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February 15th, 2013

Dear Members of the Appropriations Committee:

For a lesson in the specific challenges of supporting individuals with Prader Willi Syndrome I refer you to the previously forwarded letter from The Prader-Willi Syndrome Association regarding four young adults who are now living in Massachusetts through the support of DDS Connecticut. I also refer you to the Pittsburgh Partnership letter. For the past 36 years I have worked as a social worker with populations of individuals with special needs and their families. This is by far one of the most challenging populations to work with that I have ever seen.

Three years ago, our family was in crisis with our daughter, Alexandra Pope, a client of DDS because she has Prader-Willi Syndrome. After graduating from high school, her behavior began to decline and her weight escalated as she has no internal controls regarding satiety, among other things. With the support of DDS, we arranged several day programs for her that failed and resulted in injury to a staff member. She was no longer able to participate in her main physical activity, caring for horses and riding. She entered The Children's Institute in Pittsburgh, Pennsylvania, where she began a behavioral and dietary management program specific to Prader-Willi Syndrome. Because the diligent search for a group home in Connecticut was fruitless, DDS arranged to place her with the Latham Centers, a program world renowned for success in working with people with Prader Willi Syndrome, in Massachusetts.
<http://www.lathamcenters.org/>

There Alexandra continued to lose weight (overall 100 pounds), found a barn to ride and work in, and successfully completed a program for those with learning disabilities at the local community college. She has found her place within the Latham Community, gaining as much independence and self respect as possible. She now has a greater understanding and acceptance of her syndrome helping reduce her ongoing anxiety. Her tantrums are fewer and more manageable. She was even able to bring back a gold medal in the Special Olympic World Games, Equestrian division, in Athens, Greece. We are totally amazed at how far she has come under the care of Latham Centers' knowledgeable and experienced staff.

Now we are learning from Dr. Macy, that DDS's goal is to return those they serve back to Connecticut, strictly a fiscally based decision. Connecticut can be reimbursed 50 % by Medicaid only if services are rendered in Connecticut. At the time of her placement at Latham, the cost for service was considerably less than the cost would have been in Connecticut had we been able to find an agency willing to take on the complexities of care required. This may still be the case.

Our concerns:

1. Moving the four young adults at the Latham Centers in Massachusetts back to Connecticut could result in a major digression in behavior and health, potentially resulting in intensive increased costs.
2. Our four young adults have established deep ties within the local educational, religious, social, recreational and medical communities in Massachusetts. This is priceless.
3. Could Connecticut be reimbursed 50% by Medicaid for the expenses incurred in supporting our young adults in Massachusetts?

We are grateful that our young adults with Prader-Willi have found a true home. Disrupting those ties could be life threatening.

We hope that DDS will continue to support these citizens where they thrive.

Thank you for your attention,

Martha J. McDonald