

HOME AND SCHOOL ASSOCIATION OF THE SOUTHURY TRAINING SCHOOL

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

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

FROM: Home and School Association of the Southbury Training School
Martha M. Dwyer, President

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

DATE: December 29, 2015

Introduction

The Home and School Association (HSA) of the Southbury Training School presents these recommendations in response to the October 2, 2015 memorandum from Commissioner Murray to DDS Stakeholders calling for public recommendations on the future of Southbury Training School (STS). We are happy to have the opportunity to present these ideas to the Commissioner and her team. The overarching recommendations of HSA are that STS remain open, that a fair assessment of costs be made by DDS, that STS services be expanded, in some cases using public-private partnerships, and that residence at STS be made available to individuals on the waiting list who desire it. In light of the recent passage in Connecticut of a bill requiring a report regarding the closure of STS and the five regional centers, we believe that our suggestions should be applied to both STS and the regional centers.

RECOMMENDATION #1 – Community vs. STS Cost Comparison

Recommendation #1: DDS should conduct a comprehensive cost comparison study to fairly compare the costs of STS and community-based services that takes into account the factors described below.

JUSTIFICATION – Recommendation #1

Misinformation abounds. The difference in costs of care between institutional and community settings is one of the areas in which misinformation is widespread. Consider the message that the citizens of Connecticut read in a *Hartford Courant* editorial on the subject last month.¹ The editorial claimed that care for a person in STS costs more than twice as much as the average cost of caring for someone in a group home – and refers to this difference as “a waste.” This is a comparison of

¹ Hartford Courant editorial (11/25/2015). *What keeps waiting list for DDS placement so long.*
<http://www.courant.com/opinion/editorials/hc-ed-making-disabled-wait-is-cruel-20151124-story.html>

apples to oranges and as such is simply incorrect. Cost comparisons of services *must* take into account the characteristics of the individuals and the type/quality of the services needed. Therefore, the HSA recommends that DDS conduct a comprehensive study that is transparent in its methods and that its findings be shared with DDS stakeholders in user-friendly ways. The study must take into account the following factors.

Costs and “Case-Mix.” The most severely and profoundly disabled individuals – such as those in STS – cost more to care for than those with milder levels of disabilities who need fewer services and supports. A reliance solely on *average* costs derived from the two populations as a whole is of little value. Although there are equally disabled individuals in community settings, they likely represent an increased cost base as well, unless their services are not equivalent to those in STS. Furthermore, they clearly represent a small percentage of individuals in community settings. By addressing case-mix variables, better comparisons will be possible. “Case-mix” here refers to the process of taking into account the characteristics of individuals and groups when making comparisons – that is, groups that are compared must be equivalent to the extent possible. In common parlance this means comparisons must be “apples to apples.”

Common sense dictates that if someone has severe or profound disabilities and is receiving a specific set of services (i.e., the level of care provided at STS), then moving that person to the community should not appreciably change the service needs or the costs of meeting those needs. Moving more people with fewer needs into places like STS is a sure way to make per capita costs at STS drop; just as moving individuals like those in STS into community settings is surely a way to increase costs in the community.

Cost “Shifting” vs. Cost “Saving.” When individuals move from ICF/ID services, like STS, to community-based waiver services, many costs aren’t really “saved.”² Rather, some of the costs are “shifted” from the DDS budget to other parts of the overall Connecticut budget. This is so because at STS services are “bundled” and in the HCBS waiver they are not. For example, medical and nursing services and other therapeutic services are included in the STS budget such that the costs of physicians and nurses working at STS are borne by DDS – they are “on the DDS budget.”³ However, in community settings medical care is *not* part of the DDS budget. Someone receiving DDS services under the waiver will get medical care from community-based physicians and health care providers and these costs will, for the most part, be covered under the State’s Medicaid Plan. There are several other instances of cost-shifting that a cost study must consider in order to conduct a fair institution vs. community cost comparison.

When the implications of the “case mix” phenomenon and the “cost shifting” described above are taken into account, it is highly likely that it will become clear that there aren’t substantial savings to be had by closing STS. That is, there is likely to be no “windfall” in state funds that can provide expansion for community service systems. Similarly, there would be no substantial reductions in

² The Home and Community-Based Services (HCBS) waiver, initiated in 1983, provides funding for services other than “institutional care” under section 1915(c) of the Social Securities Act, giving states the option to receive a waiver of Medicaid rules governing institutional care. In 2005, the HCBS became a formal Medicaid state plan option.

