



STATE OF CONNECTICUT

COUNCIL ON DEVELOPMENTAL DISABILITIES



Southbury Training School Recommendations

Date: December 28, 2015

To: Commissioner Morna Murray, DDS

From: Shelagh McClure, Chair, CT Council on Developmental Disabilities
Molly Cole, Director, CT Council on Developmental Disabilities

Re: STS Recommendations

The mission of the CT Council on Developmental Disabilities is to promote the full inclusion of people with disabilities in their communities. The Council believes that people with disabilities deserve a model of support that promotes belonging, inclusion, full citizenship and a good life for everyone. In November 2014, the DD Council voted to initiate a plan to close Southbury Training School and the remaining five regional institutions by the year 2020. The Council sought support from a number of agencies to join this 2020 campaign and the UCEDD, the Office of Protection and Advocacy, Arc Connecticut, the State Independent Living Council and the Cross Disability Lifespan Alliance all signed on as supporters of the 2020 campaign. These recommendations are submitted by the Council in collaboration with the 2020 Campaign Committee.

Recommendation: **It is our recommendation that Southbury Training School (STS) be closed by the year 2020.** The 2020 Campaign Committee has developed the attached document detailing the elements of the plan to close STS and also contains appendices with background information. Due to the high cost of institutional care, closure of STS should result in significant savings which can then be re-invested by DDS to address the needs of families who are on the waiting list for residential supports.

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The Elements of a Comprehensive Plan for the Closure of Southbury Training School

Submitted by

**The Connecticut Council on Developmental Disabilities
and the 2020 Campaign Committee**

**Arc Connecticut
Office of Protection and Advocacy for Persons with Disabilities
University of Connecticut Center for Excellence in Developmental Disabilities**

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December 29, 2015

***"Long range planning does not deal with future decisions,
but with the future of present decisions."
Peter Drucker***

Preamble to the Elements of a Comprehensive Plan

Department of Developmental Services Commissioner Morna Murray has requested recommendations on the future of Southbury Training School for purposes of providing a recommendation to Governor Dannel Malloy.

No objective examination of the future of Southbury Training School (STS)¹ would conclude that it should remain open.

- (1) The delivery of services in a large, isolated, segregated setting is not only not best practice for individuals with intellectual disabilities, but it is contrary to the U.S. Supreme Court's Olmstead² decision. Decided in 1999, the Olmstead case holds that individuals with intellectual disabilities have the right to live and to receive services in the community, in the most integrated setting appropriate to their needs consistent with Title II of the ADA, regarding the use of all publicly funded services.

¹ Although we are submitting this plan specifically in relation to Southbury Training School, we believe it to be equally applicable to the five Regional Centers, which also should be closed and the residents moved to the community.

² Olmstead v. L.C., 527 U.S. 581 (1999)

- (2) There is overwhelming evidence across the United States that Individuals who move from institutions to the community with appropriate supports do better after they move, and that those who show the greatest improvement in their daily living skills are individuals with severe and profound disabilities.³
- (3) The cost per person in a Connecticut institutional setting is more than double the cost of quality, community-based services in Connecticut such as private group homes, even taking into account severity of disability and level of service needs. Many additional people⁴ with intellectual disabilities will be able to receive person-centered, individual tailored community integrated services and supports with the money saved if STS was closed.

Connecticut can no longer afford to operate a dual system – a system that attempts to support simultaneously both institutional and community services, but which, in reality, is producing incoherent policy and gross inequities that do not align with the DDS Mission, Vision and Core Values. Southbury Training School exists as an antiquated, expensive, de facto entitlement for a few people, while thousands of individuals with intellectual disabilities are being denied services - told they must wait until their families are in the throes of extreme personal crises before receiving critically needed support. As long as the state of Connecticut maintains segregated institutions, DDS will continue to waste taxpayers' resources, and to send confusing messages to the public about the needs of the people it supports and the fundamental direction of State policy.

To address these issues, DDS also must recognize and correct other structural conflicts in its current roles. Most notably, there is a clear conflict inherent in operating as a provider of direct services, while simultaneously having the responsibility to foster, support, fund and assure the quality of a community service system comprised of private provider organizations that are also working to provide direct services. Inevitably, the State operated programs compete for scarce resources with private sector programs (with the State operated ones having “first tap” in budgeting and allocation processes). Experience in other states demonstrates that whenever a state operates services in competition with the private sector, the first dollars allocated and last dollars cut are from state operated facilities. Over time, this widens the gap between public and private sectors. Competition for budgetary resources is only part of the picture: As long as the state operates direct services, it competes with private providers for experienced staff, draining away personnel that private providers have recruited and trained and need to retain in order to assure workforce stability and develop internal leadership, both

³ See eg, James W. Conroy, Ph.D, *Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was this Good Social Policy?* Center for Outcome Analysis 2012, compiling the longitudinal studies of individuals who have moved from institutions to the community.

