

# Helping Albert

What \$114 million in tax dollars buys for 1,850 developmentally disabled and socially isolated Vermonters

March 2003



*An Ethan Allen Institute Report*

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## **Helping Albert: What \$114 million in tax dollars buys for 1,850 developmentally disabled and socially isolated Vermonters.**

### **Executive Summary**

**T**he developmentally disabled are those who have a severe chronic disability, manifested before age 18, that results in mental retardation, autism, pervasive developmental disorder, and significant “deficits in adaptive behavior”.

In FY 2001, the state spent \$114 million to support 1,850 developmentally disabled people- more than \$60,000 per person. The caseload has been growing steadily for a decade.

Since 1993, when the Brandon Training School closed, Vermont’s policy has been to place developmentally disabled people “in the community”. The Department of Developmental and Mental Health Services is proud that the average number of clients in this program per housing unit is only 1.2, and it opposes group homes for clients.

The system allows persons within it to define who is eligible for receive expensive services. This invites the classification of clients in ways that expand the power and budget of the program. These considerations may well come to prevail over what is the best for the people defined as developmentally disabled.

Mental health workers funded with public dollars surround clients with services, activities, regulations, and relationships. The Department and its nonprofit designated agencies are not funded or encouraged to promote greater independence, for that would reduce their clients’ reliance on compensated mental health workers.

The report recommends that Vermont policy for the developmentally disabled should shift from a client control and protection model to a consumer choice model that recognizes client assets and capabilities, expands their choices, affords them a chance to make a contribution instead of passively receiving services, and draws on family members and volunteers to provide support and integration. Government programs must be required to prove that the benefits of their interventions outweigh negative effects on the people served.

DDMHS should end its bias against allowing clients to live in a caring private group home. Two leading examples of such homes in other states are Camphill Communities and L’Arche Homes. These little communities have been successful and cost-effective because they provide a positive social structure for clients who have an opportunity to contribute, rather than obeying the directives of a government-paid monitor who tends to control their lives.

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## I. Introduction

Meet Albert.

Albert (not his real name) is a 56-year-old Vermonter who loves to draw houses and landscapes, using brightly colored markers and big sheets of paper. His Newport apartment is decorated with his art. He likes watching war movies, and imagines that he was a U.S. Marine. He is a good bowler, plays a decent game of softball, and is proud of his ability to stack wood and shovel snow.

Since childhood Albert has been a client of the state Mental Health system. At various points in his life, mental health professionals have labeled Albert as mentally ill and mentally retarded. In 1998 Albert drank too much beer after helping a neighbor stack wood. That got him a week in the Brattleboro Retreat. As a result of his Retreat stay, Northeast Kingdom Human Services (NKHS) determined that he was not mentally ill, but developmentally disabled (DD). That made him eligible to join 1,850 other Vermonters on the Medicaid-financed Home and Community Based Services (HCBS) program. (This program accounts for 94.5 percent of all funding for people served through the Division of Developmental Services of the Department of Developmental and Mental Health Services.<sup>1</sup>)

**Developmental disability** means a severe, chronic disability of a person that is manifested before the person reaches the age of 18 and results in:

- (a) mental retardation, autism or pervasive developmental disorder; and
- (b) deficits in adaptive behavior at least two standard deviations below the mean for a normative comparison group.

In this program mental health professionals closely manage Albert's life. He has almost no human relationships other than those with his professional managers. His dependence on the "system" is near-total, and will almost certainly continue to the end of his life.

Five mornings a week a mental health worker visits Albert to make sure he eats, takes his medication, and keeps himself and his apartment reasonably clean. Twice a week the worker takes Albert to a fast food restaurant for a breakfast date. A mental health worker accompanies Albert on his visits to the laundromat and the grocery. A special treat is being driven by a mental health worker across the border to Quebec to buy low cost cigarettes. When the worker believes Albert is talking too much about his imaginary Marine Corps career, she schedules a visit for him with a state-paid psychiatrist (at \$150 per hour).

For these services totaling 12 hours a week, NKHS bills Medicaid's HCBS account \$16,518 annually. Albert's designated agency justifies enrolling him in the HCBS by citing a need to protect his safety, maintaining he would become homeless without oversight by their staff. Albert is a low end user of the HCBS program. The average cost of an HCBS client is \$37,400 a year.

In addition, Albert is supported by \$24,238 more in public funds: \$10,740 from the Supplemental Security Income (SSI) program; \$7,930 in health services, \$3,744 in food stamps, and \$1,824 in rent subsidy. His total annual taxpayer support comes to more than \$ 40,756. (Fuel assistance figure not available.) When one considers the fact that Albert receives \$20,000 less than the average HCBS client, this total annual support figure could easily be more than \$60,000.

Albert is one of about 2,500 Vermonters (500 are children) receiving services through the developmental services division of the Department of Developmental and Mental Health Ser-

vices (DDMHS). Another 21,500 receive counseling, therapy and substance abuse treatment services funded by the Department's other division, the mental health division.

So, how did Vermont, with a per capita income of \$28,594 (2001), end up running a DD system that can cost taxpayers more than \$60,000 per client?

## II. The Rise of Community-based Developmentally Disabled System

### The Brandon Training School

A century ago the mentally retarded were cared for at home by their families, or in large public institutions with very little financial and social support from the government.

Vermont's only public institution for people with mental retardation and developmental disabilities was the Brandon Training School (BTS), which opened in 1915 and closed in 1993. During its 78 years of operation, a total of 2,324 people lived at BTS. Until the late 1970s there was virtually no other publicly funded service available to retarded Vermonters

Brandon's admission policy was written, in theory, to encourage community placements. As a 1966 document stated: "The care and training of the retarded is a community responsibility, and referral to the Brandon Training School should occur only after community resources have been exhausted. In addition, any referral should be based on the fact that the BTS can best meet the identified specific needs of the applicant. In all instances, admission to the facility should be viewed as a temporary measure until such time as appropriate community based resources can be identified."<sup>2</sup>

Despite this policy, many regarded BTS as Perpetual Training School. It even had a geriatric unit for students who had been living *temporarily* at the institution for more than 40 years.

In the 1960s, throughout the United States, an increasingly vocal advocacy movement exposed poor – and sometimes shocking – treatment of institutional patients. Movement lawyers brought sweeping class action lawsuits. The movement's legal and political victories changed public policy. The new policy was based on deinstitutionalizing persons with developmental disabilities who were capable of living in the community, and giving them a more flexible service delivery system.<sup>3</sup>

As a result, the number of people with developmental disabilities in public institutions declined nationally from 149,892 in 1977 to 51,485 in 1999.<sup>4</sup> Ironically, even as the advocacy movement criticized the medical model of the large state-operated institution, the same diseased-and-dependent philosophy followed the clients into community settings.

