

Date: December 31, 2015

To: Commissioner Murray, Department of Developmental Services

From: Nancy Clarke, parent of son with Autism/ID.

Re: STS Recommendations

I am writing to you as the mother of a 22-year-old son with autism/ID. He has a level of need (LON) score of 7, and he lives at home with me and my husband.

I would like to thank you for the opportunity to provide input on this topic. However, I am concerned about how your request for public input was disseminated because I did not learn about this until three days ago from the ARC of CT. This brings into question whether many other families will be denied the opportunity to also provide input. I think this is important to note if you are hoping that the response will be indicative of the majority of families of the 20,000+ individuals currently on the rolls of DDS.

This lack of time also limits my ability to fully flesh out my arguments using charts, case studies, and financial records, etc., but I am sure you have access to these records yourself, and I am sure that there will be others who will present that kind of information in a cogent and convincing way.

I learned so many of those details during the last legislative session in Hartford, so it will come as no surprise that my #1 Recommendation is that STS is closed just as quickly and as humanely as possible.

I believe that this is as important for the current residents at STS as it is for the 2,000 plus individuals on the waiting list for residential services, and the thousands of others who might be served by DDS, who receive nothing.

Nothing.

If the measure of a country is based on how it treats its most vulnerable citizens, what is the measure of a department specifically tasked to support the most vulnerable of the vulnerable, who qualify for services, yet receive none?

Recommendation #2: It is absolutely imperative that any savings that may ultimately come to DDS due to the closure of STS be redistributed to other consumers of DDS, and NOT returned to the state's General Fund. The DDS budget has been cut, and cut again, against the backdrop of increasing needs, not decreasing needs.

I would like to conclude by telling you a little about my son and a recent family situation. First, my son is lovable, when he is lovable. He also has a LON of 7 which is higher than the average LON score for STS residents. He earns that score every day! Whether due to acts of aggression (we have a healthy relationship with the local police department), the need to be watched 100% of the time, the bed wetting and/or bed soiling at night, we have our hands full.

Two weeks ago, my husband was awakened by heart pain and numbness in his left arm. He has had heart issues in the past, so I needed to get him to the hospital ASAP. My son was still asleep. I called a neighbor who could step in until I was able to contact any of our son's caregivers. I had difficulty getting

a response from the caregivers, so basically, while I was at the hospital, I spent the whole time managing care for my son at home. This is just ridiculous and untenable.

Please help my family and the thousands of families like mine where the parents are aging and wondering whether they will have to die in order for their child to receive a residential placement. Closing STS is just one step in this process.

Thank you.  
Nancy Clarke