³ A recent cost study in Kansas, for example, reported that 13% of the operating expenses of an ICF/ID congregate facility in that state went to medical costs. Legislative Division of Post Audit, State of Kansas, December, 2011. *Performance Audit Report: Kansas Neurological Institute*, p. 9.

the DDS waiting list as implied by the *Hartford Courant* editorial and maintained by advocates of closing STS. In fact, cost studies in some states have reported that when individuals move from ICF/ID facilities like STS to waiver-based services in community settings costs can actually increase substantially.⁴

Sources of Funds. Related to the idea of cost shifting, cost studies must account for multiple sources of funding. Although Medicaid funds (either in the ICF/ID or the HCBS waiver program) account for most of the funds, there are other sources of funding. For example, many individuals with intellectual and developmental disabilities (I/DD) are eligible for Medicare funds and for SSI or SSDI payments as well as funding devoted to vocational training. Cost comparison studies must take into account all sources of state and federal funding that support individuals across settings because funds can derive from other sources, including other state funds. This is reinforced by the “State of the States” information from 2013 which identifies three other sources of funding in addition to Medicaid ICF/ID and HCBS waiver funds in Connecticut: Other State Funds (4%), Other Federal Funds (7%), and Related Medicaid (3%).⁵

Cost Variation and Intensity of Services. Costs can vary widely across service systems based on the geographical location of services, whether the service provider is publicly owned or private, whether it is unionized or not, and on the level of need of the individuals served. Cost variation is common and has been found consistently in I/DD service systems as well as in other systems (e.g., health care). Paying attention to such cost variation becomes especially important when comparing costs in formal studies in order not to bias or skew the findings.

A cost comparison study must also distinguish between cost variation and the intensity or level of services between systems. For example, because many services are on-site at STS their intensity or level may be higher than similar services in community settings. Frequency of access to therapists or specialists and the duration of therapeutic encounters must be taken into account in cost comparison studies. An on-site behaviorist, nurse or other therapist at STS is quite likely to provide a more intense level of service and more responsiveness than can be provided by practitioners who serve community settings, who typically require prior appointments, transportation arrangements, and staff escorts. Consider, for example, a situation at STS in which a medical care need arises and a nurse is on-site and immediately at hand compared to a community group home in which there is no nurse available and the individual is instead transported to a hospital emergency room incurring additional transportation, personnel, and health care costs.

Staffing. Because personnel make up one of the major cost centers in human services, it is important to understand the effects of staffing on costs. Variability in staffing levels, coverage levels, and staff member compensation will result in effects on the costs of services. For example,

⁴ In a study that compared the costs for individuals before leaving a public institution in Oklahoma and then after these same individuals were relocated to community-based settings, it was found that in the community the same individuals cost, on average, \$34,000 more per person (pre-1999 dollars) compared to when they were in the facility. Reported in Jones, J., Conroy, J.W., & Spreat, S. (1999). *Costs of support for the former residents of Hissom Memorial Center* (Report #8 in the Oklahoma Outcome Series); submitted to Oklahoma Department of Human Services, Developmental Disabilities Division. Rosemont, PA: Center for Outcome Studies.

⁵ Braddock, et al. (2015). *State of the States in Developmental Disabilities*. University of Colorado at Boulder. State profiles are available at: <http://www.stateofthestates.org/index.php/intellectualdevelopmental-disabilities/state-profiles>

in public settings, state hiring freezes may be imposed to control the overall number of state workers; however facilities such as STS are required to maintain certain coverage ratios by regulation and may experience increased overtime use (and in some cases) mandatory overtime during such periods.⁶

The literature generally suggests that when differences are found in institution–community cost comparisons, that these differences are often related to staff compensation (typically to more generous compensation packages in the public setting). Thus, if individuals are moved from STS and union members employed at STS are given other jobs with the state or paid to retire, it may be that there are no savings at all in personnel costs.

In large systems like DDS it is also important to know which positions to “count” when computing costs in both sectors. For example, it is not unreasonable to include in the institutional category personnel costs of those whose role it is to transition individuals from ICF/ID settings to the waiver settings. However, it is just as reasonable that the costs for such individuals could be included in the community category. It is not necessarily a matter of where such staff members are administratively placed; rather the question should be answered based on the primary function they carry out.

