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**Testimony of Mary Ann Barile
Mother and legal guardian for Vincent Demetro
Of Pelham Avenue, Hamden, CT**

To: Public Health And Human Services Committee:

My name is Mary Ann Barile. I reside in New Rochelle, New York and I am employed in Bronx, New York. My son is Vincent Demetro, He resides in the home known as 4 Pelham Avenue, Hamden, Connecticut.

Please allow me to thank you very much for your time and attention in this very important matter that has been entrusted to both of us. I am pleased and honored that you are allowing me to explain my son's unique history and present circumstances to you and I am quite certain that you invited this comment in order to make the best decision possible in this matter.

BRIEF HISTORY OF VINNY IN PLACEMENT

Vinny came into the care of the former Department Of Mental Retardation at the age of eighteen years. Vinny's DSM IV diagnosis is schizophrenia paranoid type, and mental retardation. When he was first placed, it was because Vinny had repeatedly exhibited violent behaviors such that he had to be contained in a hospital setting. Without enhanced and professional support he engages in self injurious behavior and in assaultive behavior. After he loses control in this way Vinny feels immense remorse and depression which leads to even further self injurious behavior. He has obsessive thoughts, mostly around food, and he repeats himself in conversation, engaging in obsessive statements.

Vinny also soothes himself by rocking, and sometimes he can bang his head quite hard in doing so. Additionally, if left to his own choice, Vinny will eat without stopping. Vinny is illiterate. Vinny has some mild impairment in his hands, and his gait is a bit unsteady.

Vinny was first placed with a private provider after experiencing multiple psychiatric hospitalizations. The staff associated with this private provider consisted of teenagers and young adults who had no special training. While Vinny was followed by psychiatrists and other medical professionals, his behavior was not stabilized and there was no staff with the ability to work with the professionals with this goal in mind. Added to this, one of the teenage girls who worked in the home called me nearly daily demanding that I take Vinny back home because his needs were too great and the staff did not wish to handle him on a daily basis. I received no less than twenty calls of this nature.

One evening, while Vinny was placed with this private provider, I called to speak to him. I learned he was out and so I inquired as to where Vinny was and I learned that one of the other staff members had taken Vinny and two other residents for a ride to the Bronx! Another evening I called and nobody knew where Vinny was for hours. Staff at that private agency told me then, and would continually tell me that they would not and could not direct Vinny; if Vinny wanted to walk away from the home they could not and would not stop him from doing so. I was told as well that Vinny was free to associate with whomever he pleased and the staff would not intervene, even to keep him safe.

While Vinny was placed with the private provider I had to replace his clothing and personal items for him many times. As soon as I bought him clothing it would be missing from his closet or his drawers, and when I asked for an explanation none was provided to me. I replaced clothing many times and it was missing just as many times.

While with the private provider as well Vinny engaged in overeating and in stealing food, neither which was controlled. Staff at the private provider told me they could not and would not control his eating because they were not allowed to do so.

For all of these reasons I became very fearful for Vinny as it certainly seemed as though staff at this private provider could not keep him safe. Accordingly, I took him home for weekends. One Saturday evening, Vinny became agitated and assaulted his sister. He broke furniture and smashed windows. He had to be brought to the hospital for his behavior was out of control. I realized I could no longer manage him at all in his home.

As a result of further multiple hospitalizations, and further defeats for Vinny coupled with the inability of the private agency to maintain Vinny in the group home, the former DMR decided to move him to a home where staff was better trained to handle his behaviors. In the view of DMR, Vinny required a higher more professional level of care, as well as consistency in his plan for care and continuity of staffing. I concurred.

Vinny has been at the home at Pelham Avenue for seventeen years. When he first came to care with State employed workers, present staff, I was met at the front door by the cheerful and optimistic workers who had a written plan for his care in hand. I was told, "we know how to do our job so please trust us, and let us do our job." With state employed staff Vinny improved immensely in every aspect of his life. Hereinafter I shall refer to Vinny's state employed staff as "present staff".

