

ANNUAL REPORT

2006

DEVELOPMENTAL DISABILITY SERVICES

PLEASE NOTE

**This is a text-only version of the
Developmental Disability Services Annual Report.
For a complete copy with photographs, please call
802.241.2648**

**DIVISION OF DISABILITY AND AGING SERVICES
DEPARTMENT OF DISABILITIES, AGING AND INDEPENDENT LIVING
AGENCY OF HUMAN SERVICES
STATE OF VERMONT**

JANUARY 2006

Cover photo:

Artwork by Larry Bissonette
of Milton, VT

See related story on page 70.

Annual Report 2006

Developmental Disability Services

**Division of Disability and Aging Services
Department of Disabilities, Aging and Independent Living
Agency of Human Services
State of Vermont**

**Prepared by:
June E. Bascom
Division of Disability and Aging Services
103 South Main Street
Waterbury, VT 05671-1601
(802) 241-2648
<http://www.dail.state.vt.us>**

January 2006

**This issue of the Annual Report
is dedicated to**

GREEN MOUNTAIN SELF-ADVOCATES

**in celebration of over ten years
supporting people to advocate for themselves.**

TABLE OF CONTENTS

INTRODUCTION.....	1
Silence Isn't Always Golden	1
DAIL Mission Statement	2
DAIL Core Principles	2
THE DEVELOPMENTAL DISABILITIES SERVICE SYSTEM.....	3
Principles of Developmental Services	3
Division of Disability and Aging Services	5
Developmental Services Providers	5
<i>Designated Agencies</i>	5
<i>Specialized Service Agencies</i>	5
<i>Contracted Providers</i>	6
<i>Management Options for Services</i>	6
Highlights from FY 2005.....	8
Pressures on Community Services.....	11
New Caseload Funding – FY 2005	13
Financial Summary	14
Quality Assurance and Quality Improvement.....	17
SERVICES & FUNDING.....	21
Funding Sources.....	21
Types of Services Provided	22
Total Served.....	23
SERVICES & SUPPORTS	25
Service Planning and Coordination	25
Home Supports.....	26
Employment Services	35
Community Supports	39
Family Supports	42
Children's Services	45
Medicaid Entitlement Services	47
Clinical & Crisis Services.....	50
Nursing Home Reform.....	53
Self-Advocacy.....	55
Office of Public Guardian.....	58
Offenders with Developmental Disabilities.....	62
Real Choices Grant	64
Communication.....	67
Consumer Survey.....	70
National Comparisons.....	76

ATTACHMENTS

Acronyms	Attachment A
Division of Disability and Aging Services Staff.....	Attachment B
Vermont Developmental Services Providers	Attachment C
Members of the State Program Standing Committee for Developmental Services.....	Attachment D
Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities.....	Attachment E
Organizational Chart: Agency of Human Services.....	Attachment F
System of Care Plan Funding Priorities.....	Attachment G
Division of Disability and Aging Services FY 2006 Fiscal Resources	Attachment H
Green Mountain Self-Advocates: Local Chapters and Map.....	Attachment I

Notes:

All data represented in this report are for FY 2005 unless otherwise stated.

See **Attachment A** for a list of *Acronyms*

Highlights are sections in the report used to showcase achievements.

Areas of Focus are sections in the report used to identify specific issues or areas that need attention or improvement.

INDEX OF TABLES AND FIGURES

THE DIVISION OF DISABILITY AND AGING SERVICES

Vermont Developmental Services Providers (map)	7
Reasons for Receiving New Caseload Resources – FY 2005.....	13
Developmental Services New Caseload Numbers Over Time: 2000 – 2005	13
Average Waiver Cost per Person / Average Cost per Person – All Services:	
FY '92 – FY '05.....	14
Local Agency Total Administration Costs: FY '93 – FY '05	15
Per Person Service Rates of Individuals Served: FY 2005.....	15
Comparative Annual Cost of Services: Institution (1994) vs. Community (2005)	16
Percentage of Funding & Percentage for People by DS Funding Type: FY 2005	16
Quality Service Reviews – 2005.....	17

SERVICES & FUNDING

Funding Sources – Numbers Served: FY 2005.....	21
Home and Community-Based Waiver Services	21
Flexible Family Funding.....	21
Total Number of People Supported by Service Provider: June 30, 2005	23
Total Number of People Served: FY 1992 – FY 2005	23
Age Breakout of People with Developmental Disabilities Receiving Services:	
FY '01 – FY '05.....	24

SERVICES & SUPPORTS

Service Planning and Coordination – Numbers Served: FY 2005	25
Home Supports – Numbers Served: FY 2005.....	26
People Supported by Type of Living Arrangement: June 30, 2005	27
Number of People in Residential Settings by Size of Setting: FY '94 – FY '05.....	27
Percentage of People in Residential Settings of 1-3 People: FY 2004.....	28
Residential Care Home Use by People with Developmental Disabilities:	
FY '97 – FY '05.....	28
Number of Residences by Size of Residential Setting: FY 2005	28
Total Number of People Receiving Home Supports: FY '95 – '05.....	29
Cost per Person (Waiver Funding) by Type of Home	
Compared to Numbers Served: FY 2005.....	29
Population Change by Type of Home Setting: FY '92 – FY '05	30
Average Cost per Person by Type of Home: FY '95 – FY '05	31
Employment Services – Numbers Served: FY 2005	35
People with Developmental Disabilities Receiving Supported Employment to Work:	
FY '95 – FY '05.....	35
Community Supports – Numbers Served: FY 2005	39
Number of People Receiving Community Supports: FY '99 – FY '05.....	39
Family Supports – Numbers Served: FY 2005	42
Family Support to People Living at Home (Flexible Family Funding and Waiver):	
FY 2005 – Total People Served & People Served per 1,000 Population	43
Children's Services – Numbers Served: FY 2005	45
Children (under 18) on Medicaid Waiver: FY '99- FY '05.....	45
Medicaid Entitlement Services – Numbers Served: FY 2005	47
Children's Personal Care Services Hours Allocated vs. Hours Used: FY '01 – FY '05.....	48

Overlap of Funding: FY 2005.....	49
Clinical & Crisis Services – Numbers Served: FY 2005 – Vermont Crisis Intervention Network	50
Vermont State Hospital Utilization by People Diagnosed with Mental Retardation: FY 1988 – FY 2005	51
Nursing Home – Numbers Served: December 31, 2005.....	53
People with MR/DD who Reside in Nursing Facilities: 1991 – 2005.....	53
People with MR/DD as a Percentage of All People who Reside in Nursing Facilities: 1991 – 2005	54
People with MR/DD in Nursing Facilities as a Percentage of All People with MR/DD Receiving Residential Supports: June 30, 2004	54
Office of Public Guardian– Caseload: June 30, 2005.....	58
Consumer Survey – Numbers Surveyed: 2005.....	70
Consumer Survey Results: 2005.....	70
Demographic Summary – 2005	72
Comparison of Vermont’s 2002 and 2005 Consumer Survey Results	73
National Comparison of Vermont’s 2004 Consumer Survey Results	74
MR/DD State Spending per Capita: FY 2004.....	76
State Fiscal Effort – Total MR/DD Spending per \$1,000 in Personal Income: FY 2004.....	76
Percent of State MR/DD Budget Paid by State Funds: FY 2004	77
Number of People in MR/DD Residential Services & Nursing Facilities per 100,000 Population: FY 2004.....	77
Family Support Fiscal Effort – Total Spending per \$100,000 Personal Income: FY 2004	78
Family Support Spending as Percent of Total MR/DD Budget: FY 2004	78
Total Amount of Spending per Family: FY 2004.....	79

The following poem was presented as one of the keynote speeches at the *Making Communication Happen II* conference in November 2005. Sherry Thrall shared her perspective as the Executive Director of Lincoln Street Incorporated as to what it takes to support someone to be able to communicate.

SILENCE ISN'T ALWAYS GOLDEN

*You sat there so silent but I believed you were in there.
I answered all your gestures to show you how much I cared.
We struggled to get it right, I worried as I watched you fight
When you pressed your cheek to mine, I'd known we'd gotten it right.*

*We believed there was a real person, fighting to be heard.
Who was sometimes sunk in apathy, maybe you felt to try was just absurd.
Were you tired, hungry, hot or thirsty, or was this another of your tests?
Or were you simply feeling powerless, we could only guess.*

*I longed to offer choices beyond just milk or juice
To help you to get the life you want and not offer some excuse.
I wanted to know what you think and really how you feel
And when I saw you sinking, to help you sail on an even keel.*

*We signed, we gestured, we told you how, we gave you non-verbal cues
Good for you, you didn't comply and I knew we didn't have a clue.
Then FC came, we took the leap, our whole world began to open.
You shared the dreams for which you had never stopped hoping.*

*You told us more than "milk" or "juice" you said how you felt.
The first time you said you loved someone, I felt my heart just melt.
You talked and talked and talked and talked, I had to learn to wait.
After many years so much I'd longed to know, our times always ran late.*

*I had to learn to be quiet while we went through the process
Set work and practice more so we wouldn't have to guess.
Validity yes is critical but so is monitoring our intent
So what if you're not always "on" whoever is always a hundred percent?*

*Now you struggle with the other end, responsibility for what you say.
It's been wonderful to see the thoughtful adult part of you come into play.
It's easier now that you can talk anywhere and you can say anything.
It's amazing the true partnership that real communication can bring.*

*In twenty years you've grown up a decisive person who dares.
Yes, I confess I nearly choked the time you decided on purple spiky hair.
I guess it shows that I come from times that you consider olden.
Thank you for your patience teaching me that Silence isn't always golden.*

– Sherry Thrall, Executive Director
Lincoln Street Incorporated

DAIL MISSION STATEMENT

The mission of the Department of Disabilities, Aging and Independent Living is to make Vermont the best state in which to grow old or to live with a disability – with dignity, respect and independence.

DAIL Core Principles

- ★ **Person-centered** – the person will be at the core of all plans and services.
- ★ **Respect** – individuals, families, providers and staff are treated with respect.
- ★ **Independence** – an individual’s personal and economic independence will be promoted.
- ★ **Choice** – individuals will have options for services and supports.
- ★ **Self-determination** – individuals will direct their own lives.
- ★ **Living well** – the individual’s services and supports will promote health and well-being.
- ★ **Contributing to the community** – individuals are able to work, volunteer, recreate, and participate in local communities.
- ★ **Flexibility** – individual needs will guide our actions.
- ★ **Effective and efficient** – the individual’s needs will be met in a timely and cost effective way.
- ★ **Collaboration** – individuals we serve will benefit from our partnerships with families, communities, providers, and other federal, state and local organizations.

THE DEVELOPMENTAL DISABILITIES SERVICE SYSTEM

The Developmental Disabilities Act of 1996 requires the Department of Disabilities, Aging and Independent Living (DAIL), Division of Disability and Aging Services (DDAS), to adopt a plan describing the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. The Division of Disability and Aging Services *Annual Report*, together with the *Vermont State System of Care Plan for Developmental Services – Three Year Plan (FY 2005 – FY 2007 and FY 2006 Update)*, cover all requirements outlined in the developmental disabilities statute¹.

Principles of Developmental Services

Services provided to people with developmental disabilities and their families must foster and adhere to the following principles:

- ★ **Children's Services.** Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. The quality of life of children with developmental disabilities, their families and communities is enhanced by caring for children within their own homes. Children with disabilities benefit by growing up in their own families; families benefit by staying together; and communities benefit from the diversity that is provided when people with varying abilities are included.
- ★ **Adult Services.** Adults, regardless of the severity of their disability, can make decisions for themselves, can live in typical homes and can contribute as citizens to the communities where they live.
- ★ **Full Information.** In order to make good decisions, people with developmental disabilities and their families need complete information about the availability, choices and costs of services, how the decision making process works, and how to participate in that process.
- ★ **Individualized Support.** People have differing abilities, needs, and goals. To be effective and efficient, services must be individualized to the capacities, needs and values of each individual.

¹ Developmental Disabilities Act of 1996, 18 V.S.A. § 8724. This statute currently references the Department of Developmental and Mental Health Services (DDMHS), but as of July 1, 2004, reorganization of the Agency of Human Services placed developmental disability services under the newly formed Division of Disability and Aging Services (DDAS), Department of Disabilities, Aging and Independent Living (DAIL).

- ★ **Family Support.** Effective family support services are designed and provided with respect and responsiveness to the unique needs, strengths and cultural values of each family, and the family's expertise regarding its own needs.
- ★ **Meaningful Choices.** People with developmental disabilities and their families cannot make good decisions without meaningful choices about how they live and the kinds of services they receive. Effective services shall be flexible so they can be individualized to support and accommodate personalized choices, values and needs, and assure that each recipient is directly involved in decisions that affect that person's life.
- ★ **Community Participation.** When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.
- ★ **Employment.** The goal of job support is to obtain and maintain paid employment in regular employment settings.
- ★ **Accessibility.** Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services, thereby forfeiting natural community support systems.
- ★ **Health and Safety.** The health and safety of people with developmental disabilities is of paramount concern.
- ★ **Trained Staff.** In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by Section 8731 of this title.
- ★ **Fiscal Integrity.** The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

Division of Disability and Aging Services

The Division of Disability and Aging Services (DDAS) plans, coordinates, administers, monitors, and evaluates state- and federally-funded services for people with developmental disabilities and their families within Vermont. The Division provides funding for services, systems planning, technical assistance, training, quality assurance, program monitoring and standards compliance. The Division also exercises guardianship on behalf of the Commissioner for people who are under court-ordered public guardianship. See **Attachment B: *Division of Disability and Aging Services Staff***.

The Division of Disability and Aging Services contracts directly with fourteen (14) private, nonprofit developmental services providers who provide services to people with disabilities and their families. Services and supports offered emphasize the development of community capacities to meet the needs of all individuals regardless of severity of disability. The Division works with all people concerned with the delivery of services: people with disabilities, families, guardians, advocates, service providers, the State Program Standing Committee for Developmental Services, and state and federal governments to ensure that programs continue to meet the changing needs of people with developmental disabilities and their families. See **Attachment C: *Vermont Developmental Services Providers***; and **Attachment D: *Members of the State Program Standing Committee for Developmental Services***.

Developmental Services Providers

Designated Agencies

The Department of Disabilities, Aging and Independent Living (DAIL) authorizes one Designated Agency (DA) in each geographic region of the state as responsible for ensuring needed services are available through local planning, service coordination, and monitoring outcomes within their region². There are ten DAs responsible for developmental services in Vermont. Designated Agencies must provide services directly or contract with other providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines. Some of the key responsibilities of a DA include intake and referral, assessing individual needs and assigning funding, assuring each person has a support plan, providing regional crisis response services, and providing or arranging for a comprehensive service network that assures the capacity to meet the support needs of all eligible people in the region.

Specialized Service Agencies

A Specialized Service Agency (SSA) is a separate entity that is also contracted by DAIL. It must be an organization that either: (1) provides a distinctive approach to service delivery and coordination; (2) provides services to meet distinctive individual needs; or (3) had a contract with DAIL originally to meet the above requirements prior to January 1, 1998. There are four SSAs who serve people with developmental disabilities.

² For developmental services, geographic regions are defined along county lines.

Contracted Providers

Contracted providers do not have a direct contract with DAIL but are non-profit agencies subcontracted through DAs and SSAs to provide supports to people in the region. Any organization that wishes to provide direct services to people with developmental disabilities and receives state or federal funds administered by DDAS must meet the standards identified in the Regulations Implementing the Developmental Disabilities Act of 1996. Organizations that provide supports and services must meet basic quality standards and have the capacity to support people to achieve the outcomes they desire.

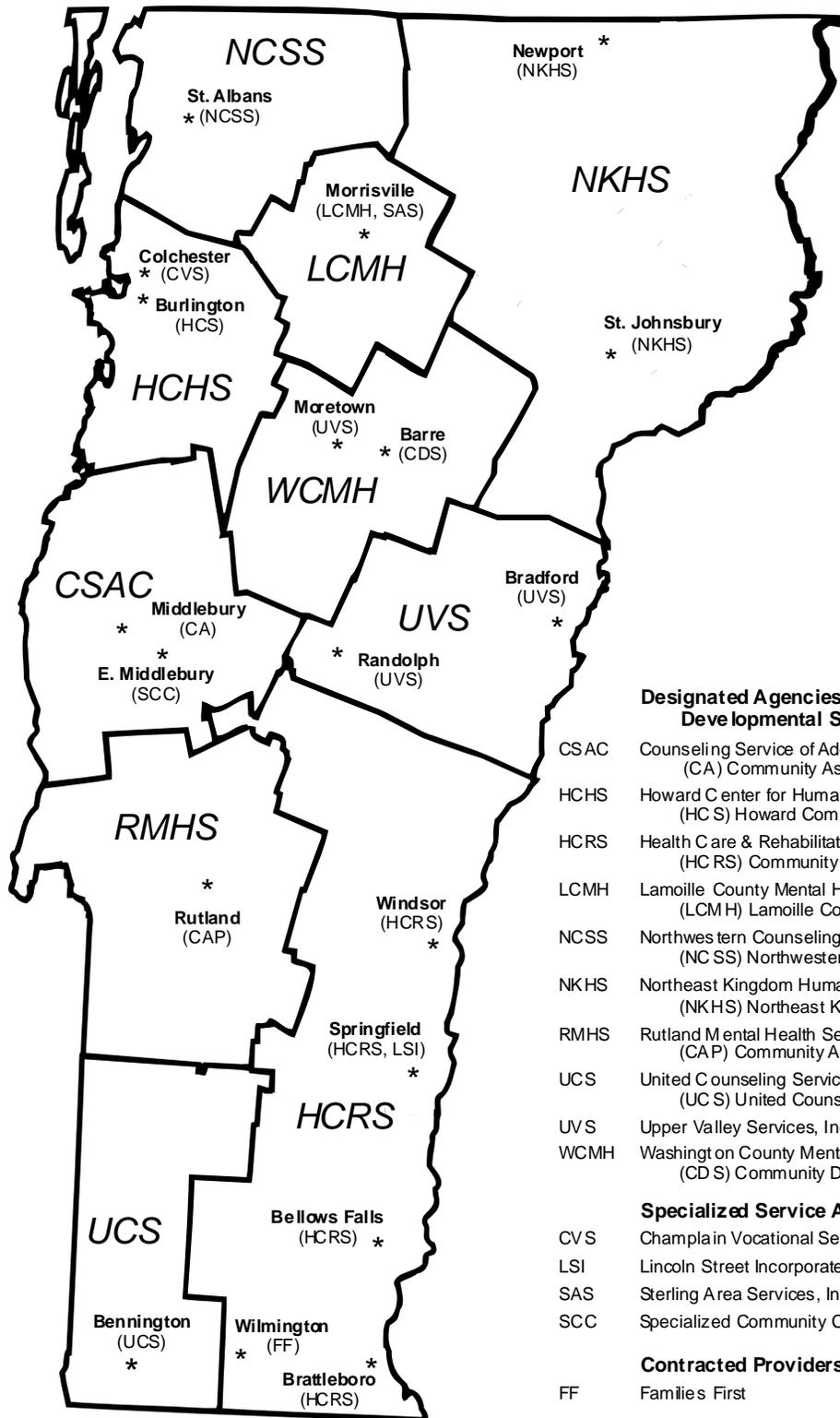
Management Options for Services

Traditionally, developmental service providers have managed all the services funded through DDAS on behalf of people with disabilities and their families. Today, people have a choice of who will manage their services³. There are four options available to people:

- **Agency-Managed Services:** When the developmental service provider manages **all** of a person's services, whether it is by the Designated Agency, a Specialized Service Agency or other contracted provider. This is the most common method of how services are managed.
- **Shared-Managed Services:** When the developmental service provider manages **some**, but not all, of the services for the person or family. For example, the service agency provides service planning and coordination and may arrange for other services, such as home supports, while the person or a family member manages other supports separately, such as respite or work supports. Many families, as well as some people with developmental disabilities, have chosen a shared-management arrangement.
- **Self-Managed Services:** When an individual chooses to manage **all** of his or her developmental services. This means that the person has the responsibility of hiring his or her own staff and overseeing the administrative responsibilities associated with receiving developmental services funding. Some of these responsibilities include contracting for services, developing a service plan, fulfilling the responsibilities of the employer, and planning for back-up support or respite in the case of an emergency. Fiscal and Supportive Intermediary Service Organizations (ISO) are available to people who self-manage to do many of the bookkeeping and reporting responsibilities of the employer.
- **Family-Managed Services:** When a person's family member chooses to manage **all** of his or her developmental services. The same responsibilities and resources noted above for self-management are also associated with and required for family-managed services.

³ A guide for people who are self-/family-managing their developmental disability services funded through Medicaid was developed by DDAS. A comprehensive self-/family-management handbook was also completed.

Vermont Developmental Services Providers



**Designated Agencies (DA)
Developmental Services Programs**

- CSAC Counseling Service of Addison County (CA) Community Associates
- HCHS Howard Center for Human Services (HCS) Howard Community Services
- HCRS Health Care & Rehabilitation Services of Southeastern Vt. (HCRS) Community Services Division of HCRS
- LCMH Lamoille County Mental Health Services, Inc. (LCMH) Lamoille County Mental Health Services, Inc.
- NCSS Northwestern Counseling & Support Services, Inc. (NCSS) Northwestern Counseling & Support Services/DS
- NKHS Northeast Kingdom Human Services, Inc. (NKHS) Northeast Kingdom Human Services, Inc.
- RMHS Rutland Mental Health Services (CAP) Community Access Program of Rutland County
- UCS United Counseling Services, Inc. (UCS) United Counseling Service, Inc
- UVS Upper Valley Services, Inc. (DS Only)
- WCMH Washington County Mental Health Services, Inc. (CDS) Community Developmental Services

Specialized Service Agencies (SSA)

- CVS Champlain Vocational Services, Inc.
- LSI Lincoln Street Incorporated
- SAS Sterling Area Services, Inc.
- SCC Specialized Community Care

Contracted Providers

- FF Families First

(7/1/05)

Highlights from FY 2005

- ★ **New 3-year State System of Care Plan Adopted** – The Division of Disability and Aging Services adopted a new three year *Vermont State System of Care Plan for Developmental Services* effective FY 2005 – FY 2007. The plan describes the nature, extent, allocation and timing of services that will be provided to people with disabilities and their families. An *FY 2006 Update* to the plan became effective on July 1, 2005.
- ★ **Agency of Human Services Reorganization Finalized** – The Agency of Human Services and its four associated departments, including the newly named Department of Disabilities, Aging and Independent Living (DAIL), began operating in its new capacity (see **Attachment F: AHS Organization Chart**). The Division of Disability and Aging Services is one DAIL's four divisions.
- ★ **Children's Personal Care Services (CPCS) and High Tech Home Care (HTHC) Moved to DDAS** – The Division of Disability and Aging Services completed a smooth transition in assuming responsibility and management of both personal care services to children under 21 who are eligible for Medicaid to help them with activities of daily living, and the intensive home care program serving both adults and children with nursing services. Efforts began to redesign the CPCS assessment and develop new guidelines.
- ★ **Autism Specialist Position Hired** – A new Autism Specialist position was developed and hired to address systems issues within the Agency of Human Services that relate to services for individuals with Autism Spectrum Disorders (ASD) in their homes and communities. The initial task of the Autism Specialist will be to conduct a statewide assessment of what currently exists to support individuals with ASD, to identify gaps and develop recommendations to addressing service gaps.
- ★ **Conducted Survey of Children's Personal Care Services** – A survey was mailed to all families receiving CPCS in August 2004. Results from the survey were published in the *Vermont CPCS Status Report* and have helped guide efforts to improve CPCS.
- ★ **Designated Agency Study Completed** – A consulting group was hired to undertake an independent evaluation of Vermont's designated agency system for mental health, substance abuse and developmental services. The review culminated with a *System Evaluation and Five-Year Projection of Service Demand and Cost Analysis*.
- ★ **Behavior Support Guidelines Issued** – *Behavior Support Guidelines for Support Workers Paid with Developmental Services Funds* were published and distributed to developmental disability service providers.