⁴ Connecticut DDS currently maintains various “lists” of individuals waiting for residential services. Those lists include 638 individuals who currently receive no residential support, that DDS has classified as Emergencies or Priority 1 (P 1), meaning they need services within 1 year, 250 individuals who receive some support but who still are classified as Emergencies or P 1 by DDS, and 1214 individuals classified as Priority 2 or 3, meaning their needs are less urgent. Sources: Office of Fiscal Analysis Presentation to the I/DD Caucus, October 29, 2015.

prerequisites for quality services and supports. . The huge difference in salaries and benefits for state workers and those for private sector staff exacerbates the problem.

Fortunately, Connecticut can build on the lessons learned from other states that have completed the institutional closure process during the past twenty-four years. Today there are fifteen states and the District of Columbia (see list below) that operate NO state institutions, the most recent being Oklahoma, which closed its last facility in August 2015. The evidence is clear from those states that with appropriate services and supports, no person with a developmental disability, regardless of complexity of disabilities, needs to reside in a state operated institution. Moreover, in many of these states today very few individuals with developmental disabilities reside in privately operated institutions (ICFs/DD) (see list below) or in nursing homes. Ten of the states with no institutions also have fewer persons with intellectual disabilities per 100,000 state population residing in nursing homes than the national average of 8.5/100,000, while Connecticut has 10.8 or 25% above the national average. The lessons and summaries from some of the states are included in this report as Appendix C.

States with NO State Institutions

Alabama*
 Alaska*
 Hawaii*
 Indiana
 Maine
 Michigan*
 Minnesota
 New Hampshire
 New Mexico
 Oklahoma
 Oregon*
 Rhode Island*
 Tennessee
 Vermont*
 West Virginia

**States with Less than 100
 Persons in ICF's/DD (2013)**

Alabama	41
Alaska	00
Delaware	66
Hawaii	79
Maryland	54
Michigan	00
Montana	55
N. Hampshire	25
Oregon	00
Rhode Island	42
Vermont	06
Wyoming	79

*State also has less than 100 individuals residing in ICF s/DD

THE FOUNDATIONS FOR PLANNING: VISION AND MISSION

All planning must begin with the organization's mission. The mission of an organization describes its purpose and the reason(s) why it exists. The planners can then quantify and measure the mission in terms of impact and outcomes over time. An outcome is something that happens as a result of an activity or process.

The Department of Developmental Services Mission Statement:

“The mission of the Department of Developmental Services is to partner with the individuals we support and their families, to support lifelong planning and to join with others to create and promote meaningful opportunities for individuals to fully participate as valued members of their communities.”

This mission statement and the complete Vision Statement and Values are contained in Appendix A.

It is essential that any plans to be developed and implemented by the Department of Developmental Services be consistent with and build upon the Mission, Vision and Values or the plan will be devoid of its essential foundations and result in an exercise in futility with no formal context.

ELEMENTS OF A COMPREHENSIVE CLOSURE PLAN

1. Stakeholder Engagement.

- a.** Develop an open and transparent public process for closure of Southbury Training School. All stakeholders should have input into the process and its evaluation throughout the length of the institutional closure. Be inclusive and invite everyone.
- b.** Establish a work group/advisory committee made up of the stakeholders of the DDS system. This work group should meet regularly for the duration of the closure process and may need to continue thereafter.
- c.** All information about the work group/advisory committee and the stakeholder process should be prominently displayed on the DDS website and easily accessible to all residents of the state.
- d.** DDS should make every reasonable effort to reach out to all current recipients of services as well as individuals/families on the waiting list to make them aware of the planning process, to inform them about meetings and to solicit their input on a regular (at least quarterly) basis.

2. Public Policy Alignment.

- a.** Review and begin the process to amend, as needed, all DDS state statutes, regulations and licensing standards for alignment with the following policies:
- Olmstead decision, the Department of Justice June 29, 2011 Guidance on Olmstead and Title II of the ADA (see Appendix F) <http://www.ct.gov/ctcdd/cwp/view.asp?a=1997&q=574704&ctcddNav=|>)
 - The CMS final rules for HCBS waivers, including person centered planning, informed choice and “settings” (see Appendix D) <http://www.ct.gov/ctcdd/cwp/view.asp?a=1997&q=574704&ctcddNav=|>)
 - The Dignity of Risk by Robert Perske (see Appendix E) <http://www.ct.gov/ctcdd/cwp/view.asp?a=1997&q=574704&ctcddNav=|>)
 - The use of “best practice” individually tailored supports in integrated community housing, employment, recreation and leisure time.

Ensure that DDS policies and procedures are in full compliance with the CMS final rule of January 16, 2014 for Medicaid HCBS Waivers on the elements of Person-Centered Planning and Informed Choice, enforceable effective March 14, 2014.

- b.** Review all service definitions in all of the Medicaid HCBS waivers operated by DDS with a focus on the waiver that is due for renewal in the spring of 2016 and amend, as needed, to reflect “best practice” services including a comprehensive definition of assistive technology, devices and services, customized employment and integrated day supports.
- c.** Evaluate all federal and state housing programs or develop new ones to allocate resources for low interest loans and rental subsidies for individuals with ID/DD and their families to support both traditional and creative solutions for integrated community living, stability and control and empowerment to choose housemates and providers.
- d.** Reform the state’s budgeting process with sufficient and stable funding to recognize the critical role of private providers as business partners with the State of Connecticut, and to add fairness and certainty to the process. Private providers currently are responsible for providing 85-90% of supports and services to individuals and families receiving services funded by DDS, and the sustainability of private providers is a matter of great importance to them. For years, the State budget has consistently undervalued private providers, placing the community service delivery system at great risk.