HIGHLIGHTS OF STAFF INTERVENTIONS AND VINNY'S PROGRESS AT PELHAM AVENUE

For your information, I wish to provide you with a few of the many notable accomplishments of Vinny's present staff:

1. For ten years thereafter, present staff, in partnership with medical providers, worked with Vinny on a daily basis. Because of the tireless daily efforts of this present staff Vinny was able to come home for holidays, but always accompanied by

a staff member. By the time Vinny's sister was to be married in 1996, Vinny came with present staff to her wedding. Nobody could tell the difference between Vinny and any of the other single guys at the wedding. Present staff had spent weeks preparing Vinny for behaving as he would want to exhibit at the wedding. How gratifying that was for all of us, including Vincent!

2. In 1998 Vinny's stepfather of nearly twenty years died. Vinny had been very bonded to him. Present staff was with Vinny, supporting him day and night, through the entire process from Hospice to his burial, and well beyond, helping him through the most painful loss in Vinny's life.

3. By 2000, and almost annually thereafter, in addition to holiday visits, Vinny now visits with me for overnight stays. I had full confidence that he would be fine because present staff had inculcated him with a winning behavioral regimen. While with me, Vinny has gone to Yankee games, and he is able to dine in notable restaurants in New York City, socializing with my friends and colleagues. He shops with me, we go to the zoo, and he unfailingly adheres to all the rules of behavior set for him by staff. I attribute his ability to spend this time with me to the dedication of Vinny's present staff to his well being and success.

4. In 2004, during his annual visit, the superintendent of my office took Vinny for several hours around to the law offices he maintains on 161st Street, and Vinny made many friends among the lawyers and court staff while helping the superintendent with his duties. This was such a triumph for him! The hard work of the present staff is reflected in Vinny's commendable behavior and charming personality.

5. In 2005, as a result of the planning by present staff and Vinny's willingness to please them, he lost over one hundred pounds through a weight reduction diet and exercise regimen. The present staff organized his meals and snacks and inspired Vinny to adhere to this plan. To this day, present staff manages to control his insatiable urge to eat and to reward his success in this regard. Vinny now remarks with pride about

how he can fit into clothing like other men and need not purchase or wear oversized clothing.

6. Also in that same year, during our annual overnight visit I had to bring Vinny into Bronx Family Court to handle an emergency hearing. Vinny sat in the lawyers' waiting area while I handled that matter before the court for about two hours. Vinny made friends and socialized with many lawyers and court officers causing no concern whatsoever. I attribute this remarkable behavior to the dedication and tenacity of Vinny's present staff.

7. By 2006 during an overnight stay I took Vinny again into the Bronx Family Court where he and the Presiding Judge of that court had a private half hour long robing room conference. Because of present staff's intervention and their commitment to Vinny's continued well being, I believe I can present Vinny to anyone with pride.

8. By 2006 Vinny hosted a surprise party for his sister's tenth wedding anniversary. Vinny greeted over one hundred guests. Staff devoted their energies toward inspiring Vinny to be the best host he could be and he brought pride to himself as a most gracious host.

9. In 2008 we had planned Vinny's annual overnight stay but there was a death in our family and those plans were cancelled. Vinny handled this disappointment very well as his staff provided abundant assurances and support to him.

Most notably, this present staff, through its hard work and dedication to their profession, have improved Vinny's life to a point where I can again be a mother to him, his family members can enjoy him, and Vinny can take pride in the young man he has become.

IMPORTANT POINTS TO KNOW ABOUT VINNY

In an effort to provide some description of Vinny, I highlight aspects of his behavior and personality which must be carefully considered when planning for his future care:

1. When Vinny cannot control his behavior he cannot stop engaging in injurious behavior. In this event, Vinny requires intervention and hospitalization immediately. While out of control, he punches people, walls, and glass and he will pound on a wall with no regard to injuries he or others receive. He feels immense remorse thereafter and he cannot stop feeling such remorse, which in turn leads to further escalation of his behavior. After years of working with him, present staff has learned to avert such behaviors most of the time.

2. When Vinny can control his behavior he is pleased and proud. He requires almost constant affirmation and exhortation to maintain this control. Often he will seek affirming comments over and over again about how he is doing, asking, "am I being good?" or "am I staying out of trouble?". Just as the violent behavior tends to perpetuate itself, the victories over his behavior lead to further efforts at good behavior, but only when praise is meted out and when he is reminded and reminded by staff about what such successes mean to him.

