higher wage. A work environment created to accommodate and develop her abilities would be ideal. But again the same forces are at work to eliminate these optimized settings as discriminatory.

Here is the link to the full post:

<http://blog.autismspeaks.org/2012/01/04/autisms-fly-over-population/>

See also "Choice v. Olmstead":

<http://ltoventures.org/news/articlesop-ed/choice-v-olmstead/>

In many ways our son parallels Mr. Olson's daughter and will never be considered "independent."

May we again urge you to expand your program initiatives to our more "dependent" citizens and to reconsider your opening remarks to read as follows:

"We must ensure all Americans have equal access to opportunities afforded to all citizens to live in a community of choice without discrimination and as guaranteed by the Developmental Disabilities Act, 42 U.S.C par 6 15001 (c) (3) 2000."

Sincerely,

Lila Klausman, Pres.

Parents Planning Programs (PPP) for the Developmentally disabled of Florida, Inc.
Member, Family Care Council Area 7, Agency for Persons with Disabilities, Florida
Member, ASHA as Licensed Speech Pathologist

Cc: Kathleen Sebelius, Executive Director, HHS
Marilyn Tavenner, Administrator, CMS
Laverdia Roach, Acting Exec. Dir., President's Committee for People with Intellectual Disabilities
Cindy Mann, Director, Center for Medicaid & State Operations, CMS
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, ADD
Kareem Dale, first Special Assistant to the President for Disability
Gov. Rick Scott, Florida
Bryan Vaughan, Executive Director of the Governor's Commission on Disabilities
Sen. Bill Nelson, Sen. Marco Rubio, Sen. Thad Altman, Rep. Bill Posey
Pam Kyllonen, Medicaid Services Program Analyst, AHCA
Leigh A. Meadows, Program Administrator, Developmental Disabilities, AHCA
Mike Hansen, Director, Agency for Persons with Disabilities, Florida

Encl: Letter from Barack Obama, July 27, 2011

Letter to President Obama, May 16, 2011