3. Address Funding and Reinvestment of Savings.

- a.** Mandate the state reinvest all savings from the closure of STS into the DDS budget/system for community services and supports and that all of these funds will be used to maximize federal matching funds in the Medicaid program. The State's own data demonstrates that the cost per person for services provided at institutions is more than twice the cost of services in the community, for individuals with similar levels of service needs. While the State has chosen to operate inefficient, expensive, anachronistic and segregated institutions, the waiting list for community residential services has grown to over 2,000 people. It is critical, therefore, as the State closes Southbury, that it maintains its fiscal commitment to individuals with developmental disabilities and their families by supporting the individuals moving from STS into the community and using the dollars saved to address the waiting list systematically, through development of necessary infrastructure and provision of needed services and supports.
- b.** Sell the remaining acreage of the STS campus at fair market value and the proceeds reinvested as outlined in subparagraph a. of this section. The State has already given away, **for \$0**, over 900 acres of the STS campus: approximately 900 acres was deeded to the state Department of Agriculture for farmland use, and 45 acres was given to the Town of Southbury for senior housing. It is ironic that during this time of fiscal crisis, the State chose to give away this valuable acreage, located in Fairfield County. For the remaining acreage, the State should act as a responsible steward of its assets, sell the property, place the proceeds in a nonlapsing fund, and use the proceeds for individuals with intellectual disabilities⁵.

4. Rates and Reimbursement Methodology.

- a.** Carefully review and analyze the Rate Transition Plan and develop proposed service definition additions and revisions and expectations, provider staff qualifications and competencies, and performance outcomes as well as appropriate wages and benefits.
- b.** Continue to work to assure that Direct Support Professionals receive a "living wage" and can develop a career path. The wages and career path should be based on performance-based competencies, including use of the nationally recognized College of Direct Support curriculum from the University of Minnesota University Center for Excellence in Developmental Disabilities. A stable workforce allows individuals to receive services and supports with continuity and by high quality workers.

⁵ See for example, Conn. Gen. Stat. sec. 17a-451d, which provides that the proceeds of any sale or transfer of a Regional Center property shall be retained by the state in a nonlapsing fund and used for individuals with intellectual disabilities. This statute could be amended to include STS.

- b.** Provide funding for real-time electronic records for both tracking time and performance outcomes.
- c.** Review current reimbursement strategies and revise as needed to incentivize mission and vision valued outcomes for individuals with developmental disabilities. They should be consistent with the National Core Indicators (NCI) developed by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) and the 21 Personal Outcome Measures developed by the Council on Quality and Leadership (CQL).

5. Enhance Current Community System and Providers.

- a.** Expand the Provider Mentoring Initiative of 2014-15 for both public and private providers. This initiative, funded by DDS for eight providers to access nationally recognized consultants who were paid by the state to train provider staff within the eight agencies on how to provide supported living, conduct group home closures or conversion to shared/supported living and engage in robust person-centered planning. All DDS employees should complete this training, with emphasis on its case managers and regulatory staff.
- b.** Encourage the development of core competencies in positive behavioral interventions and supports and age related medical and healthcare needs of individuals with ID/DD including the provision of telehealth consultation and training and technical assistance to local physicians and clinics across the state.

6. Invest in Continuing Staff Development, Training, and Coaching.

- a.** Provide a dedicated line item in the DDS annual budget for staff development training to assure that all staff have the skills and competencies for emerging and existing “best practices” to meet personal performance outcomes and for career advancement.

7. Provide for Community Visits and Transition Counseling.

- a.** Throughout the institutional closure process, develop and sustain a core of competent case managers/service coordinators committed to the DDS Vision and Mission and dedicated to working with this group of individuals and families to address their legitimate anxiety, fears and concerns.
- b.** Recruit, train, and support family members who have been through the process of moving from either the Mansfield Training School or the Southbury Training School to the community with good outcomes for their loved ones, to serve as peer mentors and support.

- c. Assure that individuals and families are provided sufficient time and provider choices to make an experientially based, informed decision.

8. Deployment of Current State Employees at the State Operated Institutions.

- a. Treat all current state employees with dignity and respect during the closure process.
- b. Establish an employee counseling and job placement service at STS as soon as the state announces its closure. Services would include individual counseling, job relocation and transfer planning, job fairs, resume writing and retirement planning.
- c. Many State employees at STS have worked with residents for many years and the residents and State employees have personal relationships. Some workers may be interested in providing community-based services—for example, operating a community companion home—for residents moving from STS who have had long-term relationships with their staff, and such possibilities should be considered and fostered, where feasible. The State should offer employees from STS preferential status for opening such community companion homes if they meet the necessary state licensing requirements, which is a policy successfully in the states of Vermont and Washington.
- d. The plan should provide information on the total number of STS employees as well as those STS employees eligible or soon to be eligible for retirement. Other states closing institutions have offered retirement incentives to employees. The State should be willing to analyze the economic efficacy of offering retirement incentives, as for some STS employees, that will be the desired option.
- e. The plan should include options for employees choosing to move to a different job, to receive preference for state employment for which they are qualified or can receive training to be qualified. The plan also should provide for a fixed payment for moving expenses for moves of greater than 50 miles from STS.
- f. The plan should offer temporary extension of health insurance benefits for laid-off workers and their families throughout the first year if the worker remains unemployed
- g. Begin discussions with the employees' collective bargaining representatives early in the closure process.