Vermonters connected to the developmental disability service system trace the idea of closing BTS back to the mid-1970s, when the institution's census had dropped from nearly 700 in 1968 to around 450 in 1976. A few key people attended workshops conducted by Dr. Wolf Wolfensberger of Syracuse University, and urged adoption Wolfensberger's principles of "normalization" as a philosophy for Vermont. That principle is defined as "... making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society."<sup>5</sup>

In 1975 Governor Thomas Salmon created the Division of Mental Retardation and established a budget for services. In 1978 the Brandon Judicial Review Act provided for a bienni-

al judicial review of each BTS resident's need to stay in the institution. The reviews determined that almost all residents could live in the community if they had the appropriate services.

In 1979 a law<sup>6</sup> was enacted establishing local community mental health centers as fixed points of information, referral, planning, and services. Another law created the public guardianship program.

A year later the state settled a lawsuit filed by the Vermont Developmental Disabilities Law Project on behalf of six BTS residents who wanted to move into the community. The settlement, called the *Brace Decree*, provided for a 10-year plan for developing community resources and moving most of the remaining 300 residents out of Brandon Training School. It did not mention closure of Brandon, but according to one of the lawyers, "We knew that in fact they carried out the terms of the settlement...they were going to end up with three people in the place," and it would have to close.<sup>7</sup>

Between June 1988 and June 1993 the number of residents at Brandon dropped from 186 to 31 and the number of people living in community residential settings rose from 381 to 701. This relocation was made possible by the state's use of the Home and Community Based Services waiver (HCBS) option of the Medicaid law.<sup>8</sup>

The department's policy was to go quickly from a public institution for the developmentally disabled (BTS) to distributing program clients as widely as possible. In June 1993, with BTS in the final stages of closure, Vermont had the nation's lowest average number of developmentally disabled persons per residential setting, 1.7. In the years since, Vermont has retained its position by steadily lowering that average to 1.2.<sup>9</sup>

In 1999 Vermont's use of the Federal HCBS waiver was the third highest in the U.S. At 259.3 per 100,000 population, Vermont far exceeded the national average of 96.1 per 100,000. In 2002, Vermont still exceeded the national average.

Other states followed the same trend. Two years before Brandon closed, New Hampshire became the first state to close its only public institution for the mentally retarded. Vermont was second, followed by six others, including Maine and Rhode Island. In June 1999 the U.S. Supreme Court ruled in the *Olmstead* case that states are required to provide community-based services for people with mental disabilities if treatment professionals determine that it is appropriate, and if the affected individuals do not object to such placement. The Court further concluded that states are responsible for community-based placement if they have the available resources to provide community-based services.<sup>10</sup>

National experts have remarked on Vermont's leadership in this direction. "By many different standards, Vermont is a national trendsetter in community services for persons with developmental disabilities....it has the highest percentage nationwide of residential service recipient living in settings of three or fewer residents<sup>11</sup> and it ranked fourth nationally in the rate of supported employment of people with MR/DD per 1,000 of state population.<sup>12</sup>

### **The Developmental Disabilities Act**

With the passage of the Developmental Disabilities Act in 1996<sup>13</sup> Vermont again distinguished itself by adopting its own unique definition of developmental disability. For years the nationally accepted definition of mental retardation/developmental disability was an IQ of 70

or below. The new act changed the definition to one no longer grounded in relatively objective IQ tests:

“Developmental disability” means a severe, chronic disability of a person that is manifested before the person reaches the age of 18 and results in:

(A) mental retardation, autism or pervasive developmental disorder; and

(B) deficits in adaptive behavior at least two standard deviations below the mean for a normative comparison group.”<sup>14</sup>

The new and expansive Vermont definition made use of measures tied to categories in the American Psychiatric Association’s Diagnostic and Statistical Manuals. For example, classification could be far more subjectively made by “the presence of a pervasive developmental disorder” and “deficits in adaptive behavior”.<sup>15</sup>

The DDA requires the state adopt a State System of Care Plan (adopted every three years, updated annually) describing the nature, extent, allocation and timing of services provided to people with developmental disabilities and their families. The Plan determines eligibility criteria for services and funding, and identifies funding priorities for new and current services and programs. The current Plan in force expires June 30, 2004.

The Plan defines a recipient as:

1. A person with a developmental disability or
2. A family member who supports a person with a developmental disability who receives services supports, vouchers, or case benefits funded by the Division of Developmental Services.

Under the law, payments made to families for respite or other support of a person with a disability are exempt from state income tax and are not counted as income in determining eligibility for state benefits. This policy mirrors a similar exemption in the federal income tax code.

Further, the DDA grandfathered all existing program clients: people with developmental disabilities and families who were receiving services on July 1, 1996, continue to receive services consistent with their needs and the system of care plan.

Eligibility for all supports and services to Medicaid-funded clients is governed by Medicaid income and resource rules. The DDA requires that any services or supports provided to Medicaid recipients must also be made available to Vermonters who are able to pay for their own services. These higher income clients are charged for services at the same or lower rate charged the Medicaid program. This rate “may be discounted to reflect lower administrative or implementation costs, if any, for non-Medicaid recipients.”<sup>16</sup>

Parents of developmentally disabled children under 18 are responsible for costs not covered by Medicaid or not otherwise funded by DDMHS, such as room and board, clothing, non-medical transportation and personal items.

In 1993, when the Brandon Training School shut its doors, a participant remarked “those who have the least deserve more.” From the advocate and provider communities, one fre-

quently is told the mentally retarded, “deserve to live as normally as possible, in the least restrictive environment.”

These simple statements explain Vermont’s state mental health policy, and why the state spends more money on services to those diagnosed as “developmentally disabled” than on any other population served. Perhaps to publicize this priority, the DDA act renamed the department from the Department of Mental Health and Mental Retardation to the Department of Developmental and Mental Health Services (DDMHS).

### **Program Growth**

In the mid-1980s, government-funded developmental disability programs served about 1,200 developmentally disabled Vermonters at an annual cost of around \$13 million. The number of labeled individuals served was 2.3 per thousand of the state’s population.

By the mid-1990s, after the Brandon Training School had closed, government-funded programs served about 1,655 developmentally disabled Vermonters, at a total cost of \$52.5 million. The percentage of labeled individuals served was 2.8 per thousand. By 2002 the programs served had grown to about 2,700, at a cost of \$82.4 million. This population served now represents 4.4 per thousand of the total state population.<sup>17</sup>

In 16 years the number of developmentally disabled individuals served in Vermont expanded by 225 percent, while the cost for these services ballooned by 639 percent. In constant dollar terms, the costs still increased by 368 percent.

### **The Developmental Disability Program Today**

DDMHS Commissioner Susan Besio oversees the developmental services division, which manages three programs providing services to developmentally disabled Vermonters:

#### **1. Flexible Family Supports**

Approximately 675 eligible families with children or adult family members with disabilities living at home receive a little over \$1,000 a year in discretionary funding through this program. The DDMHS directs recipients to use the funds “for services and supports that are in the family’s best interest to maintain stability, and include such things as respite supports and special needs and services not paid for by insurance.”<sup>18</sup> This small program costs around \$700,000 per year.