- ★ **Presented 2nd Annual Communication Conference – *Making Communication Happen II*** statewide conference provided workshops and vendor displays on how best to support people to communicate.
- ★ **Guardian’s Handbook Updated** – An updated version of the *Guardian’s Handbook: A Guide to the Responsibilities of Guardians of Adults with Mental Disabilities* was written and distributed to developmental service providers and each of the state’s Probate Courts.
- ★ **Nursing Facility Use at an All-Time Low** – People with MR/DD who live in nursing facilities maintained its all-time low of 27 people once again in 2005. There has been a steady decline in this number since the inception of PASARR (pre-admission screening and resident review) services in 1988, including the recent dramatic 31% decrease since 2002.
- ★ **Vermont Voices and Choices Conference a Huge Success** – An impressive 420 people attended the 2005 Voices and Choices self-advocacy conference. Most of the participants were self-advocates and each presentation included presenters who were self-advocates. The two-day event, organized by Green Mountain Self-Advocates, had a record 300 people staying overnight.
- ★ **Network of Local Communication Resource People Supported** – Representatives from all developmental service agencies continued to meet as a statewide communication network. Three training opportunities offered tools, skills and resources for working with others at their agencies to better support people to communicate more effectively.
- ★ **Real Choices Grant Unifies Quality Management Process** – The Division of Disability and Aging Services received a 3-year Real Choices Quality Assurance/Quality Improvement Systems Change Grant from the Centers for Medicare and Medicaid Services. This funding will be used to develop a comprehensive quality management system across DDAS home and community-based services.
- ★ **Consumer Survey Tool Updated** – The Vermont consumer survey interview tool was updated to better reflect the National Core Indicators’ consumer survey and to clarify wording of questions.
- ★ **Funding Communication Guide Updated** – *A Guide to Medicaid Funding for Communication Evaluations and Devices* was updated and published.

- ★ **National Consumer Survey Results Rank Vermont Highest** – Vermont is listed #1 in a national comparison of consumer survey results in the areas of life decisions, everyday choices and community inclusion⁴.

- ★ **Self-/Family-Management Handbook Finalized** – As part of the Real Choices Grant, work was completed on a comprehensive handbook to give guidance to people and families who wish to manage their own Medicaid waiver services.

- ★ **Supportive ISO Developed** – The Division of Disability and Aging Services contracted with Transition II to be the new Supportive Intermediary Service Organization to assist people and families to manage their developmental disability services.

- ★ **Vermont's Designated Agency System received Independent Evaluation** – A study was completed of Vermont's Designated Agency System for developmental and mental health services⁵.
 - *“Vermont leads the nation in terms of the percentage of the population of developmentally disabled persons being served in individual or very small group (less than 6 persons) living arrangements, with 97% of all persons served in such settings.”*
 - *“Vermont ranked number 1 in terms of the percentage of developmental services...expenditures matched with federal funds through the Medicaid program.”*
 - *“It is a ‘values-based’ system designed to draw forward those in need and provide them with the tools to achieve their best possible quality of life.”*
 - *“The financial plan should address both inflationary effects in the system...and funding for caseload growth, at least for essential services. The people whose lives are deeply affected by these decisions are counting on responsible and compassionate stewardship.”*
 - *“In summary, the Designated Agency system...provides a cost-effective system of services based on the needs and desires of Vermonters.”*

⁴ Data based on results from sixteen states that participated in the 2004 consumer surveys as part of the National Core Indicators. Results published in *Consumer Outcomes – Phase VII Final Report – Fiscal Year 2004-2005 Data (preliminary report)*, National Core Indicators.

⁵ Quotations taken from The Pacific Health Policy Group's report: *System Evaluation and Five Year Projection of Service Demand and Cost Analysis*.

Pressures on Community Services

In FY 2005, the Division of Disability and Aging Services provided supports to **3,095** people with developmental disabilities in Vermont, approximately 28% of the eligible population⁶. However, the population is constantly growing with an estimated 113 children born each year with developmental disabilities⁷. The need for developmental services is generally life-long and only an average of 33 people who are currently receiving services die each year⁸. The demand for supports continues to outpace the available resources. The following are some of the many factors influencing this.

- ◎ **New Medicaid waiver services for children have been discontinued** – The number of children who accessed new funds appropriated for caseload growth doubled in fiscal years 2000 and 2001. Funding to serve newly identified children with comprehensive services was discontinued on December 1, 2001 due to fiscal pressures. Supports needed for children and their families are extensive and exceed the system's capacity, yet no new funding to children has been available since that time⁹.

- ◎ **Waiting list continues** – At the end of FY 2005, the waiting list included 28 people who are eligible for developmental services. Those people were funded and began receiving services starting in July 2005. As of December 2005, there were 13 people on the waiting list.

- ◎ **Special education graduates need supports to keep them employed and living at home**¹⁰ – There were an estimated **106** graduates with developmental disabilities from Special Education programs expected to exit the educational system in FY '05. These young adults looked to the developmental service system to provide the necessary supports and services to help them continue to learn new skills, live in their own home and find or maintain employment. Of those **106**, it was expected that **96** people would be eligible under FY '05 funding priorities for home and community-based waiver funding and **10** for Division of Vocational Rehabilitation grant-funded employment services. This number of high school graduates is at an **all time high**; the increase coming primarily from a proliferation of young adults who are graduating earlier.

⁶ Based on projected national census figures for 2005 obtained from the Massachusetts Institute for Economic Research, University of Massachusetts, Amherst (625,935 for Vermont).

⁷ Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6,589 live births (State of Vermont 2003 Vital Statistics).

⁸ Based on an average of the past seven years (*NCI Mortality Data*).

⁹ See **Attachment G: System of Care Plan Funding Priorities**.

¹⁰ Designated Agencies survey local schools each year to find out exactly how many students with developmental disabilities are expected to graduate and who are eligible for developmental services and need funding.

- ◎ **People who live with aging parents often need additional supports** – People often need additional supports as they get older. Aging parents who have never asked for help before are seeking support before they die.

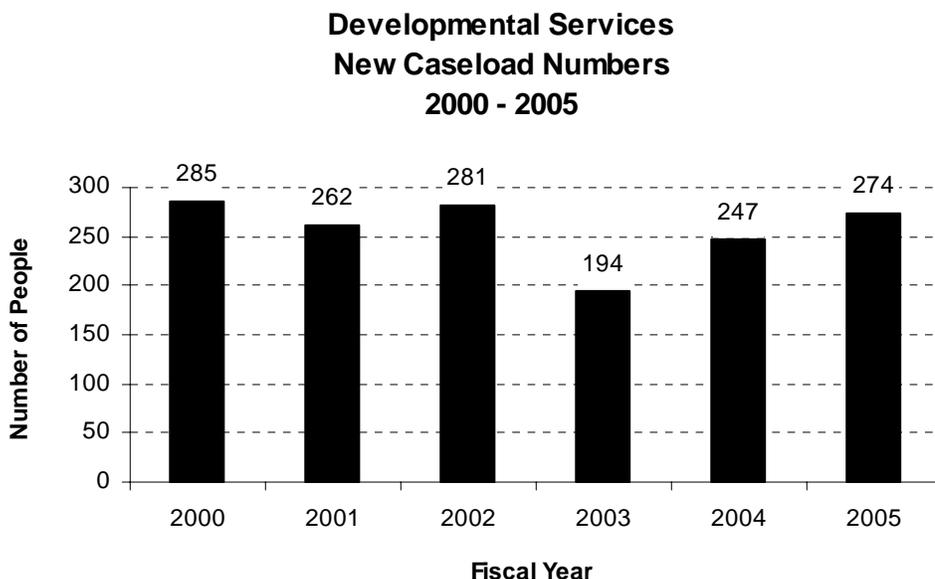
- ◎ **Offenders with disabilities need specialized supports** – When individuals with developmental disabilities commit crimes, the courts and correctional system may not be able to respond to their special needs for supervision and treatment, and the public looks to developmental services to meet the need. Approximately 160 offenders with developmental disabilities are supported by developmental service agencies, a number that has increased steadily in recent years. Developmental services agencies experience many stresses and dilemmas when expected to serve a public safety function for these individuals in the context of a system designed to promote self-determination and community participation for law-abiding Vermonters with developmental disabilities and their families.

- ◎ **New caseload funding allocated to those most in need** – New caseload resources were provided to 274 individuals in FY '05 who met the State System of Care Plan funding priorities for developmental services. The chart on the following page provides a summary of the reasons people received new caseload funding.

New Caseload Funding¹¹ – FY 2005

Reasons for Receiving New Caseload Resources¹² - FY 2005	
Imminent risk to person’s health or safety – for adults	130
Loss of home / imminent risk of homelessness – for adults	106
Risk of abuse, neglect or exploitation – for adults	25
Loss or reduced capacity of caregiver – for adults	35
High school graduation and job loss prevention	26
Risk to public safety	47
Risk of institutional placements or diversion from institutional placement – for children and adults	22
Age out of DCF ¹³ custody	15
Total people served from new caseload resources (unduplicated)	274

The Division of Disability and Aging Services manages its resources each year by making sure new caseload funding goes to those most in need of new and increased services. Anyone getting new caseload resources must meet the State System of Care Plan funding priorities. The following chart shows the change in people served by new caseload funding over time.



The nature of developmental disabilities often leads to services that support people throughout their lifespan. Of the 49 people who left waiver-funded services in FY '05, 22 died, 14 became ineligible for Medicaid or declined services, 11 moved out of state, and 2 terminated for some other reason.

¹¹ “New Caseload” funding includes all newly appropriated caseload, Equity Fund, High School Graduate Fund, and Public Safety Fund. Individuals may be counted in more than one category.

¹² See **Attachment G** for a complete listing of funding priorities or the *FY 2006 Update of the Vermont State System of Care Plan for Developmental Services Three-Year Plan FY 2005 – FY 2007* for more details.

¹³ Department for Children and Families.

Financial Summary

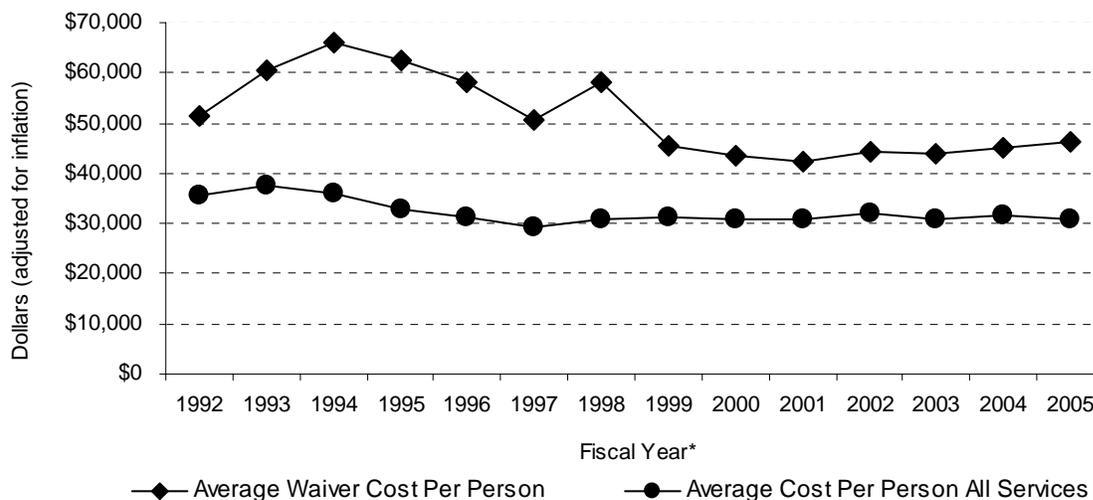
People with developmental disabilities have a greater likelihood of experiencing limitations in major life activities than those with any other major class of chronic mental, physical, or health condition. As a result, people with developmental disabilities need individualized services that are comprehensive and generally life long. To capitalize on the resources available, the Division of Disability and Aging Services emphasize cost effective models and maximization of federal funds. See **Attachment H: Division of Disability and Aging Services FY 2006 Fiscal Resources**.

★ The **average waiver cost per person (\$43,064)** rose by approximately 8.8% between FY 2002 and FY 2005 for the following reasons:

- Elimination of services to new children, which tend to have lower per person costs;
- Increase of 177 in the number of adults receiving 24-hour home supports; and
- Cost of living increases for worker wages and other workforce costs (e.g., health insurance, Worker’s Compensation, etc.).

★ The **average cost per person for all services (\$31,006)** has **remained stable**. An increase over time in individuals supported by less costly (non-residential) family support contributes to the stability of the average cost per person¹⁴.

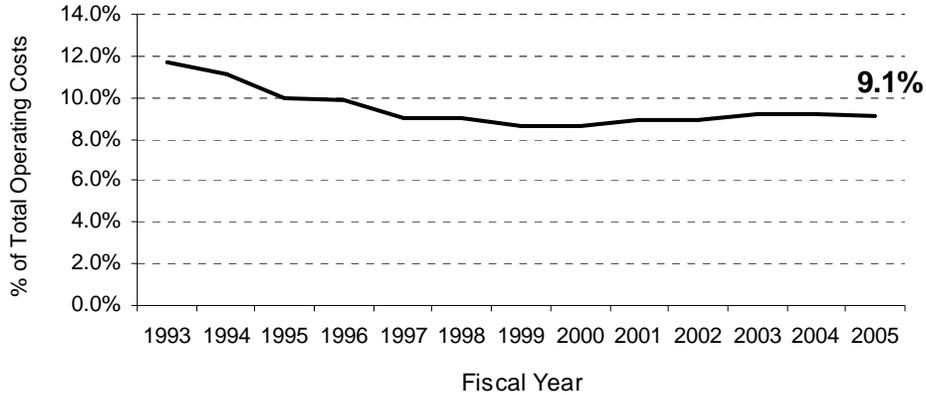
**Average Waiver Cost per Person
Average Cost per Person - All Services
FY 1992 - 2005**



¹⁴ For “Average Waiver Cost”, waiver years 1992 – 1997 ended on 3/31. From 1998 on, waiver years ended on 6/30. Due to this change over, waiver year 1998 reflects costs for a 15-month period. For “Average Cost per Person – All Services”, year-end numbers are used for waiver years ending on 6/30.

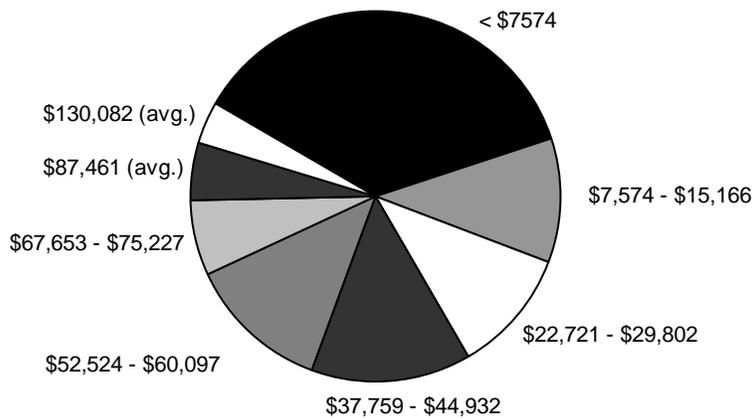
★ **Administrative expenses** include those that are required to run the total local agency¹⁵. These costs have **remained stable** over time.

**Local Agency Total Administration Costs
FY 1993 - FY 2005**



★ The **average cost of all services per person** in FY '05 was **\$31,006**. Almost one-half of all individuals served (**48%**) are funded for **less than \$20,000** per person per year. The average per person cost of supports in the most intensive community services category¹⁶ is **\$130,082** per year, which is still **45%** less than what the estimated annual per person cost would have been at Brandon Training School in today's dollars (\$235,924). Sixty-one percent (**61%**) of all families served receive their support through Flexible Family Funding at the low annual rate of \$1,122. Supporting people living with their own families continues to be the most cost effective method of support.

**Per Person Service Rates of Individuals Served
FY 2005
(N=3,095)**

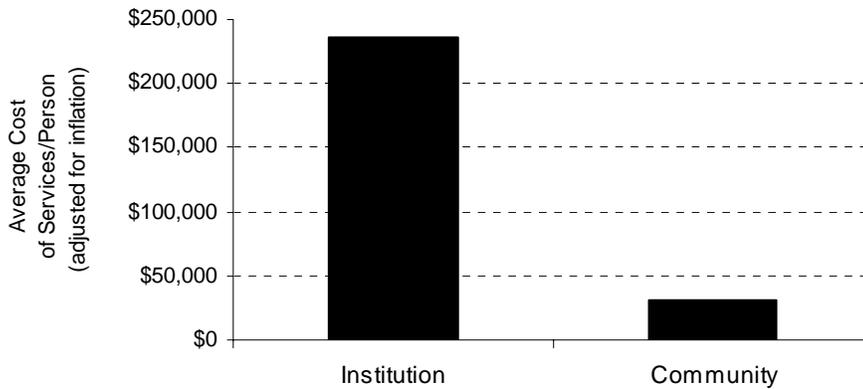


¹⁵ Management expenses (e.g., developmental service director, buildings) relating to major program areas (e.g., developmental services) are considered program expenses, not administration.

¹⁶ The highest rate category includes 6 people with intensive medical needs in an Intermediate Care Facility for People with Developmental Disabilities (ICF/DD) – formerly known as Intermediate Care Facility for People with Mental Retardation (ICF/MR).

★ Since the closure of Brandon Training School in FY '94, the average cost of waiver services per person served has declined. In the last two full years of BTS, it cost an average of **\$235,934** per year for each person served. In current dollars, **9** families can be supported with intensive in-home support, or **210** families can be supported with respite support, for the same amount of money (adjusted for inflation).

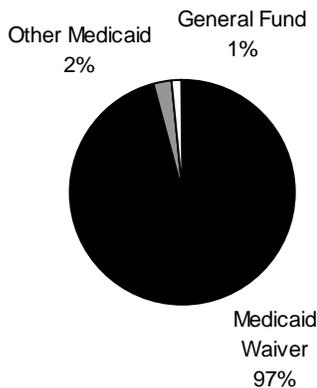
**Comparative Annual Cost of Services:
Institution (1994) vs. Community (2005)**



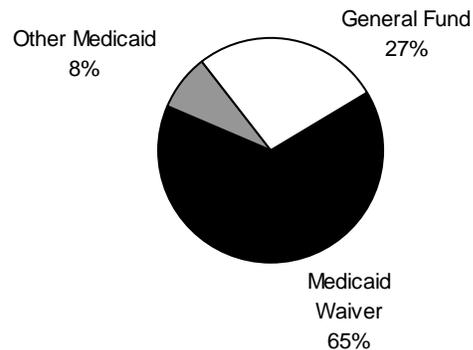
★ Flexible Family Funding, a cost-effective, family-directed support, is provided through general funds (GF) resources at DDAS. It results in a relatively large number of people receiving services that are low cost, thus the significant difference in the graph below. In addition, because almost **99%** of developmental services funding is from **Medicaid**, Vermont’s developmental service system leverages a higher proportion of federal funds compared with other states.

**Percentage of Funding & Percentage of People¹⁷ by DS Funding Type¹⁸
FY 2005**

Percent of Funding by Funding Type



Percent of People by Funding Type



¹⁷ The “percent of people” are based on unduplicated count across funding types. Any duplication in people receiving both “General Fund” and “Medicaid Waiver” are counted in the waiver count only. Any duplication in people receiving both “General Fund” and “Other Medicaid” are included in the GF count only.

¹⁸ “Other Medicaid” = Targeted Case Management, Rehabilitation, Transportation, Clinic, ICF/DD and Social Services Block Grant. General Fund (GF) = Flexible Family Funding.

Quality Assurance & Quality Improvement

Quality Service Reviews – 2005	
Agencies reviewed	15
People reviewed	340
Percentage of people reviewed getting Medicaid-funded services	16%

Assessment, assurance and improvement of service quality are critical functions of the Division of Disability and Aging Services. Annually, Community Alternative Specialists (CAS) conduct on-site reviews of all Medicaid-funded services provided by each agency. The CAS teams assess the quality of services with respect to the Division of Disability and Aging Services' quality goals and outcomes to assure compliance with state and federal Medicaid standards and individuals' desires for their supports. The quality of individual services is evaluated as well as systems and organizational issues.

Priority Areas for Improvement: The following areas were most frequently noted as needing improvement during on-site reviews across all the agencies in 2005:

- Internal Quality Assurance/Quality Improvement Process
- Employment Services
- Individual Support Agreements
- Health and Wellness Guidelines, Medical Services, Special Care Procedures
- Clinical Resources/Supervision – Behavior Support, Nursing, Medication
- Staff Supervision

The annual quality reviews also inform the designation process that takes place for each agency every four years. Because of changes during the Agency of Human Services reorganization, designations have been extended until June 30, 2005 through a temporary suspension of the designation process. To date, all agencies have gone through re-designation at least once.

As part of the agency review process, the Community Alternative Specialists incorporate information from the following DDAS quality assurance activities:

- **Critical Incident Reporting** process to track certain incidents, such as the death of someone receiving services, use of restrictive procedures or allegations of abuse.
- **Complaint and Appeals** processes for people applying for or receiving services, their family members, guardians and other interested individuals.
- **Safety and Accessibility Reviews** conducted for all new unlicensed residential settings funded by DDAS.
- **Consumer and Family Surveys** to measure the satisfaction of people receiving services and to assess how families feel about services they receive.
- **Ethics Committee** to review any decisions by a Public Guardian to abate life-sustaining treatment for a person receiving services.
- **Human Rights Committee** to review behavior support plans which include the use of restraints to safeguard the human rights of people receiving developmental services.

The Vermont developmental services system has numerous other quality assurance components that provide independent oversight from both outside and within the service system. See **Attachment E: Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities.**

Training and technical assistance are provided as part of the Division of Disability and Aging Services' commitment to quality and quality improvement.

- **Training** that ensures workers gain the expertise necessary to meet the needs of people they support is arranged or provided by DDAS on several levels:
 - Formal training programs provided to agency staff include Supervisory Training, Vermont Safety Awareness Training, Service Coordinator Training and Introductory Training.
 - Training to staff of each agency about new guidelines and better ways of supporting persons with developmental disabilities.
 - Support of local and statewide training efforts by making funds available and giving groups flexibility to tailor training to their own needs.
- **Technical assistance** is provided to each agency by DDAS staff in a wide variety of areas including:
 - Intake process
 - Funding of services
 - Individual Support Agreements
 - Data and other information reporting
 - Positive support strategies and behavior support plans
 - Policies and guidelines
 - Best practices
 - Organizational development

Collaboration with consumers, families, advocates, service providers, local and regional community organizations, and departments within state government is a fundamental aspect of the work of the Division of Disability and Aging Services. Continuation of liaison and interagency agreements with Adult Protective Services, Division of Vocational Rehabilitation, Department for Children and Families (DCF), and the Departments of Health and Education is key in helping to maintain quality services and assure seamless and effective supports. The Division of Disability and Aging Services convenes a number of advisory and work groups with representation from various advocacy and service organizations, including:

- State Program Standing Committee for Developmental Services
- Vermont Communication Task Force
- Social/Sexual Education Resource Network
- Vermont Safety Awareness Training Workgroup
- Training Advisory Group
- Human Rights Committee
- Ethics Committee
- Sex Offender Discussion Group

Highlights



Community Alternative Specialists provided training and technical assistance focusing in the following **specialty areas**:

- Children's and Family Services
- Employment Services
- Training and Staff Development
- Health and Wellness

- ★ **Specialized training** was provided in the following areas:
 - Estate planning
 - Inclusion and developing community presence
 - MAPS and PATHS
 - Ongoing support and training for local communication resource people

- ★ A second **ten-day training series** for service coordinators and independent support brokers was completed.

- ★ Agency personnel continue to be trained in **Vermont Safety Awareness Training (VSAT)** through a network of trained, local instructors and an advanced training in Safety Mechanics was made available to VSAT instructors.

- ★ The Division of Disability and Aging Services continues to focus on increasing opportunities and supports for individuals to improve their **communication as a priority goal** for the system.

- ★ Additional **training activities** for 2005 include:
 - Dialectical Behavior Therapy Training
 - Service Coordinator Training
 - Training for families and parents on supporting school-aged children
 - Employment grant training (e.g., customer service, transition supports)
 - Supervisory Training
 - Contingence Conference in collaboration with Children with Special Health Needs, the Department of Education, and the University of Vermont
 - Alzheimer's Disease and Developmental Disabilities in collaboration with other DAIL partners as part of the Alzheimer's Demonstration Grant

- ★ To help maintain consistent and quality services and supports across the state, the Division of Disability and Aging Services has the following **policies**:
 - *Critical Health Care Decisions* (1996)
 - *Complaint and Appeal Processes* (1998)
 - *Guidelines for Critical Incident Reporting* (2002)
 - *Flexible Family Funding Guidelines* (2002)
 - *Individual Support Agreement Guidelines* (2003)
 - *Background Check Policy* (2003)
 - *Policy on Education and Support of Sexuality* (2004)
 - *A Guide for People who are Self/Family Managing Medicaid-Funded Developmental Services* (2004)
 - *Qualified Developmental Disabilities Professional (QDDP) Definitions, Qualifications and Roles / QDDP Endorsement* (2004)
 - *Health and Wellness Standards and Guidelines* (2004)
 - *Behavior Support Guidelines for Support Workers Paid with DDS Funds* (2004)
 - *Guidelines for Quality Services* (being revised)

Quality Assurance/Quality Improvement Systems Change Grant

The State of Vermont/Division of Disability and Aging Services is one of nine 2004 Real Choice Systems Change Quality Assurance/Quality Improvement (QA/QI) grantees. This funding from the Centers for Medicare and Medicaid Services will be used to develop a comprehensive quality management system across DDAS home and community-based services (HCBS) over a three year period. These home and community-based services are provided to individuals with developmental disabilities as well as older Vermonters, individuals with physical disabilities, and individuals with traumatic brain injuries.