9. Reform of the DDS Community Services System.

- a. Although outside the scope of the requested recommendations for the closure of Southbury Training School, it will be essential for the Department of Developmental Services to thoroughly review, analyze and reform the current services and supports utilization in the community.

- b.** The current DDS funded community system is overly reliant on licensed group homes and facilities. This structure will not endure scrutiny under the new CMS “settings” rules that require individuals who are receiving services be provided equal opportunity and access to the generic resources of the community that are the same as for individuals who are not receiving Medicaid funded HCBS. Reform also should include increased opportunities for families to truly partner with DDS for housing options.
- c.** The average HCBS waiver costs in Connecticut are not sustainable at an average of \$81,466 per person (4th in the country) compared with a national average of \$45,795 and the state’s outcomes are not as high as many other states using the National Core Indicators data or the University of Minnesota Residential trends and size of community living settings. The average state has 51% of individuals receiving HCBS living in settings of three or fewer, while in the states of VT, NH, GA, NM, KY, CO, and AK have 89-95% of such individuals are living in settings of three or fewer. Connecticut is below the national average at 49%. Smaller settings result in increased opportunities for experientially based choice, better relationships, increased community integration and membership.
- d.** A critical part of the reform must include an in-depth analysis of every rule and regulation for licensing and quality assurance for their consistency and compatibility with person-centered planning, experientially based informed choice, competitive integrated employment and the dignity of risk. The analysis should include the status of formal interagency agreements between DDS and the State Department of Education and the Department of Rehabilitation Services, with a focus on youth ages 14-24 pursuing community integrated employment.

10. Develop Benchmark Data and Measurable Outcomes for Implementation of the Plan.

- a.** No plan is complete without the development of goals, objectives, strategies, responsible persons and timelines to measure impact and outcomes.
- b.** The plan should have at least annual reporting to the Legislature.
- c.** Given the current census of STS and the fact that every resident has received comprehensive assessments in preparation for moving into the community, the goal of institutional closure with carefully implemented person-centered plans will not take more than three years to complete.

Conclusion

Although recent budget cuts have strained Connecticut's residential services for individuals with intellectual disabilities, Connecticut's allocation of resources to the Department of Developmental Services is still generous compared with that of many states.

It is incumbent on the State, as it plans and implements the closure of all state operated institutions, that it maintains and enhances this level of fiscal commitment in order to rebalance the DDS system. Redirect all public resources from segregated facilities to cost-efficient individually-tailored, person-centered community integrated services and supports that provide valued outcomes for each individual to have a meaningful life in the community; and, to recognize that life is "not a program" for any person with a disability any more than it is for any person without a disability!

When making the recommendation regarding Southbury Training School to Governor Malloy, the goals of the Developmental Disabilities Assistance and Bill of Rights Act: independence; productivity; integration; interdependence; and full inclusion; and the goals of the Americans with Disabilities Act: equality of opportunity; independent living; economic self-sufficiency; and full participation should be the benchmarks by which the process is judged. If the recommendation does not further the goals of those civil rights laws, then the process will have failed. When judged against those goals, closure of STS (and the five regional centers) should be the recommendation that DDS makes to Governor Malloy in order to assure the advancement of the civil rights of all individuals with intellectual disabilities in Connecticut.

APPENDIX A
Common Themes for Success from the States

- 1. Political will and culture.** The support of key legislators and decision makers in the Governor's office and state agencies is THE key factor.
- 2. Leadership** at every level in stakeholder organizations, from families and self-advocates.
- 3. A clearly identified, consistent and predictable funding source** to ensure that providers, individuals and families can plan for transition. Stakeholders must have confidence that adequate and appropriate funding will follow the individual to life in the community.
- 4. Recognize short and long-term fiscal realities.**
- 5. Ensure the ability to broker a reasonable transition for state employees** affected by the closures.
- 6. Provide frequent, timely and factual communication with individuals and their families who will be affected by the closures** to create a dialogue that engenders trust and minimizes the understandable concern that will accompany the transition into the community.
- 7. Invest in financial and human resources** to create and sustain the appropriate infrastructure for an array of person-centered, individually tailored community supports and services.
- 8. Create open dialogue and build trust among all those invested in and affected by the closure of facilities.**
- 9. Develop a robust and effective emergency Positive Behavior Intervention Support (PBIS) statewide system.** It must consist of well trained, immediate (one hour or less) mobile response teams and short-term stabilization services.
- 10. Identify and/or enhance the capacity of healthcare provider systems** that are accessible and accepting of individuals with developmental disabilities, including individuals with more challenging healthcare and behavioral needs.
- 11. Engage the media** to highlight the benefits of community living.