Finally, it is important to note that if individuals are transferred to community settings from STS certain service personnel who are part of the STS complement will need to be duplicated, adding to costs in the community setting. For example, aging people with complex disabilities, like those at STS, will require more community-nursing staff availability than is currently typical in community settings. It is also likely that additional specialized equipment will also be needed. Similarly, again because of the level of disabilities of STS individuals, if they were placed in community settings, providers would need to increase certain staffing levels. For example 3rd shift staffing levels would need to be increased to effectively care for former STS residents.

The types of cost effects described here are not new; they have been known in the professional literature on the costs in systems providing services and supports to persons with I/DD for many years.⁷

RECOMMENDATION #2 – Transition Study: Costs and Capabilities

Recommendation #2: DDS should conduct a short term “transitional study” to identify all costs and related short-term issues associated with the closure of STS and transition to community services.

JUSTIFICATION – Recommendation #2

It is highly likely that most of the current community-based providers, funded under the waiver, are not prepared to address the needs of all of the individuals who now reside at STS. A lack of preparedness in community-based providers has been a recurring problem when states have closed

⁶ Recent data suggest that STS has drastically reduced the amount of staff overtime.

⁷ For example, see Walsh, K.K., Kastner, T.A. & Green, R.G. (2003). Cost comparisons of community and institutional residential settings: Historical review of selected research. *Mental Retardation*, 41, 103-122.

facilities such as STS.⁸ Community providers in Connecticut have received minimal, if any, increases in funding for many years and a number of them have closed or transferred the operation of homes over the past several years. Therefore, in addition to costs associated with the closure of STS itself, there will be additional costs and issues in community-settings that must be addressed to prepare providers to serve the STS clientele. Of course, as aging and complex STS residents move to community-settings, community costs would rise.

To the extent that STS residents are transferred and community providers are unprepared or unwilling to accept them, then the functional health of STS residents will likely suffer. Therefore, DDS must conduct a focused study – here referred to as a “transitional study” – to identify the costs, both financial and opportunity costs, as well as the related short term issues that will be faced in community-settings if STS is closed, including the following:

- **Capital Costs and STS Closure Costs** – Accommodating current STS residents in community settings will require as many as 90 3-bedroom homes. Such homes have thus far cost approximately \$500,000 each. Larger homes and homes with special features for complex and aging individuals from STS would be even more expensive.⁹ Alternatively, adaptation of existing homes would also be exorbitantly expensive given the physical disabilities associated with the aging and complex individuals living at STS. At the same time there will be costs associated with actually closing the STS facility and campus itself.
- **Residential/Day Provider Identification and Provider Upgrading** – A study of the provider community must be made to identify specifically which providers will be willing and have the capacity and service array to care for STS residents going forward. Meeting health and safety needs in community settings has often been a challenge in institutional de-population efforts.¹⁰ In fact, no medically fragile individuals in STS have requested transfer to the community to date. Provider capabilities are going to need enhancement in caring for persons who are aging or who have complex disabilities; providers will also need additional staff training, and expansion with regard to space, equipment, and manpower to close STS.
- **Therapeutic/Ancillary Provider Identification** – A study must be made to identify the credentialed medical and therapy providers who will be needed, and available, in community settings. Personnel here include general practice and specialty physicians, nursing personnel, mental health practitioners, rehabilitation therapists (occupational

⁸ Frank Berry, the Georgia Commissioner of the Department of Behavioral Health and Developmental Disabilities, commented on transition problems following that state’s 2010 DOJ settlement noting that it has been easier to meet transition goals for mental health patients than for individuals with developmental disabilities. In Miller, A. (June 23, 2014). *Transfers of disabled patients still a problem*. *Georgia Health News*. Access at: <http://www.georgiahealthnews.com/2014/06/problems-developmental-disabilities-program/>

⁹ If Regional Centers are included even more residences will be needed. Also, there are additional requirements in homes for four or more residents which add significantly to the cost of building them.

¹⁰ For example, see Corwin, T. (March 29, 2015). In Georgia, parents of developmentally disabled worry over community placements. *The Augusta Chronicle*. Access at: <http://www.centerforhealthjournalism.org/fellowships/projects/gracewood-parents-brace-move-out>

therapists, physical therapists, and speech therapists), psychologists, behaviorists, dietitians/nutritionists, and other disciplines.