#### **2. Public Guardianship Services**

Approximately 570 individuals with developmental disabilities, determined by family court to be, “in need of supervision, protection and assistance to live safely within the community and to protect them from violations of their human and civil rights,”<sup>19</sup> receive guardianship services from 20 DDMHS employees. The program cost \$1.36 million in FY 2002.

#### **3. Medicaid Home and Community Based Services (HCBS)**

The bulk of the funding and clients served by the developmental services division are enrolled, like Albert, in the Medicaid Home and Community Based Services program. Approximately 1,850 Vermonters are enrolled in this program, 35 percent living with their families. To receive services, participants must:

- Have mental retardation or pervasive developmental disability that occurred prior to age 18;
- Be eligible for institutional level of care if not for receiving these comprehensive services; and
- Meet the Vermont System of Care Plan funding priorities; have needs related to protection of the individual's health and safety, security, independence, or legally mandated services and community safety.

“Institutional level of care” is defined by the federal government as an Intermediate Care Facility for the Mentally Retarded (ICF-MR) or a nursing home or hospital. Group homes are not considered institutions.<sup>20</sup> The average HCBS waiver cost per person was \$37,400 in DDMHS funds for fiscal year 2002<sup>21</sup>.

Theresa Wood, director of the Developmental Services division that distributes HCBS money, estimates about 100 new clients enter the system a year; and that somewhere between 20 and 34 die in the same time period<sup>22</sup>. According to the DDMHS annual report, “People with developmental disabilities need individualized services that are comprehensive and generally life long.”<sup>23</sup> Only 20 percent of the existing DD caseload is over the age of 50. There is no hard mortality data for this population, though it is generally known that those labeled DD have a shorter life span the general population. “Since the need for developmental services is typically life-long in duration, this means that this program (HCBS) has grown by an average of 100 people each year since its inception.”<sup>24</sup>

The Department further estimates that only 25 percent of eligible Vermonters are served, and that “it is expected that approximately 115 children will be born each year (in Vermont) with developmental disabilities.”<sup>25</sup>

The HCBS waiver essentially buys relationships, room, board and regulation. Services and supports vary widely, from full residential support in a staffed setting to support while living in one's own home. The Department assigns to each client one of 12 possible funding limits from \$7,500 to \$200,000, based on the client's annual Individual Support Agreement (ISA).

In FY 2001 704 Vermonters labeled DD were employed through Supportive Employment, earning an average of \$6.58 an hour, working an average of 13 hours a week. The Supported Employment Program is funded by DDMHS and Vocational Rehabilitation.<sup>26</sup> When last surveyed by the division, 32 percent of the participants in the Supported Employment Program said they would like to work more hours.<sup>27</sup>

At the heart of the Vermont model is a policy that no more than four DD-labeled individuals will live under the same roof. This preferred model is called the Developmental Home Model, and costs about \$23,600 annually per person in DDMHS funds. Vermont has “the most people living in the smallest settings in the country,” said Marliiss Walker, Development Services coordinator for the Vermont Council of Community Mental Health Services. The developmental home is considered “so cost effective, it has been expanded vastly, probably more than we wished we had,” Walker added. “People might prefer their own apartment, but that is a much costlier alternative if they need substantial support.”<sup>28</sup>

The department considers the developmental home model to be cost effective when compared to group homes in Vermont, which run \$52,000 per person, per year. About 15 group homes are in operation, mostly privately owned and leased to a state-funded “Designated Agencies”.

Unlike larger scale residential programs serving different populations (prisons, nursing homes) Vermont's group housing units for the developmentally disabled (group homes) do not experience traditional economies of scale. Rather, the cost of a group home per individual is more than twice the individual cost of the smaller developmental home model. As staffing is the biggest driver of costs, it may be that the Designated Agency-operated group homes pay staff higher wages than staff in other settings. Perhaps employee benefit packages are the cause; in smaller homes staff are independent contractors, not agency employees.

Besides the developmental home and group homes, some HCBW clients live with their families, in supported residences, staffed residences and Intermediate Care Facilities for the Mentally Retarded. FY 2003 only two ICF-MRs remained open in Vermont (Barre and Rutland), housing six residents each at a cost of approximately \$147,500 per person.<sup>29</sup> The Barre ICF-MR is being re-licensed as a Level Three residential care home, a less medical facility. "The clients are the same," Theresa Wood said, noting the licensure change is in part triggered by a desire to avoid the "ridiculous hoops" associated with qualifying an ICF-MR.

While the developmental services division, "prefers individualized residential situations," Wood says, "there are people who prefer to live with peers. We limit the size of any new residential group living situation funded by DS funding to four people."<sup>30</sup>

### Designated Agencies and Real Estate

Thirteen group homes for the developmentally disabled are operated by seven Designated Agencies in Vermont and funded by the Home and Community Based Waiver.

The DDMHS does not keep records on who owns these properties. One of the agencies, Northeast Kingdom Human Services, reports that it owns a group home for four in Lyndonville, leases another housing four individuals from a nonprofit trust in Waterford, and is exploring purchase of a property for six it currently leases in Newport.

In Bennington, United Counseling Services owns two group homes. Union House is paid \$153.89 per person per day for six residents. Autumn House receives \$328.32 per person per day for four residents, nearly \$480,000 annually.

The other five agencies operate a total of eight group homes, but none of them responded to requests for information. According to records obtained from the Vermont Municipal Bond Bank, Howard (Burlington) Community Health Services and Washington County Mental Health own a total of 47 properties between them: offices, group homes and apartments, day programs, outpatient clinics, storage space, parking areas, land and a cemetery.

When our case study, Albert, lived in a privately-owned group home in Waterbury for more than five years in the late eighties and early nineties, he paid for his care with his monthly SSI check, totaling around \$7,000 annually (he was allowed to keep \$45 a month for personal needs.) Today that same group home continues to receive SSI payments for housing and feeding developmentally disabled clients, at roughly \$9,000 annually per client.

When a state-funded agency acquires housing units, qualifies persons to live in them, and bills the state for their support, close scrutiny of the arrangement is certainly warranted, to make sure that the agency is not placing individuals in the home simply to create additional income.

The budget for the developmentally disabled is now 48 percent of the total DDMHS budget, and the Department anticipates that, “new funding in excess of \$1 million (general fund) will be required each year to serve those most in need.”<sup>31</sup>

The 1996 DDA’s expanded definition of those eligible for services caused a remarkable expansion of programs, population served and associated costs. In fiscal year 1985 Vermont’s developmentally disabled population was 2.3 per 1,000 population. In 2002 it had risen to nearly 4 per 1,000.<sup>32</sup> After Brandon’s closure, it seems likely that many families who cared for DD family members at home, rather than sending them away to Brandon, jumped at the opportunity to move their family members into nearby state-financed community settings.

A person qualifying as developmentally disabled by Vermont standards who moves into Vermont is entitled to take advantage of the Vermont DDMHS program. Some have speculated that clients are moving from other states to Vermont, attracted by Vermont’s generous benefits – especially our preference for small and dispersed residential settings – but there is no data to confirm the speculation.