Grant Funds will be used to:

- Develop a Quality Management Plan addressing the HCBS waiver programs;
- Include consumers, their families and community members as active participants in Vermont's quality management activities;
- Develop and implement quality management activities to improve supports and services to Vermont's older citizens and those with disabilities;
- Develop a technology-based system to manage and analyze critical incidents, and;
- Develop an ongoing system of technical assistance to all providers of services across age and disability and provide training to service recipients and relevant staff.

Highlights

- ★ Hired a Quality Management Development Specialist.
- ★ Formed a Quality Management Committee with consumers, family members, service providers, and state staff that meet on a monthly basis.
- ★ Through discussions of experiences with services, personal values and training, the Quality Management Committee began development of quality outcomes and indicators that guide the delivery of services and quality assessment.
- ★ Explored ways to seek public feedback and input about the grant's products.
- ★ Reorganized the structure of the quality review teams that will include two part-time consumer positions that will be involved in quality management activities.

SERVICES & FUNDING

Funding Sources

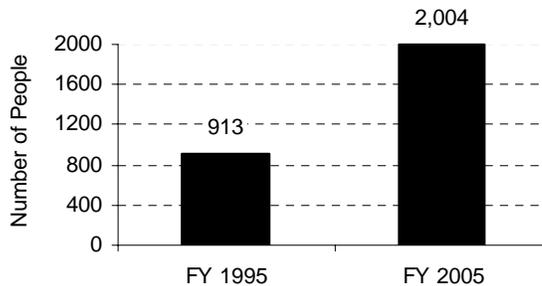
Numbers Served – FY 2005	
Home and community-based waiver recipients	2,004
Flexible Family Funding recipients (some dups. with waiver)	840
Other	363
Total people served (unduplicated)	3,095

Medicaid (waiver, fee-for-service and ICF/DD) accounts for **98.6%** of all DDAS funding (including the state match). The remaining **1.4%** is paid by **state general funds**.

- **Home and Community-Based Waiver (HCBW) – 2,004 people**

The home and community-based waiver, often referred to as “the waiver,” is the primary funding source for people receiving developmental services in Vermont. The waiver accounts for **96.2%** of all funding for people served through DDAS.

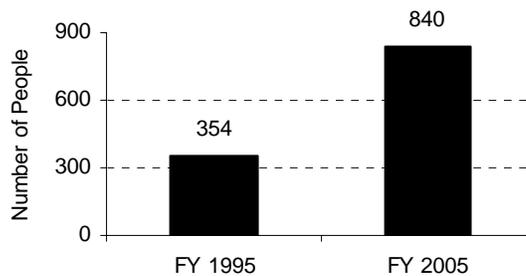
HCB Waiver Services



- **Flexible Family Funding (FFF) – 840 people**

Flexible Family Funding is money, provided to eligible families with children or adult family members with disabilities living at home, used at their discretion toward services and supports that are in the person’s/family’s best interest. The maximum amount available is generally \$1,122/year. Flexible Family Funding accounts for **1.4%** of all funding for people served through DDAS.

Flexible Family Funding



- **Other** – Other funding sources are Medicaid fee-for-service (e.g., targeted case management), Intermediate Care Facility (ICF/DD), vocational grants in partnership with the Division of Vocational Rehabilitation, Medicare and other 3rd party insurance. This accounts for **2.4%** of all funding for DDAS.

Types of Services Provided

Developmental services providers offer a comprehensive range of services designed to support individuals and families at all levels of need. Services encompass a wide range of support options designed around the specific needs of an individual. Supports include:

- **Service Planning and Coordination** – Assists individuals and their families in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services for a specific individual.
- **Community Supports** – Specific, individualized and goal oriented services which assist individuals in developing skills and social supports necessary to promote positive growth.
- **Employment Services** – Assists individuals in establishing and achieving career and work goals; includes employment assessment, employer and job development, job training and ongoing support to maintain employment.
- **Home Supports** – Services, supports and supervision to individuals in and around their residences up to 24 hours a day.

Supervised/Assisted Living (hourly) – Regularly scheduled or intermittent supports provided to an individual who lives in

- (1) his or her home, or
- (2) the home of a family member (i.e., in-home family support).

Staffed Living – Residential living arrangements for one or two people, staffed full-time by providers.

Group Living – Group living arrangements for three to six people, staffed full-time by providers.

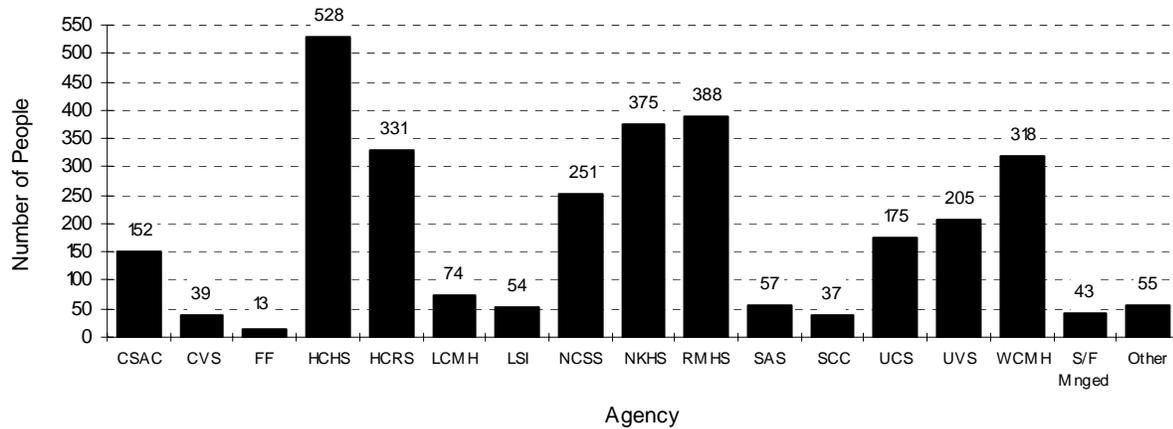
Home Providers – Individualized shared-living arrangements for one or two people offered within a contracted home provider's home.

ICF/DD (Intermediate Care Facility for people with Developmental Disabilities) – A highly structured residential setting for up to six people that provides needed intensive medical and therapeutic services.

- **Respite (hourly or daily)** – Services provided on a short-term basis because of the absence or need for relief of
 - (1) family members/significant others or
 - (2) home providers normally providing the care to individuals who cannot be left unsupervised.
- **Clinical Interventions** – Assessment, therapeutic, medication or medical services provided by clinical or medical staff.
- **Crisis Services** – Time-limited, intensive supports provided for individuals who are currently experiencing, or may be expected to experience, a psychological, behavioral or emotional crisis; includes crisis assessment, support and referral, and crisis beds.

Total Served

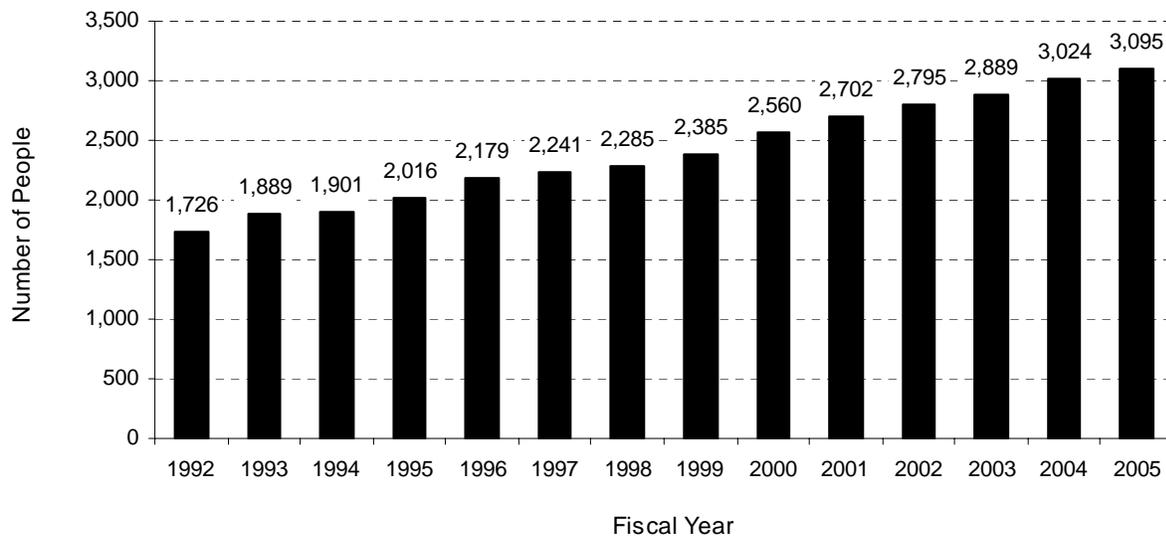
**Total Number of People Supported by Service Provider
June 30, 2005**



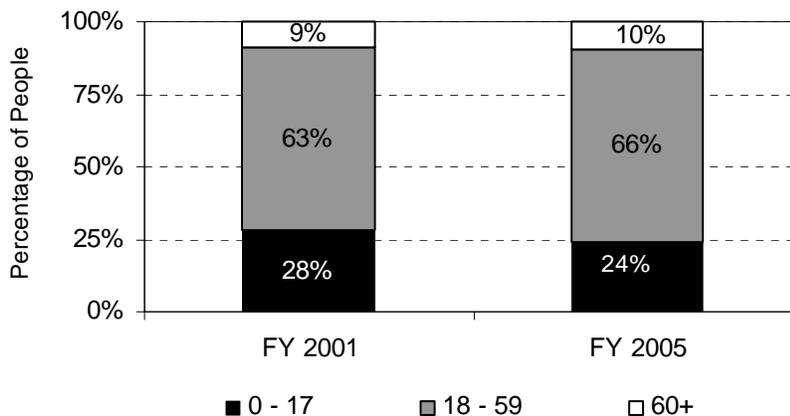
Developmental Disability Services Providers

CSAC	Counseling Service of Addison County	SCC	Specialized Community Care
CVS	Champlain Vocational Services, Inc.	UCS	United Counseling Services, Inc.
FF	Families First	UVS	Upper Valley Services, Inc.
HCHS	Howard Center for Human Services	WCMH	Washington County Mental Health Services, Inc.
HCERS	Health Care and Rehabilitation Services of SE Vt.	Self- or Family-Managed	Includes all people who use the Supportive ISO (Transition II).
LCMH	Lamoille County Mental Health Services, Inc.		
LSI	Lincoln Street Incorporated		
NCSS	Northwestern Counseling and Support Svcs., Inc.	Other	Includes people supported by Transition II Employment Services or the Office of Public Guardian and who are not served by any other DS agency.
NKHS	Northeast Kingdom Human Services, Inc.		
RMHS	Rutland Mental Health Services		
SAS	Sterling Area Services, Inc.		

**Total Number of People Served
FY 1992 - FY 2005**



**Age Breakout of
People with Developmental Disabilities
FY '01 - FY '05**



Highlights



What **consumers** said about their agency¹⁹:

- **93%** said they are listened to at their support plan meetings.
- **90%** said things in their support plan are important to them.
- **82%** said people at their agency listen to them.
- **91%** said they get the help they need from people at their agency.
- **84%** said they are happy with the help they get from their agency.

Areas of Focus



What **consumers** said about their agency:

- **77%** said they are happy with their agency.
- **50%** said they are not told how much money is in their budget.
- **70%** said they have not been told about their agency's appeal process.

¹⁹ This data and other references to the consumer survey throughout this report refer to the *Survey of Adult Consumers of Developmental Services: 2005 (preliminary draft)*.

S E R V I C E S & S U P P O R T S

Service Planning & Coordination

Numbers Served – FY 2005	
Waiver-funded service coordination	2,004
Fee-for-service service coordination	183
Total people receiving service coordination	2,187

Service coordination assists individuals and their families in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services for a specific individual. The role of service coordinators is quite varied and individualized, and often can be instrumental in helping people get and maintain services.

The primary functions in which service coordinators assist people and their families include:

- Person-centered planning process
- Individual Support Agreement
- Periodic Review/Assessment of Needs
- Medicaid billing
- Evaluations and assessments
- Waiting and Applicant Lists
- Overall health and safety
- Maintaining individual case record
- Positive Behavior Support Plan
- Critical Incident Reports
- Complaints and appeals
- Quality assurance/improvement

Highlights

- ★ Service coordinators assist **most people** receiving developmental services. Individuals who only receive Flexible Family Funding often get assistance from agencies to find other supports and services, but generally do not get ongoing service coordination.
- ★ What **consumers** said about service coordination:
 - **79%** said they were happy with their service coordinator.
 - **80%** said they got to see their case manager when they wanted.
 - **93%** said they got what they needed when they ask their service coordinator for something.

Areas of Focus

- ◎ What **consumers** said about service coordination:
 - **69%** said someone else chose their case manager.
 - **19%** of the people who said they had a lot of different case managers said it was a problem for them.

Home Supports

Numbers Served – FY 2005	
Number of homes (6/30/05)	1,080
Average number of people per residential setting	1.2
Total people getting home supports (6/30/05)	1,278

Home supports are made up of a variety of services, supports and supervision provided to individuals in and around their residences up to 24 hours a day.

Types of Home Supports

- **Home Provider:** Individualized shared-living arrangements offered within a contracted home provider’s home for one or two people. Home providers are contracted workers and are not considered agency staff in their role as provider.

Number of people – 979

Number of homes – 864

- **Supervised Living:** Regularly scheduled or intermittent supports provided to an individual (or two) who lives in his or her home. Generally the home/apartment is owned or rented by the person with the disability.

Number of people – 184

Number of homes – 174

- **Group Living:** Group living arrangements for three to six people, staffed full-time by providers (there may be exceptions of less than full-time supervision for some individuals).

Number of people – 79

Number of homes – 17

- **Staffed Living:** Residential living arrangements for one or two people staffed full-time by providers. Generally the home is owned or rented by the provider agency.

Number of people – 30

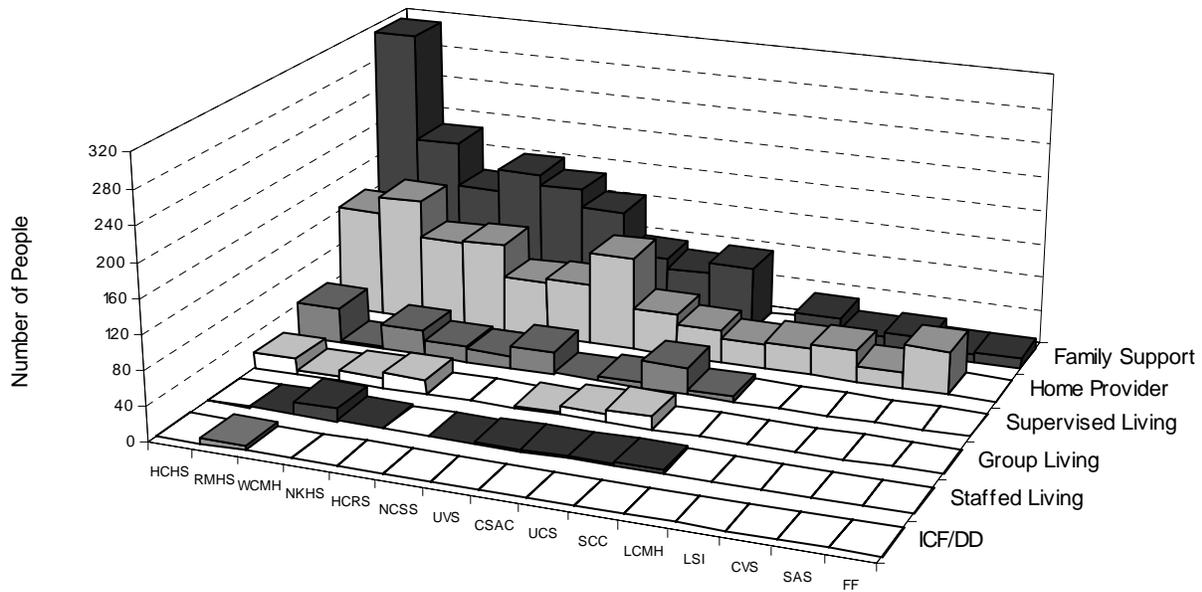
Number of homes – 24

- **ICF/DD** (Intermediate Care Facility for people with Developmental Disabilities): A highly structured residential setting for up to six people that provides intensive medical and therapeutic services.

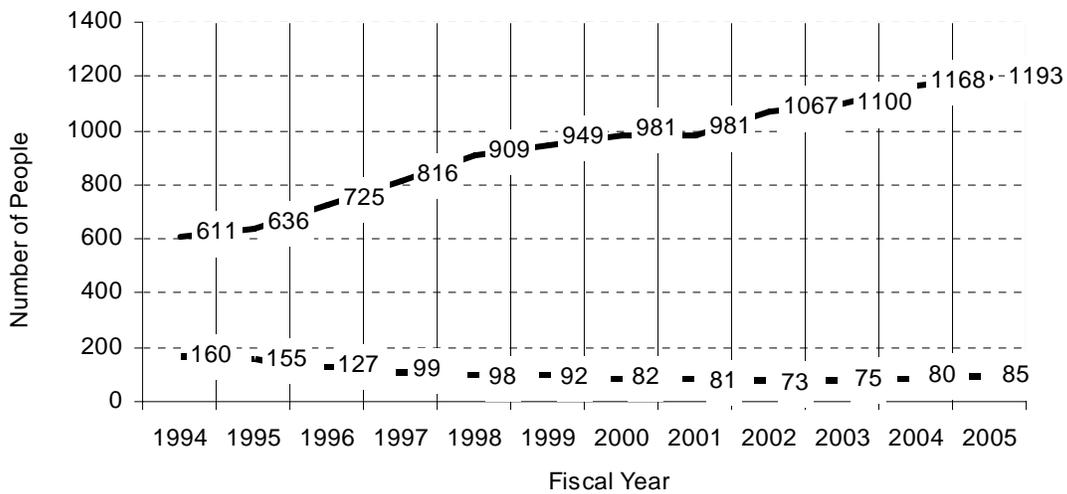
Number of people – 6

Number of homes – 1

People Supported by Type of Living Arrangement 6/30/05



Number of People in Residential Settings by Size of Setting FY '94 - FY '05

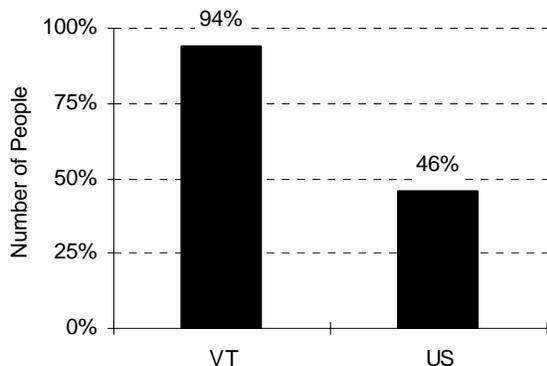


- - - Group Living (3-6 people)
(Group Homes & ICFs)
- Individualized Supports (1-2 people)
(Home Providers, Supervised & Staffed Living)

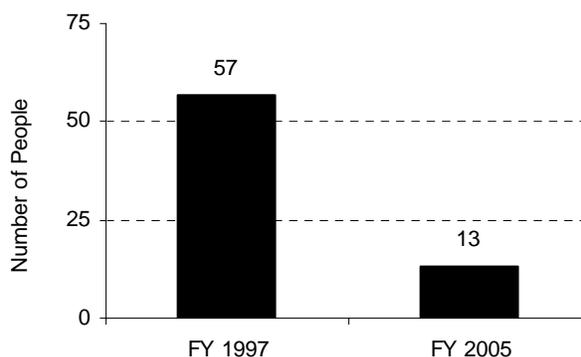
Highlights

- ★ Vermont continues to support **individualized home support options** for people, such as living in their own homes, with shared-living providers or with 24-hour staff support. Small, individual home settings are the norm in Vermont.

Percentage of People in Residential Setting of 1-3 People²⁰
FY 2004

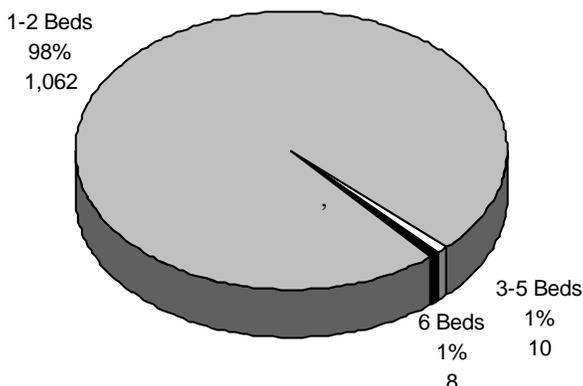


Residential Care Home²¹ Use by People with Developmental Disabilities
FY '97 – FY '05



- ★ There are **no** large congregate settings for people with developmental disabilities funded by DDAS.
- ★ Vermont is the only state in the country that has **100%** of the people funded for home supports living in residential placements with six or fewer consumers²².

Number of Residences by Size of Residential Setting
FY 2005



²⁰ Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2005.

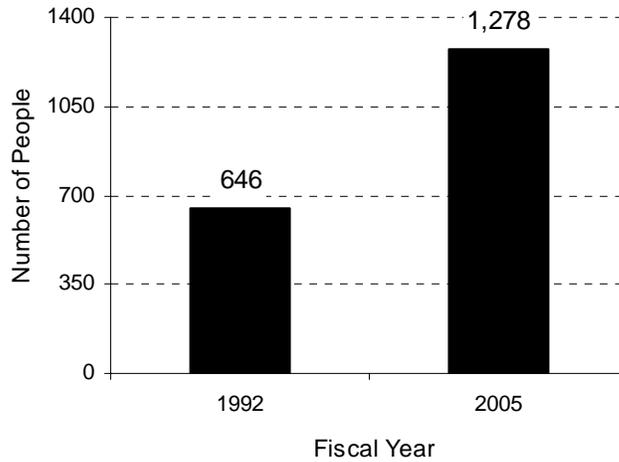
²¹ Data reflects people receiving developmental disability services living in licensed homes other than group homes managed by developmental disability service providers.

²² Source: Prouty, R, Smith G. and Lakin C. (see footnote 20 for full reference).



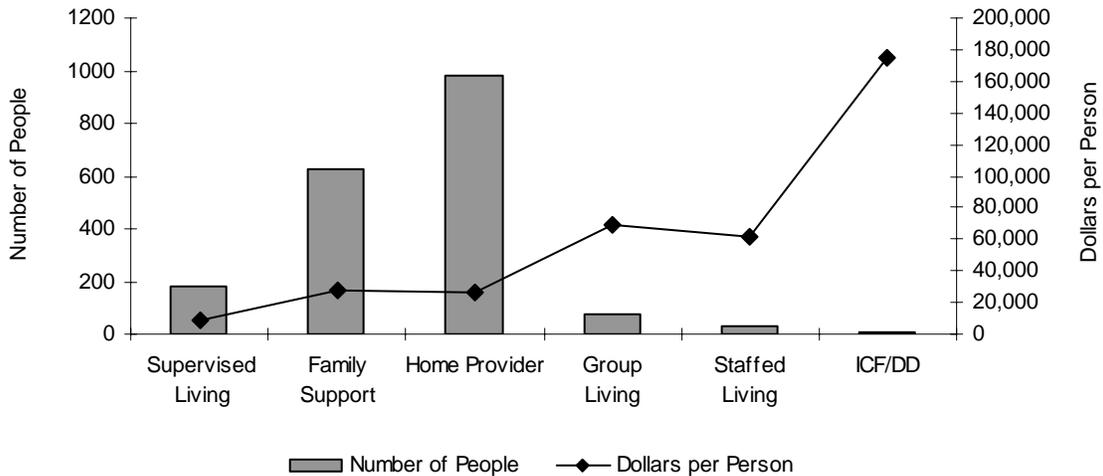
Although the need for home supports has steadily increased, Vermont has maintained an average of **1.2** number of people supported per residential setting; still the lowest rate in the country compared with the national average of 2.8²³.

**Total Number of People Receiving Home Supports
FY '92 – FY '05**



Vermont continues to focus on using less costly **in-home family support and individualized home support** options (e.g., home provider and supervised living) as compared to more costly congregate, staff intensive settings (e.g., group living, staffed living and ICFs/DDs)²⁴.

