

Annie Seaboldt

I would like to bring to your attention a serious and urgent situation regarding four Connecticut families who each have an adult child afflicted with Prader-Willi Syndrome (PWS). These individuals, currently funded by the Connecticut Department of Developmental Services, are cared for in a highly specialized Prader-Willi facility in Massachusetts.

Please note that by Statute, to qualify for CT DDS, the Client must be identified as "Mentally Retarded" or have PWS. The point is the State has long recognized that PWS is a special condition different than "general" Mental Retardation. DDS acknowledges that PWS is a disability so severe that in spite of IQ, it is recognized as eligible for services. PWS Clients need the constant presence of specially trained staff to deal with their medical/psychiatric/behavioral issues.

PWS is a rare disorder. It is characterized by: damage to the hypothalamus, incessant hunger often leading to morbid obesity and early death, self-injurious behaviors, chronic anxiety, Obsessive Compulsive Disorder, inability to regulate body temperature, *inability to adapt to change*, and significant disruptive conduct. These are just a few of the challenges that plague sufferers of this extremely complex disorder.

In December 2012, the four families met at the DDS with Commissioner Macy. At that time we were notified of DDS's intention to move our family members back to CT. Our disabled loved ones would have no choice and be voiceless in this process.

It is also important to recognize that in addition to residential services, our young adults require other special services and programs. The Hyannis area, influenced by the Kennedy family philosophy, is well known for their long established, extensive network and accommodating environment for those with special needs. Hyannis and the surrounding area offers: hierarchical day habilitation services, tailored special educational programs at Cape Cod Community College, social skills evening groups and a variety of opportunities for Special Olympic activities. These are integral to the management of their needs and make their lives productive.

My son, Matthew Mansourian, lives in a residence in Barnstable that houses four other PWS clients. He has been provided with many opportunities that have enabled him to participate as a productive community member. Matt has completed a special vocational/educational program called Project Forward at Cape Cod Community College. He works part-time with a job coach, attends a day-habilitation program, participates in Special Olympics, attends a special needs weekend program called Friday Night Socials sponsored by the Barnstable Recreation Department, volunteers at the library and is a regular attendee at the Vineyard Church in Kingston.

He also has been working with a counselor that specialized in adults with special needs. His counselor has been instrumental in helping Matthew accept and manage his challenges.

Matthew receives his psychiatric medical care at Tufts New England Medical Center in Boston. His expert doctor has managed his intricate disorder with the precision and sensitivity that results after years of working closely with a complex patient.

Without the customized level of support he has received in all of his programs and from the community, Matthew would be isolated. Over the five years my son has been in Massachusetts, he has developed deep ties within the Cape Cod community. He now calls Barnstable home.

After *years of residency* (our young adults have been there from 3 to 11 years), our family members have *finally* attained a place they call home where they are equally committed with their PWS peers under the care of staff and management that have extensive skills, expertise, and experience in creating a secure, appropriate, specifically designed environment with established routines. Each one of these adults has established broad and deep ties over the many years they have lived in Massachusetts.

The previous DDS administration had all but guaranteed that these placements were permanent. The lives of these four special adults, as well as the lives of their families, have been planned around this assumption. To move these individuals would be detrimental to the time and funding that has been invested in their care.

We recognize and appreciate circumstances of the current fiscal economy and the prudence of in state care. Despite any budgetary issues, however, maintaining their Massachusetts residency is the right thing to do.

As a parent, there is nothing I want more than for my child to be a happy, healthy, productive member of an accepting society. I ask you not to shatter the lives and success of these four, whom everyday face, and conquer, challenges at a level others may not face in a lifetime. Please give them every consideration and ensure that the place in Massachusetts that they call home is secure. Thank you.

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