- **Transition Costs** – Transition costs here generally refer to the costs of moving individuals between service systems. These costs are likely to escalate because each group of subsequent individuals will be more difficult to transition. Costs associated with transition need to be carefully identified (including clinical preparation, administrative transition, personal exploration and choice, and so forth). Presently it takes between 18 and 24 months to transition a single individual from STS to community-based services. If the number of individuals being moved from STS into the community is increased, there will be an extended transition period during which STS would need to remain open. Finally, to integrate the STS population into community settings will require more community-based administrative personnel. Experience in other states has shown that it is likely that an appropriation of “bridge” funds would be needed to carry out the complete transition.
- **Oversight and Monitoring Costs** – If individuals from STS (and possibly regional centers) move into community settings, DDS will need to create special teams to provide oversight and monitoring of service access and quality to assure appropriate services, and to avoid the types of problems that have arisen after institutional closures in other states (see citations at footnotes 4, 8, 10, 14, 15, & 16).
- **Transportation Costs** – Transportation costs exist in both systems. However, transportation costs are likely to be much higher in community settings as many services that are provided on the STS campus are not available on-site in community settings and thus require transportation. The capital costs for a dispersed fleet of specialized vehicles operated in communities by community-based provider agencies must be assessed, as must the staff time required for transportation. For example, many STS residents require two staff members in order to travel – one to drive, the other to attend to the individual.
- **Opportunity Costs** – The closure of STS would present certain opportunity costs. For example, federal financial participation at enhanced ICF/ID rates would be lost. Additionally, the possibility of future expansion of or increases in such federal payments would also be forgone. Perhaps most important, the possibility of addressing the waiting list without capital costs (i.e., using existing STS cottages rather than constructing new residences) would be lost as well.
- **Possible Litigation Costs** – Nearly every major recent public institution closure in the country has given rise to litigation on behalf of individuals (often class-member plaintiffs) in suits seeking to retain their placement in the ICF/ID setting and protect the federal rights described below. There is no reason to believe that this will not be the case for STS as well. In addition to direct litigation costs, lawsuits typically produce delays which also add to costs.
- **Budgetary Considerations and Other Administrative Costs** – Currently there are no funds allocated to the transition of individuals from STS (or the regional centers) to group homes and other community settings. In addition to transition costs, DDS must identify the administrative costs necessary to maintain STS residents in community settings. For

example, additional personnel will be needed in either the DDS central office or in regional community-service offices, or both. As noted above there is also a question as to what funds could be used. They cannot come from the allocations to services already being provided, as these funds are committed to ongoing care of individuals and the maintenance of services and structures – and these funds have recently been sharply reduced. It is highly likely that additional appropriations will be needed.

RECOMMENDATION #3 – Quality of Life and Quality of Services

Recommendation #3: In studying the need for continuing services at STS, DDS should review the quality of services in all settings. This review should extend beyond a general review of services (i.e., typical quality assurance auditing) and include specific comparisons of the quality of services and supports accessed and received by individuals from each setting who are matched on level of need.

JUSTIFICATION – Recommendation #3

Quality/Capability Differences Across Services. Historically there have been quality and capability differences in community settings as compared to ICF/ID settings. Unfortunately, not all community providers have developed the broad array of services or the service intensities needed by individuals at STS. This has long been a tenet of parent/family/guardian resistance to facility closures and movement to community-settings. Specifically, problems in health and mental health care access for this group have been documented in the literature and identified as a “disparity” in a report by the U.S. Surgeon General.¹¹

Furthermore, individuals who remain in state-run facilities (STS and the regional centers) typically are older, have more complex needs, often are medically fragile and often have associated mental health and/or behavioral problems. In general, for all persons with I/DD the rates of mental health diagnoses (i.e., dual diagnosis) or associated behavioral health needs is typically found to be between 30% and 50% depending on the study. As in most other states, DDS continues to serve the most severely and profoundly disabled individuals and those who are older at STS and in similar facilities. They are the individuals who are most likely to need the most intense level of services, and the most expensive services, regardless of the setting in which they live. At the very least, placement in facilities such as STS should be available to individuals in emergency situations or when no appropriate provider can be found.