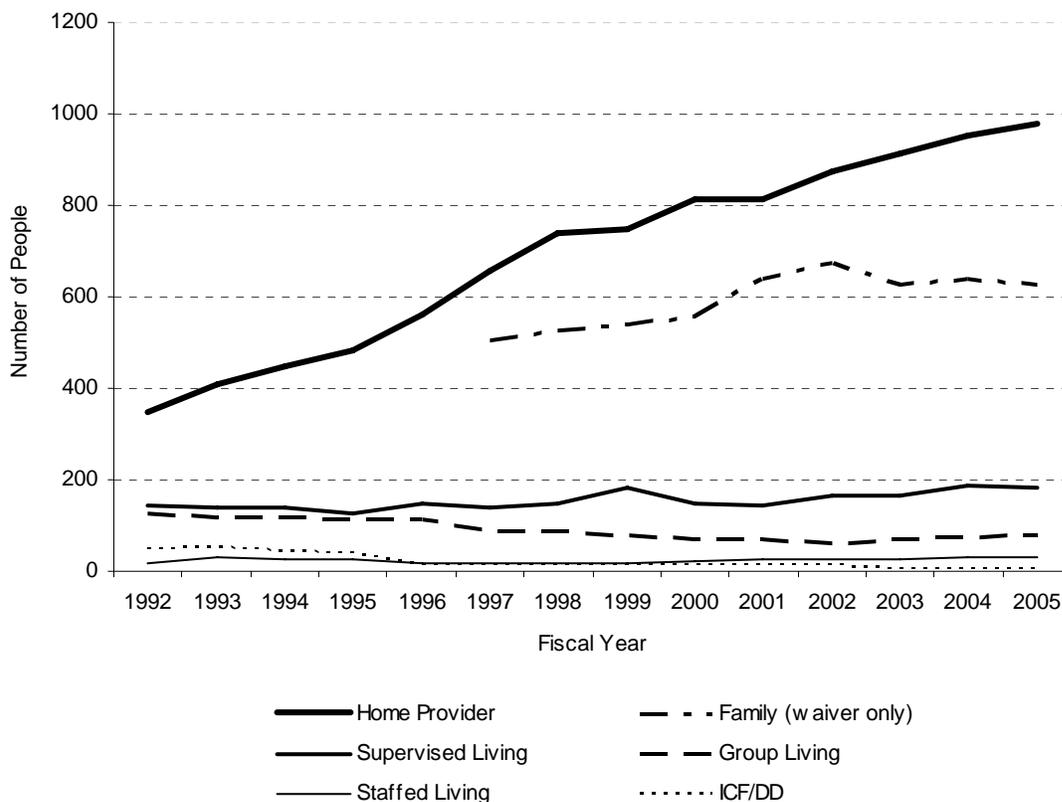
**Cost per Person (Waiver Funding) by Type of Home Compared to Numbers Served
FY 2005**



²³ Ibid.

²⁴ The per person cost of Group Living was higher than Staffed Living in FY '05 due to an unusually high number of occasional group home vacancies during the year.

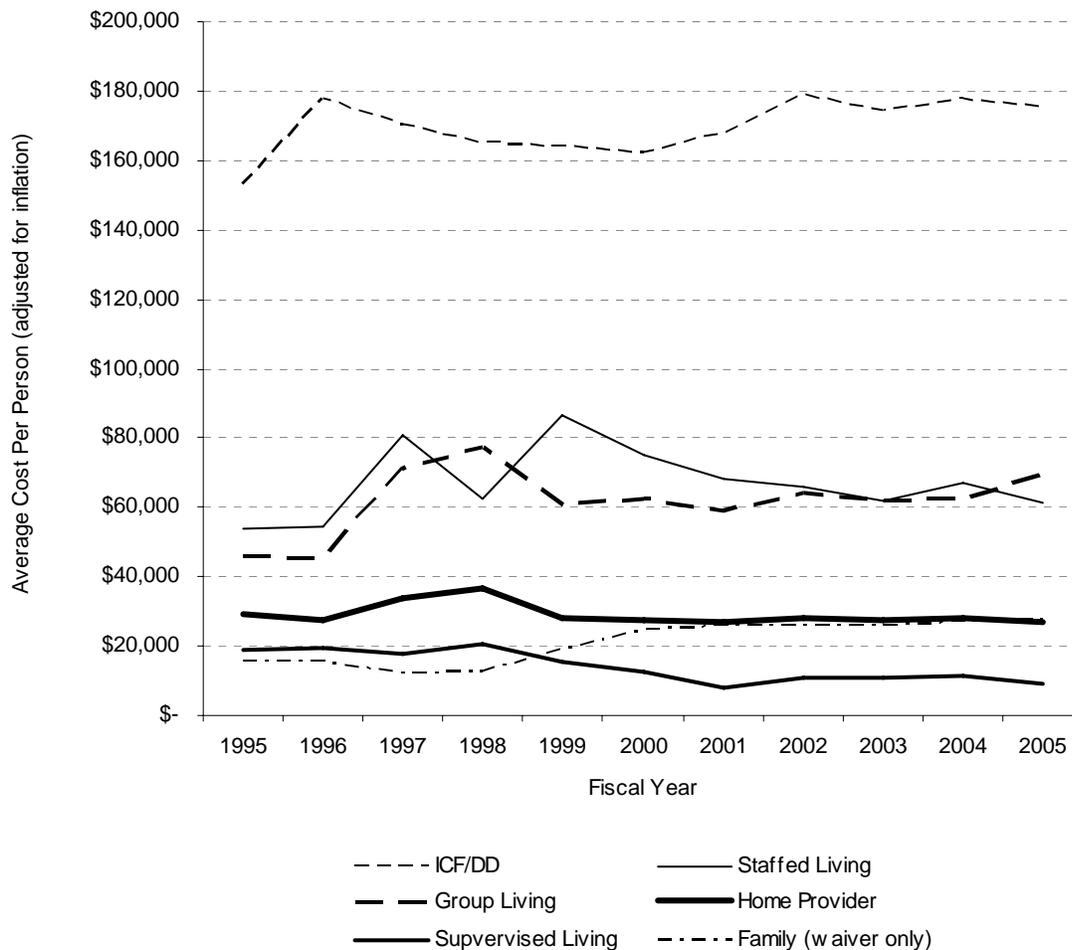
Population Change by Type of Home Setting FY 1992 – FY 2005



- **Home Provider** residential settings have **steadily increased** throughout the past decade. They make up **77%** of all residential support options.
- **Families** whose family member lives at home and receives waiver-funded supports has been in a **recent downward trend**. This is due in part to the elimination of waiver funding for newly identified children (under age 18)²⁵.
- **Supervised Living** has fluctuated over time, with the numbers having **increased slightly** overall.
- **Group Living** **steadily decreased** over time, though rose slightly in FY '03 (conversion of six-bed ICF to group home), FY '04 and FY '05 (opening of two new homes to address unmet needs).
- **Staffed Living** dropped down to a low of 19 in the late 1990s, but has been on a **slow but steady rise** the past few years.
- **Intermediate Care Facilities for people with Developmental Disabilities** have **steadily decreased** over time; only one remains open.

²⁵ Data for family (waiver) supports for FY 1998 and FY 1999 are estimated.

Average Cost per Person by Type of Home Setting FY 1995 – FY 2005



- The cost of **Intermediate Care Facilities** has **steadily increased** over the years, then leveled out, reflecting the intensity of medical support provided since 1998 in this type of home.
- The cost of **Staffed Living** has generally been on a **decline** the past few years, with a brief increase in 2004.
- The cost of **Group Living** has fluctuated some, but overall costs have **remained stable**. The costs in FY '05 were a bit higher due to an increase in vacancies.
- The cost of **Home Provider** settings has remained fairly **steady** over time. Since home providers make up the majority of residential options, these shared-living arrangements continue to be cost effective.
- The cost of **Supervised Living** has **decreased steadily** over time.
- The cost of **Family Support** funded by the waiver has **risen steadily** over the past number of years.



What **consumers** said about home supports:

- **91%** said they liked where they live.
- **80%** of the people who live alone said they like living by themselves.
- **89%** said they like the people they live with²⁶.
- **96%** said they like the food where they live.

Areas of Focus



In FY 2005, an estimated **263** people were reported as living in a home they either **own (22) or rent (241)**. Efforts to support more people to successfully live in their own home or rent their own apartment need to be increased.



Vermont continues to increase in-home family support while decreasing more costly, congregate residential settings, yet more focus needs to be put on developing alternative **individualized home support options**.



Home safety reviews were conducted on **184** homes and **accessibility reviews** were done on **11** homes in FY '05. Of those inspected homes, 154 were or became in compliance. There were a remaining 30 homes that had not yet met compliance at the end of FY '05. Three agencies²⁷ arranged for their own safety and accessibility reviews.



What **consumers** said about home supports:

- **51%** said someone else chose the place where they live.
- **37%** said someone else chose who lives with them.
- **35%** said they would like to have more chores to do at home.
- **39%** said someone else decides when they can have friend or family over to visit.
- **22%** said they cannot be alone with friends when they come to visit.
- **35%** said when people in their house go somewhere they have to go too.
- **43%** said they do not have a key to their house.

²⁶ This percentage is based on the person with whom the individual lives (paid and unpaid) that the individual's first response was about.

²⁷ HCS, NKHS and UCS.

Scott's Story

This year has been quite monumental for Scott. In the short three years that Scott has lived independently, he has identified and achieved remarkable goals, which have required practice and skill building. Scott continues to appreciate living in his apartment in Newport. Scott has remained in-touch with his parents who have been supportive "from afar" and who are proud of his efforts and successes.

Scott has had several part time employment positions in the past, but this spring Scott connected with Al's Snowmobile, a local business, and was invited to "try it out" by substituting for a custodian who needed time off. This was so successful, and Scott performed the duties so well, that the employer extended the custodial duties and offered him a few hours each week at minimum wage. Scott's performance surpassed the owner's expectations and he was invited to move from this position to that of "parts cleaner". Scott's hours grew in this position from six to fifteen hours per week. Scott understood his duties, performed them independently, and enjoyed going to work each morning. Scott anticipated these hours growing to between 20 – 25 hours by fall. Scott deposited each paycheck to meet his financial responsibilities and to save enough for the "fun things and times" he wishes for.

This employment opportunity gave Scott the skills and experiences, which led him to his current job performing custodial services for an off-campus alternative site sponsored by North Country Union High School. He works 14 ½ hours each week with minimal support. Scott's hope is that he will work through the school calendar year at this job and then clean parts at Al's during the summer months.

Scott budgets his time to include the many activities he enjoys. Scott likes having adequate time each day to meet with and enjoy friends, spend time with his girlfriend, frequent the Drop In Center in Newport, participate in Global Campus classes, and perform skill-building practices as part of his Assisted Living Skills support plan. Scott expresses that his life is full of the activities he enjoys, and he wishes to continue to grow and learn, assuring that his independent lifestyle will continue.

Last semester Scott led a discussion group at Global Campus entitled, "Disability Studies Language." This experience was so meaningful to him that he has offered to again lead a group this semester. When discussing his teaching endeavor Scott comments that he has always been afraid of school and being taught things he did not need or use. Global Campus has made him comfortable with exploring new areas of study and thought.

Several months ago Scott released information to his Service Coordinator regarding his diminished vision, which apparently has been an ongoing problem for him since elementary school. Scott has hidden this fact from his family and staff at Northeast Kingdom Human Services because he believes reading glasses will make him look badly and that friends will pick on him. His doctor recently suggested that Scott would probably need to be fitted for corrective lenses within a couple of years. Scott is accepting this possibility and understands if he does not correct the problem soon he may suffer the consequence of faster deterioration of vision. He does not want this to happen.

Scott loves the independent lifestyle he has become accustomed to including maintaining his own apartment with only minimal support from the agency. Scott continues to grow in experiences and knowledge. He is willing to participate in many new activities within his home and in the community at large. Scott has proven that he is capable of living independent of his parents, and he looks forward to the day when the skills he is now practicing become second-nature and he is able to live with only very minimal support from the agency.

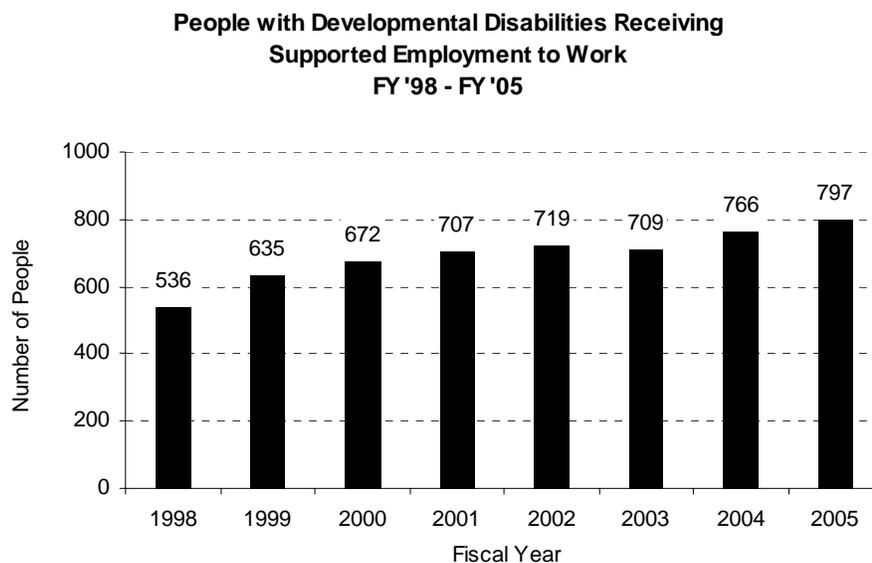
Employment Services

Numbers Served – FY 2005	
Average hourly wage	\$7.74
Average hours worked per week	12 hr./wk.
Estimated public benefits (SSI) saved	\$1,090,296
Total people employed	797

Employment Services assist individuals in establishing and achieving career and work goals; includes employment assessment, employer and job development, job training and ongoing support to maintain employment. Participation in the workforce results in a lasting positive impact to the person and to the public by way of an increased presence of people with disabilities making up the social fabric of Vermont. Supported Employment has traditionally been funded through a collaborative effort between the Division of Disability and Aging Services and Division of Vocational Rehabilitation (VR) by using home and community-based waiver and VR Transition grant funds.

Highlights

- ★ The number of adults with developmental disabilities getting supported employment to work continues to rise; going up **49%** in the past **7 years**²⁸.



- ★ **37%** of working age adults receiving developmental services are supported to work. This is about the same as the national percentage of people with *all* disabilities that report being employed²⁹.

²⁸ The reported number of people receiving supported employment in FY '04 and FY '05 does not include people self-/family-managing their work supports. It also does not include some individuals who transitioned out of follow-along supports to fully independent work.

²⁹ 2004 National Organization on Disability, *Harris Survey of Americans with Disabilities*.

- ★ Vermont is ranked **#1** in the nation (FY '04) in the number of people with developmental disabilities who receive supported employment to work per 100,000 of the state population³⁰.
- ★ Vermont is ranked **7th** nationally (FY '04) in people in supported employment as a proportion of total people getting community supports and/or work supports³¹; 43% in Vermont compared with the national average of 24%.
- ★ The average wage for people receiving employment services (\$7.74) continues to rise every year and is considerably **higher** than minimum wage in Vermont in 2005 (\$7.00).
- ★ What **consumers** said about work supports:
 - **90%** said they like their job.
 - **90%** said the work they do is important.
 - **81%** said people respect them at work.
 - **89%** said they get a vacation from work.

Areas of Focus

- ◎ National data show that 2 out of 3 unemployed adults with disabilities want to work³²; yet over **1350** adults with developmental disabilities (ages 18 – 65) in Vermont who receive services are not employed. Of those interviewed who are unemployed, **58% said they want a paid job**³³.
- ◎ What **consumers** said about work supports:
 - **58%** said someone else chose their job coach.
 - **14%** of the people who said they had a lot of different people support them at work said it was a problem for them.
 - **51%** said they have to go to work; it was not their choice.
 - **51%** said they would like to work more hours.

³⁰ *The State of the States in Developmental Disabilities: 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Preliminary Report, 2005.

³¹ Ibid.

³² Ibid.

³³ Data is based on results from *Survey of Adult Consumers of Developmental Services 2005 Report* and include all participants (those interviewed and those not interviewed).

Suzanne's Story

Suzanne has received services through Supported Employment for the past several years. Suzanne has always been interested in jobs that are typically performed by males, such as furniture manufacturing (sanding department) and janitorial positions. Suzanne had a great desire to break out of entry-level work. With the help from her team, Suzanne pursued training with the Northern New England Trades Women – Step Up for Women out of Montpelier, VT. This six-week program trained Suzanne in plumbing, carpentry, and electrical fields.

Upon completion of the program, her team helped her land a plumbing apprenticeship position with Bell Construction based out of NY. She worked with Master Plumbers learning all aspects of plumbing and heating. Suzanne did this for two years and, because of her training and experience, she was able to earn a higher rate of pay than what an average entry-level job could offer. For the past several years, she has worked with companies such as McCarthy Construction out of St Louis Missouri working on the project at Dartmouth Hitchcock Medical Center, and MJ Hayward out of Lebanon, NH working as a carpentry assistant.

Suzanne currently is working as an insulation installer for Dayco Inc. out of Sharon, VT. Because of Suzanne's determination and desire to boost her vocational options and interests, she has been able to purchase her own home, drive a newer vehicle and have financial stability in her life.

Jonathan's Story

Jonathan³⁴ has been employed successfully at Bisbee's Hardware in Waitsfield for just over 5 years. He has many co-workers who offer a wide range of supports for him. These natural supports complement nicely the part time support he receives from United Employment Services.

One of Bisbee's staff works primarily as Jonathan's supervisor, with a co-worker as backup throughout the week. Both collaborate and plan how to best assist during all hours of Jonathan's employment, especially when the supervisor is not on hand. Jonathan's knowledge of the products and inventory is of great benefit to the business. He is often referred to by co-workers for assistance. Jonathan has shown some significant gains and improvements during this time.

Jonathan strives to build relationships with co-workers. He and his supervisor have a unique bond which enables them both to get thru each day. Jonathan takes great pride in succeeding and seems to want to do the right thing. United Employment Services acknowledges the tremendous amount of effort that both Jonathan and his supervisor work on to create the quality employment setting that has grown over the years. Everyone involved participate in good humor and all employees are treated with respect. This makes for a good atmosphere for people to share in a quality work experience.

³⁴ Jonathan is a pseudonym.

Community Supports

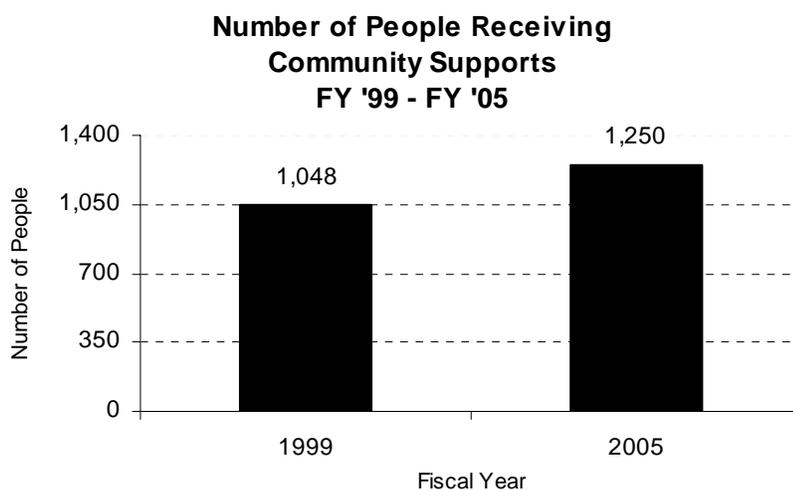
Numbers Served – FY 2005	
Total annual cost of community supports	\$17,443,449
Total people receiving community supports	1,250

Community supports provide specific, individualized and goal oriented services that assist individuals in developing skills and social supports necessary to promote positive growth. These services may include support to participate in community activities, assist with daily living, and build and sustain healthy personal, family and community relationships.

Highlights

- ★ Community supports are **tailored to the needs and interests of the individual** as determined by the person’s individual support plan. Community supports typically take place in and around a person’s home and community.

- ★ There has been a **steady increase** in people getting community supports over time.



- ★ What **consumers** said about individual community supports:
 - **96%** said they like their community supports.
 - **90%** said people who they spend time with during the day respect them.
 - **89%** said they go shopping; of whom **55%** go as often as they want.
 - **94%** said they go out on errands, of whom **77%** go as often as they want.
 - **88%** said they go out to eat; of whom **63%** go as often as they want.
 - **89%** said they play sports; of whom **59%** play as often as they want.

Areas of Focus

- ◎ People continue to report the desire for more work opportunities; yet, the percentage of people receiving community supports (versus work supports) remains fairly high. Over 300 people have decided to split their funding for both work and community supports. More people need to be **informed about the option** to transfer some or all of their community support funding to work supports so they can get a job.

 - ◎ Creative development of activities and community connections are needed to strengthen supports that allow adults to pursue their interests and achieve their **personal and educational goals**.

 - ◎ What **consumers** said about individual community supports:
 - **46%** said they would like more hours of community supports.
 - **35%** said they do not make the choice to go to their community activities.
 - **41%** said they wish they had more friends.
 - **61%** said they don't ever go to church, of whom **43%** would like to.
 - **30%** said they don't ever go out for entertainment, of whom **54%** would like to.
-
-

Hearts to Hands

Hearts to Hands was born in 2002. It was founded on the philosophy that all consumers are entitled to receive quality programs that meet their emotional, physical, educational, and recreational needs and wants. Anne, Kim and Suzanne are long term direct support workers to people served by Howard Community Services (HCS) and initiated a person centered group. The group strongly supports the persons' right to spend time with their peers engaged in meaningful activities. The Hearts to Hands belief is that these activities should encompass a process of life-long learning and purposeful contributions to the community at large. Hearts to Hands has a mission that dovetails nicely with the HCS vision of a community which embraces all people, respects their unique contributions, and provides them with opportunities to live, learn and grow together.

The Hearts to Hands program provides multiple benefits for consumers and other direct support workers. Anne, Kim, and Suzanne, serve as positive role models and embrace an attitude that anything is possible with a focus on the abilities of people rather than the disabilities. The three women each bring a unique and caring perspective to the program:

- *Anne majored in social work which is reflective of her belief that "learning is lifelong". She is caring, compassionate, and always puts other people before herself. She is appreciated for her willingness to go above and beyond in providing quality service, a strong work ethic, and true caring of others.*

- *Kim describes herself as “always having a soft spot for people with special needs.” Her positive attitude is reflected in her belief that “No matter what kind of day you’ve had, you can always find one good thing to be thankful for.” She is seen as the “eternal optimist” and is appreciated for her great sense of humor and unending enthusiasm.*
- *Suzanne provides Hearts to Hands with “comic relief”. She is passionate about providing quality services and feels the three women “bring out the best in each other”. She is appreciated for her calm caring nature, her terrific ability to plan parties, and her zest for humor.*

Hearts to Hands offers many different activities that include opportunities for skill building, community connections, recreation, and self-advocacy. Some of the many ongoing activities include craft classes, cooking classes, brunches, birthday parties, volunteer opportunities, individually-tailored exercise programs, Bingo, holiday parties, spa days, day trips, advocacy opportunities, and basket and flower making. Each activity or program planned is in keeping with the concept of being purposeful and actively engaging consumers and their support people. The reoccurring themes that resonate throughout Hearts to Hands are that activities must be inclusive and accessible, promote participation and positive experiences, and involve giving to others.

Offering activities and programs like these does not come without challenges. Hearts to Hands has had to be very creative. Anne, Kim, and Suzanne devote substantial amounts of time planning and implementing these programs. One of the most challenging problems has been finding large enough, cost-free space for events that is conveniently located. However, Hearts to Hands has shown that excellent person-centered programs can be created without a lot of money. Anne, Kim, and Suzanne are truly exemplary in their enthusiasm, bringing with them collaboration, networking, knowledge and a passion for the true meaning of “human service.”

Family Supports

Numbers Served – FY 2005			
Funding/Supports for Families	Adults (22 and over)	Children (under 22)	Total
Flexible Family Funding recipients	150	690	840
Home and community-based waiver recipients	372	253	625
Respite/In-home supports	248	237	485
Other Supports (Employment/Community Supports)	317	84	401
(Duplications between FFF and HCBW)	(62)	(34)	(96)
Total family supports (unduplicated)	460	908	1,369

Family Supports: Flexible Family Funding or home and community-based waiver-funded supports (e.g., respite, family support, employment services, community supports) provided to people living with their natural or adoptive family.