3. Vinny's behaviors have diminished. *His behaviors have not been eliminated.* His present staff have not cured his disability; they have stabilized him. DDS has specifically identified Vinny's home for privatization among others because it is now stable and successful, and DDS concedes that each of these homes chosen are so because of the consistency, the continuity and the hard work of their present staff. DDS said so in their literature they provided to me. DDS ignores the fact that the success of these homes are wholly contingent upon the *continuing* work of the staff. There are still many days that, when I speak with Vinny, I know from his remarks and his affect that he is one step or less away from turning his victory into a crushing defeat. Most of the time I cannot tell what triggers these angry and psychotic episodes. Vinny's present staff knows, and, most times they know how to diffuse him. Vinny is not cured because of

staff intervention. Also, Vinny's diagnosis is quite serious. He requires constant monitoring and constant reassurances to keep the upward spiral from becoming a downward spiral again, and, if he is spiraling downward, he needs staff to recognize the emergent need to assure his safety and that of others.

4. Vinny will eat without stopping. He cannot stop once he starts, and he will consume dangerous amounts of food and soda if allowed to do so. I have been told that he once ate a week's worth of groceries in an evening. After he is extricated from the dinner table he becomes quiet, almost trance like and this lasts for several hours. Last week, when he was told by DDS that the present staff was changing Vinny told me he was happy for that because he wanted to be able to eat as he pleased.

5. Vinny craves the love and admiration of staff, and he particularly craves the admiration and role modeling that his male staff provides. Staff, in turn, constantly discuss his behavior with him and he derives an awful lot from such discussions. Vinny is bonded with present staff. Staff is family to him and he will feel loss akin to death were he to be deprived of his long familial relationships with his present staff. One of the staff members, Glenn, a supervisor, left Pelham home as he was deployed closer to his own home. This caused Vinny quite a bit of distress for a while. And he expressed his sadness and anxiety to me. He was somewhat consoled, however, because no other staff had changed and because Glenn calls him frequently to assure Vinny that he shall still have contact with him. There have been very few changes to this family in 17 years, thus his relationships with present staff have been very long lasting. I also believe that he needs the continuity that has been afforded to him for the last 17 years in order to remain successful in his program

6. Vinny resides in a one bedroom apartment above a three bedroom single family dwelling unit. Three men live downstairs all who require enhanced twenty four hour care. This unique living arrangement affords Vinny some privacy, some independence, and, most importantly, the ability to work with staff daily and access staff twenty four hours a day. Staff checks on Vinny at least twice each and every night.

When Vinny is not in the main part of the dwelling, he unfailingly accesses staff, reaching out for a variety of reasons. Because of his delicately balanced and potentially volatile moods and his dual needs for the comforts staff provides and the privacy he enjoys, I believe very strongly that he requires the same high level of care, with daily attention paid to every aspect of his life.

7. Last year, it was decided that Vinny would have the benefit of a home health aide who would, in place of present staff, assist him with his morning regimen. After several weeks I learned that the home health aide was found at Vinny's kitchen table with Vinny and a cup of coffee, and with nothing accomplished. Apparently Vinny convinced the home health aide that he did not need to adhere to a daily regimen. Vinny will not respond to efforts from anyone other than present staff, and he can be quite convincing to the untrained and uncommitted person who attempts to make him adhere to his plan for day to day care. Vinny poses challenges which can only be met by those most committed to his continuing care and those willing to commit for the very long term.

MY OBJECTIONS TO CHANGES IN VINNY'S PRESENT STAFF

I speak for Vinny's circumstance but I believe my sentiments are shared with many if not all parents and other family members who are subject to these changes as contemplated by DDS. I believe that any change to Vinny's present staff program is ill considered, contra his best interests, and dangerous for the following reasons:

1. Vinny has a 17 year familial relationship with each and every member of his present staff. They are his family and he feels deep love for each of them and he trusts them. They are the only ones who have had any success in controlling and stabilizing him. Just as removing a child from his family, even for a short period of time, irreparably injures the psyche of the child removed, removing the staff of these

vulnerable individuals turns them into unloved "lone wolves". It is well known that in the private sector the turnover rate for direct care workers is one hundred percent per year; what privatization is doing amounts to severing a most intimate bond, without replacement. And at this high rate of turnover there shall be no replacement bond for these very vulnerable people. Now, without the nurturing relationships they have so long enjoyed and with an ever changing staff, these individuals will become the unloved "lone wolves" of the system. Please bear in mind that these disabled individuals are not puppies in the local animal shelter; they are quite human and they need the consistency and continuity as well as the love and security that they now enjoy. I have read psychological literature that clearly concludes that such transitions cause irreparable harm to those disabled who are subject to the transition and such transitions cannot be done without adverse, long lasting if not irreparable effects. This harm is further discussed in Paragraph 3 below.