Recently, as reported in the *Hartford Courant*, one man with profound disabilities, identified as Patrick in the article, was placed in a rehabilitation hospital after both group homes and nursing homes were unable to provide care.¹² The rehabilitation hospital does not have staff prepared to care for an I/DD individual or programs that are appropriate for I/DD individuals. The article noted that Patrick was put in a room with three other residents who were on life support and that no

¹¹ US Public Health Service (2002). *Closing the gap: A national blueprint for improving the health of individuals with mental retardation*. Washington, DC: US Public Health Service. Report of the Surgeon General’s Conference on Health Disparities and Mental Retardation.

¹² 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>

interaction with them was possible. Clearly, the specialized services provided under the ICF/ID program at STS would have been appropriate for Patrick. The fact that such services were not accessible is deeply problematic. Neither nursing home care (ICF) nor, especially, a rehabilitation hospital should ever be a replacement for ICF/ID services for an individual with developmental disabilities.¹³ This case illustrates the crucial issue of who will provide care to individuals like Patrick in the future.

Additionally, as of 2013 there were 388 individuals with I/DD living in nursing homes in Connecticut (data from Braddock, et al. for 2013; see citation in footnote 5). It is highly likely that some, perhaps many, of these individuals do not require nursing home care but find themselves in such facilities because of the limited access to STS and the regional centers, coupled with the lack of capabilities to care for complex cases in community-based providers. The case of Patrick – that is, a person with profound developmental disabilities who was unable to access a specialized DD placement – should serve as cautionary tale for DDS in its planning for the future of STS. In fact, arguably, STS should serve as a facility that is able to *reduce* the reliance on nursing facilities.

Regulatory Differences. STS meets a standard set of federal ICF/ID regulations that define “conditions of participation” in the federal program for the facility and “active treatment” for each individual resident. When Georgia sought to depopulate its state-run centers, a number of serious quality problems (including abuse and neglect and deaths) arose in the community settings.¹⁴ Because HCBS waiver services are developed along different lines by each state, there is no comprehensive body of standards similar to the ICF/ID standards that must be met. This has often led to quality problems in various waiver-based systems across the nation.

Using a matched set of individuals, DDS should study the effects of regulatory differences on the actual treatment services that are accessed by individuals in STS and community settings. To accomplish this, DDS needs to establish an ongoing quality management system that monitors service quality and other issues after individuals are transferred from public institutional settings.

Quality of Life. At the same time, STS is most assuredly *not* the rigidly controlled place that some envision where people are “locked away.” Individuals living at STS routinely take part in community life. A substantial number, possibly as many as a third, leave the facility daily for day programs in the community. Like others, STS residents dine, shop, recreate, and worship in community settings. Similarly, the community is part of STS. Community members are routinely at the facility as volunteers and for concerts, events, lessons, parties, and other activities.

It is critical for DDS personnel to keep in mind that, in America, *communities consist of people and their institutions*. Instead of simply wiping out institutions, they should be viewed as assets upon which to build for future needs. Community hospitals and high schools today look nothing like the hospitals or high schools that existed at the beginning of the last century. That is, community institutions change over time. The initiation of the federal ICF/DD program in 1971 after the

¹³ Nursing facilities are not generally set up to provide ICF/ID level services (i.e., providing *active treatment* as defined in the ICF/ID standards); this is so because nursing facilities are ICFs (i.e., “intermediate care facilities”) while ICF/IDs are “intermediate care facilities” specializing in “intellectual disabilities.” Thus ICF services are *not* equivalent to ICF/ID services.

¹⁴ Judd, A. (June 21, 2014). *Mentally disabled suffer in moves from Georgia institutions*. The Atlanta Journal-Constitution. Access at: <http://www.myajc.com/news/news/state-regional/leaving-state-hospitals-takes-some-disabled-adults/ngPJZ/>

institutional exposés of the past has led to high quality, comprehensive, federally-regulated services in facilities such as STS that are less available in community settings, if they are available at all.

DDS needs to study and report data that specifically addresses integration in community settings across its service system; when comparing STS and community settings, a matched comparison group (taking into account case-mix) must be used.

Mortality. Although sometimes disputed by community activists, there is compelling evidence in both the professional literature¹⁵ and the lay media¹⁶ that deaths are associated with transfer of individuals with IDD to community settings from facilities like STS. Landmark studies in California have identified increased mortality after transfer to community settings. In Nebraska, more than a dozen individuals died after transfer from the Beatrice Center to community settings (including transfers to acute care hospitals). In Georgia, a Community Mortality Review Board was established to examine community deaths after a number of deaths occurred following de-population of institutions individuals with I/DD to meet a DOJ settlement. Because of this recurring finding, DDS needs to establish historical death rates in ICF/ID and HCBS waiver settings and maintain appropriate and publicly-accessible statistical records to track mortality in all DDS settings.