Enrollment has also ballooned tenfold within the Home and Community Based Services waiver program, from 185 in FY 1986 to 1850 in FY 2001. DDMHS has two explanations for this tremendous rate of growth: “Obviously the number of recipients was greatly affected by the closure of BTS. All former BTS residents went to the waiver either directly or indirectly. The greatest expansion of waiver services aside from the closure of Brandon has been to children, particularly children with Pervasive Developmental Disorders (PDD).”<sup>33</sup> Commissioner Besio notes that the PDD population has exploded nationally, but she has no explanation for this fact.<sup>34</sup>

In fact, since FY1996, when eligibility for services was extended to those with a diagnosis of PDD, the population of children served under the HCBS waiver with this diagnosis has grown from 5 to 182. Another 60 children with this diagnosis are served through the flexible family funding program.

The \$82.7 million DDMHS budget for developmentally disabled Vermonters does not include other public dollars spent on these individuals. Additional public dollars reach individuals via:

- Supplementary Social Insurance (SSI) payments, estimated to average around \$650-\$750 per month, per person. The 2,500 clients draw down an estimated \$21 million a year, at \$700 a month. This increases the annual public support from \$27,000 to \$35,400 per client and for HCBS clients from \$36,600 to \$45,000 per client.
- Medicaid coverage for billable medical services: 2,148 clients are enrolled in the Medicaid fee for service plan. In fiscal year 2000 the cost of the service was reported as “\$7,930 per capita annual expenditure for all other Medicaid services to waiver recipients, including home health, personal care, adult day health and expanded Early Periodic Screening, Diagnosis and Treatment (EPSDT) services expenditures (prescription drugs are included.)”<sup>35</sup> Adding this expenditure to the total public dollar support of clients brings the average annual cost per person to between \$43,330 and \$52,930.
- Department of Prevention, Assistance, Transition, and Health Access (PATH), Department of Health, Department of Aging and Disabilities (DAD), child support, Social Re-

habilitation Services (SRS), and Alcohol and Drug Abuse Program (ADAP) programs. (No figures available.)

- Vocational rehabilitation funds for supported employment: “Around \$1.2 million in FY 2003.”<sup>36</sup>
- Section 8 subsidized housing certificates. (No figures available.)
- Fuel assistance. (No figures available.)
- Assistive Community Care Services (No figures available.)

There are also special education costs. In FY00, special education costs in Vermont averaged \$10,136 per special education student. For the 500 developmentally disabled youth, this expenditure increases the public support paid by that amount.

Between fiscal years 1995 and 2000, the cost of educating a special education student increased 25 percent, as did the “special education K-12 count.”<sup>37</sup> Within preschool special education funding, costs increased from \$4.2 million in FY90 to \$8.7 million in FY00.<sup>38</sup>

“We can tell you how many kids are on the waiver. We cannot tell you, though, what their level of involvement in education is, except to suffice it to say that they all have educational services. If they are eligible for our waiver, it would seem logical to me that they also are eligible for Individualized Education Plan (IEP) services, since we serve folks with significant disabilities,” said Theresa Wood.<sup>39</sup>

“One of the changes to the special education formula made by Act 60 was the increase in the threshold for extraordinary reimbursement, from 3.5 times the foundation per pupil cost (\$16,258 in FY98) to \$50,000.”<sup>40</sup> In FY 2000 statewide, there were 62 students whose special education costs exceeded \$50,000, for a total cost of \$5,083,302. In FY 2000, two of the highest cost special education students received services for \$188,677 and \$193,037.

Since December 2001 the expansion of DDMHS services to new PDD diagnosed children has been suspended, due to a budget rescission. According to Commissioner Besio, the December 1, 2001 funding priority amendments to the System of Care Plan marked the first time the Department reduced services due to a shortage of funds. (As of March 2003, no lawsuits had been filed challenging the Department’s new client enrollment freeze.)

The Dean Administration’s December 2001 budget cuts suspended 12 of the Plan’s 31 funding priorities, and limited one. Among the suspended priorities is one calling for an increase in services that relate directly to an individual’s quality of life, and another calling for assisting adults to become independent or move to minimal services within two years.

Within the state’s current Plan of Care, when reallocating funds, designated agencies are directed to, “consider reducing or eliminating services that are not needed, wanted or valued by people receiving supports.”<sup>41</sup>

**To summarize: Vermont’s policy is to adopt a very flexible and subjective eligibility test to qualify persons as developmentally disabled. Once determined to be eligible, clients are installed and closely supervised in dispersed community residential settings of no more than four clients (average 1.2). The Department’s policy opposes larger group**

living arrangements on the grounds that they tend to isolate clients with their own kind instead of integrating them into “the community”. Mental health workers funded with public dollars surround clients with services, activities, regulations and relationships. Clients often seek greater independence in living arrangements and activities. The Department and its designated agencies and contractors are however not funded to encourage or promote greater independence, for that would reduce their clients’ reliance on compensated mental health workers. This system is steadily growing in clients and in costs.

### III. What Isn’t Working

In the name of protecting a vulnerable population, Vermont’s developmentally disabled system denies them access to the community and limits their choices and opportunities. Developmentally disabled Vermonters aren’t so much protected from risks as they are prevented from experiencing authentic living.

Out of his experience as executive director of the Pennsylvania Developmental Disabilities Planning Council, David B. Schwartz wrote a landmark work, *Crossing the River*.<sup>42</sup> In it he calls for change in how society supports the lives of those labeled developmentally disabled. Schwartz questions the value of government regulations and licensing, arguing that all human beings, regardless of label, need the same kinds of protections, namely, real relationships with other people.

“I am fortunate to have a family and friends. It is they whom I count on, and they count upon me. This is how the world works, and how it has always worked. In the case of vulnerable persons, however, we have forgotten this idea, driven by our vision of formal advocacy. Somehow we have gained the belief that what is a safeguard for us is not a safeguard for people with disabilities. In doing so we have created two classes of people: citizens and clients. Our error in the developmental disabilities field is not in thinking that safe-guards based upon personal and community relationships offer less than total security, but in believing that there is something better.”<sup>43</sup>

Helen Zipperlen and John O’Brien write of the psychological damage unavoidably done by ever-present regulation, “not the requirements, but the feeling of being ‘owned’ by an authority who judges how a relationship measures up to alien standards.”<sup>44</sup>

One of the main reasons some privately operated communities serving both the disabled and nondisabled have resisted involvement with government is a strong belief that regulations are expensive tools that often do more harm than good.

Coleman Lyles, president of Camphill California, one such community, says true safe-guards for vulnerable people, “arise out of partnerships, not regulation. Regulations have never safeguarded people. Abuse and rights violations still occur”. Affiliated with Camphill for 25 years, Lyles says, “parents live in fear and dread of providers, providers live in fear and dread of regulators, and regulators live in fear and dread of families. We need to create circles of trust and support, replacing our cycles of fear and dread.”<sup>45</sup>

Helen Zipperlen echoes both Schwartz and Lyles: “Regulations are reactive. We don’t think licensing has kept anyone safer; something else keeps people safe.” Zipperlen stresses the importance of good neighbors, who, “care about, not care for, each other.”

