

TO: Morna A. Murray, JD. Commissioner, State of Connecticut, Department of Developmental Services

VIA: Katie Rock-Burns, Chief of Staff; Kathryn.Rock-Burns@ct.gov

FROM: Hugo Dwyer, Brother and Co-Guardian of Tom Dwyer, Resident of Southbury Training School

RE: Recommendations Concerning the Future of the Southbury Training School

To the Commissioner, the Governor, and all parties involved in determining the future of STS, the Connecticut State Regional Centers, and the direction of the Department of Developmental Services for decades to come,

I would like to go on record to say that I have read the submission from the Home and School Association of the Southbury Training School (H&S/STS), and that I endorse the positions outlined in that document.

This, however, is a different and more personal appeal. I am writing as the brother and co-guardian of Tom Dwyer, a long-time resident of the Southbury Training School (STS), and as the son of his two parents, now deceased, who, after years of searching for the appropriate treatment and residence for their developmentally disabled son, determined that STS was the right home for him. My sister, also co-guardian, and I both still believe that STS is the best home for Tom. I ask that you consider investing and improving STS, rather than dismantling this vital facility.

I would like to ask you all to take a step back from the details of this decision and look at the bigger picture, regarding the mission of the DDS, the role of the State of Connecticut as defined by the Malloy administration – specifically the value of public ICF's within a comprehensive system of care - and how *any* decision will affect the well-being of individuals involved, including the lives of their friends, peers, caregivers, and their families and guardians.

Before I proceed with my recommendations, I would respectfully request that every member of this committee who has not had a formal tour of STS in the last five years make an appointment with Eugene Harvey, the Director of STS, and request a tour of the facility and a chance to see the people whose lives are being discussed, whose futures are at stake in this decision making process.

Recommendation One: Build on the safety net that has been part of Connecticut's heritage since the 1930's, don't dismantle it.

Justification One: Southbury Training School was built in the 1930's under Franklin Delano Roosevelt's Work Progress Administration. It first opened its doors in 1940. At the time, it was constructed as a state of the art home for the mentally retarded (now termed persons with intellectual and developmental disabilities). Over the years, its services grew and STS was viewed as a model self-sustaining facility attracting parents from all over the country seeking a safe environment for their severely disabled sons and daughters to live out their lives. Then came Willowbrook. New York's Willowbrook State Developmental Center was a poorly run, abusive environment that suffered not only because of internal abuse but also due to a failure of the NY State authorities to provide oversight and regulation. Willowbrook was closed in 1987, but its reputation left a stain on all ICF/IID facilities, regardless of the quality of their service or the standards of care that they achieved. The new model was to move individuals with I/DD into smaller group settings, with parents or guardians signing waivers allowing for a lower set of service and care requirements. Many people thrived on this system, but not everyone. Many people with severe I/DD with medical conditions or problem behaviors did not do well in the community.

STS was never like Willowbrook, and in the decades since that scandal STS families made certain that it never would be like Willowbrook. STS has improved its services over the years, despite being hampered by having been closed to new admissions under an ill-advised state law, hastily enacted in the wake of Willowbrook.

The individuals that live at STS today represent the largest single population of the most profoundly disabled people in Connecticut. Almost all of these remaining individuals have severe or profound I/DD along with medical and behavioral complications. They remain at STS because their families and guardians know that they receive the level of care that they need there, and that the private provider system has not offered the same level of care in enough homes to meet the needs of these all of these individuals. STS has provided a safer, more stable environment for decades than that offered in smaller residences. For many of the residents of STS, group homes offer a more isolated environment and less of a sense of community for the individual, despite being located 'in the community'. Specifically for my brother Tom and many of his cottage-mates, STS is their community.