APPENDIX B
The Foundation for Planning; Vision and Mission

State of Connecticut
Department of Developmental Services
Mission and Vision Statement

Mission

The mission of the Department of Developmental Services is to partner with the individuals we support and their families, to support lifelong planning and to join with other to create and promote meaningful opportunities for individuals to fully participate as valued members of their communities.

Vision

All citizens supported by the Department of Developmental Services are valued contributors to their communities as family members, friends, neighbors, students, employees, volunteers, members of civic and religious associations, voters and advocates. These individuals:

- Live, learn, work and enjoy community life in places where they can use their personal strengths, talents and passions.
- Have safe, meaningful and empowering relationships.
- Have families who feel supported from the earliest years and throughout their lifetimes.
- Have lifelong opportunities and the assistance to learn things that matter to them.
- Make informed choices and take responsibility for their lives and experience the dignity of risk.
- Earn money to facilitate personal choices
- Know their rights and responsibilities and pursue opportunities to live the life they choose.

The Connecticut DDS mission and vision statements above are consistent with the lessons learned in other states, the ADA, and HCBS rules. For example, the guidance from the National Council on Disability's 2012 report, "Deinstitutionalization: Unfinished Business", states:

- A state should not unnecessarily restrict a person's quality of life, social interactions, or basic human rights based on disability status.
- The social environments of people with ID/DD should be as much as possible like those of their nondisabled peers.
- An individual should not be required to give up the right to live in the community in order to receive needed services and supports.

- People with ID/DD should be allowed to make decisions about their own lives to the maximum extent possible.
- Research supports the fact that community settings result in improved quality of life in areas such as opportunities for integration and social participation, participation in employment, opportunities for choice-making and self-determination in quality and duration of services received, contact with friends and relatives, adaptive behavior, and other indicators of quality of life.
- The community is for EVERYONE. This includes people who have medical or behavioral issues that complicate their care and support.

APPENDIX C

Summaries of the Experiences of Four States, Including Three New England States – Maine, New Hampshire and Vermont -that Eliminated State Institutions: (published by the National Conference of State Legislatures in 2000)

From: National Conference of State Legislatures 2000 Report - Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators, page 16.

Available at: <http://mn.gov/mnddc/parallels2/pdf/00s/00/00-DPD-NCS.pdf>

Michigan

Michigan provides an example of a state's persistently innovative role in transforming its MR/DD services delivery system. In 1979, 80 cents of every dollar spent on mental retardation (**sic**) residential and community services was allocated to state institutions. Several developments helped transform Michigan's delivery system into a model for other states that want to decrease reliance on their institutions.

- The Macomb-Oakland Regional Center, opened in 1973, focused on family support services, family preservation and permanency planning. The center helped avert unnecessary institutional placement when support and services could be found in a community setting.
- A lawsuit, Michigan Association for Retarded Citizens vs. Smith, focused on the conditions found in the Plymouth Center, a large state institution.
- The Community Mental Health Act, enacted by the Michigan Legislature, provided financial incentives to county boards of mental health and retardation to provide community services. Funds that were saved from closures were reallocated to finance community residential services and family support.
- The Michigan cash subsidy program provides \$250 per month for families earning up to \$60,000 to pay for clothing, education aids, out-of-pocket medical expenses and transportation. The program allows people with developmental disabilities to combine their cash subsidy with the \$5,500 from SSI. The subsidy eliminates the routine practice of reducing benefits from public programs when persons with MR/DD receive additional benefits from other programs.

As a result of Michigan's determined efforts, nine state institutions were closed between 1981 and 1996. **In 1998, only 283 residents remained in state institutions, down from 12,615 in 1965** (emphasis added). Furthermore, the cash subsidy program provided support to 4,645 individuals with MR/DD and their families in 1996. Nearly 7,000 families received respite care, counseling and in-home services. Michigan allocated 95 percent of its total mental retardation resources for family support and community care, compared to a national figure of 72 percent.

From: National Conference of State Legislatures 2000 Report - Deinstitutionalization of Persons with

Developmental Disabilities: A Technical Assistance Report for Legislators, page 14.

Available at: <http://mn.gov/mnddc/parallels2/pdf/00s/00/00-DPD-NCS.pdf>

New Hampshire

New Hampshire was the first state to move to an exclusively community-based system. The state became an early innovator of a community-based system by enacting RSA-171-A in 1975, a law which mandated the development of individual service plans and created 12 area agencies designated to provide community-based services. Although New Hampshire had only one institution, a federal court decision in 1981 decreed that the state develop a community-based service system and eliminate unnecessary institutionalization. Thus, New Hampshire's Division of Developmental Services decided to pursue a plan that combined institutional reform and community placements.

In 1984, New Hampshire received a HCFA waiver to expand its community-based service system. Its use of HCBS waivers was more extensive than that of many other states, including case management, personal care and residential support, supported employment and environmental modifications such as home adaptations. This use of the waiver was the centerpiece of the Division of Developmental Services' plan to create "individualized housing and regular work opportunities."