Schwartz writes, “Only by admitting that we can’t create a totally safe-guarded environment via regulation, can we create a publicly funded support system that works. What would happen if one invited a real cross-section of people from healthy community enterprises outside the formal human services system to identify together the factors they believed they shared? Perhaps one might begin to develop a fairly refined list of factors to help one see what is, by its very nature, hard to see and under the surface, unlike file notes or medication schedules...”<sup>46</sup>

Developmentally disabled individuals are denied natural opportunities for relationships and access to community because they are surrounded by professionals. Schwartz argues for a much less regulated, natural way of simply supporting people in their lives, instead of weighting them down by bureaucratic care plans and regulations. “It is important, then, that in rediscovering the ancient value of community we have our eyes open. Community is not a programmatic tool to be harnessed, a useful environment to be used. It will not cure affliction and disability, either.”

As Jack Yates has concluded, “The problem is not that mental retardation cannot be cured; the problem is that life cannot be cured...We need to remember that community, like the other things we have been tempted to romanticize, cannot be judged by whether it fixes people or situation; like deinstitutionalization and like associations and like friends, and maybe like life, community is worthwhile for other reasons”<sup>47</sup>

Community-building advocate John McKnight of Northwestern University warns that, “As the power of profession and service systems ascends, the legitimacy, authority and capacity of citizens and community descend. The citizen retreats. The client advances. The power of community action weakens. The authority of the service system strengthens. And as the human service tools prevail, the tools of citizenship, association and community rust.”<sup>48</sup>

A Vermont advocate tells the story of being called repeatedly by a person troubled by seeing a man with Down’s Syndrome walking along a city street every morning. “Shouldn’t something be done about him?” the person asked.

“She said she couldn’t talk directly to him, because she didn’t have any training, and she knew it was my job,” the advocate relates, noting that the system has become overbearing in not only the lives of those labeled disabled, but towards other citizens as well. Had the person entered into a normal conversation with the man walking by, she would have learned that he was on his way to work.

Project Friendship is a small, nonprofit citizen-based resource clearinghouse in Prince George, B.C. Its program matches people with disabilities with community organizations. It supports community by identifying the assets of the disabled and meeting their interests. Once an individual identifies his or her interests, such as wanting to go to hockey games or be in a theatrical production, the two-person paid staff at Project Friendship looks to existing community groups for a match. Sandra Nahornoff, the coordinator, tells of members of a biker club who include a disabled man in their party when they go to hockey games.<sup>49</sup>

Canadian scholar and advocate Judith Snow describes this radical yet common sense approach as identifying an individual’s interests and using them to guide how one spends the day. She tells the story of a young man whose interaction with the world was limited to standing and smiling at policemen. After a creative supporter went to several police stations, they found a one that welcomed the young man to come and stand in the corner and smile at the police-

men. The officers in that barracks developed a deep and abiding relationship with this young man, and came to care about his well being...as unpaid friends.

Snow cites the example of the young man who only liked to ride a tricycle. As he got older, the tricycle got larger, until he was a man, peddling a big tricycle around his city. A clever friend in advertising suggested that he sell advertising space on a small trailer. The young man earned enough money to live on through his advertising service.

Albert, introduced at the beginning of this report, has a fascination with public safety and military officers. He would love to go regularly to an Armory, VFW or American Legion hall. He would love to wear a uniform and have a badge.

When living in another town, through a community member, he was given some uniforms. An open-minded store owner entered into an informal agreement with Albert that he would “oversee” her store’s security. Every day, Albert would drop by the store, in his uniform, and check on security. The girls at the soda fountain got a kick out of his visits, and he felt terrific. These kinds of arrangements only happen when an individual is genuinely involved in the community and the community is involved in his life. Mental health system professionals rarely if ever create such relationships.

David B. Schwartz observes, “There is increasing evidence that caring has deteriorated as formalization has progressed. ...It means that one must seriously recognize the role of professionalism as an unconscious belief system in modern society. Such professionalism, we can see, always tends to displace ordinary community practices. The task of people trying to do this work, then, is not only to re-discover community, but to find ways to counter the tendency to drift toward professionalization.”

Vermont’s closed system of care is essentially one of pre-approved and pre-funded services, operated through Designated Agencies. The system minimizes consumer choice and forces segregation and isolation upon its clients.

Despite the flexibility provided by the range of services available under HCBS and Medicaid optional services, many advocates for people with disabilities remain frustrated with the kinds of services available, their quality, and their responsiveness to clients’ needs. Advocates often complain that provider agencies “dictate” the service plan for clients, and do not do enough to assist clients to integrate fully in community life. They want more influence over the services they can receive, who delivers them, and how and when they are delivered. This is known as the “self determination movement.” Self-determination and choice are rapidly becoming dominant themes for people with disabilities and their families.

Most clients of the current system view Vermont’s rules and methods for managing one’s own service provider as complicated and unattractive. The Department-funded Designated Agencies are required to inform clients that they can choose to manage their own resources at the time their program eligibility is determined. “Not many natural families choose this option because it is not a customer-friendly model”, reports Betty Milizia, government affairs director for the Champlain Area ARC (Advocacy, Resources and Community, formerly the Association for Retarded Citizens).

“When people self manage, they can get more bang for the buck, up to twice the hours of service the agency can,” Milizia observed. She and two other women have been training individuals to become independent support or service brokers, who could contract with develop-

mentally disabled clients who opt for self-management. Such brokers replace the Designated Agency case manager, and work outside of the mental health bureaucracy.

This self-management approach calls for converting government benefits into the equivalent of cash, scrip (like food stamps), or debit cards with which beneficiaries can purchase services and equipment, hire their own attendants, acquire their own transportation and so on, without a requirement of pre-approved, prepaid service plans or providers.

This is not a new approach to service delivery. This is the hallmark of the most popular social program in the nation, Social Security. Recipients of Social Security retirement and SSI checks are not required to have a government-approved plan spelling out how or where their money will be spent. Implementing such an approach will require administrative waivers from current federal law, or possibly an amendment of the law.

Current Vermont policy serves clients and taxpayers badly. It is time to embark in a new direction.

#### **IV. Helping Albert: Recommendations for Change**

State policy should shift from a service delivery and client control model, based on government-run human service agencies labeling and serving human deficits, to a model that identifies the assets of developmentally disabled Vermonters and expands their opportunities to develop natural community relationships and make worthwhile contributions to their community.

DDMHS should abandon segregating policies that support systems in favor of inclusionary policies that support people. State policy should be based on two governing principles, implemented by seven action steps.

**First Principle: Government supported programs meant to help persons with disabilities must be grounded in consumer choice, to assure the development of authentic community relationships for the people served.**

Choice means that program participants should have the maximum opportunity to act in matters affecting their own lives without an expert's approval or an authorized plan. They should have the authority to choose among and define their own relationships with service providers. They should have maximum discretion to allocate program resources, instead of merely receiving what service providers think is good for them. They should have the opportunity to make informed choices about living on their own or becoming a member of a residential community program.