STS exemplifies what is arguably the most crucial part of the state's social safety net. The residents of STS are the very people who most frequently fall through the cracks in the system. Their needs require more expensive services, better trained caregivers, increased numbers in staff ratios on every shift, more attention from medical professionals, skilled nurses, psychiatrists, and physical therapists, whether they live in an ICF or in a smaller group setting. Private group homes exist not only to serve the needs of the I/DD community, but to make a profit – or at least to break even. The population of STS are, for the most part, the most difficult cohort to service, and the most difficult to service properly while making a small profit. The severely and

profoundly disabled are the most likely individuals to slip through the cracks of the social safety net.

Unfortunately, there is a tendency to treat all people with I/DD as if they suffer from similar maladies or disorders when discussing treatment methodologies, residential options, and costs. That is a dangerous assumption. Legislators should consider at least three classes of Intellectual and Developmental Disabilities when discussing matters such as allocation of funds or types of service provided. There are those who are capable of living independently, or semi-independently, and interacting with their community. There are those who need assistance to live, some level of supervision, and are capable of limited interaction with their community. And there are those, like my brother, who need constant supervision, attention to physical needs and behaviors, and do not interact well with the community at large even on supervised field trips and excursions. The third group is the subject of this discussion.

Recommendation Two: Assess the political views of this administration in regard to the most vulnerable members of our society.

Justification Two: Ask yourself, “What is the character of the Malloy administration and DDS regarding social services and the State of CT’s role regarding its most vulnerable citizens?” Does this administration follow the belief put forth by George W. Bush and others that government should privatize Medicare and Social Security? If so, should that extend to the most vulnerable and profoundly disabled? Does this administration trust that the invisible hand of the market will see to it that private providers meet and fulfill the needs of the Developmentally and Intellectually Disabled (I/DD) community?

Or does this administration believe in the principles of FDR and adhere to a more progressive tradition, knowing that there will always be those who slip through the cracks of a privatized system and need the greater protections that can only be provided by facilities that operate on public funds?

The private sector in CT does an admirable job of meeting the needs of thousands of the states residents, including a number of severely disabled and medically fragile individuals. But can they do it all? If so, why is there so little movement on the waiting list? The laws of supply and demand have not struck an equitable balance in providing sufficient private residential and treatment options for the I/DD community. There is no reason to believe that closing STS, or the Regional Centers, or both, will solve this problem. The private providers will create whatever number of residences and beds seem appropriate to their resources, not to the needs of the I/DD community. That is the very definition of the private sector.

A truly comprehensive system of care would offer the widest range of choice to individuals and families and include both private providers and state run facilities. The state run facilities should not try to duplicate the services provided by private institutions. They should fill out the system by providing the levels of care and the type of residential services that are missing from the private system. Not everyone thrives in the environment provided by small group homes, much the same way some students like attending small private colleges while others benefit from the wider range of resources available at a large state-run university system. One size does not fit all.

Connecticut's safety net should provide coverage not only for the gaps in the private system, but for the inability of some individuals with I/DD to adapt successfully to environments where less attention is given to certain behaviors, like Pica, self-harming, or various manifestations aggression.

Losing STS and the Regional Centers will change the nature of DDS from a participant in the system of care to an overseer, a regulator of outside interests. We all know how much private companies like to be regulated. There will be a push to take funds away from DDS once it no longer has an active part in the care of individuals with I/DD. Then there will be a push to further de-fund the department, and to allow the private institutions to regulate themselves, as many already do. This will likely result in further cases of abuse and neglect in CT, as it has in many other states.

Facilities like STS and the Regional Centers cover the holes in our social safety net that is otherwise reasonably well handled by the private provider system. All of the various types of facilities have their place in the greater system of services. The State of Connecticut should not abandon its stake in this system and turn the responsibility of providing residential options over to the private sector. If anything, the state should play a greater role in addressing the needs of its most vulnerable. Expanding services and reopening admissions at the Southbury Training School is the best way to do that.

Recommendation Three: View STS as an asset, not a liability.

