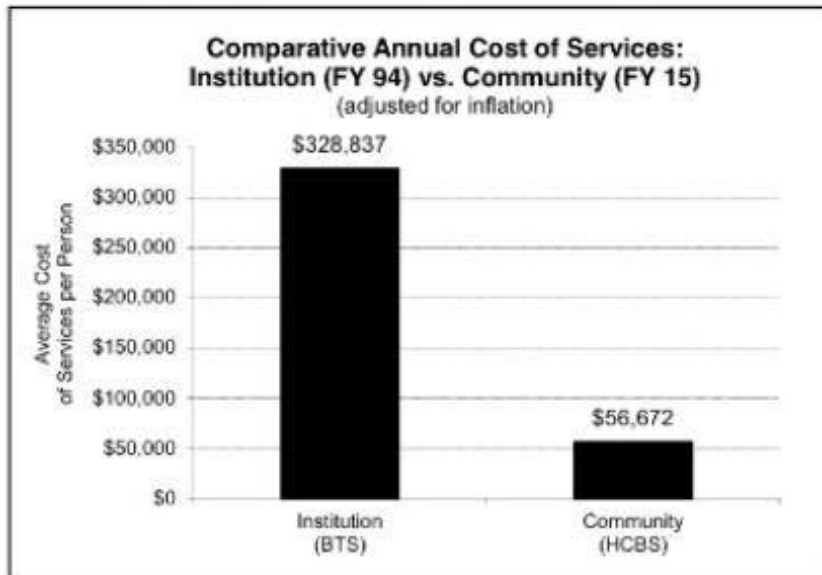


**Closing Brandon Training School Saved VT Tax Payers, or so you thought. Now VT Tax Payers are paying to outsource Residential Treatment for the most vulnerable and costly Vermonters. Can we build the infrastructure to meet this need here, in Vermont, one school district, one supervisory union at a time?**

Since the closure of Brandon Training School (BTS) in FY '94, the average per person served cost for home and community-based services (adjusted for inflation) has declined. In FY 15, the average per person cost for HCBS was \$56,672. In the last two full years of BTS it cost an average of \$328,837 per year for each person served (adjusted for inflation).



(Source: DDS-REVISED ANNUAL REPORT State Fiscal Year 2015 Annual Report. Page 57)

- Is it fair to say that the cost of de-institutionalizing VT has saved Vermont tax dollars? (not in Martha's case)
- Is it also fair to say that VT children in need of residential no longer have 24/7 intensive services to meet their severe needs? (Martha can access this level of care, with ONE-TIME funding)
- What happens to the children who need this level of care? (most leave VT to seek out of state residential placements)
- Are the children with this level of care able to access this need at home, now that VT's System of Care Plan is funded to supports that mission of keeping children at home and in their communities? (not without a legal action, I am in the midst of an ACT 264 crisis, being told my request for funding will be denied but I may appeal)
- My daughter has significant safety needs that require skilled care at a 24 hours in the day, 7 days per week, can she receive this care at home, as the System of Care Plan supports? (MARTHA CAN RECEIVE THIS CARE AT HOME, once ONE-TIME funding is in place and accommodations are built to meet her safety needs to remain at home)

Kathleen Burke Kourebanas, Essex, VT [kathleenbk@comcast.net](mailto:kathleenbk@comcast.net)

## DAIL'S SYSTEM OF CARE PLAN

**“the commitment to create those supports and services necessary for people to live with dignity, respect and independence outside of institutions.”**

*Vermont State System of Care Plan  
Effective July 1, 2014*

### SECTION ONE – INTRODUCTION

#### I. Background

##### A. History

The closure of Brandon Training School in 1993 was a significant milestone in the history of Vermont's system of care for individuals with developmental disabilities. It marked the end of reliance on an institutional model of care and underscored the commitment to create those supports and services necessary for people to live with dignity, respect and independence outside of institutions.