- **Flexible Family Funding (FFF):** Money provided to eligible families with children or adult family members with disabilities living at home used at their discretion toward services and supports that are in the person’s/family’s best interest. Examples of what may be purchased with the funding include, family respite, special needs/services not paid for by insurance, household items, etc. The maximum amount available to a family of an adult or child is generally \$1,122 per year.
- **Home and Community-Based Waiver Funding (HCBW):** Varying degrees and types of more intensive family supports intended to help maintain family stability, enhance positive family interaction and keep the family intact. Services may include providing support to the individual, family-directed respite, service coordination, work supports, community supports, behavioral consultation and skills training that, consequently, help the individual to continue living at home with his or her family.

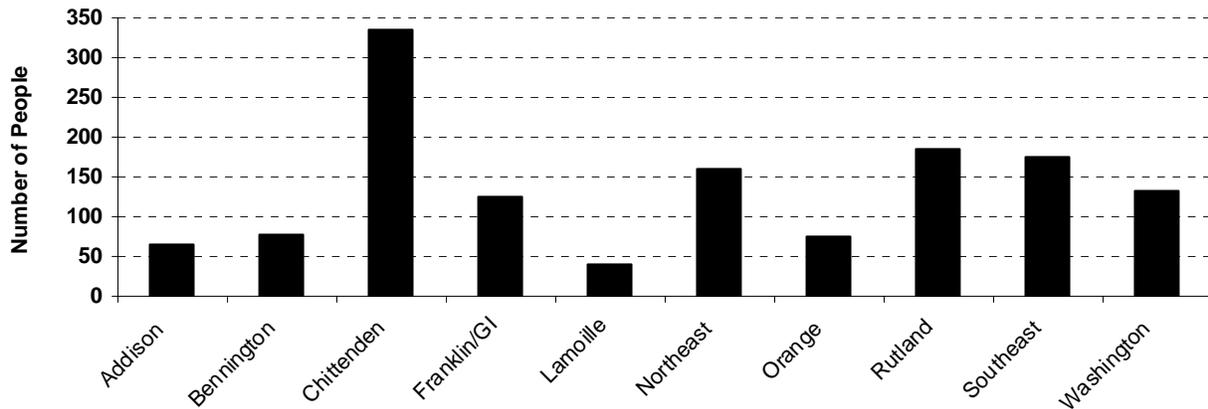
Highlights

- ★ The number of families getting just Flexible Family Funding almost **doubled** in the past **8** years, versus 24% growth in waiver-funded family support and 40% growth in home supports.
- ★ People receiving family support represents **44%** of all people served. This is up from 30% back in FY '96.

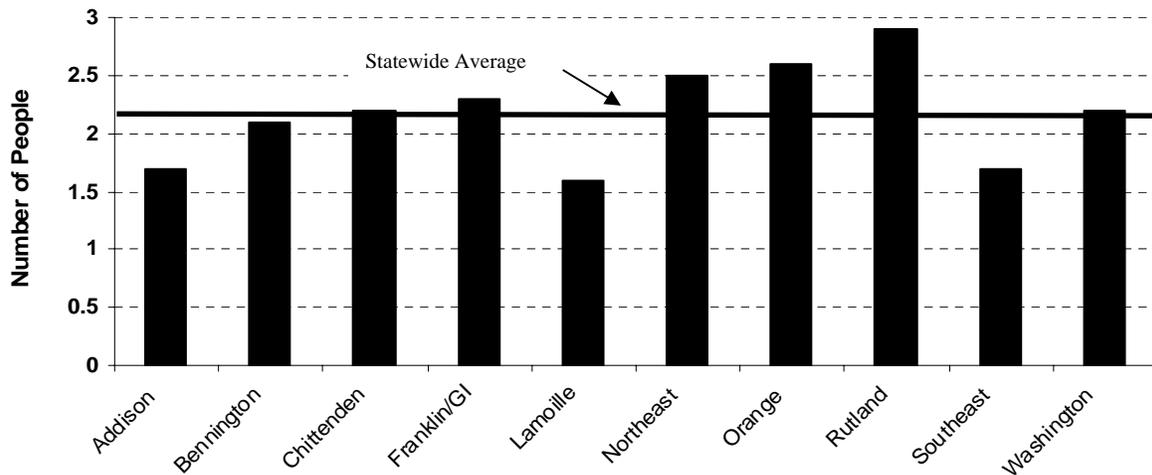
★ Family supports are provided statewide to an average of **2.2 people per 1000 Vermonters**³⁵.

Family Support to People Living at Home (Flexible Family Funding and Waiver) FY 2005

**Total People Served Living at Home with Family
(unduplicated)**



**People Served Living at Home with Family Per 1,000 Population
(unduplicated)**



³⁵ Population estimate source: State and County Population Projections 2000 - 2020, Massachusetts Institute for Social and Economic Research, University of Massachusetts, Amherst, August 2003.

- ★ The Division of Disability and Aging Services funded **four** respite homes around the state to provide planned out-of-home respite support to **44** eligible individuals. In FY '05, **29 adults** and **15 children** received out-of-home respite for a total of **609 days**.
- ★ Transition II became the **Supportive Intermediary Service Organization** (Supportive ISO) to assist people with disabilities and families to manage their own services and hire their own workers. In FY '05, **43 people self- or family-managed** their developmental services.
- ★ Vermont ranks **6th** in the country in terms of total family support spending per family³⁶ as a percentage of total developmental disability spending.
- ★ One third, or **31%**, of people who receive home and community-based waiver services live with their family.

Areas of Focus

- ◎ Waiting lists continue for families applying for **Flexible Family Funding**. This small fund is a valuable resource for families and also helps avoid the need for more intense and costly out-of-home services.

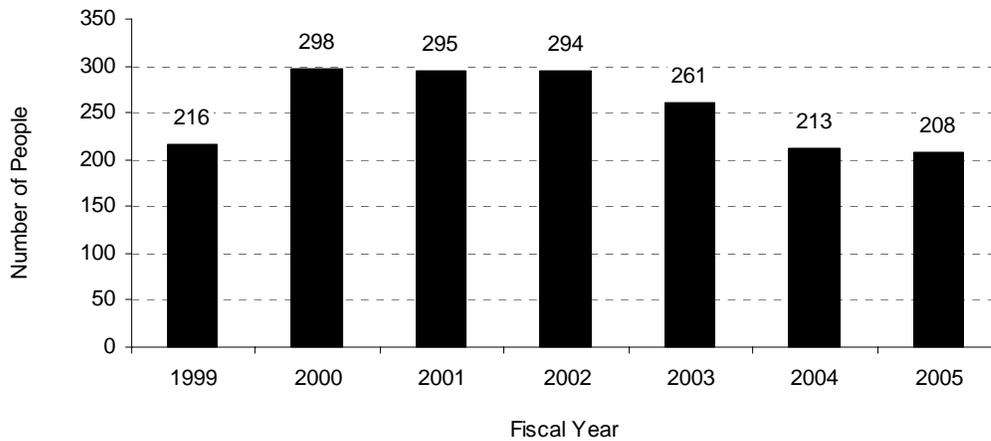
³⁶ *The State of the States in Developmental Disabilities: 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Preliminary Report, 2005.

Children’s Services

Numbers Served – FY 2005				
Funding/Support for Children	Birth – 6	7 – 18	19 – 21	Total
Flexible Family Funding recipients	136	457	97	690
Home and community-based waiver recipients	9	222	150	381
Lives with family	5	184	65	254
Does not live with family ³⁷	4	38	85	127 (37 w/DCF)
Other: Medicaid, vocational grant, self/private pay	0	18	35	53
(Duplications between FFF and HCBW)	(1)	(29)	(11)	(41)
Total children services (unduplicated)	144	668	271	1,083

Children’s Services are provided to children and youth with developmental disabilities who live with their biological or adoptive families and those who live with other individuals (e.g., other relatives, foster care). Services may include Flexible Family Funding, service coordination, respite, clinical and/or support in the home. Services for youth over age 18 may include work or community supports as well as home supports.

**Children (under 18) on Medicaid Waiver
FY '99 - FY '05**



Highlights

★ Children’s Personal Care Services (CPCS) and High Technology Home Care (HTHC), Medicaid-funded services, were transferred to the Division of Disability and Aging Services on July 1, 2004 (see page 47). The eligibility definition for these services is broader than the Vermont definition used for developmental disabilities services.

³⁷ The four children under age 7 who are listed as “not living with family” live either in a shared parenting situation and therefore live with family on a part time basis, or the child receives foster care through the Department for Children and Families (DCF). Thirty-seven (37) of the 38 children ages 7 – 18 who do not live with family receive foster care through DCF.

- ★ DDAS developed a new Autism Specialist position in FY '05 to address systems issues within the Agency of Human Services that relate to services for individuals with Autism Spectrum Disorder (ASD) in their homes and communities. The initial task of the Autism Specialist will be to conduct a statewide assessment of what currently exists to support individuals with ASD, to identify gaps and develop recommendations to addressing service gaps.

Areas of Focus

- ◎ There continues to be an **increase** in the number of children being diagnosed with **Pervasive Developmental Disorders**. However, no new waiver funding except for children at risk of institutionalization has been available to children since the December 2001.

Kristen's Story

Kristen is a lovely, little 11 year-old girl who moved in with her aunt, uncle and cousins, approximately two years ago. While this arrangement was expected to be temporary, Kristen has found a stable and happy home, where she—with the help of a blend of supports—is thriving.

Kristen has non-ketotic hyperglycinemia, a rare genetic disorder, which necessitates technology and nursing for her survival and to remain at home. Until about 6 months ago, the services that Kristen accessed were High-Tech Home Care, including shift nursing, and Flexible Family Funding. Faced with difficulties in scheduling nursing shifts, Kristen's family was quickly becoming burnt out and she was at risk of losing her home to a pediatric nursing home placement.

Community Access Program and the Rutland Area Visiting Nurse and Hospice quickly assisted the family in applying for Children's Personal Care and developmental services waiver funding to help support Kristen to remain at home and receive her needed care from people who love her. It became clear that the fragmented mix of services were not meeting Kristen's needs. A new concept – Unified Service Plans – was developed, creating a full package of supports allowing for an ever changing mix of caregivers responsive to Kristen's specific needs. This provides nursing level oversight, but also the flexibility for her aunt to hire her own employees who have been trained for Kristen's unique needs.

Since developing the new supports, Kristen's life has only continued to improve; she has been able to remain with her family and friends and to attend her local school. As a whole, her family can better enjoy quality time together, and for times when Kristen can't attend community events with her family, they are comforted knowing that skilled caregivers are home with her.

Medicaid Entitlement Services

Numbers Served – FY 2005	
Children’s Personal Care Services recipients	1,302
High Technology Home Care recipients ³⁸ (some dups with CPCS)	119
Total people served (unduplicated)	1,364

Children’s Personal Care Services (CPCS) provides 1:1 staffing for Medicaid eligible children (under age 21) with disabilities to assist with activities of daily living (e.g., bathing, dressing, feeding, toilet use, grooming, positioning, transferring and walking) and to enhance skill building to achieve greater independence. These services are a state-plan Medicaid service and are therefore an entitlement for those children who qualify, and can be either family-managed or provided by an agency.

Demographics of CPCS enrollment:

- **12 years old** is the average age of children who are enrolled in CPCS.
- **25 hours** is the average number of hours authorized per week for CPCS.
- **68%** of the total hours allocated is used by recipients.
- **52%** of people getting CPCS received developmental disability waiver funding or Flexible Family Funding.
- **79%** of CPCS are family-managed.

High Technology Home Care (HTHC) is an array of intensive home care services for both adults and children. The program provides skilled nursing care and high technology aids for technology-dependent Medicaid beneficiaries and coordinates treatments, medical supplies and sophisticated medical equipment. The goal is to support the transition from the hospital or other institutional care, to the home, or prevent institutional placement. The number of active recipients in FY ‘05 was 119, with the majority of these being children.

Highlights

- ★ A broad stakeholder group helped guide the **redesign** of the CPCS program. The group provided assistance in the development of written guidelines and a new assessment of need.
- ★ The six month **assessment of need** renewal period was **extended to one year**.
- ★ A **Quick Reference Guide** was developed to help families manage their CPCS. An estimated **79%** of families getting CPCS hire their own employees.

³⁸ This number was adjusted from an earlier published estimate of 125 after reviewing EDS data.

- ★ The number of people receiving High Tech Home Care services reached an all time high in FY '05 with a **21% increase** from the year before.

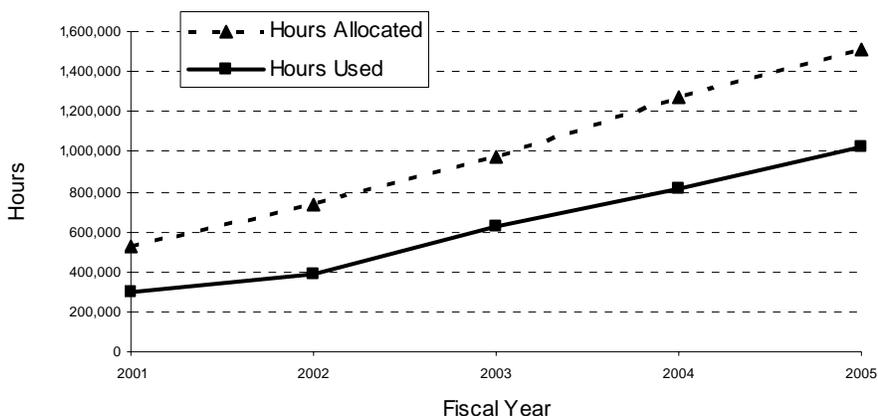
- ★ A confidential statewide **family survey** was conducted in August 2004 to ask about satisfaction with Children’s Personal Care Services. The Division of Disability and Aging Services had only just taken over management of the CPCS program and this survey was an effort to get some baseline data to guide and assess future changes to the program. The survey was sent to 1,237 families of individuals who were receiving CPCS, of whom 379 responded (33% response rate). The *Vermont Children’s Personal Care Services Program Status Report*, provides results of the survey.

- ★ What **families** said about Children’s Personal Care Services:
 - **78%** said the application process happened in a timely way.
 - **83%** said the Notice of Decision was provided in a timely way.
 - **85%** said Personal Care services made a positive difference in their family member’s life.
 - **95%** said Personal Care services are available when needed.
 - **88%** said Personal Care services are helpful overall to their family member’s well being.
 - **Additional benefits** are provided from Children’s Personal Care Services (e.g., respite, social and community activities, supervision, skill training)

Areas of Focus

- ◎ Despite the increase in percentage of hours used, only **68%** of the total hours allocated are able to be used by recipients of CPCS.

**Children's Personal Care Services
Hours Allocated vs. Hours Used
FY '01 - FY '05**



- ◎ Initial efforts have been made to **integrate children’s services** within DDAS through the developmental disabilities waiver, Flexible Family Funding, CPCS and HTHC in order to be more flexible, creative and economical. Currently there are 311 people who get CPCS and/or HTHC funding in addition to waiver funding.

Overlap of Funding – FY 2005

	CPCS	HTHC	WAIVER	FFF
CPCS		57	300	413
HTHC			22	29
WAIVER				96

- ◎ A shortage of nurses has made it difficult to get the needed care though HTHC. This has been partially remedied by some families and agencies using a variety of caregivers with differing nursing degrees and training.

- ◎ Finalize the new *Children’s Personal Care Services Program Guidelines* and *Children’s Personal Care Services Application, Assessment of Need and Care Plan*.

- ◎ What **families** said about Children’s Personal Care Services:
 - **45%** said they had problems with workers not showing up or canceling at the last minute.
 - **55%** said a frequent change in workers was a problem.
 - **28%** said some or all Personal Care hours are not used because families can’t find workers due to low wages, times when work is needed, difficulty of work, and lack of benefits.

Clinical & Crisis Services

Vermont Crisis Intervention Network Numbers Served – FY 2005	
Level II – Technical assistance Number of people supported (est.)	90
Level III – Crisis beds	
Number of stays	27
Number of total days	607
Avg. length of stay (range 4-48 days)	22 days
Institutional diversions Number of people diverted (est.)	18

Clinical services include assessment, therapeutic, medication and/or medical services provided by clinical or medical staff. **Crisis services** are time-limited, intensive supports provided for individuals who are currently experiencing, or may be expected to experience, a psychological, behavioral or emotional crisis, and includes crisis assessment, support and referral, and crisis beds. Designated Agencies are required to provide crisis services in their region. The Vermont Crisis Intervention Network provides statewide crisis services.

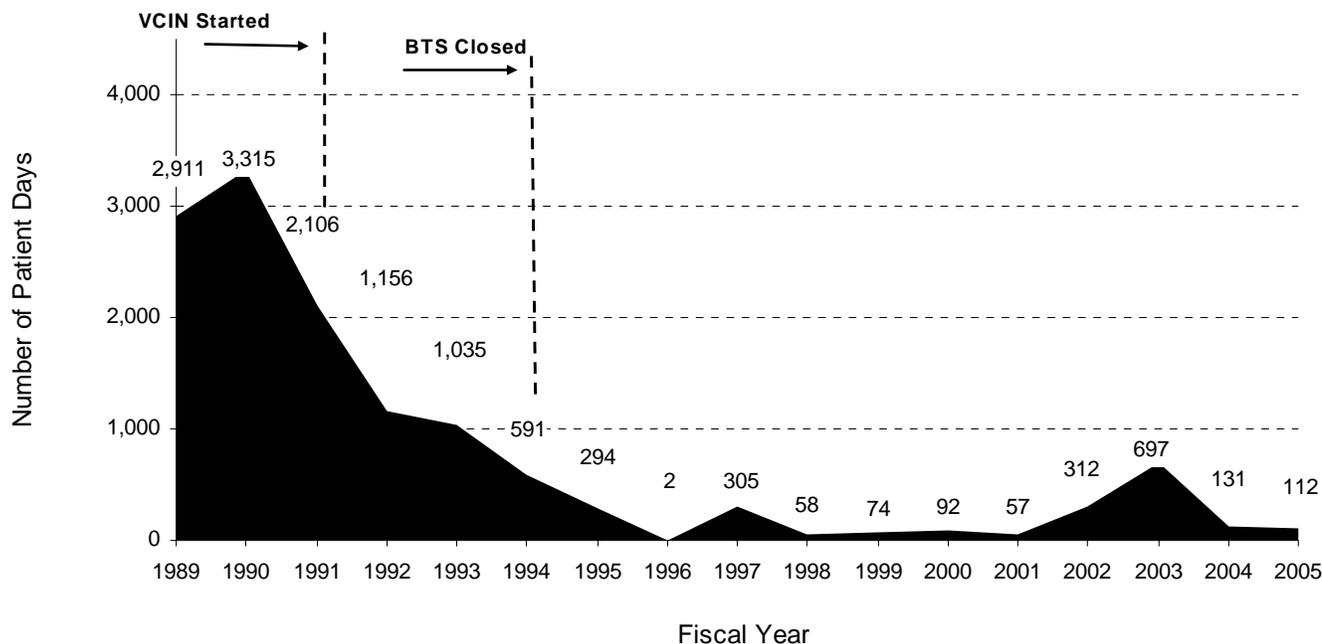
Vermont Crisis Intervention Network (VCIN), established in 1991, develops services and supports for people with the most challenging needs in the community to prevent their being placed in institutional care. The Network combines a proactive approach designed to reduce and prevent individuals from entering into crisis with emergency response services when needed.

Highlights

- ★ The availability of the statewide **Human Rights Committee** to review restraint procedures and the provision of training in the development of positive behavior support plans have assisted agencies to provide safer and more effective supports to people with the most challenging needs. There were nine case reviews of Behavior Support Plans by the Human Rights Committee in FY '05.
- ★ Expanded the Human Rights Committee for review of public guardian’s decisions to change a person’s home placement.
- ★ Developed a system for collecting **regional crisis bed** usage to begin in FY '06.

★ The inception of the **Vermont Crisis Intervention Network** in March 1991 greatly reduced use of the Vermont State Hospital by people diagnosed with mental retardation. In addition, local community resources were developed as part of the Brandon Training School closure efforts (FY '91 – '94) and further enhanced during FY '01 – '02.

**Vermont State Hospital Utilization³⁹
by People Diagnosed with Mental Retardation
FY 1988 – FY 2005**



Areas of Focus

- ◎ Improve documentation of local crisis bed use and continue evaluation of local and regional **crisis bed use** to assist in the efforts to increase local and regional clinical and crisis capacity.
- ◎ Explore the expansion of the **Human Rights Committee** to other DDAS services.

³⁹ These numbers do not include people with dual diagnoses who are being served through the mental health system and/or are not in need of developmental services. It does include people served by developmental services but paid in full by mental health or who were grandfathered into services by having received services on 7/1/96, but who are not diagnosed with MR/DD. As of FY '97, these numbers include people diagnosed with Pervasive Developmental Disorders (PDD).

Janet's Story

I met Janet⁴⁰ when she was 20 years old in January 2005. I was assigned as her case manager as she began the process of leaving her parents home. After searching for a place to live, Janet eventually moved to a shared living home in Brandon. Things started out very well and have continued for the most part. Janet wants to do many things and has a lot of ideas and plans.

One of the big issues for Janet was deciding that she did not want her mom and dad to be her guardians anymore. We helped her figure out how to do that and supported her in the paperwork and meetings to make that happen. Janet wrote a great letter to the judge explaining why she did not want her family to be her guardian. It was probably one of the first times Janet had said she wanted something to happen, been supported to get through all the steps and had it turn out the way she wanted in the long run.

We have been working hard to help Janet make long term plans for her life and help her figure out all the steps to get there. Janet will continue to need help recognizing that she can't get there overnight. Going through the change of guardianship was the first step in recognizing that there is a process for things to happen. Janet couldn't just go to the judge and automatically get the guardianship modified. This change caused some problems in her relationship and contact with her mom and dad, but that has improved as time has passed. Janet is a good advocate for herself and knows that you don't take no for the first answer and sometimes you have to accept that it's not going to go the way you want right away. She's learning the process we all go through as we "grow up".

– Marcia Gadway, Case Manager
Community Access Program

⁴⁰ Janet is a pseudonym.

Nursing Home

Numbers Served – December 31, 2005	
People receiving specialized services	17
PASARR screenings	18
Diversions to keep people out of nursing facilities	6
Community placement of people from nursing facilities	0
Total people living in nursing facilities⁴¹	27

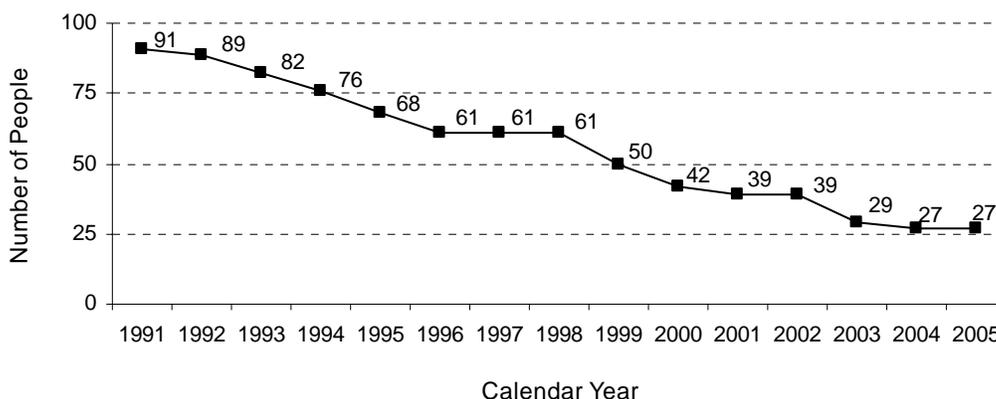
Pre-Admission Screening and Resident Review (PASARR): The Omnibus Budget Reconciliation Act of 1987 established PASARR which mandates the screening of all nursing facility residents and new referrals to determine the presence of mental retardation and/or related conditions and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services.

Specialized Services: The Division of Disability and Aging Services provides support to individuals with developmental disabilities who live in nursing facilities. These Specialized Services greatly improve the quality of life for people living in nursing facilities by providing support to address social and recreational needs as well as the person’s overall well being.

Highlights

- ★ The number of people with MR/DD living in nursing facilities has steadily declined (**78% overall**) since 1988⁴². There was a **31%** decline since 2002. It reached an all time low of 27 in December 2004.

