

Date: December 31, 2015

To: Commissioner Murray, DDS

From: Marina and Bryan Derman

Re: STS Recommendations

We are writing as the parents of two sons, ages 20 and 22, both of whom have autism and intellectual disabilities (ID). Our sons are both DDS consumers. Our younger son has been lucky enough to receive a residential placement, and currently lives in a group home run by a private agency. Our older son is on the waiting list for residential services, and currently lives at the Chapel Haven School – although without DDS funding for a residential placement, he may have to return to live in our home and lose all his hard-earned independence. Therefore, our sons, and truly our entire family, have a vested interest in DDS's fair and wise use of its funding.

We argue that keeping Southbury Training School and the regional centers open is an unfair allocation of scarce resources. Although many will debate about the exact number (\$250,000? \$400,000? Somewhere in between?), it is clear that the per capita cost of maintaining a resident at Southbury or a regional center is extraordinarily high, and much more than community-based group home options. Our son, currently living in a group home, has a DDS budget of \$139,000, and this number will go up to around \$160,000 when he starts a day program next year. Southbury Training School and the regional centers cannot come close to this level of efficiency.

If our state had abundant resources at its disposal, we would say that this is fine. Let everyone live where they prefer. As parents, we have some sympathy for the desires of Southbury families to keep their loved ones where they are currently comfortable. However, we are far from this state of affairs. We are constantly reminded of the desperate condition of the CT budget, and DDS has had its budget

slashed repeatedly, several times a year (between annual budget cuts and rescissions). Therefore, we can ill-afford to maintain a “have” and “have not” double standard. A dramatic proportion of the DDS resources are going to maintain a few in an extraordinarily expensive setting, while thousands of others wait with little or nothing. This is unjust, and untenable.

We would also note that DDS consumers who are currently in group homes do not have lifetime security in those specific homes. Houses may close, private agencies running the houses may close, and DDS makes no commitment that my son at House A will stay in House A forever. In contrast, residents at Southbury Training School and the regional centers imply that they are being abused by a request to move to less resource-intensive housing. We argue that DDS consumers have the right to ask for an appropriate level of quality and service (based upon their Individual Plans), but NOT the right to ask for a specific housing location. (As an analogy, in the educational setting the families of school-aged students have the right to demand services that meet their child’s IEP, but do NOT have the right to demand a particular teacher.)

DDS has a fiscal and moral responsibility to use its scarce resources for the benefit of ALL of its constituents in a fair manner.

Therefore, we respectfully recommend the following:

**Recommendation 1: Governor Molloy should immediately direct the closing of Southbury and the regional centers.**

Justification: There are more than 2,000 people currently on the DDS residential waiting list. Many of them have Level Of Need (LON) scores equal to or higher than many of the current residents of Southbury. Many have been on this list at Priority 1 for decades. However, due to the high level of funding required at the institutions, funds are diverted to that small group, and the larger group languishes with no hope of receiving their own residential placements. *Please note that in-home supports are helpful, but do NOT replace the need for residential placements. Many parents are getting older themselves, and are exhausted from caring for their adult children with ID. For both the needs of the individuals with ID*

*themselves (who deserve an independent life outside of their parents' homes) and the caregivers (who are faced with the never-ending requirements of parenting), actual residential placements are needed.*

**Recommendation 2: A thoughtful and humane plan should be developed to close Southbury Training School and the regional centers and find appropriate placements for each resident.**

Justification: A plan should be developed to move each of the residents, as rapidly as possible given his or her specific needs, into an appropriate group home or ICF. This plan should consider each resident's medical and developmental situation, without unduly delaying the closings. In the short term, DDS must address the millions of dollars in overtime and waste reported, and take advantage of those potential savings to begin funding the Residential Waiting List.

**Recommendation 3: Fund the DDS Residential Waiting List using savings from Southbury Training Center and the regional center closings, keeping such savings within the DDS system**

Justification: We are told that any potential savings from closing Southbury Training School and the regional centers would typically go into the CT General Fund, instead of being kept within DDS. *Do not allow this to happen.* Treat this as one transaction, not two; In the same way that a family typically purchases a house, partially or fully funded by the sale of a previous house, funding the Residential Waiting List should be directly attached to the resources freed up from the closing of the institutions. This money is critical for DDS to continue performing its important mission, and should not be allowed to go to other statewide needs (leaving our ID citizens still without adequate resources).

Thank you for collecting information from the public on this important matter. We recognize that there is pressure to keep Southbury Training School and the regional centers open as long as possible – pressure from the families who want their family members to stay there (even at the expense of other DDS consumers) and from union workers. It is unfair to let the needs of a few (no matter how well-

organized their lobbying efforts) outweigh the needs of the broader population. DDS has a vital role to play, which it is hampered from fully accomplishing due to continuous and repeated budget cuts. Please take this opportunity to distribute DDS resources more fairly, so that more of the population you are charged with serving can be helped.

Respectfully,

Marina Derman  
Bryan Derman

Westport, CT