In 1996, the Vermont State Legislature embedded in law the process by which the state continues that commitment. The Developmental Disabilities Act of 1996 (DD Act) requires the Department of Disabilities, Aging and Independent Living (DAIL), through the Developmental Disabilities Services Division (DDSD), to adopt a plan known as the *State System of Care Plan* that describes the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. The *State System of Care Plan*, (from here on called the “*Plan*”), along with the *Regulations Implementing the Developmental Disabilities Act of 1996* and the *Developmental Disabilities Services Annual Report*, cover all requirements outlined in the developmental disabilities statute.

In 2013, Vermont marked the 20<sup>th</sup> anniversary of the closing of the Brandon Training School (BTS). This major milestone in the history of Developmental Disabilities Services (DDS) created an opportunity for us not only to remember the past and celebrate our accomplishments to date, but to begin thinking about the future of Developmental Disabilities Services and what we want the system of care to look like 10 – 20 years in the future. To assist in this effort the Commissioner of DAIL created the DDS *Imagine the Future* Task Force to help create the future vision. The Task Force is made up of consumers, families, individuals who were involved in the closing of the BTS 20 years ago, providers, advocates and other stakeholders. At the time of the writing of this *Plan*, the Task Force is continuing to meet and develop the vision. As part of this process, the Task Force will be reviewing the DD Act as it is currently written and will make recommendations regarding any necessary changes to the Act in order to achieve the vision for DDS in Vermont. Some of the Task Force's ideas, as well as the ideas from a DDS Legislative Policy Work Group, are reflected in this *Plan* (the DDS Legislative Policy Work Group met in 2013 and was tasked with coming up with innovative and cost-effective ways of

- **WHERE ARE THE RESOURCES IN VT** to keep our most severely disabled children safe and learning at home and in their communities? Are you supporting these services and supports in your policies?
- What happens to the children who needed this level of care? Where are those resources? **WHERE IS THE POLICY TO FUND THESE HOME-BASED SUPPORTS?**

- **PLEASE MEET MARTHA KOUREBANAS**, age 16, SEVERE AUTISM, OCD, MOOD DISORDER, Essex, VT

#### **B. Creation of the Plan**

Gathering information about the needs of people with developmental disabilities in Vermont and the effectiveness of our services and supports is an ongoing endeavor. The *Plan* builds on experience gained through previous plans and is developed every three years and updated annually, as needed, with input from a variety of individuals interested in services and supports for people with developmental disabilities. Input is obtained by the State through a process of gathering information from conversations with stakeholders, Local System of Care Plans, public hearings, written comments, online survey and satisfaction surveys of individuals receiving services (see Section Five). One of the key groups consulted during the development of this *Plan* is the Developmental Disabilities Services State Program Standing Committee. In accordance with the Developmental Disabilities Act, specifically 18 V.S.A. §8733, this Governor appointed body is charged with advising DAIL on the status and needs of people with developmental disabilities and their families and advising the Commissioner on the development of the *Plan*. All these methods of input provide the perspective of a wide range of individuals.

2

Martha lives at home in Essex Jct. with her loving family. Martha is currently on a wait list for out of state residential placement.

Martha needs one time funding to stay home and not leave VT for many years of costly residential treatment. The ACT 264 crisis process is not addressing Martha's need for one-time funding. Martha is being told that there is no way to fund a home addition to address her level of safety need to remain home; however out of state residential (at an EMORMOUS cost) has a funding policy. Martha is currently on a waitlist for Melmark New England in Andover, MA (specifically chosen by her IEP team as it has an adult group home post age 22) If Martha's one-time funding can not keep her in VT to receive the services that she needs, Martha will leave VT for many years, costing VT millions of dollars when until age 22, when she is no longer on an IEP. If at age 22, there are still no resources in VT to meet her level of need, Martha will stay at residential, continuing to cost VT millions of dollars for outsourcing her care.

"Get a loan, call Habitat for Humanity, Call VCIL and get on the waitlist, host a fund raiser."  
"you may submit a home estimate, if it is to be denied, you may appeal within 90 days" -Those are some of the answers I am getting when I ask for 1 time funding to keep Martha safe at home rather than leave for out of state residential.

I have started a petition with Change.org to address VT's issue of funding children to stay home with their families; so far it has 562 signatures. I have testified on Martha's behalf to the Senate and House Education Committees to advocate for policy change.