RECOMMENDATION #4 – Service Expansion

Recommendation #4: Keep STS open and make necessary repairs to increase capacity for individuals on the waiting list who wish to be at STS on a temporary basis or for as long as STS is open. Additional services for I/DD individuals should be provided at STS, possibly by public-private partnerships.

JUSTIFICATION – Recommendation #4

Retain STS and Expand Capacity. Connecticut should expand the capacity of STS to address the continuing needs of existing residents as well as to provide additional capacity for individuals on the waiting list. Although, individuals who choose and can benefit from living in community settings must be able to do so, for those who want to choose STS (or a regional center) as a permanent or temporary residence, this should be an option. Expanded capacity at STS should be seriously explored to address the needs of individuals with severe and profound disabilities who are on the waiting list. It is entirely possible that a number of families and individuals with intense and complex needs would choose STS over waiting further for community wavier services.

¹⁵ Strauss, D. & Kastner, T.A. (1996). Comparative mortality of people with mental retardation in institutions and the community. *American Journal on Mental Retardation*, 101, 26-40. **ALSO** Strauss, D., Kastner, T.A., & Shavelle, R. (1998). Mortality of adults with developmental disabilities living in California institutions and community care, 1985-1994. *Mental Retardation*, 36, 360-371.

¹⁶ Jenkins, N. *Journal Star* (July 11, 2010). *After Move and Deaths at BSDC No Lessons Learned*. Access at: http://journalstar.com/news/state-and-regional/nebraska/after-moves-and-deaths-at-bsdc-no-lessons-learned/article_b9982a9e-8d3f-11df-a554-001cc4c03286.html **ALSO** Editors – *Savannah Now* (June 24, 2014). *Editorial: Group Home Deaths Shocking*. Access at: <http://m.savannahnow.com/opinion/2014-06-24/editorial-group-home-deaths-shocking#>

Such expansion could be accomplished relatively easily because there are cottages at STS that have been closed but could be improved and opened in a very short time. Such an expansion will require amendment of the provision in a 1986 appropriations bill that prohibits admission of additional I/DD individuals to STS. Because this provision does not appear to extend to the regional centers, it should be possible to make them available to waiting list individuals until the provision is removed. It is clear that capacity could be made available to individuals and families in need.

Expand the Services Provided at STS. Expansion of STS could take various forms: (1) DDS could simply expand the ICF/ID bed capacity at STS in order to capture additional federal revenue; (2) DDS could seek to develop a nursing facility within STS; (3) DDS could explore the development of, or partner with, a Medicare Special Needs Plan (SNP) to provide services at STS or perhaps add new services to I/DD or other groups (e.g., MH) and should specifically consider providing intensive behavioral programs for autistic individuals; (4) STS should be used as emergency short-term support and respite for individuals on the waiting list and others needing care or relief from caring for others; (5) DDS could use STS and the regional centers as bases for developing separately-funded medical, neurological, mental health and ancillary service centers that would provide services similar to those offered through ICF/IDs, but to those living in community settings. STS already has successfully accomplished this type of service expansion in its model dental program that has extended improved dental care to individuals living in the community. This suggestion is similar to the well-known “regional resource center” concept although it should go beyond that model to develop separately-funded services and supports that fill the identified “gaps” in the community-based supports and services. Some of the new services could be provided through partnerships with private entities.

Promote Choice. DDS needs to scrupulously promote choice. There is a long history of personal choice in the I/DD field that locates “primary decision-making” in individuals and families. The findings in the DD Rights Act state that “...individuals with developmental disabilities and their families are the primary decision-makers regarding the services and supports such individuals and their families receive, including regarding choosing where the individuals live from available options...” (42 U.S.C. 15001(c)(3)). This emphasis on choice is also found in the Olmstead decision¹⁷ (see below).

Because of the importance of choice, DDS needs to work to set aside any Connecticut legislation that prevents admissions to STS. As stated in its federal HCBS waiver, in meeting federal regulations DDS needs to make the choice of ICF/ID (such as at STS) or waiver services clear and truly available when individuals and their families/guardians apply and plan for services, and then respect the choices that are made.¹⁸ In this process, individuals who are seeking services should be clearly informed about the advantages and disadvantages of all service settings. Conversely, respecting choice also requires that STS residents and their families not be pressured to seek community placement if they do not desire it.