The state continued to pursue a more extensive community-based system of care when the New Hampshire legislature passed the Family Support Act of 1989. The act provided direct financial support for community services by providing public funds for the 12 area agencies, which previously were not appropriated any public funds. The area agencies consist of private, autonomous providers that contract with the state to provide services.

The 12 area agencies are responsible for submitting to the state detailed plans—as well as progress reports and proposed budgets—for placing the disabled in the community. The agencies usually emphasize enhanced family care and out-of-region placements.

- Enhanced family care placement—Case managers attempt to locate people's most significant familial and community ties, regardless of the region, as the first setting for potential placement. If a patient's family no longer lives there, managers pursue placements in surrogate families in the region where MR/DD patients grew up.
- Out-of-region placement—Case managers place the disabled in the regions in which they grew up as opposed to the regions where they may have received services in an institution. Because some regions may have a more extensive network of community-based services, managers are more likely to seek placements in those regions. However, attempts to place those with MR/DD in

regions that may not have the most extensive network of care—but in which the patient once lived—prevents the overutilization of services in a particular region.

By 1991, all the developmentally disabled (**sic**) had been placed in community settings. The last state institution, Laconia, finally closed because the vast majority of residents had been placed in the community. **The state legislature aided the further development of the community system by allowing institutional funds to be transferred directly into the community services system instead of into the state general fund.** (Emphasis added). In 1998, total spending for developmental disabilities was \$123.5 million, with community spending accounting for 99 percent of the total (\$122 million).³⁸ The remaining spending included federal ICF/MR reimbursements and state matching funds. From: National Conference of State Legislatures 2000 Report - Deinstitutionalization of Persons with Developmental Disabilities: A Technical Assistance Report for Legislators

Available at: <http://mn.gov/mnddc/parallels2/pdf/00s/00/00-DPD-NCS.pdf>

Maine

The conditions in Maine's only institution, Pineland, resulted in a 1978 consent decree that required Pineland to provide better living conditions and treatment for its disabled residents. Between 1978 to 1994, local providers of community services began to expand and to improve the community-based service delivery system. As the disabled moved into the community, the money was available for those who needed services outside the institution, further expanding the community system. Community spending—as well as spending to finance institutional reform—increased steadily until 1992, when institutional spending began to decline and Pineland faced closure.

In 1994, another consent decree declared that the original 1978 decree could be vacated if Pineland were closed. The momentum already had moved away from providing institutional care. The executive and legislative branches allowed the courts and the bureaucracy to determine the movement to community-based care. The 1994 consent decree further expanded the use of community-based care by proscribing the use of a crisis response system in which emergency beds are made available for those who need them until a longer-term community setting is found.

From: Closing the Doors of the Institution: Opening the Hearts of Our Communities, December 1993, Vermont Agency of Human Services

Available at: <http://www.ddas.vermont.gov/ddas-publications/publications-dds/publications-dds-documents/ddas-publications-other/closing-thedoor-brandon-training-school-10>

Vermont

Between 1915 and 1993, a total of 2,324 people resided at the Brandon Training School (BTS). During the 1960's, BTS housed more than 600 men, women, and children.

In 1978, the Vermont Legislature enacted the Brandon Judicial Review law. This provided a legal process to review each resident's need for continued institutionalization. The individual reviews established that virtually all residents could leave if they had support services. (Emphasis added) However, Vermont's fledgling community mental retardation system lacked the resources to provide services and safety for the 300+ residents who remained at the school.

A lawsuit on behalf of Robert Brace and other residents who wanted to move out established a ten-year plan for developing resources around the state. The settlement of this case became known as "the Brace Decree." In the same period, the U.S. Congress enacted the Medicaid Home and Community-based Waiver program. State administrators recognized that this program was an ideal mechanism for using federal Medicaid dollars — heretofore available only to pay institutional costs — to develop individualized community support services. Vermont was one of the first states in the nation to use the Medicaid waiver to pay for the resources people needed to move out of the institution.

The new waiver-funded programs proved decisively that community-based services could support even the most severely disabled residents of BTS. In the early 1980's nearly 100 people moved to community programs from the Training School, but in the ensuing years the community placement process floundered for lack of resources and political support.

In 1989, Vermont was facing critical challenges:

- We knew we were not providing the best services we could. We knew that community services would be better for BTS residents, and we knew how to deliver quality services for them.
- BTS costs were consuming the Division of Mental Retardation (DMR) budget. Institutional costs were rising twice as fast as the costs for community services. **More than 40 percent of DMR's budget went to cover the costs of just 13 percent of the people served.**
- **Children, families, and recent school graduates were not getting needed services. A generation of children who grew up at home and attended public schools were reaching adulthood. They and their families wanted services in their own communities, but the resources were not there.**
- Community resources were stretched to the limit. Tight finances had forced community service providers to take on more and more clients within existing programs. The community service system lacked the infrastructure to take on a major placement initiative.