I have reached out to US Representative Peter Welch, Governor Shumlin, US Senator Leahy and US Senator Sanders. Today, I am asking you all to please address this important issue, on behalf of Martha and the other "Marthas" at risk of having to leave VT for services.

Kathleen Burke Kourebanas, Essex, VT [kathleenbk@comcast.net](mailto:kathleenbk@comcast.net)

**As Martha's mother, I am asking, please amend the one-time funding policy to fund Martha's home placement. At the end of the fiscal year, Martha's waiver will have unused funds, please let these funds contribute to her ONE-TIME FUNDING COST need.**

Vermont State System of Care Plan  
Effective July 1, 2014

### **C. Intention of the Plan**

The *Plan* is intended to help people with developmental disabilities, their families, advocates, service providers and policy makers understand how resources for individuals with developmental disabilities and their families are managed. It lays out criteria for determining who is eligible for developmental disabilities services and prioritizes the use of resources. It is specifically intended to spell out how legislatively-appropriated funding will be allocated to serve individuals with significant developmental disabilities. The *Plan* guides the appropriate use of this funding to help people achieve their personal goals and to continuously improve the system of supports for individuals with developmental disabilities within available resources.

This *Plan* does not substitute for the State of Vermont's Medicaid State Plan. It does not guide or direct the allocation of resources for all Medicaid State Plan services, or other services administered by the Agency of Human Services or other state agencies.

This three-year *Plan* is effective as of July 1, 2014 and will be updated on a yearly basis, as needed. Feedback on the *Plan* is welcome.

Please address my daughter's need to stay home with her family.

- I have attempted to amend a bill to solve this inter-agency agreement funding issue. This amendment will not only save an enormous amount of tax dollars from leaving our own economy and our own state, but will save families from having to seek out of state residential placement when they have a child in need of such services, that VT lacks.
- This amendment will push to build the infrastructure for our most costly citizens, who are the BIGGEST tax burden on Vermont.
- Amending this bill and allocating one-time funds to keep my daughter, Martha home is in the BEST INTERESTS of the VT STATE BUDGET and in THE BEST INTEREST OF MARTHA AND HER LOVING FAMILY, SUPPORTIVE SCHOOL AND COMMUNITY.

Kathleen Burke Kourebanas, Essex, VT [kathleenbk@comcast.net](mailto:kathleenbk@comcast.net)

## **SAVING VT DOLLARS AND SAVING VT FAMILIES**

(Amending this bill for the future of Vermonters at risk of residential placement)

- Below is language to amend **Bill H.859 to encourage DOE and DAIL to communicate**, solve this funding issue for children ages 6-22, who are still living at home with their families and on IEPs (Individualized Education Programs, designed to meet the child's individualized needs).
- This amendment will push to build the INFRASTRUCTURE needed in our school districts by allowing SUPERVISORY UNIONS the authority to address individual needs. The funding cost would be ONE-TIME, as stated in the language below. This will promote instances of 'shared cost options' for individuals within school districts.
- This amendment will lessen the crisis wait time in the ACT 264 process and expedite solving a needs issue to better serve individuals in crisis and save VT dollars in the process.

### **Bill H.859 (An act relating to Special Education)**

1)"VT is committed to educating students WITHIN THE STATE OF VERMONT, as opposed to out of state placements, whenever a reasonable VT based placement exists."

2)"Funding this placement will be divided by DAIL and AOE, just like out of state placements costs are shared."

- Certain conditions must be met
- Documented long-term disability
- High cost of care
- Need for residential placement

#### **Rationale:**

- This will allow flexibility in choice for creative solutions that are stymied by the current funding system.
- This could give the school district a higher 'investment allowance' that allows them to spend a higher amount in 1 year, when they prove that it will, in turn, save SIGNIFICANT spending over the subsequent 3 years.
- In M's case, it would solve the lack of funding issue that will essentially send M out of state to seek services.
- This amendment will give school districts/supervisory unions control and push to build infrastructure needed here in VT.

Kathleen Burke Kourebanas, Essex, VT [kathleenbk@comcast.net](mailto:kathleenbk@comcast.net)