Recommendations re: Southbury Training School December 31st, 2015

To: Commissioner Murray, DDS

From: Adrienne Benjamin

My name is Adrienne Benjamin, I live in New Britain and have a 19 year old daughter who has a severe intellectual disability, autism and a seizure disorder. I also serve on the Council of Developmental Services, and was recently elected as Chairperson. These opinions are my own and not the recommendations of the Council.

My daughter attends a school for children with severe developmental needs, and will for the next school year until she turns 21. Our family greatly appreciates the DDS respite program. She has stayed for long weekends at the Newington respite center for several years and it has always been a fantastic experience for her as well as us. The staff are outstanding and take great care of her.

First, I must say that I am not an expert on all the issues surrounding the Southbury Training School. I toured STS once last year with other members of the Council. In addition, I have attended several legislative hearings and heard many STS family members describe their experiences, as well as many who insist STS must be closed.

It is important to briefly discuss the context this request for recommendations comes from. The chronic problem of the residential waiting list, which translates into many hundreds of families struggling daily with their disabled son or daughter must be kept in mind. This significant problem has existed for more than 20 years, and is not the fault of this administration, nor the leadership of DDS. This difficult, and sometimes desperate situation families face has fueled the scrutiny of the Southbury Training School.

I know there are many who hope that closing Southbury will free up millions of dollars to provide the absolutely necessary care so many need. But before any decisions are made regarding the future of Southbury, there are two crucial issues that need to be addressed.

Recommendation #1:

A thorough and accurate comparison of the costs of caring for residents at Southbury Training School (STS), versus at private group homes must be a priority. Unfortunately, the published financial information which has been in the news for the last few years is not accurate. This is not the fault of any specific agency, but represents the complexity of different funding sources as well as differences in how private homes report versus state run facilities. As I understand it, while the costs at STS are higher than in private facilities, the figures which have been utilized for the last few years greatly exaggerate these differences. DDS leadership will be presenting the true comparison shortly.

Decisions about STS should only be made after this financial information is carefully scrutinized.

Recommendation #2

For the last several years, families of the remaining 315 STS residents have received extensive information about other options, and have toured private facilities to consider a move for their loved one. Yet, they are choosing to stay at Southbury. These residents are elderly, frail and have lived there for decades. Their families believe they are comfortable, well cared for and safe.

I'm certain no one would want someone else making huge life-altering decisions for their family and it's important to respect the wishes of the STS families.

Recommendation #3

Utilize some of the available cottages at STS to address the shortage of available residential spaces for children with autism and or ID who have extreme behaviors. I am personally acquainted with two families whose children were not able to cared for in Connecticut due to the lack of residential services. Both of these families tried mightily to keep their kids at home, and were stunned that there was no facility in CT which could help. One whose behaviors posed dangers to other children in the family had to be moved to a facility in Mass. The other had to be moved to a facility in another state 4 hours away.

Since there is housing available at STS, it's far more humane and would save money to keep these children closer to their families in Connecticut. These placements (paid for by the school district) include schooling, and terminate when the child reaches age 21. It is my understanding that these cases are fairly rare, so there would not be a large number of children needing these intensive placements.

Recommendation #4

Open up the health services offered at STS to others in the community with disabilities. It is my understanding that there are vision, dental, respiratory, gynecological, and other medical providers at STS. It is often quite difficult for people with severe disabilities to obtain medical services from providers who understand their special challenges. STS could help bridge that medical gap. I would expect that this would not be an added expense, as insurance would be utilized to pay for these services.

Recommendation #5

In the last few years, the pain of too few residential services for many hundreds of DDS clients has caused quite a bit of rancor and sometimes outright hostility between the 'haves and havenots'. The frustration is understandable but unfortunately some of this has been leveled at either STS families or the employees who care for them. This kind of divisiveness and scapegoating has no place amongst families who need support and compassion. In addition, it serves as a distraction from our ultimate goal...obtaining the best services for all of our families.

Thank you.

Adrienne Benjamin New Britain