Further, when persons in the program are not able to make informed decisions without assistance, there should be community-based (not government based) initiatives to assist them in making effective choices.

Consumer choice does not by itself guarantee full access to and inclusion into community life for those with or without a disability, but it is a necessary condition for such a community to be possible.

**Action Step One: Following Canada's example, Vermont should begin moving from funding programs and agencies to funding individuals and their choices.**

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Ontario's Ministry of Children and Family Services directs three programs that provide individualized support to families and individuals, ranging in annual payments from \$12,000 to more than \$108,000. Working with a services broker, disabled individuals identify ways to meet their needs, from housing, to transportation, to attendant care.

In British Columbia, Gordon Hogg, the minister of Children and Family Development, is guiding a total transformation of that province's developmentally disabled system, on the basis of Individualized Funding. As part of this system redesign Hogg is calling for enabling individuals and their personal networks to decide on the community living options that best meet their needs, reduction of bureaucratic regulation and moving from a needs based to asset based system.<sup>50</sup> DDMHS and the legislature should study these initiatives as well as the enabling legislation.

**Action Step Two: Inclusion can be specifically encouraged by replacing trained professionals with community members and family members, to accompany developmentally disabled individuals to a variety of community settings.** Beyond going to restaurants and stores together, such partnerships could be utilized for enjoying a wide range of social, spiritual and employment opportunities.

"Protection" is the core reason given by government for why mental health programs are organized as they are, and the lives of those labeled developmentally disabled are so tightly controlled. "Protection" becomes an excuse for every limiting policy. The most overwhelming disabilities for labeled Vermonters are not their developmental disabilities, but being isolated from their communities, living in the mental health system's parallel universe.

After so many years of being walled off, the developmentally disabled need assistance in creating natural partnerships and building bridges. Unless those responsible for government programs consciously decide to facilitate such relationships, they won't happen. Organizations such as United Way and other community foundations should be called upon to jumpstart the first generation of relationships, on the model of Canada's Project Friendship, a low-cost, powerful resource for building disabled people into local communities.

Vermont should also make maximum use of volunteers in the state guardianship program. By adopting the Texas model, Vermont could reduce the cost of providing guardians to this vulnerable population by nearly 40 percent.

Texas utilizes a Guardianship Alliance to provide legally appointed advocates and decision makers for those lacking the mental capacity to make a decision, whether due to age, illness or disability. In Travis, Hays and Williamson Counties, Family Eldercare recruits, screens, trains and supports committed volunteer advocates to act as guardians. Professional care managers support the volunteers and perform the function of guardian agent or representative payee when there is no volunteer available for a client. Family Eldercare staff registers as guardians through the National Guardianship Foundation.

Fees are based on client income. All referrals are screened to determine if a least restrictive alternative to guardianship is available. These include: representative payees, case/care management, trusts, health care surrogacy, community supports, durable power of attorney and advanced directives.

Joyce Haight, Family Eldercare's director of program reports, says the state of Texas is happy with the volunteer model. Volunteer advocates work one on one with clients. Volunteer

attorneys assist with the legal process. Paid care managers manage a caseload of clients who are matched with volunteers. Haight calculates Family Eldercare's unit rate per client per year at \$1,400.<sup>51</sup>

If Vermont were to adopt the Texas volunteer model for guardianship, the cost of serving the 576 clients with the state's system is estimated to drop from \$1,360,000<sup>52</sup> to \$806,400.

**Action Step Three: The new policy should seek creative ways for people with a disability to earn the money that is now appropriated for them because they have a disability, and not because they do something productive.** "The opportunity to earn one's own means of support is central to most people sense of well-being, but this fact has rarely been considered in the design of disability-related programs."<sup>53</sup>

Make-work employment does not constitute productive employment. The current trend within Designated Agencies is to create jobs that require continual prompting. An agency employee or contractor stands with the developmentally disabled individual at the job site and repeatedly issues reminders, such as "put the coat hanger in the sleeve" or "dust the top of the can lid". This is more likely a full employment plan for agency staff, than an effort to promote independence and self-esteem. Both parties find these jobs tedious and limiting.

Working to advance the labeled individuals' real interests, creative thinkers must develop employment opportunities that aren't limited by past habits or by what seems easy. Tasks that require permanent one-on-one support are neither beneficial to the person served or fiscally responsible.

### Consumer-directed Choices

A recent report from the National Council on Aging, funded by the Robert Wood Johnson Foundation, pointedly refutes the "myths" that consumer-directed choices by the elderly and disabled are unworkable, unwanted, and of lower quality than agency-provided services. "The consumer directed method outperformed the professional agency method within three broadly defined areas: satisfaction with services, empowerment, and quality of life. No significant differences were found in outcomes between the two methods in client safety and unmet needs...Consumer-directed programs appeal to state governments for their potential for cost savings, expanding the pool of caregivers, and their ability to empower consumers to be proactive recipients of services."<sup>54</sup>

This policy parallels two other innovations growing in popularity. The Vermont legislature authorized the creation of Individual Development Accounts in 2002. These are accounts created for persons in the Temporary Assistance for needy Families program, funded by part of the welfare payment and by a government grant. The recipient may draw in the account to build assets, such as a down payment on a home, job tools, or startup costs for a small business.

The Medicaid Medical Savings Account (MSA) is a similar device for encouraging low income families to control their health care utilization. The MSA is accompanied by a major medical policy with a high deductible. The MSA is funded annually from Medicaid funds. The family uses the account to pay for needed health care (including dentures, eye-glasses, and other expenses not covered by the major medical policy) up to some fraction of the deductible. Any end of year balance can be carried forward for the following year's health-related costs. In his FY04 budget message Gov. Jim Douglas gave his support to both concepts.

**Action Step Four: The state should also give more money to families who are willing and able to take care of their own, through the Flexible Family Support program.** This program presently offers families a maximum of \$1,122 annually. Yet tens of thousands of dollars are given to non-family members to provide care.

The new policy should pay more attention to the interests and assets of the developmentally disabled individuals in the programs. Under current policy today's programs "focus on what is 'different' about them, and obscure what about them is 'the same' as the rest of us: the same needs for dignity, for pleasure, for friendship, for a sense of the future and a place in the community."<sup>55</sup>

McKnight writes that the disabled "don't always 'need' human services. More often they may 'need' justice, income and community...Policies that support citizen capacity, income and community should have preference over other forms of intervention that are necessarily second rate and second best responses."<sup>56</sup>

**Second Principle: Government-supported programs meant to help persons with disabilities must identify the negative effects of their interventions and prove the benefits are greater, just as the Food and Drug Administration evaluates new drugs.**

As more and more programs and providers become involved in a disabled individual's life, his system can react in the same way as that of a patient who is taking 10 or 20 different medications. Prescribed alone, a drug may be of value, but when taken in combination with other prescriptions the results may be harmful and even catastrophic. Over-programming is likely to make individuals to become more dependent, less confident, more frustrated, and less satisfied with their lives.