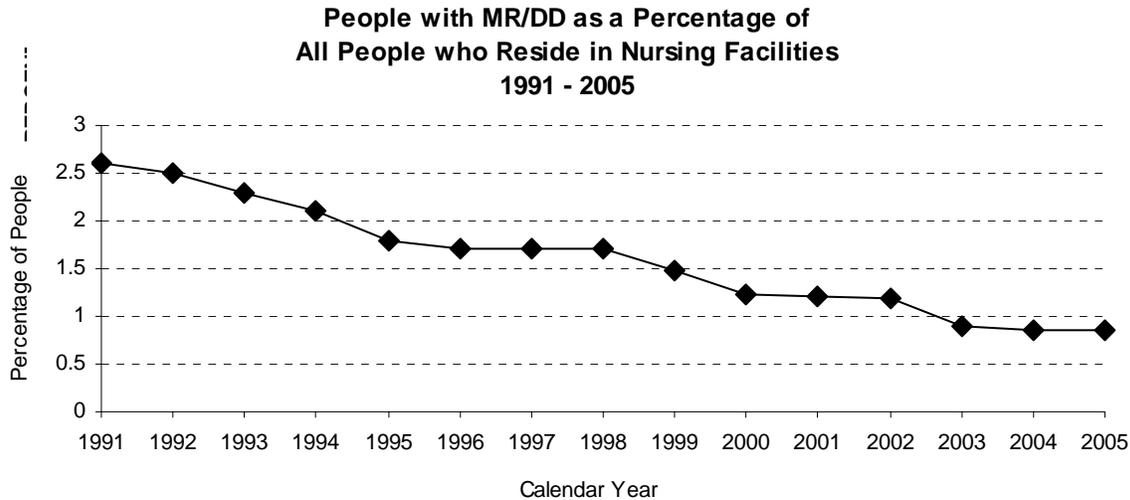
People with MR/DD who Reside in Nursing Facilities 1991-2005



⁴¹ PASARR uses the federal definition of “mental retardation or related conditions.”

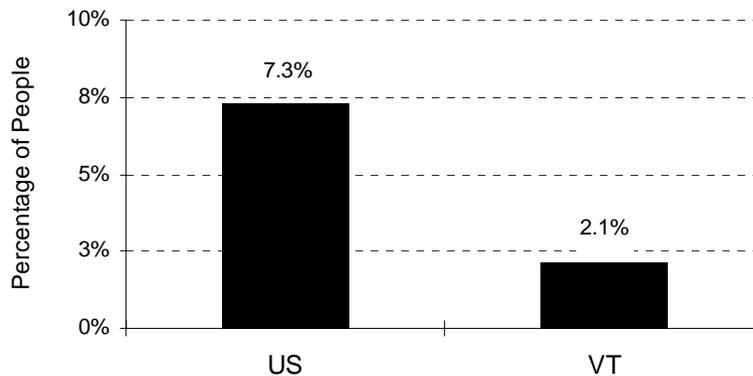
⁴² Based on the initial 1988 screening that found 125 people with MR/DD living in nursing facilities. The decrease in residents with MR/DD in nursing facilities has been accomplished, in part, through a combination of diversions through pre-admission screening and placements to more individualized settings in the community. Additionally, as would be expected from this elderly population, a number of deaths contributed to the decrease.

★ The national prevalence rate for people with developmental disabilities living in nursing facilities is estimated at 2.6% of the total nursing home population based on the federal definition of developmental disability⁴³. The Vermont rate of occurrence for people with MR/DD living in nursing facilities was **0.8%** in December 2005, **well below the national average**.



★ The number of people in Vermont with MR/DD in nursing facilities compared to all residential services for people with developmental disabilities in Vermont – **2.1%** – is **well below the national average (7.3%)**⁴⁴.

**People with MR/DD in Nursing Facilities as a Percent of All People with MR/DD Receiving Residential Supports⁴⁵
June 30, 2004**



⁴³ Based on 2002 Kaiser Family Foundation – www.statehealthfacts.com.

⁴⁴ Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2004*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2005

⁴⁵ Residential services include those provided under home and community-based waiver, ICF/DDs, and nursing facilities.

Self-Advocacy

Green Mountain Self-Advocates (GMSA) is a statewide self-advocacy network run and operated by people with developmental disabilities. The GMSA board includes representatives from the 16 local self-advocacy groups. See **Attachment I** for a listing and map of local chapters of *Green Mountain Self-Advocates*. The group comes together to listen to each other, make new friends, learn about people's rights and tell politicians and others why people with disabilities are important. Green Mountain Self-Advocates is building a movement for self-advocacy through public education and awareness, peer mentoring, support, advocacy and direct action.

- Board meetings are held monthly, four of which are on interactive television.
- Loans and grants are given to people who lived at Brandon Training School.
- Self-advocates teach free workshops on Staying Safe, Knowing Your Legal Rights, Legislative Advocacy, How to Start and Run a Self-Advocacy Group, What Allies Can Do to Support Self-Advocacy, Myth Busters, Disability Awareness, How to Support People to Make their Own Decisions, 7 Habits of Highly Effective People, and a series of 6 self-advocacy classes.
- GMSA facilitates the establishment of new self-advocacy groups and supports those already meeting.
- Members serve on local and statewide advisory boards and committees – *Nothing about us without us!*
- GMSA is an active member of a regional self-advocacy network called NEAT, Northeast Advocates Together; and the national organization SABE, Self-Advocates Becoming Empowered.

Highlights



Green Mountain Self-Advocates successfully completed the second year of a grant with the Division of Disability and Aging services to carry out objectives of the **Real Choices Project**. Activities included:

- The ***Get on Board and Make a Difference*** manual on effective strategies for including people with developmental disabilities on boards and committees was presented to an additional **6** agency boards and standing committees. Approximately **65** people participated.
- Seven local training teams consisting of people with and without developmental disabilities completed a **2-day training-of-trainers** enabling them to teach a series of six 2-hour self-advocacy workshops. These teams receive ongoing support and training from GMSA. In 2005, over **830** people participated in **49** introductory self-advocacy workshops.
- GMSA staff are certified to teach Steven Covey's ***7 Habits of Highly Effective People***. Five different **2-day leadership** retreats were held throughout the year to teach the 7 Habits to a total of **165** people. One of the retreats was specifically designed for high school students with disabilities.

- Real Choices staff from GMSA collaborated with family consultants from the University of Vermont to present **three workshops about self-advocacy to parents of high school students with disabilities**. The parents loved hearing stories about how self-advocates moved out and got their own place. It seemed to give them hope for their son and daughters to be more independent and to be making their own decisions.

★ This year's theme for our annual statewide Voices and Choices Conference was ***GMSA On The Rise***. The two-day self-advocacy conference featured 14 workshops including: Decision-Making and Talking About Sex; Rainbow Support Group for People who are Gay and have Developmental Disabilities; You Can be the Boss! Self-Managing Your Services; The Joys and Pains of Working! All You've Ever Wanted to Know about Work and Were Afraid to Ask; Learn Self-Defense with Police Officer Chris; and Safety Awareness for Everyone. A total of **420** people attended the conference, with 300 staying overnight for a dinner and dancing which included a conversation with the Governor.

★ Presented a half-day **training to Service Coordinators** about self-advocacy and how to support people to make their own decisions.

★ Organized two mini-conferences about **healthy and unhealthy relationships** (one in the north and one in the south) with Katherine McLaughlin from Planned Parenthood.

★ In March, GMSA presented a day-long training of trainers for 40 special educators and providers on ***Stay Safe and Know Your Legal Rights***. This curriculum is used to teach high school students how to live and work safely in the community and protect their constitutional rights as US citizens. Each participant received a free copy of the curriculum plus student materials.

★ Four members participated in the ***Alliance for Full Participation Summit*** in Washington DC. This historic event brought together family and self-advocates, providers, and government and university officials to agree on a common agenda for the future.

★ Local self-advocacy groups from Rutland and Burlington were supported to teach **Disability Awareness** workshops to students at elementary and high schools. These classes are typically taught as part of diversity and anti-harassment programs.

★ Two self-advocates were hired to serve as **legislative advocates** one day a week at the State House during the legislative session. Self-advocates from across the state received support and encouragement when visiting their elected representatives in Montpelier. A toolkit was developed on how to speak up at the State House.

- ★ Sponsored a statewide **employment focus forum** on why people have a hard time finding and keeping jobs.
- ★ Collaborated with the Vermont Center for Independent Living and Vermont Domestic Violence Network to make **programs for survivors of abuse** more accessible to women with disabilities.
- ★ What **consumers** said about self-advocacy:
 - **48%** said they went to a self-advocacy meeting, conference or event.
 - **75%** of those who went to a self-advocacy meeting want to go again.
 - **86%** said they see themselves as being a self-advocate.
 - **76%** said they have a group of friends or family to help them make decisions.
 - **78%** said they think they have enough control over their life.

Areas of Focus

- ◎ Collaborate with providers to organize a **statewide conference on sexuality**.
- ◎ Publish a toolkit on **Alternatives to Guardianship**.
- ◎ Complete the **website** for Green Mountain Self-Advocates.
- ◎ Support members to present at the **national self-advocacy conference**.
- ◎ Contract with Vocational Rehabilitation to provide **peer leadership** activities to increase employment for people with developmental disabilities.
- ◎ Continue collaborating with **Vermont Center on Independent Living**.
- ◎ Increase **public awareness** about self-advocacy.
- ◎ Collaborate with Protection and Advocacy to offer workshops on **voting**.
- ◎ What **consumers** said about self-advocacy:
 - **53%** said they want to know more about self-advocacy.
 - **40%** of those who did not go to a self-advocacy meeting wanted to go.
 - **45%** of those who did not go to a self-advocacy meeting or event said they did not go because they did not know about it.
 - **57%** of those who did not vote in an election said they wanted to vote.
 - **45%** said they need to know more about how to interview their support workers.
 - **44%** said there are choices they wish they could make that they don't make now.

Office of Public Guardian

Caseload – June 30, 2005	
Guardianship services (developmental disability specialty)	554
Guardianship services (aging specialty)	53
Case management (developmental disability specialty)	17
Guardianship services – pending (developmental disability specialty)	12
Commitment order – Act 248 (developmental disability specialty)	25
Commitment order – pending (developmental disability specialty)	3
Total people in Office of Public Guardian program (unduplicated)	657
Total representative payee services	306

Guardianship Services are provided to individuals with developmental disabilities and people aged 60 and over and who have been determined by the Family Court or Probate Court to be in need of guardianship supports to live safely and to protect them from violations of their human and civil rights.

As part of Agency of Human Services reorganization, public guardianship for people with developmental disabilities and public guardianship for elderly Vermonters were combined into a unified Office of Public Guardianship. The transition to a unified program began July 1, 2004. The combined program has a staff of 25 public guardians; 20 specializing in supporting individuals with developmental disabilities and 5 specializing in supporting individuals aged 60 and over. Additionally, there are two full time representative payee staff. See **Attachment B: Division of Disability and Aging Services Staff**.

The Public Guardians work with individuals living throughout Vermont. They make regular home visits to the people they serve and take part in planning and monitoring. They make sure people have the supports needed to be safe and protected from abuse, neglect and exploitation. They help people to make their wishes and needs known, to become more independent, and to make connections with friends and family. As medical guardians, staff provide active medical advocacy and coordination and make decisions about medical treatment. Public Guardians are available for emergencies 24-hours a day.

In addition to guardianship, Public Guardians provide:

- **Case management services** as a means of preventing public guardianship or assisting a person to transition out of guardianship.
- **Oversight and service coordination** to people who have been committed to the custody of the Commissioner of DAIL after being found incompetent to stand trial for a criminal offense (Act 248).
- **Support and assistance to private guardians.**
- **Family reunification** for people with developmental disabilities who have been separated from relatives for years.
- **Representative payee services** to assure people's income from Social Security, SSI and earnings are invested responsibly, accounted for, and that bills are paid on time.

Highlights

- ★ Integrated Vermont's two public guardianship programs into a **unified Office of Public Guardian**.
- ★ Developed and implemented written **procedures for review** of certain Public Guardian decisions.
- ★ Revised the *Guardian's Handbook*, a 30-page manual for private guardians in Vermont. Provided copies to each of the State's Probate courts.
- ★ Provided successful advocacy for language in the new state law on **Advance Directives**, making it easier for a person with developmental disabilities to appoint a **Health Care Agent**.
- ★ Developed and published the *Vermont Best Practices Manual: Supervision and Treatment of Sexual Offenders with Developmental Disabilities*.
- ★ The **Ethics Committee** continues to meet bi-monthly, or as needed, to review decisions by Public Guardians to abate life-sustaining treatment for individuals who receive services. The group reviewed ten cases in FY '05 and has discussed a total of 132 cases since its inception in 1994.
- ★ What **consumers** with developmental disabilities said about guardianship:
 - **87%** said they were happy about their guardian.
 - **85%** said they got to see or talk to their guardian whenever they wanted.

Areas of Focus

- ◎ Develop **training and materials** on how to appoint a **Health Care Agent** as an alternative option to appointing guardianship.
- ◎ Explore possibility of a **pooled trust** in Vermont for management of certain funds.
- ◎ What **consumers** with developmental disabilities said about guardianship:
 - **69%** said someone else chose their guardian.
 - **63%** said their guardian let them make some decisions for themselves.

Donald's Story

I met Donald in 1996 when his public guardian retired and I was assigned as the new guardian. Donald was living at the Royce St. group home in Rutland with five peers. Donald had a reputation for acting out with many compulsive behaviors. He had been diagnosed with major depression including suicidal thoughts. As we were getting to know each other, I asked Donald what he liked to do. He responded that he liked to go to Dunkin Donuts for coffee and he liked cows, ducks and steam shovels. So began a monthly ritual which continues today of going to Dunkin Donuts for a cup of black decaf coffee and 3 chocolate donut holes, followed by a ride to look for cows, ducks and steam shovels (a backhoe or bulldozer will do).

Donald speaks in short phrases with rapid, enthusiastic speech. He likes to talk about his favorite foods which include cod fish gravy, maltex cereal, hash, peanut butter and jelly sandwiches and chocolate pudding. When we're out riding, Donald often initiates conversation on the topic by saying the name of a food he likes. We do a verbal back and forth, naming as many foods as we can think of that he likes. He seems to take great pleasure in this, and often adds no "spicy" foods. A few times when we've been out for a drive, Donald has touched my arm and with the most earnest facial expression said, "I like you." I know it's genuine and it means a lot.

Donald was born August 31, 1938. He lived with his family until 1947 when, at age 9, he was admitted to the Brandon Training School. Three years later, he returned to live with his parents. Donald told me recently that his father was a cook in a restaurant and used to make his favorite dish, cod fish gravy. At age 23, Donald returned to BTS. He moved out again in 1978 and lived in a number of different group homes. Donald still speaks fondly of Brandon Training School and wishes he could live there again, but he says it's "closed up." We have driven there a few times at his request and driven around the grounds. Donald often mentions a staff person he liked at Brandon named Tom Schultz. I had hoped to locate this man but have been unable to do so.

Donald has had a number of medical conditions and complications over the past three years that has involved many hospitalizations and medical appointments. He has dealt with broken bones from osteoporosis, surgery and follow-up therapy for tumors, reoccurring pneumonia, hip surgery, ongoing management of diabetes, as well as heart problems. Due to these medical complexities, Donald was unable to continue living in the group home and needed to move to Westview Court, a group home that has around-the-clock nursing coverage.

Donald has handled the move to Westview better than I expected. He misses his friends at Royce St., especially "Eddie" with whom he had shared a room, but he calls to talk on the phone regularly and sometimes has visitors from Royce St. Donald was able to go to Royce St. for a wonderful birthday party on August 31st.

Donald makes friends quickly and is fond of many of the staff he's known over the years. If he says someone has a "big head," it means he thinks that person is pretty special. Donald has a younger brother and a sister who live in Vermont. Both siblings have disabilities. There are no other known surviving relatives.

Donald has an advance care directive for no CPR which was approved by the Ethics Committee this fall. Donald has a basic understanding of my role as his guardian. When told by a doctor at the hospital that he would need to have an operation, his immediate response was to say "Ask Dale." Donald and I talked about the guardianship recently in preparation for this review and when I asked him if he would like me to continue as his guardian, his response was a slow and deliberate head nod.

– Dale Severy, Public Guardian
Office of Public Guardian

Offenders with Developmental Disabilities

The Division of Disability and Aging Services is proud of its public safety record of supporting and treating offenders in non-institutional settings. When individuals with developmental disabilities commit crimes, the courts and correctional system may not be able to respond to their special needs for supervision and treatment, and the public looks to developmental services to meet the need.

Developmental services agencies experience stresses and dilemmas when expected to serve a public safety function in the context of a system designed to promote self-determination and community participation. To serve the unique challenges of this group, DDAS has undertaken the following initiatives in the past two years.

Highlights

- ★ Funds designated for offenders are managed through the **Public Safety Fund**. The Fund is supervised by the Public Safety Funding committee, which meets twice a month to review proposals. Criteria for access to the fund are included in the *Vermont System of Care Plan – FY 2006 Update*. Twenty-four (24) people received new Public Safety funding in FY 2005. Monitoring the use of this fund provides an effective way to document and analyze the new fiscal needs of this group.
- ★ Opened **Roy Mountain**, a specialized crisis and respite program for sex offenders with developmental disabilities. Collaborated with Northeast Kingdom Human Services to develop **procedures and practices** for the crisis bed and respite bed.
- ★ Created a summary report on “*Comprehensive Approaches to Sex Offender Management*” outlining the work accomplished through the grant from the U.S. Department of Justice:
 - Agreed upon a Vision and Statement of Principles, Beliefs and Values.
 - Designed and implemented a data management system.
 - Provided training and information to law enforcement, correctional and court offices about the specific needs and characteristics of offenders and victims with developmental disabilities.
 - Wrote, published and distributed the “*Vermont Best Practices Manual: Supervision and Treatment of Sex Offenders with Developmental Disabilities*”.
 - Developed, published and distributed the “*Treatment Intervention and Progress Scale for Sexual Abusers with Intellectual Disabilities (TIPS-ID)*”.
 - Provided consultation, training and support for residential supervision and treatment staff.
 - Through collaboration between Green Mountain Self-Advocates and special education staff, developed and published “*Stay Safe; Know Your Rights*”, a prevention curriculum to train individuals with developmental disabilities about legal rights and responsibilities.

- ★ A new staffed living arrangement for offenders was opened and supported by Howard Community Services.

- ★ The Division of Disability and Aging Services continued to collect **data** regarding all sex offenders served through the developmental disabilities services system in order to track the efficacy and cost of treatment, training needs and support of offenders. Information on demographics, offense characteristics and Treatment Progress Scale scores collected and analyzed on an annual basis contributes to our understanding about best practices in serving this group.

Areas of Focus

- ◎ Continue to analyze the results from the **Treatment Progress Scale** and provide additional training to program staff, as needed.

- ◎ **Analyze usage** of the Roy Mountain crisis and planned respite beds.

- ◎ Analyze data from the statewide **Sexual Risk Management Information System** questionnaire. Make adjustments in the data collection methodology. Use data collected through this information and monitoring process to assess program efficacy.

Real Choices Grant

Vermont was awarded a three-year **Real Choices System Change Grant** in the amount of \$2,000,000 to increase community integration, real choice and control for elders, younger adults with physical disabilities, people with developmental disabilities and their families, and adults with severe mental illness. The grant is a collaboration between DAIL and the Vermont Department of Health (VDH)/Division of Mental Health. The Division of Disability and Aging Services' share of the overall grant is \$620,599.

The goals of the Real Choice Systems Change Grant are to effect enduring systems that:

- Promote continued progress toward community integration of services, and
- Provide real choice about how, where and by whom, services and supports are delivered.

The specific goals of the DDAS portion of the Real Choices Grant are:

- Research regulations that pose barriers to **direct consumer funding** and propose changes to permit direct consumer funding of Medicaid home and community-based services. The primary outcome is to design and implement a pilot project for direct consumer funding.
- Increase self-advocacy and self-determination by providing **education and training** to consumers and their families. The goals are to identify best practices to foster self-determination and self-advocacy and develop methods for expanding the implementation and availability of those practices.
- Participate in the following grant activities with Real Choices Grant partners:
 - Improve and coordinate mechanisms across systems to provide consumers with easy access to independent, consistent and accurate information, and assistance in **navigating service delivery systems**.
 - Create a valued, **adequately reimbursed and well-trained workforce** across DAIL and VDH.

In 2005, grants were awarded to the Green Mountain Self-Advocates and the I-Team from the Center on Disability and Community Inclusion (CDCI) at the University of Vermont to carry out the Division of Disability and Aging Services' objectives to provide training in self-advocacy skills to people with developmental disabilities, their families, and DDAS and service provider staff. Resources were developed and numerous workshops and training opportunities were presented in 2005.

The following highlights are from the three-year grant period:

Highlights

- ★ The ***Get on Board and Make a Difference manual*** was presented to 19 agency boards and standing committees. Approximately 245 people participated in activities on effective strategies for including people with developmental disabilities on boards and committees.

- ★ Eleven local teams made up of self-advocates and support workers taught 52 **self-advocacy workshops** to over 700 participants. The workshops included:
 - *Know Yourself*
 - *Being Part of the Community*
 - *Communication*
 - *Problem Solving*
 - *Rights and Responsibilities*
 - *How to Be a Strong Self Advocate*
 - *Improve Knowing Yourself*

- ★ Nine different 2-day leadership retreats were held to teach the **7 Habits of Highly Effective People**. A total of 325 people participated. Three of the retreats were designed specifically for high school students.

- ★ GMSA worked together with the I-Team from the CDCI to develop the *Alternatives to Guardianship* manual.

- ★ Two **Home Ownership Forums** were held with representatives from VT State Housing Authority, Burlington and Springfield Land Trusts, Housing and Urban Development (HUD), as well as a local real estate agent and a homeowner. Information was presented about the home buying process, including how and where to start and what programs are available to secure funding. There were 48 participants.

- ★ **Three series of six workshops** for family members of individuals with developmental disabilities were held in Rutland, St. Johnsbury and South Burlington. Workshops topics included:
 - *Transition and the Future: Introduction to Self-determination and Self-advocacy*
 - *What Self-determination and Self-advocacy Mean to Real People* (video and panel)
 - *Developmental Services 101: Identifying Supports and Options for Managing Them*
 - *Person-Centered Planning; Circle of Support; Alternatives to Guardianship*
 - *Having a Voice in How Systems Work: Board and Committee Membership*
 - *Living My Own Life* (video, conversations and problem solving for real life)

- ★ **Direct Consumer Funding Work Group** advised the Division of Disability and Aging Services on:
 - Practices to promote self- and family-management of services.
 - Implementation of a Supportive Intermediary Service Organization (Supportive ISO) for direct consumer funding.
 - Development of a consumer handbook to assist individuals and their families in managing their supports and services.

★ **A Supportive Intermediary Service Organization** was developed and became operational July 1, 2005. Proposals were reviewed by the Direct Consumer Funding Workgroup and a grant was awarded to Transition II of Burlington to operate the Supportive ISO. Transition II assists individuals who are self- and family-managing their developmental disability Medicaid waiver services to understand and carry out their employer responsibilities.

★ **A Handbook for People Self- or Family-Managing** was published in September of 2005. This handbook included detailed information regarding self- or surrogate management of services, including examples of forms, job descriptions, interview questions, and other practical tools to assist people in their role as employer, as well as all of the regulations and guidelines currently in place. The Direct Funding Workgroup provided feedback and editing to the handbook as well as recommendations on ways to design it to be accessible to people.

Communication

The Division of Disability and Aging Services continues to focus attention on the communication goal to: *Increase opportunities and supports for individuals to improve their communication and increase awareness of the need for people to communicate beyond the basics and familiar.*

The ongoing **action plan** addresses support for communication from different levels:

- **Individual Level** – Individual Support Agreements identify communication needs of individuals and those needs are addressed.
- **Agency Level** – Developmental service providers all have “in-house” resources to support people to communicate more effectively.
- **State Level** – Division of Disability and Aging Services provides resources, training and technical assistance to support people to communicate.

The **Vermont Communication Task Force** was established in the spring of 2000 so that adults with developmental disabilities who live in Vermont can communicate more effectively to participate fully in community life, make decisions and better advocate for themselves. Ongoing efforts provide information, education, training and resources to people with disabilities, family members, service providers and community members. The Vermont Communication Task Force is working in partnership with DDAS, service providers, Green Mountain Self-Advocates and other communication specialists to help realize the goals of the statewide communication initiative.

Highlights

- ★ Provided periodic **training and technical assistance** to service coordinators and other agency staff.
- ★ Provided three **full-day workshops** to local communication resource people from all the agencies.
- ★ Updated the *Vermont Communication Resource Guide – Version 4*.
- ★ Updated the *Guide to Medicaid Funding for Communication Evaluations and Devices*.
- ★ Published the *Vermont Developmental Services Communication Initiative*, a summary report on the collaborative work between the Vermont Communication Task Force, DDAS and service providers, including developing the statewide communication network and providing system-wide training and support.
- ★ Organized and presented the second **statewide Making Communication Happen conference** on supporting people to communicate.