- The state was in violation of the Brace Decree. The ten-year time period had passed, and 180 people were still awaiting placement.
- Vermont had no programs for people found incompetent to stand trial. In 1988, the Legislature enacted Act 248. Under this law, people who commit serious crimes but are not competent to stand trial can be committed to the Commissioner of Mental Health and Mental Retardation. However, Vermont did not have programs to implement the law.
- Crisis services were needed. The system lacked capacity to respond to individuals in crisis in the community, and to meet the needs of individuals with the dual diagnoses of mental illness and mental retardation **In response to these challenges, DMR developed a plan to close BTS and "unify" the system around community programs. The Unification Plan had three objectives:**
 1. **To convert the system of services to Vermonters with mental retardation from a two-tiered structure supporting both the institution and the community, to a unified community-based system.**
 2. **To move all remaining residents of BTS to the community.**
 3. **To build the capacity of the community mental retardation system to respond to the needs of:**
 - * **Special education graduates,**
 - * **Families who need in-home support,**
 - * **Young adults aging out of SRS custody,**
 - * **Persons with mental illness and mental retardation,**
 - * **Persons with mental retardation who commit crimes, and**
 - * **Persons in crisis.** (Emphasis added)

It was not as simple as just moving money from the institution to the community.

During the transition period, both institutional and community systems had to maintain quality services. Funding had to be available to develop community programs and infrastructure before savings could be transferred from BTS. **More than 400 state workers would be displaced from their jobs.** (Emphasis added) Community service providers had to develop the necessary infrastructure to enable them to address the needs of increasing numbers of individuals.

In FY '92 and FY '93, the Legislature approved "bridge" funding to support new community services until savings could be transferred from the institution. Approximately \$406,000 was appropriated each year to set up placements in the community for people leaving the institution.

Meanwhile, the Division of Mental Retardation continually revised its institutional downsizing plan to meet changing conditions. Personnel costs were the largest item in the budget, and careful planning was critical. Staff reductions and building closures had to be coordinated with the rate of placement into community services. Adherence to a placement schedule that allowed for expenditure reduction was

the key to freeing up resources that could leave the institution. At the same time, flexibility to assure that quality community services were in place was essential. Many key institutional staff moved on to new jobs during the phasedown, creating unwanted staff shortages in some areas while planned staff reductions were occurring in others.

Results

The Community Placement Process

Between July 1991 and November 1993, 156 people moved from Brandon Training School to community placements. Overall, the placements were extremely safe, stable, and successful. (Emphasis added)

Where Did People Go?

When residents had friends or family members in Vermont, every effort was made to locate a placement nearby. Residents moved to 12 of Vermont's 14 counties. In general, the counties closest to BTS had the most placements. The majority of residents had originally come to BTS from these adjoining counties. One person moved to be with family out-of-state.

Fourteen community mental retardation provider agencies sponsored or developed community placements.

Most people moved to homes that had been individually developed or recruited for them. The majority live in homes where they are the only person with mental retardation. Some live with one other "consumer." Some live in group homes or small ICF/MR homes with three to six residents. Only two persons went to a large congregate setting (i.e., a place that houses more than six people with disabilities). These two moved to a nursing home, and one has since moved to a small ICF/MR.

Key components of the successful placement process:

1. **We obtained the commitment and support of the provider system at the outset.** The community placement process had the support and commitment of the state community mental health and mental retardation system. All agencies participated, and all felt a shared responsibility for a successful outcome. Agencies had mutual expectations for one another, and provided support to one another. The community agencies accepted the "zero reject model" (i.e., all persons with mental retardation should be served through the community system, and there is no subgroup that still "belongs" to the state).
2. **We addressed issues of growth at the service provider level.** Agencies had to build their capacity and expertise in order to take on new clients with challenging needs. Funding was provided to meet critical infrastructure needs that each agency identified (for example, a training specialist, a part-time nurse, an

additional supervisor, a new computer). Each agency had its own particular needs, and funding to build capacity was negotiated program by program.

3. **We emphasized individualized budgeting.** Budgets to support each individual who moved were approved individually at the state level. Funding was tailored to fit people and their needs. There was no budgeting by categories or level of care.
4. **Deinstitutionalization was integrated into ongoing community services development.** The BTS community placement process was integrated into the state's overall development of services for people with mental retardation. There was not a separate placement process or separate placement staff or separate placement agencies for people coming out of BTS. As a result, finances and resources were shared. The money following BTS clients could also strengthen services for individuals in the community. Duplication and competition were minimized.
5. **The Vermont Crisis Intervention Network (VCIN) was established.** This three-tiered program is designed to serve individuals in crisis and individuals who present severe behavioral challenges in individualized community settings. Thus far, none of the last 156 individuals to leave BTS has had to use the Vermont Crisis Intervention Network because the placements have their own built-in resources. But VCIN played a critical role in preventing any new institutional admissions during the phase-down period. In addition, the existence of VCIN gave stakeholders a greater sense of security as they worried about all the "what-ifs."
6. **Community staff respected and relied on Brandon Training School staff.** It was important for individuals who were developing community placements to recognize and rely upon BTS staff as people who knew the residents best. Lots of effort went into avoiding a "them" and "us" mentality between community and institutional staff.