Justification Three: The state already owns STS. It is an asset that can be further developed through investment and is capable of returning more for the investment than the state could possibly realize through abandoning it, selling off the land, and paying to raze its remaining buildings. STS is not a liability unless the state determines to close it.

The campus and community of STS are wonderful, valuable assets to the state of CT. They have provided jobs and commerce for the surrounding region for decades. Losing them would not only hurt the residents of STS and the people who work there, but the town of Southbury and its neighboring communities. In general, group homes do not enrich their communities in the same manner. In many cases, they have been said to have lowered property values. The jobs they provide are less permanent, and fewer workers in group homes consider this a career or a calling like many of the credentialed and certified caregivers at STS and the Regional Centers do.

Rather than disposing of STS and turning it into apartment complexes or another unneeded shopping mall, consider the possible uses of the land to create a community of service to those who need services, such as creating homes for veterans with severe physical injuries, veterans with PTSD, elderly people and Alzheimer's patients, Community Resource Centers and Respite facilities for people receiving Home and Community Based Services, and skilled nursing facilities. Additionally, STS could provide dental, vision and bio-psychosocial services for those individuals in area group homes. Cottages could be built to transition those in immediate need of services after a parent or sibling caregiver passes on while the individual is waiting for a bed in the appropriate permanent setting. Connecticut could provide more services at greater savings by taking advantage of STS as an asset.

Realize too that there will be no going back. Once STS has been de-commissioned, its land sold and buildings razed, that asset will be gone. It will be impossible for a future governor to recreate this system, to build new facilities like STS or the Regional Centers, should the private sector fail to fulfill its promises. If the needs of the most profoundly disabled are not being met in the years to come, which is highly probable no matter what decision is made today given taxpayers' reluctance to fund DDS services, that failing will be viewed as part of the legacy of this administration. By preserving STS and other publicly funded facilities and structuring them so as to serve more people, the administration will be viewed as having done its best to serve the most vulnerable, in spite of a very vocal and well-funded opposition.

Recommendation Four: The Home and Community Based Services (HCBS) waiver system was developed to be an option to choose a less restrictive treatment and residential alternative for those who would benefit from such, not a mandate to force people into an inappropriate environment. Keep the HCBS waiver an option, as it was intended.

Justification Four: The HCBS Waiver was originally developed as an option for individuals and guardians who desired to live in non-ICF facilities to waive their rights to ICF care, enabling them to sign up for smaller, less restricted alternatives. Group homes have proven to be the right option for over ninety percent of the I/DD population. But they are not right for everyone. The families of the remaining residents of STS and the Regional Centers have chosen not to waive their rights. They are not uninformed. If anything, they are fully informed and quite aware of the needs and requirements of their loved ones, and they know that ICF's like STS provide the level of care their loved ones require. Quite a few of the families on the waiting list would be happy to choose that level of care if they were given the chance.

Moving all services to the private sector takes away that choice. Yes, there are privately run ICF's, but they are few and far between and certainly not enough to cover all of the families that would be displaced by closing STS and the Regional Centers. Many of these families and guardians would be pressured into signing the waiver so to continue to receive services. And that is not an option. It's coercion. Do not usurp the right to choice for those at STS and the Regional Centers by adopting legislation that forces them to sign waivers.

Note: Should you opt to close STS – heaven forbid – please carefully consider the following three recommendations.

Recommendation Five: Look before you leap. The state must demand a guarantee from private providers that there will be enough appropriate beds in privately run facilities within the state, and that they will be made available in a time frame that will ensure that this move is feasible economically while guaranteeing safety for all of the vulnerable people who will be displaced.

Justification Five: If you do go through with closing STS, please proceed with caution and thoughtful planning as you finalize the privatization process. Get a guarantee from the private service providers that a full complement of appropriate beds will be created before you begin taking people out of a facility. If there are only half enough beds for the population of STS in the next three years, then the costs of the remaining residents at STS will skyrocket, taking away resources that could go to creating new beds for them in the private sector and forcing the state to

act more quickly and less carefully in order to save costs. While it is clear that the closure of STS will divert funds away from the needs of moving people off of the waiting lists, it is even more obvious that any overages in either time or financial commitments will hurt them further.