- ★ What we learned about people's ability to communicate from the **Consumer Survey**⁴⁶:
- **66%** have adequate, reliable speech which allows them full expression.
 - Of those reported *not* to have adequate, reliable speech:
 - **90%** are *able* to communicate with people who are known and familiar to them.
 - **88%** *have* consistent communication partners.
 - **93%** *have* support from their team.
 - **18%** are believed to be communicating *more* effectively than last year.

Areas of Focus

- ◎ Work with Green Mountain Self-Advocates to **increase participation** of people in self-advocacy activities who have limited communication.
- ◎ Continue to provide **training, technical assistance and tools** to local communication resource people.
- ◎ Work with agencies to provide incentives and supports to the local communication resource people and continue to **build capacity** for communication supports at each agency.
- ◎ What we learned about people's ability to communicate from the **Consumer Survey**⁴⁷:
 - **20%** do *not* have spoken language as their primary means to communicate.
 - **34%** do *not* have adequate, reliable speech which allows them full expression.
 - Of those who do *not* have adequate reliable speech:
 - **61%** do *not* have access to communication aids or devices.
 - **60%** are *not* able to communicate with people who are *unfamiliar* to them.
 - **53%** are *not* able to communicate for a variety of purposes beyond basic wants and needs (e.g., social interactions, sharing and getting information from others).
 - **58%** do *not* have consultation or support from an SLP or other communication expert.

Larry's Story

The following is the keynote speech written by Larry Bissonnette for the *Making Communication Happen II* Conference that took place on November 2, 2005. Larry was not able to present his speech in person as he was in Munich, Germany speaking at a film festival about his newly released autobiography, "*My Classic Life as an Artist, A Portrait of Larry Bissonnette.*" Larry's film has been accepted for inclusion in three film festivals to date.

⁴⁶ Data are from the demographic survey completed by service coordinators for all 355 participants of the 2005 Consumer Survey Project.

⁴⁷ Ibid.

Words of Wisdom from a Not Always Wise Person with Communication Disabilities

I am picturing what all of you are thinking about why I am not here today. Ways that I can make reasons to excuse myself range from sleeping late to legging it with my aging walking stride and once here, needing to take a nap in a luxurious hotel room while you all sit and listen to my awfully longwinded remarks.

I am really flattered. Coming to this conference would have been enjoyable. Big lunches and stimulating sessions are what you have your, curbed from regular routines, day totally overtaken with.

Kindly, I habitually say that your most helpful work with worse disability, than physical disability, of speech problems is to learn about keys to locks of motor planning, sensory and easily not seen proprioceptive problems and also to ask yourself what learning is needed by the person (with speech problems) to communicate like anyone on the street or at large and small social parties.

Painting art isn't hard as long as I use quality brushes and paints and get wise guidance from skilled artists. Learning to communicate requires greater level of support, calling on communication partners, watching these shrewd words of mine quietly scroll down the page, to learn training methods for clearing cobwebs of meaningless thoughts from a person's nearly molded for rote communication mind, amidst a daily world of ever changing ideas about being intelligent.

I elected to ride the train of fc (facilitated communication) to express my sometimes, stilted towards exaggeration, ideas but there are as many ways to communicate as titles read off in the president's administration. Tales will be told in the freedom to communicate future, of words streaming out of newly speech improved mouths, programmed for saying everything under the sky devices, and coordinated for pointing and signing, vital for eating too, hands.

Year is almost over so you might want to start resolution making, like Christmas shopping, now. I hope you learn as much as you can and thank you for listening to me.

Consumer Survey

Numbers Surveyed – 2005	
Number of participants – Consumers interviewed	134
Demographic survey only	221
Total number of adult participants	355

Consumer Survey Project: The Division of Disability and Aging Services contracts with an independent group to conduct interviews on a statewide basis of adults who receive services. In addition to the personal interview, basic demographic information is collected from service coordinators for all adults selected whether or not they are able to individually participate in the interview. Over the course of three years, an estimated 65% of adults who receive services will participate in the survey. 2005 was the second year in the survey cycle. In 2005, interviews were conducted at five agencies⁴⁸. The data presented below are aggregate data representing statewide results. This is just a small sampling of the data collected from the survey. For the complete report, contact the Division of Disability and Aging Services.

Consumer Survey Results⁴⁹ – 2005

Highlights

- ★ **Residential: 91%** said they like where they live.
- ★ **Work: 90%** said they like their job.
- ★ **Community Supports: 96%** said they like their individual community activities.
- ★ **Guardianship: 87%** said they feel happy about their guardian.
- ★ **Agency: 79%** said they feel happy with their service coordinator.
- ★ **Agency: 93%** said they feel listened to at their ISA meetings.

⁴⁸ The five agencies that took part in the Consumer Survey Project in 2005 were Health Care and Rehabilitation Services, Howard Community Services, Northwestern Counseling and Support Services, Sterling Area Services and Upper Valley Services.

⁴⁹ Not all consumers answered all the questions in their interviews. Percentages are based on the total number of consumers who responded to the questions. Consumer survey data needs to be taken in the same context as any study of satisfaction, as a general reflection of a person's perspective of life. Results from the surveys are anonymous and confidential.

- ★ **Transportation: 91%** said they had a way to get there if they wanted to go someplace.
- ★ **Self-Determination: 78%** said they feel they have enough control over their life.

Areas of Focus

- ◎ **Residential: 37%** said they did not choose who they live with.
- ◎ **Residential: 51%** said they did not choose the place where they live.
- ◎ **Work: 58%** of the people who do not work said they wanted a paid job.
- ◎ **Community Supports: 46%** said they would like more hours of individual community supports.
- ◎ **Friends: 41%** said they wish they had more friends.
- ◎ **Friends: 29%** said they need to know more about dating.
- ◎ **Friends: 39%** said someone else decides when they can have friends and family over to visit.

Demographic Summary⁵⁰ – 2005

Basic Information

Gender		Guardian Status		Representative Payee	
Males	56%	Private	48%	Yes	77%
Females	44%	None	24%	No	18%
		Public	26%	Unknown	5%
		Unknown	2%		
Marital Status		Court Ordered Restrictions		Family Involved in Person's Life	
Never married	95%	No	86%	Yes	86%
Married/Civil Union	3%	Yes	12%	No	12%
Single/Married in past	2%	Unknown	2%	Unknown	2%

Residential Summary

Residential Type		Household Composition		Paid Residential Support	
Home provider	48%	Non relatives	53%	24-hour	52%
Lives with parents	32%	Parents	30%	Daily	9%
Own home	13%	Lives alone	8%	Less than daily	6%
Group home	1%	Other relatives	5%	As needed	2%
Staffed living	2%	Spouse and/or children	2%	None/Family	30%
Residential Care Home/ Nursing Home/Other	4%	Unknown/Other	2%	Unknown	1%
Who Own/Leases the Home		Residential Location		How Long Living in Home	
Family member	32%	Rural/Physically remote	49%	Over 5 years	57%
Unrelated person in home	46%	Walking distance to town/city	31%	3 – 5 years	16%
Provider	3%	Centrally located in town/city	18%	1 – 2 years	14%
Person rents home	12%	Unknown	2%	Less than 1 year	10%
Person owns home	2%			Unknown	3%
Unknown/Other	5%				

Health Concerns Summary

Is weight a concern?		Does person smoke or chew tobacco?		How physically active is person?	
No	60%	No	90%	Moderately	57%
Yes, overweight	31%	Yes	7%	Inactive	20%
Yes, underweight	6%	Unknown	3%	Very	21%
Unknown	3%			Unknown	2%

⁵⁰ Data is based on results from *Survey of Adult Consumers of Developmental Services 2005 Report* and include all participants (those interviewed and those not interviewed who only had the demographic survey done).

Comparison of Vermont 2002 and 2005 Consumer Survey Results

The method for collecting the consumer survey data for the past four years has been by random selection of consumers from a sampling of agencies based upon size of agency and regional representation. The same five agencies took part in both the 2002 and 2005 survey⁵¹. The following are some comparisons of specific survey responses from the two years.

	2002	2005
Residential		
• You like where you live	83%	91%
• You had a say in where you live	54%	49%
• You cannot think of a better place to live	74%	72%
• I feel safe at home	91%	91%
• You can invite friends over when you want	85%	79%
Neighborhood		
• You like your neighborhood	75%	86%
• You feel safe in your neighborhood	88%	89%
Work		
• You like your job	91%	90%
• You chose your job	83%	87%
• You chose who helped you at work	40%	42%
• You work enough hours	55%	46%
• There is nothing else you'd rather do during the day	85%	68%
Community Supports (Individual)		
• You like your community supports	97%	96%
• You like the people you spend time with	96%	83%
Activities		
• You shop as much as you want	80%	55%
• You exercise as much as you want	82%	59%
• You go to church /synagogue as much as you want	71%	67%
Friends		
• You are not often lonely	58%	63%
• You can see your family when you want	66%	72%
Service Agency		
• You chose your service coordinator	42%	31%
• You get to learn new things	72%	68%
Self-Determination		
• You make all the choices you want	20%	68%
• You have enough control over your life	81%	78%

⁵¹ Data is based on results from *Survey of Adult Consumers of Developmental Services 2005 Report*. The five agencies that took part in the Consumer Survey Project in 2005 were Health Care and Rehabilitation Services, Howard Community Services, Northwestern Counseling and Support Services, Sterling Area Services and Upper Valley Services.

National Comparison of Vermont's 2004 Consumer Survey Results⁵²

Highlights – Categories⁵³

- ★ **Community Inclusion:** Vermont ranked **highest (87%)**; with the highest average proportion of people who say they:
 - Go shopping (96%)
 - Go out on errands or appointments (98%)
 - Go out for entertainment (87%)
 - Go out to eat (95%)
 - Got to religious services (57%)
 - Exercise or play sports (77%)

- ★ **Everyday Choices:** Vermont ranked **highest (85%)**; with the highest average proportion of people who say they:
 - Choose the people they live with (58%)
 - Choose their daily schedule (91%)
 - Choose how to spend free time (96%)
 - Choose what to buy with spending money (96%)

- ★ **Life Decisions:** Vermont ranked **highest (83%)**; with the highest average proportion of people who say they:
 - Choose the place where they live (68%)
 - Choose staff who help them at home (70%)
 - Choose their place of work or community supports (74%)
 - Chose staff who help them at work or with community supports (69%)
 - Chose their service coordinator (57%)

Highlights – Individual Questions

- ★ **Choice of how to spend free time:** Vermont ranked **1st (96%)**
- ★ **Choice of what person buys with spending money:** Vermont ranked **1st (96%)**
- ★ **Feel safe in person's home:** Vermont ranked **2nd (97%)**
- ★ **Feel safe in person's neighborhood:** Vermont ranked **2nd (94%)**

⁵² Data is based on results from sixteen states that participated in the 2004 consumer surveys as part of the National Core Indicators. Results are published in *Consumer Outcomes – Phase VII Final Report Fiscal Year 2004-2005 Data (preliminary report)*, National Core Indicators.

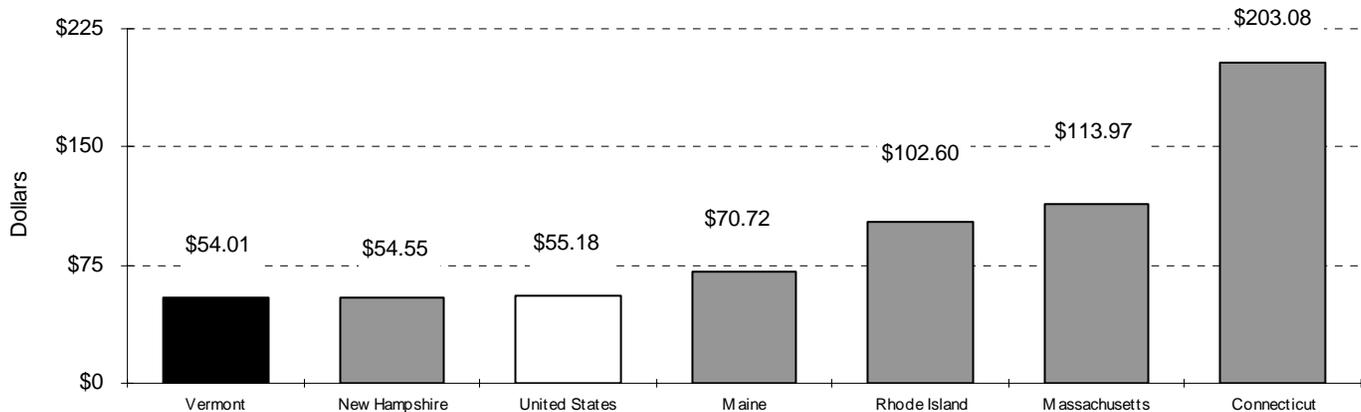
⁵³ Data was analyzed by category (grouping of questions based on certain commonalities) and individual questions. Categorical data presented in this section is outcome or “risk” adjusted to control for differences in the individual characteristics of people interviewed across states.

- ★ **Satisfaction with the person's work or community supports:** Vermont ranked **2nd (97%)**
- ★ **Does not usually or ever feel lonely:** Vermont ranked **2nd (90%)**
- ★ **Has adequate transportation:** Vermont ranked **3rd (91%)**
- ★ **Satisfaction with where the person lives:** Vermont ranked **3rd (91%)**

National Comparisons⁵⁴

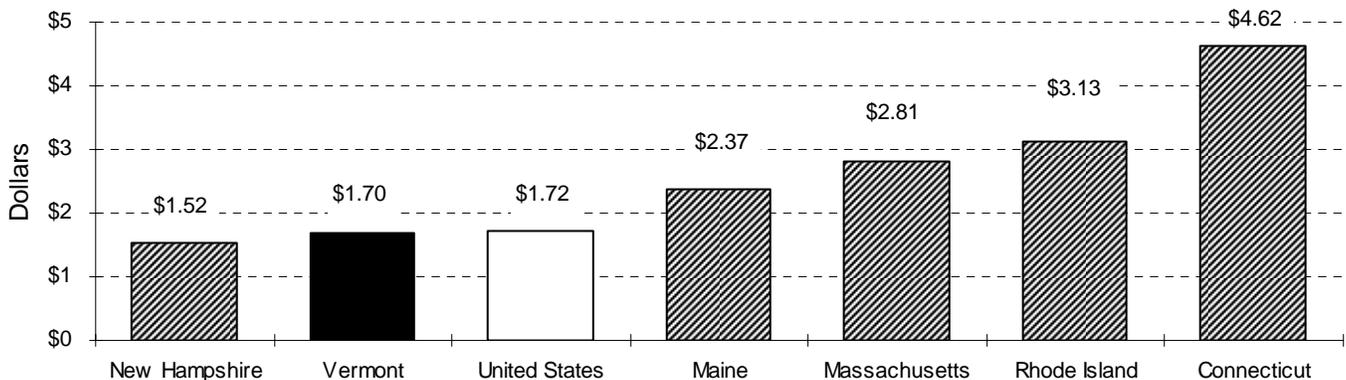
★ Vermont spends **fewer state dollars** (including Medicaid match) per state resident for mental retardation/developmental disability (MR/DD) services than any other New England state and **less** than the national average.

MR/DD State Spending per Capita FY 2004



★ The **fiscal effort** in Vermont, as measured by total state spending for people with mental retardation/developmental disability (MR/DD) services per \$1,000 in personal income, indicates that Vermont ranks **2nd** to New Hampshire as the lowest of all New England states and is **less than** the national average.

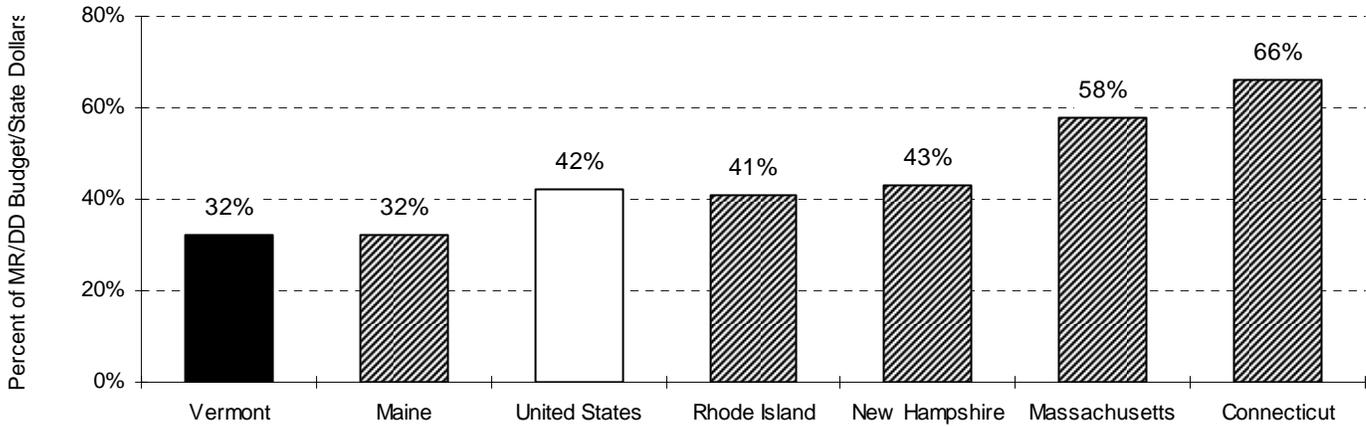
**State Fiscal Effort
Total MR/DD Spending per \$1,000 in Personal Income
FY 2004**



⁵⁴ *The State of the States in Developmental Disabilities: 2005*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Preliminary Report, 2005.

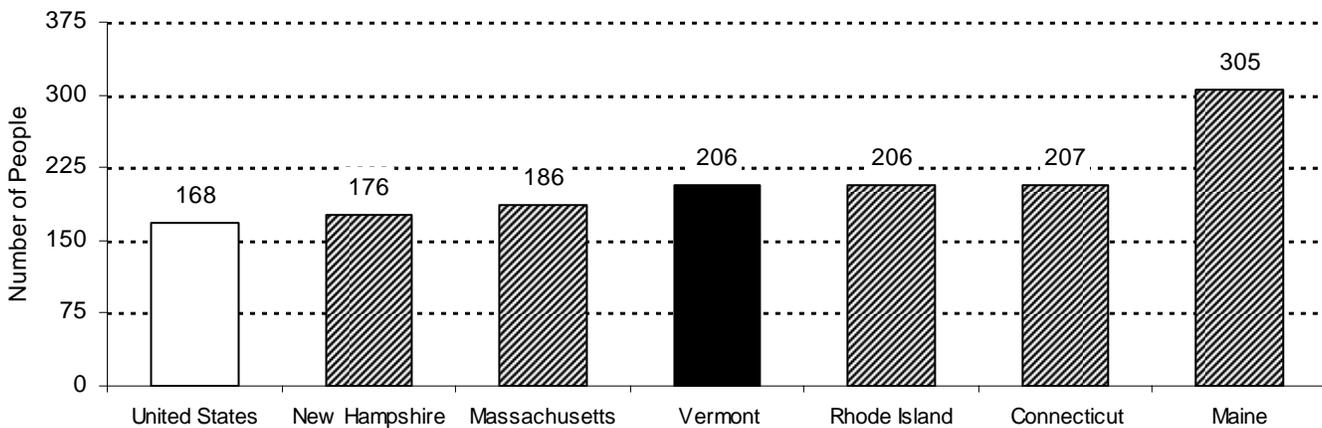
★ **State funds** (including state funds used for Medicaid match) account for a **smaller proportion** of the budget from mental retardation/developmental disability (MR/DD) services in Vermont than in any other New England State except for being tied with New Hampshire. Vermont continues to access **higher** than the national average proportion of federal dollars.

Percent of State MR/DD Budget Paid by State Funds FY 2004



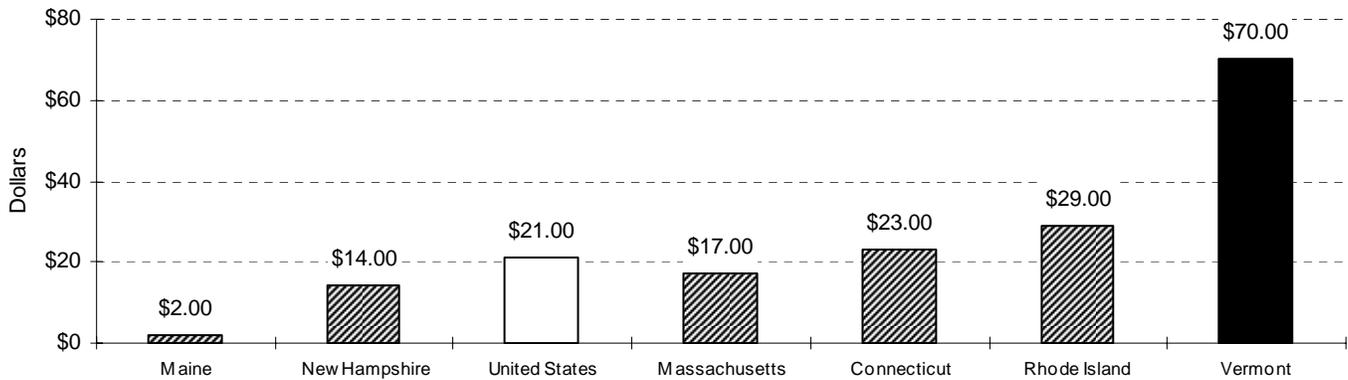
★ The number of people receiving **residential services** in the mental retardation/developmental disability (MR/DD) service system (with the addition of people living in nursing facilities) per 100,000 of the state population is **above** the national average but **on par** with the majority of New England states.

Number of People in MR/DD Residential Services & Nursing Facilities per 100,000 Population FY 2004



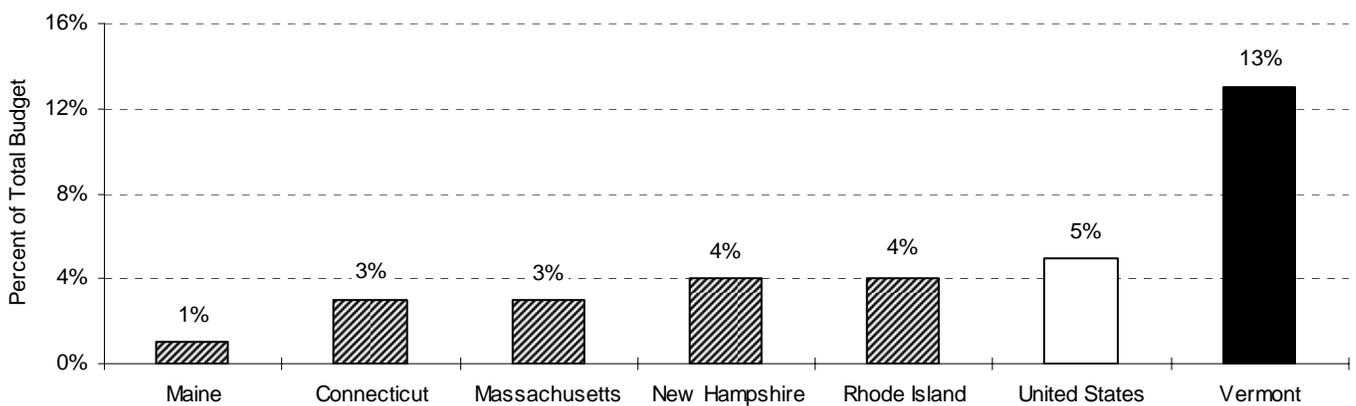
★ Vermont is ranked **1st** in New England and **4th** in the nation in total **family support spending** per \$100,000 personal income. Greater support of families results in lower costs overall.

Family Support Fiscal Effort
Total Spending per \$100,000 Personal Income
FY 2004



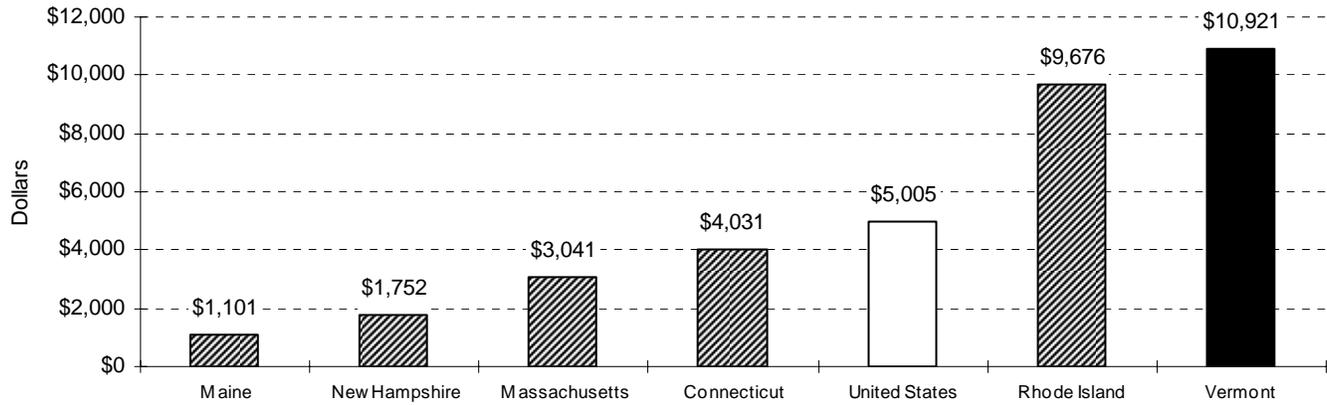
★ Vermont's **family support spending** is ranked **1st** in New England and **6th** in the nation in terms of total MR/DD budget.