A telling example of the harm of over-programming is from the highly controlled institutional environment, where disabled youngsters routinely try to injure themselves. Full of frustration and rage over their confinement, the institutionalized resident knows he will get in trouble if he hurts others, so he turns his hand on himself instead. Records are full of cases where children plucked out their own eyes and performed other horrifying acts of self-abuse while living in institutions.

**Action Step Five: Designated Agencies should be required to present a five-year plan to the DDMHS that outlines how they will shift clients from the professional system model to a true community inclusion model, thus reducing the scope and involvement of government programs in the lives of those labeled developmentally disabled.** Designated Agencies must systematically downsize themselves, becoming information clearinghouses and identifying independent service brokers and other community resources to provide resources.

**Action Step Six: DDMHS should cap per client spending and eliminate nonessential services.** Simply because the federal government considers a service Medicaid eligible, such as paying a mental health aide to take a client out to eat breakfast, is not a good enough reason for the state to include it as part of its plan.

The Developmental Services Division should aggressively and immediately eliminate services that are "not needed, wanted or valued by people receiving supports." This language is taken directly from the DDMHS's State System of Care Plan for developmental services.

**Action Step Seven: DDMHS should conduct a thorough examination and analysis of the residential options funded through the Medicaid Home and Community Based Services waiver.**

The DDMHS's decision to support no residential models housing more than three labeled individuals eliminates authentic choice. The Department should allow a range of standard community living settings.

HCBS participants should be able to use their independent funding in a private home, live independently with support with less than two other people, with no labeled people, or in larger residences of four or more labeled and nonlabeled people.

For many years successful housing programs for those labeled developmentally disabled have been in operation throughout the world, bringing people together in loving, caring group settings that maximize consumer choice and voice, and authentic community life.

Two residential models, Camphill and L'Arche, are grounded in an inclusive, spiritual philosophy, rather than the typical client services philosophy. Operating with little or no regulatory oversight, these privately operated homes are unique in that they house disabled and nondisabled individuals under the same roof.

### Camphill Communities

Camphill communities are guided by the social, cultural and economic principles, inspired by Rudolf Steiner, "a worldview which embraces a spiritual understanding of the human being and the universe... Camphill encourages each person to master his or her own life in the context of family, community and society, emphasizing both independence and interdependence....they aspire to discover, support and enhance the potential and meaningful contribution of each person."<sup>57</sup>

Camphill is a nonprofit, Christian-based, non-denominational cooperative community. More than 90 of these intentional communities operate in 19 countries. Ten are in North America. These 10 communities are located on 2,500 acres of land, where residents practice organic and biodynamic farming. Over 800 individuals (developmentally disabled and not) live, work and socialize together in Camphill communities, where life is focused on the abilities of each person.

Some Camphill communities accept state and federal funds, while others are "off the grid, taking the private route," said Coleman Lyles, president of Camphill California.<sup>58</sup> Pennsylvania's Camphill communities raise private funds, while California's communities are funded and licensed by the state.

Camphill Kimberton Hills, in Kimberton, PA, opened in 1972. The 400-acre farm community is home to more than 100 people (about half are labeled developmentally disabled) and has never been licensed by government and accepts no government money.

At Camphill Village in Copake, NY, 230 villagers (105 developmentally disabled) work in the candle shop, bakery, weavery, bookbinder, garden and wood shop. The total cost of room, board, education and work training at Camphill-Triform, also in New York, is \$28,344.

The Camphill and L'Arche models (described in greater detail in boxes) are built upon the idea of creating loving, caring, working and integrated communities for the developmentally disabled and others who share a common philosophy and principles. Each seeks to enhance their residents' self-esteem by sharing responsibility for community maintenance and productive work. Each avoids involvement with the government, recognizing that that is likely to lead to all the ills associated with bureaucratic rule-based programs that turn the developmentally disabled into clients instead of contributing participants in a community.

The L'Arche model (The Ark), "seeks to create a home and provide meaningful work for all community members in an attempt to create a world where everyone, regardless of ability or disability, is recognized as being of equal value."

Describing both the Camphill and L'Arche models, Zipperlen and O'Brien write "In these places the emphasis is less on education and therapies, and more on living and working together...(They) first explored mutuality, the need of all people to give, to do work for other people, to be appreciated as a person rather than a problem."

### L'Arche Homes

Founded in France in 1964, the L'Arche (The Ark) has grown to 120 communities in 30 countries, with 14 in the United States. Also an ecumenical organization, the L'Arche is based on living the Beatitudes, with, "covenant relationships between people of differing intellectual capacity...We seek to create home and provide meaningful work for all community members in an attempt to create a world where everyone, regardless of ability or disability, is recognized as being of equal value."<sup>59</sup>

The four fundamental aspects of L'Arche's identity in the USA are

- The recognition of the unique value of persons with a developmental disability to reveal that human suffering and joy can lead to growth, healing and unity. When their gift is received, individual, social and ecclesial change occurs;
- Life sharing where persons with a mental disability and those who assist them live, work and pray together, creating a home;
- Relationships of mutuality in which people give and receive love;
- Christian community that welcomes people from all faiths based on the Gospel and dependent upon the Spirit of God where faithful relationships, forgiveness and celebration reveal God's personal presence and love.

L'Arche's mission is threefold: To create homes where faithful relationships based on forgiveness and celebration are nurtured; to reveal the unique value and vocation of each person; and to change society by choosing to live relationships in community as a sign of hope and love.

While L'Arche originated in privately funded homes, all L'Arche communities in the U.S. now receive third party government support. Community members with disabilities are identified as core members. The nondisabled residents are called assistants, "those who choose to share life with them, live, work, play and pray creating a home together."

L'Arche homes are single-family dwellings located in residential neighborhoods, indistinguishable from the rest of the houses, plus larger compounds in rural settings.

While these models of stand-alone communities do not weave the developmentally disabled into the social fabric of the larger community, they may well be the preferred option for some individuals who lack any ties to the community into which they were arbitrarily discharged by the mental health system.

As violence and crime escalates in municipalities, many non-disabled Americans are choosing to live in safer, smaller even gated communities. Many families choosing to home school their children reflect a similar preference, believing that government schools with feeble academic standards, lax discipline, and abandonment of moral and spiritual values do not offer enough advantages to their children.

For those disabled individuals whose circumstances require services that cost more than the state average of \$37,400 annually, and who lack significant ties to the community, it is prudent to look at the economies of scale provided by such housing options.

In 2000 Hannah Schwartz and her husband Jonathan Gilbert established Heartbeat Life-sharing Community, an organic farm operation in Hardwick. Heartbeat is founded on the principles of Rudolf Steiner and Dr. K. Koenig, the founder of Camphill communities. Having grown up in a Pennsylvania Camphill community, Schwartz has experienced the communal, unregulated setting of which she speaks.

Schwartz and Gilbert are developing a self-sufficient biodynamic farming operation run by residents who are both disabled and not. The couple has two developmentally disabled individuals living with their five-member family at Heartbeat. To welcome another developmentally disabled resident, under Vermont law, Heartbeat must become licensed as a residential care home.

