

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

FROM: Martha M. Dwyer

**RE: STS Recommendations:
Considerations for Determining the Future of the Southbury Training School**

DATE: December 31, 2015

Introduction

Individuals with intellectual and developmental disabilities (“I/DD”), who are certainly among the neediest individuals in our society, have received inadequate if not terrible care in most countries for centuries. That is certainly true in the United States.

I/DD is the newest in a string of terms that have been applied to this population. The most recent was “mentally retarded”, which applied to only a portion of the population (generally those who are not autistic or who are autistic and “retarded”). Predecessors have been “idiot”, “moron” and imbecile”. Willowbrook was only a recent example of a long tradition of mistreatment.

It is time to step back and consider this tragic situation and how best to address it.

No one denies that Southbury Training School (“STS”) and many other “institutions” now provide excellent care. Leslie Simoes, the president of the ARC of Connecticut, has referred to STS as “a Lexus package”.¹ The individuals who reside at STS are indeed fortunate to be there, if the word “fortunate” can actually be applied to them. However, they are certainly not living in luxury and it is terrifying to think that anyone can actually believe that they are receiving better care than they deserve. All individuals with I/DD deserve the best care that can be provided.

Many facilities like STS have been closed throughout the US over the past several decades and the results have often been tragic. Most of these facilities have housed profoundly disabled individuals, many of whom also had serious medical problems, and many community facilities have not been able to provide an adequate level of care to these individuals.²

Furthermore, “choice” is the legal right of all individuals with I/DD.³

If the Department of Developmental Services conducts unbiased and comprehensive cost and quality studies as described in the HSA Recommendations, it is very likely that the conclusion will be that it is less expensive to provide care at STS to individuals such as those presently at STS and to those who need nursing home level care than it is to provide such care in the community. Providing such care at STS to individuals who choose STS would also reduce the burden on community

¹ Stuart, Christine (December 3, 2014). Disability Rights Advocates Lobby For Closure of State Institutions. *CT News Junkie*. Access at: http://www.ctnewsjunkie.com/archives/entry/disability_rights_advocates_lobby_for_closure_of_state_institutions/

² See studies referred to in the Recommendations submitted by the Home and School Association of the Southbury Training School (“HSA Recommendations”).

³ See references to *Olmstead v. L.C.*, 527 U.S. 581 (1999), the Developmental Disabilities Assistance Act and The Connecticut Department of Developmental Services, HCBS Waiver Operations Manual in the HSA Recommendations.

providers that seek to provide that level of care and on nursing homes and rehabilitation facilities that do not have staff trained to provide care to I/DD individuals. It would provide appropriate care to many individuals who do not presently receive it, including many on the waiting list.

In light of the recent passage in Connecticut of a bill requiring a report regarding the closure of STS and the five regional centers, these suggestions should be applied to both STS and the regional centers.

RECOMMENDATION #1 – Reopen STS to Individuals with I/DD and Make More Beds Available There

JUSTIFICATION

The story of Patrick, an individual with profound disabilities, recently published in the *Hartford Courant*, illustrates perfectly the need for STS.⁴ Patrick was placed in a rehabilitation hospital, in a room with three other residents who were on life support and could not interact with him, after both group homes and nursing homes were unable to provide care. The rehabilitation hospital does not have staff prepared to care for an I/DD individual or programs that are appropriate for I/DD individuals. This should not happen to anyone.

RECOMMENDATION #2 – Provide Nursing Home Services Appropriate to Individuals with I/DD at STS

JUSTIFICATION

Like rehabilitation hospitals, most nursing homes do not provide care that is appropriate for I/DD individuals. As the population of I/DD individuals in group homes ages more, more I/DD individuals will need the types of care available only in nursing homes, or at STS. As of 2013, 388 I/DD individuals lived in nursing homes in Connecticut.⁵ Many of these individuals are in situations similar to Patrick's.

RECOMMENDATION #3 – Expand Services Available at STS

JUSTIFICATION

STS presently provides dental care not only to its residents but also to over 400 residents of group homes. Providing dental care to I/DD individuals requires expertise and experience. The same is

⁴ Kovner, J. (November 22, 2015). "For parents of developmentally disabled adults, the wait for help never ends" *Hartford Courant*. Access at: <http://www.courant.com/health/hc-disabilities-families-1122-20151122-story.html>

⁵ See footnote 5 to the HSA Recommendations.

true of many other services, including behavior, physical therapy, ophthalmologic, neurologic services and many others. Providing these services through public/private partnerships should be considered.

Thank you for inviting stakeholders to make recommendations regarding STS. Hopefully, the HSA Recommendations, these recommendations and others submitted by supporters of STS will result in better care for the entire I/DD population and elimination of the waiting list.