Community services were greatly enriched by the skills of BTS staff who took jobs with community agencies or the Division of Mental Retardation. The BTS training division was retained and now provides training throughout the state for community providers and consumers. **Most importantly, nearly 40 BTS staff members qualified to share their home through the developmental home process with someone they had known well at the Training School.**

One of the most rewarding aspects of the community placement process has been to watch former staff and former residents move to the community and blossom together.

7. **BTS leadership respected the community.** Just as community providers had to respect BTS staff, it was essential for leadership at the Training School to recognize that community staff had the expertise about community services. The

institution did not make or supervise placements. They left final decisions about placements to the community staff. When there were rumors or complaints about a problem in a community placement, the BTS leadership referred these concerns to the community system for follow-up.

8. **We worked with families individually.** Like most institutional closings, this one began with substantial opposition from family members of residents. These family members valued the security of the institution, and they lacked confidence in the stability and safety of community programs. Staff invited family members to tour community homes to familiarize them with the community system, and engaged them in personal futures planning.

We made efforts to respond to guardian and parent anxieties by identifying BTS staff the family members trusted as communicators. Placement choices took account of guardian anxieties. Where a guardian vetoed a specific home, we developed an alternative.

We did not expect hesitant family members to agree to placement until we could show them a specific home. Most families were unable to accept a community placement in the abstract, but readily agreed when they could see the actual home and meet the specific persons who would provide residential support. The fact that so many home providers were former BTS staff made it easier for family members to put trust in community placements. They felt the former staff knew what they were taking on and trusted their proven skills and caring.

9. **We relied heavily upon the developmental home model.** In our rural state, for people who have lived long years in an institution, the developmental home is the placement of choice. It provides the person with a built-in social network and family system, and a channel for making connections with the community. It gives the person the experience of living in a healthy family setting, and positive adult companions and role models. It may provide for inter-generational contact with children and elderly relatives.

In a developmental home there is a single adult, or a couple, who are consistently responsible for the person and who provide a constant source of affection and teaching. Typical rhythms of life and typical activities occur and do not have to be simulated. Although the developmental home model is often too restrictive for a person who has grown up in a family and experienced choices and community life, a developmental home is an ideal first step for a person who needs to be introduced to community life and who lacks a social network of his own.

10. **DMR staff followed each person through her transition to the community.** We assigned a Guardianship Services Specialist to each person to monitor the placement and trouble-shoot where necessary. This individualized monitoring of the transition provided an extra level of quality assurance, and helped identify potential problems proactively before they became serious.

11. **We relied only a little on new housing.** With the support of the Vermont Housing Conservation Board, nine new homes were built or renovated to house small groups of two to six former residents. The homes are in residential neighborhoods throughout the state, and are lovely. Many parents were more comfortable with a group home than a developmental home for their family member.

However, most of the delays we experienced in the community placement process were connected with this new home construction or acquisition. Multiple hurdles before financing could be obtained, neighborhood opposition, zoning barriers, licensing requirements, and the vagaries of construction all created delays along the way. In addition, the process of readying the physical structure tended to take center stage in these projects and distracted from the more important task of getting staff trained and oriented. **Group homes are almost always more costly than developmental homes. If we were doing it again, we would rely even less on new housing.** (Emphasis added)

12. **BTS staff received active assistance in finding new jobs.** Through job fairs, seminars, bulletin boards, and a myriad of informal contacts, BTS staff received active support from the Department of Mental Health and Mental Retardation to locate and qualify for new jobs. Vermont State Employees Association representatives and Department of Personnel staff played key roles in maintaining employee morale and educating staff about their rights. As "RIFed" state employees, they received priority for openings through state government.

As of November 1993, 79 had transferred to other jobs with the State of Vermont. Community mental retardation agencies throughout the state sought out BTS staff as employees, but they found that most were unwilling to relocate. At least 60 BTS staff took jobs or became developmental home providers for community mental retardation agencies. Others found jobs in the private sector, retired, continued their education, or took the opportunity for a few months off. The State of Vermont remains committed to assisting those BTS staff who remain unemployed to find satisfying employment.

13. **We made maximum use of BTS assets.** Over the years, the Training School had accumulated substantial assets. The state loaned more than \$200,000 worth of furnishings, equipment, and vehicles to community agencies. This created substantial savings in start-up costs for new placements. The state transferred office equipment and supplies to various state offices. Unwanted items were turned into cash through various sales, and the proceeds were used to fund other needs. The campus itself is now for sale.

Conclusion

Deinstitutionalization means more than just closing the doors of the institution. Deinstitutionalization means changing the way we think about people and services, not only within the confines of a group of buildings, but also within the confines of our minds. In the years ahead, we must be careful not to settle into a particular way of providing services. We must continue to change, to give people what they want and what they tell us they need.

Although the responsibilities of the state have changed with the closure of the Brandon Training School, they have not decreased. The state must affirm its commitment, both to people with disabilities and to the people who support them with services. We need to figure out ways of enabling individuals and their families to become involved in decisions about the services we offer, yet independent of those services. **We need to continue to prove to the community at large that making life better for those with the most intensive needs makes it better for all of us.**