Recommendation Six: While assessing costs, time, staff ratios, transportation, and other critical factors of any planned move of this population out of STS, you must also acknowledge, estimate, and publish a projected mortality rate for this transition.

Justification Six: Part of the plan you make must include projections for mortality due to the move. How many people are likely to die as a result of this transition? It is most important that you make such a projection and include it with cost projections and staffing projections, short-term costs versus long-term savings, etc. because without it you will have no way of knowing how close you are meeting your goals of doing what is right for the greater good of the larger community and those on the waiting list. What constitutes an acceptable morbidity rate?

Certainly, some people would be likely to die even staying at STS. Use that number as a base rate, then assess the number of people that DDS is comfortable with seeing die during and as a direct consequence of this move. While there is really no acceptable number other than zero deaths resulting from this transition, that number is not realistic. It is more probable that there will be deaths resulting from the move. Look at states like Georgia, Nebraska, and California, where studies have been conducted showing high mortality rates during mandated transitions due to the closing of ICF's. Then, determine what number of deaths due to relocation that DDS would consider acceptable in order to provide for the greater good of others in the I/DD community.

Recommendation Seven: Contingency Planning

Justification Seven: Before you implement any plans to close STS or the Regional Centers and move the residents to new facilities, please make sure you have a contingency plan in place and that it is thoroughly considered and easy to put into effect. This contingency plan should encompass alternatives to the entire process, should it not work out as planned, as well as offer alternate solutions as backup protection for individuals who do not take well to the transition. In the first case, what actions will DDS take if the private providers are not able to fulfill their goals, or if it takes significantly longer to build and staff all of the new facilities? The state must have a backup plan in case this happens, and it must have benchmarks and milestones in place by which it can determine the point at which the contingency plan must be initiated.

Consider also the second case, wherein an individual does not adapt to the new residence or treatment protocols. *What actions does DDS take if a new facility is not right for the person displaced? Can he or she return to their previous, stable facility until other, more appropriate arrangements can be made?* How would several such cases affect the overall transition plan?

It is not enough to merely have an orderly plan for the transition. This population is too fragile to accommodate any mistakes that may be made in planning. There must be backup plans and alternatives in place in order to make this transition and close STS or the Regional Centers.

Conclusion:

There are many individuals with severe I/DD, compounded by medical challenges, aging, and problem behaviors who are thriving at Southbury Training School. It is unlikely that the private providers can create enough appropriate beds and services to meet the needs of all of the people who would be transitioned. It is even more unlikely that there will be resources available to find homes for the people on the waiting list during the period in which the residents of STS are being displaced and transitioned to the private sector.

Again, we are talking about a relatively small number of people, but they are people who are more severely disabled than anyone can truly imagine without having already seen them and spent time with them. *Again, I urge members of the committee/panel to please set aside an hour to come to STS for a walk through prior to making your final decision.*

Most of the STS residents cannot speak, nor can they themselves define the type of services that they require. Only their families, guardians, and a handful of organizations speak on their behalf. Everyone else speaks for a more able and therefore more easily integrated cohort of the I/DD community. As parents and siblings and guardians of these profoundly disabled individuals, we ask that you join with us, and do what you know is right for them, for us, and for soul and integrity of the State of Connecticut.

Please allow me to arrange and facilitate a tour of STS at your convenience and do not hesitate to contact me if I can be of any service to you during your decision making process.

I look forward to hearing from you.

Sincerely,

Hugo Dwyer

Brother and Co-Guardian of Tom Dwyer, Resident of Southbury Training School
Treasurer of the Home & School Association of the Southbury Training School
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