2. DDS has endeavored to inspire all affected parents' hearts and minds by telling us that private agencies shall provide the identical level of care as the present staff provides for less money than is now being expended for the same programs. How can it possibly be that the identical service shall be provided when private providers are well known to have far less trained staff, fewer resources, lower pay rates for employees, and far less experience? A fair reading of the RFP demonstrates that not much by way of experience and virtually no education is required of a private provider. DDS is doing nothing more than dumbing down the quality of care these very vulnerable individuals will receive. When we as parents asked DDS from where staff will come we were told that the successful bidder will hire staff. How can anyone expect new, untrained, unskilled, and lower paid workers to provide the same level of care as the present, well educated, well trained and highly committed staff? And is it not incumbent upon us, being entrusted with the care of these disabled individuals, to wonder what the effect of such changes will be upon these individuals five, ten, and twenty years from now?

3. In its literature explaining this monumental change DDS represents that the State of Connecticut will realize savings of "up to five million dollars" per year. I am

now reading that the "up to" has been dropped, and the press now reports the savings to be realized is a flat five million dollars per year. Notwithstanding, this savings, if any, does not take into account the losses which shall inevitably accrue when, upon making such changes to the staff, the behaviors of these disabled individuals escalate and they suffer from separation anxiety, depression, frequent hospitalizations, and sickness.

Perhaps this is an amount which cannot be quantified as yet, but I assure you that such a transition is doomed to failure, and failure shall take the form of separation anxiety, depression, frequent hospitalizations and sickness. And such maladies have quite a high cost associated which shall be borne by the taxpayers. Such maladies are not transient. The effects of such changes may last years, and may well be irreversible. I submit that this is a false economy when this very critical factor is taken into account.

4. DDS has, at best, been inaccurate in their representations to the parents affected by these proposed changes. DDS attempted to sell parents and affected people this plan to privatize by making representations which are now proved not to be accurate or true. For instance, I was told in late July, 2009 that the lease for the dwelling in which Vinny lives was a five year lease and Vinny was to enjoy at least two and a half years more in that dwelling. When I researched this later that day I learned that Vinny's lease was for one year and due to expire December 31, 2009. I understand as well that the landlord may not renew the lease and may sell the building with this change being contemplated which truly places Vinny in a precarious situation. DDS told me that there is nothing whatsoever I could do to protest these changes, and that these changes have received all the requisite approvals, but here I am today. In protest. I was told that DDS would graciously extend me the opportunity to be part of the process for choosing the providers, but DDS gives me no more than what is required by federal law. How can I trust any representations now being made by DDS? And why, given all the factors which attain against it, is making this change so important? And why so quickly?

5. DDS is well acquainted with all the objections borne out above as I have expressed each and every one of them directly to Commissioner O'Meara and his executive staff. DDS through that staff has responded to my concerns, remarks, and

admonitions by saying that I cannot be certain that Vincent will be negatively affected by this change. As well, DDS has said to me that I am expressing no more than my fear of the unknown. But this is the very same state agency that for years has prided itself on the inalterable fact that continuity and consistency in the provision of care is the standard of care for the disabled as well as the lodestar of this agency! What interest has priority over the health and well being of the disabled and helpless individuals at issue here and subject to these changes in their care?

You as legislators, and I, as the parent and guardian of Vinny, are entrusted with different aspects of the care of disabled individuals. I implore you to heed that spoken by Senator Ted Kennedy:

“It is the glory and the greatness of our tradition to speak for those who have no voice, to remember those who are forgotten and to respond to the frustrations and fulfill the aspirations of all We dare not forsake that tradition.”

Thanking you again for your time and attention to this very important matter, and confident that you shall make the best decision possible, this letter is

Respectfully submitted,


MARY ANN BARILE