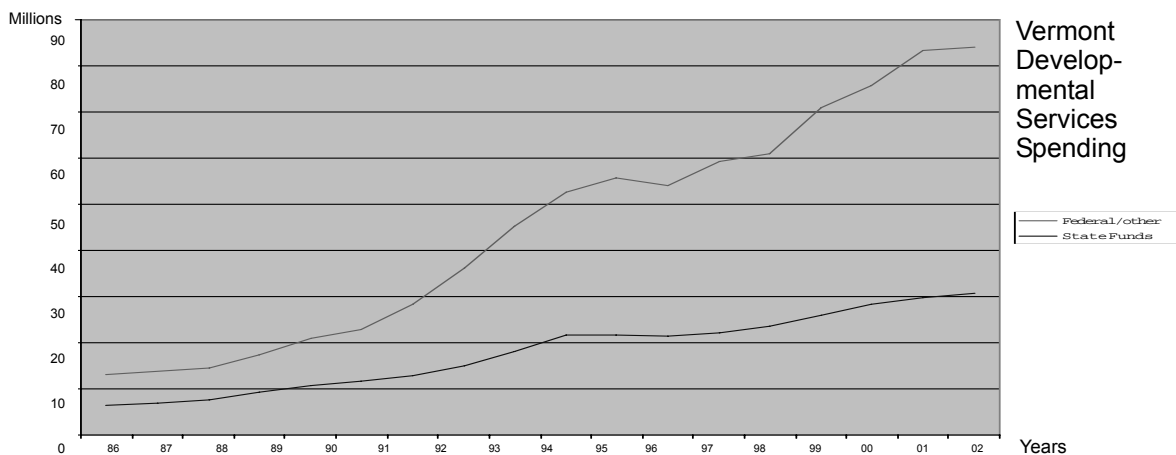
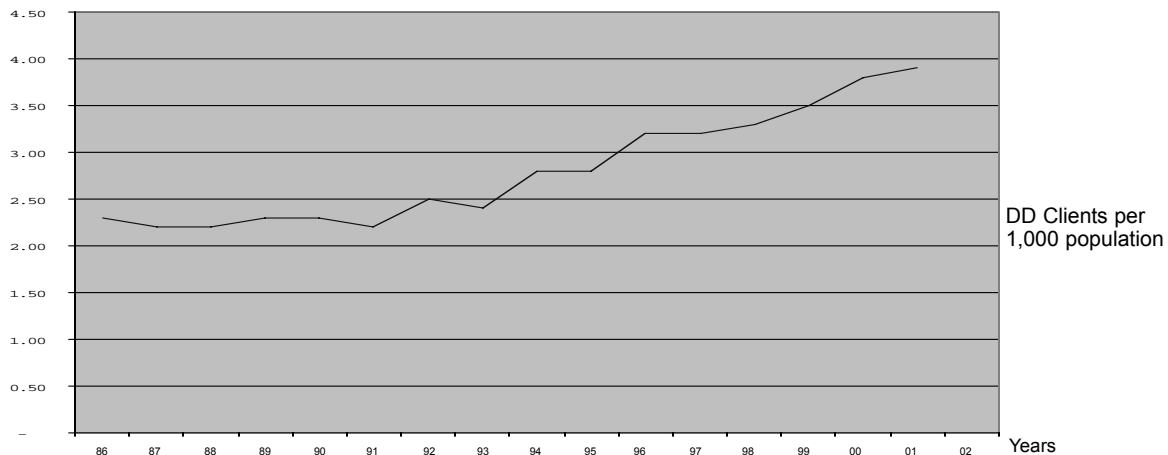
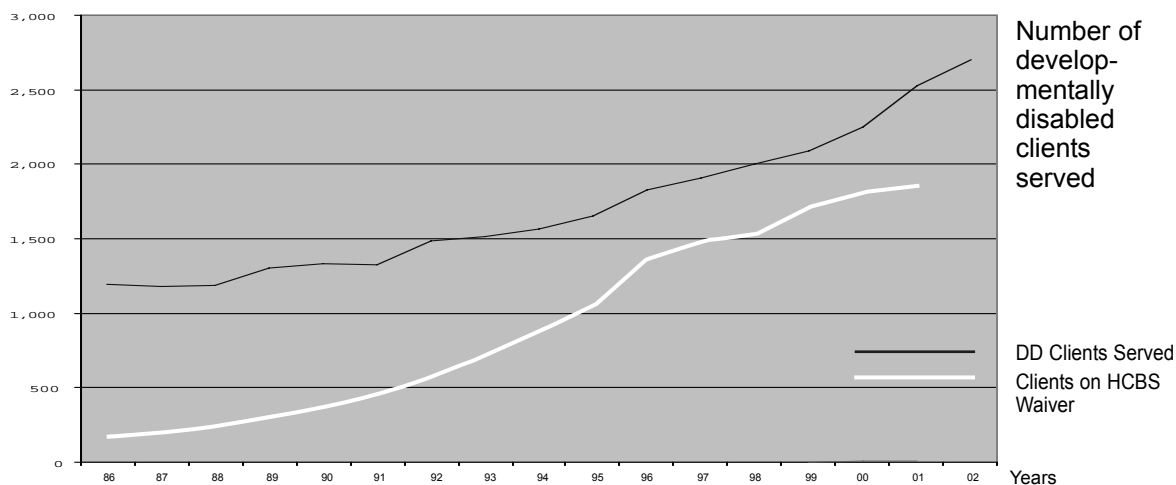
“We are a nonprofit corporation, and we have three families who are ready to send one of their loved ones here, but we have to become licensed as a therapeutic care residence, and we don’t want to,” Schwartz says.<sup>60</sup>

Describing their approach as one that offers a home to some and vacation and respite to others, Schwartz feels strongly that theirs is “not a facility. We’re life. I’m not getting paid. This is our family. There is no sense holding us back.” Schwartz envisions building five homes on the large farm, to provide private residences for those who choose to live in the Heartbeat community, focusing “Not on a person’s disabilities but rather on his or her capacities.”<sup>61</sup>

**Conclusion: The state of Vermont spends an enormous amount of taxpayer dollars – state and federal – supporting its small developmentally disabled population. The present expensive bureaucratic system should be dramatically changed, offering a better deal to developmentally disabled Vermonters as well as taxpayers.**

**This report sets forth the principles upon which a thorough reform, grounded in individual choice, should be based. It offers seven action steps toward creating highly successful – and less costly – private options to the present bureaucratic state system, with its hundreds of state employees, contractors, and Designated Agencies.**

**V. Developmental disabilities: expenditures and clients.**



The data sheet on which these graphs are based, including sources for all numbers cited, can be found on the Ethan Allen Institute's web site, [www.ethanallen.org/publications](http://www.ethanallen.org/publications). The sources are publications and other information provided by the Vermont Department of Developmental and Mental Health Services, Waterbury VT 05671, 802-241-2610.

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