¹⁷ Olmstead v. L.C., 527 U.S. 581 (1999).

¹⁸ The Connecticut Department of Developmental Services, HCBS Waiver Operations Manual (Individual and Family Support Waiver and Comprehensive Support Waiver), as required by regulations, states clearly (page 89) that: “Participants are afforded choice: Between waiver services and institutional care; and between/among waiver services and providers.”

During the upcoming process of review and study of STS and the regional centers, it is imperative that DDS does not denigrate STS or regional center services in favor of services under the waiver and that it makes clear to families and staff members that the closure of STS is not imminent. Conducting objective studies of the system requires that DDS takes the lead in assuring that all of its personnel project an objective, rational atmosphere during the study period and throughout the public policy deliberation processes that will follow.

CONCLUSION

Although DDS needs to create ways to expand community-based services through the waiver in order to serve individuals on the waiting list, closure of STS and the regional centers should not be seen as a means to that end. In fact, DDS needs facilities such as STS as a basis for creating more comprehensive services for individuals with I/DD. STS can be invaluable in providing structure and processes to assist DDS in creating a broader array of services and supports that address the needs of more individuals with I/DD. And it can actually provide placements for some persons on the waiting list. In short, this is not a time to be closing STS; rather it is a time to be renewing it, updating its role, sharpening its services and supports, and integrating it with other DDS service elements. That is, DDS needs to make STS part of the solution to current DDS problems.

The rights of individuals will be best protected, and the resources of Connecticut best used when DDS adopts a *pragmatic* perspective toward STS. Its future should be based on the needs of Connecticut citizens with I/DD and their families, the potential of STS to provide needed services and supports, and the established costs as determined in comprehensive and unbiased cost comparison studies. Where people live should not be based on an ideological mandate; rather it is a personal choice made by persons with I/DD and their loved ones, based on individual needs and preferences.

In fact, it appears to be just this type of choice that Justice Ginsburg included in the Olmstead Decision in creating the personal choice element of the three-part determination of rights violations under Title II of the ADA. That is, that “placement of persons with mental disabilities in community settings rather than in institutions...is in order when the State’s treatment professionals have determined that community placement is appropriate, *the transfer from institutional care to a less restrictive setting is not opposed by the affected individual*, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities” (emphasis added).¹⁹

Reinforcing this, the Court also noted that there is “no federal requirement that community-based treatment be imposed on patients who do not desire it.”²⁰ Taken together, these provisions of the Olmstead Decision surely are intended to preserve choice on the part of individuals and their families – and *choice* is surely the opponent of ideology. Unfortunately, the ideology of institutional closure advocates has incorporated negative terms and stereotypes that unfairly portray modern ICF/ID facilities, such as STS.

¹⁹ Olmstead at 587.

²⁰ Id., at 583.

Although the Olmstead Decision has often been portrayed as embodying a “community mandate,” even a cursory reading of the decision reveals that such a mandate is secondary to choices made by individuals and their guardians based on individual needs. In fact, Olmstead recognizes the value of institutional settings: “We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.”²¹ Olmstead clearly recognizes that some individuals will not be able to “handle and benefit” from community settings and that, for these individuals, service settings like STS may be most appropriate and preferred. Given the size of the DDS waiting list it is highly likely that some individuals with complex and challenging disabilities, through their families/guardians, would choose to move to a congregate facility such as STS or one of the regional centers instead of remaining on a waiting list for, possibly, many more years.

In the end, the Home and School Association of STS is vitally interested in the health of the overall DDS system in Connecticut. We believe that STS already plays a vital role in serving individuals with developmental disabilities and that, going forward, STS can play an even more important role in the DDS service system. It is for these reasons that the HSA recommends that DDS conduct a fair and comprehensive cost comparison study and undertake a more focused study on specific transitional issues. We further recommend that DDS study access to, and the quality of, services and supports it offers in all of its settings, and that the results be made public in useable form. Finally, we recommend that DDS retain STS and the regional centers as vital parts of the service system and do whatever is necessary to enhance and re-invigorate them for the benefit of all Connecticut citizens with intellectual and developmental disabilities.



²¹ Id., at 601-2.