Family Support Spending as Percent of Total MR/DD Budget
FY 2004



★ Vermont is ranked **1st** in New England and **7th** in the nation in the amount of **spending per family** for family support.

**Total Amount of Spending per Family
FY 2004**



A T T A C H M E N T S

Acronyms.....	Attachment A
Division of Disability and Aging Services Staff.....	Attachment B
Vermont Developmental Services Providers.....	Attachment C
Members of the State Program Standing Committee for Developmental Services.....	Attachment D
Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities.....	Attachment E
Organizational Chart – Agency of Human Services.....	Attachment F
System of Care Plan Funding Priorities FY 2005.....	Attachment G
Division of Disability and Aging Services FY 2006 Fiscal Resources	Attachment H
Green Mountain Self-Advocates.....	Attachment I

ACRONYMS

AAC	Augmentative and Alternative Communication
AAMR	American Association on Mental Retardation
ACT 248	Supervision of incompetent and mentally retarded individuals that have been charged with crimes
ADD	Attention Deficit Disorder
AFL	Authorized Funding Limit
AHS	Agency of Human Services
ANCOR	American Network of Community Options and Resources
APS	Adult Protective Services
APSE	Association for Persons in Supported Employment
ARC	Advocacy, Resources and Community
ARIS	Area Resources for Individualized Services
AT	Assistive Technology
BTS	Brandon Training School
CA	Community Associates (DS Program of CSAC)
CAP	Community Access Program (DS program of RMHS)
CARC	Champlain ARC
CAS	Community Alternatives Specialist
CDCI	Center on Disability and Community Inclusion
CDS	Community Developmental Services (DS program of WCMHS)
CDU	Community Development Unit
CIP	Core Indicators Project – Obsolete, see NCI
CIR	Critical Incident Report
CMS	Centers for Medicare and Medicaid Services
CP	Cerebral palsy
CPS	Child Protective Services
CSAC	Counseling Service of Addison County
CSHN	Children with Special Health Needs
CVARC	Central Vermont ARC
CVS	Champlain Vocational Services
DA	Designated Agency
DAD	Department of Aging and Disabilities – Obsolete, see DAIL
DAIL	Department of Disabilities, Aging and Independent Living
DBT	Dialectical Behavioral Therapy
DBVI	Division for the Blind and Visually Impaired
DCF	Department for Children and Families
DD	Developmental Disability or Developmentally Disabled
DD ACT	Developmental Disability Act of 1996
DDC	Developmental Disabilities Council
DH	Developmental Homes – see also SLP and HP
DLP	Disability Law Project (formerly DDLP)
DLP	Division of Licensing and Protection
DME	Durable Medical Equipment
DMH	Division of Mental Health
DOC	Department of Corrections
DOE	Department of Education
DOJ	Department of Justice

DS	Developmental Services
DSM	Diagnostic and Statistical Manual of Mental Disorders (most current edition)
DVR	Division of Vocational Services – see also VR
EDS	Electronic Data Systems
FF	Families First
FFF	Flexible Family Funding
FFP	Federal Financial Participation
FFS	Fee for service
FFY	Federal Fiscal Year
FARC	Franklin ARC
FY	Fiscal Year
GF	General Fund
GH	Group Home
GMSA	Green Mountain Self Advocates
GS	Guardianship Services – Obsolete, see OPG
GSS	Guardianship Services Specialist – Obsolete, see PG
HCBS	Home and Community-based Services
HCBW	Home and Community-based Waiver
HCHS	Howard Center for Human Services
HCRS	Health Care and Rehabilitation Services of Southeastern Vermont – see also HCRSSV
HCRSSV	Health Care and Rehabilitation Services of Southeastern Vermont
HCS	Howard Community Services (DS program of HCHS)
HHS	Health and Human Services
HIPAA	Health Insurance Portability and Accountability Act
HP	Home provider
HRD	Human Resources Data
ICF/DD	Intermediate Care Facility for people with Developmental Disabilities (formerly ICF/MR – Intermediate Care Facility for people with Mental Retardation)
IDU	Information and Data Unit
IEP	Individualized Education Program
ISA	Individual Support Agreement
ISO	Intermediary Service Organization
ISU	Individual Supports Unit
LCMH	Lamoille County Mental Health
LSI	Lincoln Street Incorporated
MCIS	Managed Care Information System
MI	Mentally Impaired/Ill
MMPI	Minnesota Multiphasic Personality Inventory
MR	Mental Retardation
MSR	Monthly Service Report
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NCI	National Core Indicators (formerly CIP)
NCSS	Northwest Counseling and Support Services
NKHS	Northeast Kingdom Human Services
OPG	Office of Public Guardian
OT	Occupational Therapy or Occupational Therapist
OVHA	Office of Vermont Health Access
P&A	Protection and Advocacy – see VP&A
PASARR	Pre-admission Screening and Resident Review
PDD	Pervasive Developmental Disorder
PG	Public Guardian

PMIS	Provider Management Information System
PT	Physical Therapy or Physical Therapist
QA	Quality Assurance
QDDP	Qualified Developmental Disabilities Professional (formerly QMRP)
QI	Quality Improvement
QMU	Quality Management Unit
RARC	Rutland ARC
RMHS	Rutland Mental Health Services
RWJ	Robert Wood Johnson Foundation
SAS	Sterling Area Services
SCC	Specialized Community Care
SD	Self-determination
SLP	Shared living provider
SLP	Speech language pathologist
SRS	Department of Social and Rehabilitation Services – Obsolete, see DCF
SSA	Social Security Administration
SSA	Specialized Service Agency
SSDI	Social Security Disability Income
SSI	Supplemental Security Income
TASH	The Association for Persons with Severe Handicaps
TBI	Traumatic Brain Injury
TCM	Targeted Case Management (state plan Medicaid)
T-II	Transition II
TXIX	Title XIX of the Social Security Act (Medicaid)
UC	University of Colorado
UCS	United Counseling Service of Bennington County
UVS	Upper Valley Services
VARC	ARC of Vermont
VCDMHS	Vermont Council of Developmental & Mental Health Services – formerly VCCMHS
VCDR	Vermont Coalition for Disability Rights
VCIL	Vermont Center for Independent Living
VCIN	Vermont Crisis Intervention Network
VDH	Vermont Department of Health
VP&A	Vermont Protection and Advocacy
VPIC	Vermont Parent Information Center
VPS	Vermont Psychiatric Survivors
VR	Vocational Rehabilitation – see also DVR
VSH	Vermont State Hospital
UVM	University of Vermont
WAIS-R	Wechsler Adult Intelligence Scale – Revised
WCMH	Washington County Mental Health
WISC	Wechsler Intelligence Scale for Children

DIVISION OF DISABILITY AND AGING SERVICES STAFF

January 2006

103 South Main Street
 Waterbury, VT 05671-1601
 Phone: (802) 241-2648
 FAX: (802) 241-4224

Deputy Commissioner's Office
 802-241-2648

Staff Name	Title	Phone (802)	E-mail Address
Bascom, June	Program Development & Policy Analyst	241-2644	june.bascom@dail.state.vt.us
Preedom, Lanora	Administrative Assistant	241-4592	lanora.preedom@dail.state.vt.us
Wood, Theresa	Deputy Commissioner	241-2648	theresa.wood@dail.state.vt.us
Vacancy	Clinical Services Manager	241-3955	

Community Development Unit (CDU)
 802-241-4534

Staff Name	Title	Phone (802)	E-mail Address
George, Camille	Director, CDU	241-2427	camille.george@dail.state.vt.us
Hammer-Williamson, Karin	Residential Alternatives Unit Supervisor	241-1286	karin.hammer-williamson@dail.state.vt.us
Haslett, Joan	Real Choices Grant Manager	241-4529	joan.haslett@dail.state.vt.us
Jacobs, Renita	Administrative Assistant	241-4595	renita.jacobs@dail.state.vt.us
Lyon, Veda	Community Development Manager	241-2628	veda.lyon@dail.state.vt.us
Masterson, Jennie	Employment Specialist	786-2571	jennie.masterson@dail.state.vt.us
McFadden, Clare	Autism Specialist	241-2863	clare.mcfadden@dail.state.vt.us
Merrill, Janet	Administrative Assistant	241-4253	janet.merrill@dail.state.vt.us
Mireault, Maria	Dementia Project Director	241-3738	maria.mireault@dail.state.vt.us
Nickerson, Amy	Aging & Disabilities Senior Planner	241-2930	amy.nickerson@dail.state.vt.us
Sherburn, Cecile	Administrative Assistant	241-2658	cecile.sherburn@dail.state.vt.us
Topper, Karen	Consumer Development Coordinator	241-3175	karen.topper@dail.state.vt.us
Vacancy	Supportive Housing Project Director	241-4612	

Individual Supports Unit (ISU)
802-241-1228

Staff Name	Title	Phone (802)	E-mail Address
Baraw, Samantha	Administrative Assistant	241-3624	samantha.baraw@dail.state.vt.us
Boyce, Gary	Nurse Intake Coordinator	241-4639	gary.boyce@dail.state.vt.us
Bullard, Gordon	Program Technician	241-2196	gordon.bullard@dail.state.vt.us
Castle, Robin	TBI Implementation Grant Manager	241-3719	robin.castle@dail.state.vt.us
Edelman, Adele	Medicaid Waiver Manager	241-2402	adele.edelman@dail.state.vt.us
Edwards-Orr, Merle	Cash and Counseling Grant Manager	241-4496	merle.edwards-orr@dail.state.vt.us
Garabedian, Jennifer	Independent Living Services Consultant – Children’s Personal Care	241-3813	jennifer.garabedian@dail.state.vt.us
Goodwin-Abare, Cheryl	Program Technician	241-4593	cheryl.goodwin-abare@dail.state.vt.us
Green, April	Administrative Assistant	241-3543	april.green@dail.state.vt.us
Malone, Ellen	Developmental & Specialty Services Manager	786-5047	ellen.malone@dail.state.vt.us
Marinelli, Nancy	Medicaid Waiver Supervisor	241-4431	nancy.marinelli@dail.state.vt.us
Meunier, Mike	Independent Living Services Consultant – Attendant Services	241-2431	mike.meunier@dail.state.vt.us
Roth, Amy	Children’s Services Specialist	241-2675	amy.roth@dail.state.vt.us
Tierney-Ward, Megan	Medicaid Waiver Supervisor	241-2426	megan.tierney-ward@dail.state.vt.us
Wargo, Lorraine	Director, ISU	241-3186	lorraine.wargo@dail.state.vt.us
Weaver, Erin	TBI Waiver Supervisor	241-1456	erin.weaver@dail.state.vt.us

Long-Term Care Clinical Coordinators
Choices for Care

Staff Name	Title	Phone (802)	E-mail Address
Barre Office McFarland State Office Building 5 Perry Street, Suite 150 Barre, VT 05641 Fax: 476-1654	George Jurasinski	476-1654	george.jurasinski@dail.state.vt.us
Bennington Office 200 Veterans’ Memorial Drive, Suite 6 Bennington, VT 05201 Fax: 447-6972	Jessica Bird	447-2850	jessica.bird@dail.state.vt.us
Brattleboro Office 232 Main Street P.O. Box 70 Brattleboro, VT 05302-0070 Fax: 254-6394	Mary Woods	251-2118	mary.woods@dail.state.vt.us

Burlington Office 312 Hurricane Lane Suite 201 Williston, VT 05495 Fax: 879-5919	Toni Morgan Paula Hartshorn	879-5904	toni.morgan@dail.state.vt.us paula.hartshorn@dail.state.vt.us
Hartford Office 100 Mineral Street, Suite 201 Springfield, VT 05156 Fax: 885-8879	Sally Garmon	885-8875	sally.garmon@dail.state.vt.us
Middlebury Office 700 Exchange Street Middlebury, VT 05753 Fax: 388-4637	Mary Gerdt	388-5730	mary.gerdt@dail.state.vt.us
Morrisville Office 63 Professional Drive, Suite 4 Morrisville, VT 05661 Fax: 888-1345	Maura Krueger	888-0510	maura.krueger@dail.state.vt.us
Newport Office 100 Main Street, Suite 240 Newport, VT 05855 Fax: 334-3386	Paulette Simard	334-3910	paulette.simard@dail.state.vt.us
Rutland Office 320 Asa Bloomer Building Rutland, VT 05701 Fax: 786-5882	Celine Aprilliano	786-5971	celine.aprilliano@dail.state.vt.us
Springfield Office State Office Building/ESD 100 Mineral Street, Suite 201 Springfield, VT 05156 Fax: 885-8879	Mary Woods	885-8875	mary.woods@dail.state.vt.us
St. Albans Office 20 Houghton Street, Suite 313 St. Albans, VT 05478 Fax: 527-5403	Brenda Smith	524-7913	brenda.smith@dail.state.vt.us
St. Johnsbury Office 67 Eastern Avenue, Suite 7 St. Johnsbury, VT 05819 Fax: 751-3272	Julie Bigelow	748-8361	julie.bigelow@dail.state.vt.us

Quality Management Unit (QMU)
802-241-2614

Staff Name	Title	Phone (802)	E-mail Address
Bean, Marie	QM Reviewer	241-4425	marie.bean@dail.state.vt.us
Bronson, Mary	QM Reviewer	241-4549	mary.bronson@dail.state.vt.us
Carlomagno, Joe	Director, QMU	241-2721	joe.carlomagno@dail.state.vt.us
Coy, Jeff	QM Training Coordinator	241-2727	jeff.coy@dail.state.vt.us
Freund, Avi	QM Reviewer	241-2723	avi.freund@dail.state.vt.us
McAdoo, Deb	QM Reviewer	241-1403	deb.mcadoo@dail.state.vt.us
Morabito, Steve	Quality Management Development Specialist	241-2659	stephen.morabito@dail.state.vt.us
Morse, Marty	QM Reviewer	263-5291	marty.morse@dail.state.vt.us
O'Neill, Chris	QM Reviewer	263-5305	chris.oneill@dail.state.vt.us
Parker-Moulton, Janine	QM Reviewer	785-5081	janine.parker-moulton@dail.state.vt.us
Putvain, Tammy	Administrative Assistant	241-4594	tammy.putvain@dail.state.vt.us
Spencer, Kate	QM Nursing Reviewer	786-5054	kate.spencer@dail.state.vt.us
Sterling, Sue	Program Services Clerk	241-2614	sue.sterling@dail.state.vt.us
Turchin, Bob	QM Team Leader	786-5048	bob.turchin@dail.state.vt.us
Urpsis, Al	QM Team Leader	241-3358	al.urpsis@dail.state.vt.us
Vacancy	QM Nursing Reviewer	786-5052	

Information and Data Unit (IDU)
802-241-2214

Staff Name	Title	Phone (802)	E-mail Address
Brooks, Dale	Systems Developer	241-2627	dale.brooks@dail.state.vt.us
Harrington, Tracey	Information Technology Specialist	241-2629	tracey.harrington@dail.state.vt.us
Hill, Bard	Director IDU	241-2335	bard.hill@dail.state.vt.us
Laverty, Dick	Senior Planner	241-2425	dick.laverty@dail.state.vt.us
Tighe, Deb	Systems Developer	241-2419	deb.tighe@dail.state.vt.us
Vacancy	Program Technician	241-2214	

Office of Public Guardian

<p>Waterbury Office 103 South Main Street Waterbury, VT 05671-1601 Fax: 241-4224</p>	<p>Gail Falk – Director Michele DellaSanta – Administrative Assistant</p>	<p>241-2616 241-2663</p>	<p>gail.falk@dail.state.vt.us michele.dellasanta@dail.state.vt.us</p>
--	---	---------------------------------------	--

Public Guardians – Aging Specialty

<p>Essex Junction Office PO Box 5501 Essex Junction, VT 05453 Fax: 879-2334</p>	<p>Suzan Castor – Public Guardian</p>	<p>879-2333</p>	<p>suzan.castor@dail.state.vt.us</p>
<p>Hyde Park Office PO Box 128 Hyde Park, VT 05655 Fax: 888-5869</p>	<p>Keith Ulrich – Public Guardian</p>	<p>888-3370</p>	<p>keith.ulrich@dail.state.vt.us</p>
<p>North Ferrisburg Office PO Box 122 North Ferrisburg, VT 05473 Fax: 877-6792</p>	<p>Laurie Gutowski – Public Guardian</p>	<p>877-6779</p>	<p>laurie.gutowski@dail.state.vt.us</p>
<p>Townshend Office PO Box 87 Townshend, VT 05453 Fax: 365-7935</p>	<p>Mike Attley – Senior Public Guardian</p>	<p>365-4478</p>	<p>mike.attley@dail.state.vt.us</p>
<p>West Brattleboro Office PO Box 2386 West Brattleboro, VT 05303 Fax: 251-2144</p>	<p>Beth Spicer – Public Guardian</p>	<p>251-2145</p>	<p>beth.spicer@dail.state.vt.us</p>

Public Guardians – Developmental Disability Specialty
Emergency Toll-Free Number: 1-800-642-3100

<p>Burlington Office 108 Cherry Street Box 205, Suite 205 Burlington, VT 05401 Fax: 951-4036</p>	<p>John Homiller – Public Guardian Ed Wells – Public Guardian</p>	<p>865-7720 865-7721</p>	<p>john.homiller@dail.state.vt.us ed.wells@dail.state.vt.us</p>
<p>Hyde Park Office Ken Gar Building PO Box 266 Hyde Park, VT 05655 Fax: 888-0600</p>	<p>Sedney Ulrich – Public Guardian</p>	<p>888-2525</p>	<p>sedney.ulrich@dail.state.vt.us</p>
<p>Middlebury Office 700 Exchange Street, #204 Middlebury VT 05753 Fax: 388-4694</p>	<p>Lisa Lamoureux – Public Guardian Dale Severy – Public Guardian Joan Stephens – Senior Public Guardian Linda Vondle – Public Guardian</p>	<p>388-4691 388-4692 388-4693 388-5761</p>	<p>lisa.lamoureux@dail.state.vt.us dale.severy@dail.state.vt.us joan.stephens@dail.state.vt.us linda.vondle@dail.state.vt.us</p>
<p>Montpelier Office 155 Elm Street, Suite 2 Montpelier, VT 05602-2866 Fax: 828-0243</p>	<p>Becky Guyett – Senior Public Guardian Leslie Pinkham – Public Guardian Lisa Sipsey – Public Guardian Nancy Zucca – Public Guardian</p>	<p>828-3622 828-3620 828-3621 828-3623</p>	<p>becky.guyett@dail.state.vt.us leslie.pinkham@dail.state.vt.us lisa.sipsey@dail.state.vt.us nancy.zucca@dail.state.vt.us</p>
<p>Rutland Office One Scale Ave. Suite 109 Rutland, VT 05701-4460 Fax: 786-5055</p>	<p>Rodger Goodrich – Public Guardian Timothy Haley – Public Guardian Karen Hawley – Senior Public Guardian Dave Ramos – Public Guardian Cassandra Torrey – Prog. Svs. Clerk Jan Sherman – Senior Public Guardian Vicki Wetmore – Community Financial Specialist</p>	<p>786-5049 786-5040 786-5043 786-5042 786-5840 786-5041 786-5045</p>	<p>rodger.goodrich@dail.state.vt.us tim.haley@dail.state.vt.us karen.hawley@dail.state.vt.us dave.ramos@dail.state.vt.us cassandra.torrey@dail.state.vt.us jan.shermanopg@dail.state.vt.us vicki.wetmore@dail.state.vt.us</p>
<p>St. Albans Office 20 Houghton Street Room 207 St. Albans, VT 05478 Fax: 524-5592</p>	<p>Marybeth Blakeney – Public Guardian Diane Morris – Public Guardian</p>	<p>524-7991 524-7992</p>	<p>marybeth.blakeney@dail.state.vt.us diane.morris@dail.state.vt.us</p>
<p>Springfield Office 100 Mineral Street Suite 306 Springfield VT 05156 Fax: 885-6471</p>	<p>Jay Derderian – Public Guardian Jon McGovern – Public Guardian</p>	<p>885-4980 885-8893</p>	<p>jay.derderian@dail.state.vt.us jon.mcgovern@dail.state.vt.us</p>

VERMONT DEVELOPMENTAL SERVICES PROVIDERS
January 2006

(CVS) CHAMPLAIN VOCATIONAL SERVICES, INC.

512 Troy Avenue, Suite 1
Colchester, VT 05446
Phone 655-0511 FAX: 655-5207

Exec. Director: Kelley Homiller
County: Chittenden

(CAP) COMMUNITY ACCESS PROGRAM OF RUTLAND COUNTY

PO Box 222, 1 Scale Avenue
Rutland, VT 05701
Phone: 775-0828 FAX: 747-7692

Director: Gerald Bernard
County: Rutland

(CA) COMMUNITY ASSOCIATES

61 Court Street
Middlebury, VT 05753
Phone: 388-4021 FAX: 388-1868

Director: Greg Mairs
County: Addison

(CDS) COMMUNITY DEVELOPMENTAL SERVICES

50 Granview Drive
Barre, VT 05641
Phone: 479-2502 FAX: 479-4056

Director: Juliet Martin
County: Washington

(FF) FAMILIES FIRST

PO Box 939, Wilmington, VT 05363
Phone: 464-9633 FAX: 464-3173

Director: Julie Cunningham
Counties: Windham and Bennington

**(HCRS) HEALTH CARE AND REHABILITATION SERVICES OF
SOUTHEASTERN VT**

195 North Main Street
White River Jct., VT 05001
Phone: 295-3032 FAX: 295-0820

Director: Josh Compton
Counties: Windsor and Windham

Regional Offices:

112 Hardwood Way, Brattleboro, VT 05301
Phone: 257-5537 FAX: 257-5769

118 Park Street, Springfield, VT 05156
Phone: 885-5170 FAX: 885-5173

12 Church Street, Bellows Falls, VT 05101
Phone: 463-3962 FAX: 463-3961

14 River Street, Windsor, VT 05089
Phone: 674-2539 FAX: 674-5419

(HCS) HOWARD COMMUNITY SERVICES

102 South Winooski Ave.
Burlington, VT 05401-3832
Phone: 658-1914 FAX: 860-2360

Director: Marie Zura
County: Chittenden

(LCMH) LAMOILLE COUNTY MENTAL HEALTH SERVICES, INC.

520 Washington Highway
Morrisville, VT 05661
Phone: 888-6627 FAX: 888-6393

Director: Jackie Rogers
County: Lamoille

(LSI) LINCOLN STREET INCORPORATED

PO Box 678, 374 River Street
Springfield, VT 05156
Phone: 886-1833 FAX: 886-1835

Executive Director: Cheryl Thrall
County: Windsor

(NCSS) NORTHWESTERN COUNSELING AND SUPPORT SERVICES, INC.

107 Fisher Pond Road
St. Albans, VT 05478
Phone 524-6561 FAX: 527-8161
375 Lake Street, St. Albans, VT 05478
Phone: 524-0574 FAX: 524-0578

Director: Jean Gilmond
Counties: Franklin and Grand Isle

(NKHS) NORTHEAST KINGDOM HUMAN SERVICES, INC.

PO Box 724, 154 Duchess Street
Newport, VT 05855
Phone: 334-6744 FAX: 334-7455

Director: Dixie McFarland
Counties: Caledonia, Orleans and Essex

Regional Office:

PO Box 368, 560 Railroad Street
St. Johnsbury, VT 05819
Phone: 748-3181 FAX: 748-0704

(SCC) SPECIALIZED COMMUNITY CARE

PO Box 578, 16 Orchard Terrace Park
East Middlebury, VT 05740
Phone: 388-6388 FAX: 388-6704

Executive Director: Ray Hathaway
Counties: Addison and Rutland

(SAS) STERLING AREA SERVICES, INC.

109 Professional Drive
Morrisville, VT 05661
Phone: 888-7602 FAX: 888-1182

Executive Director: Kevin O'Riordan
County: Lamoille and Washington

(T-II) TRANSITION II, INC.

346 Shelburne Road
Burlington, VT 05401
Phone: 846-7007 FAX: 846-7282

Executive Director: Kara Artus
County: Statewide

(UCS) UNITED COUNSELING SERVICES, INC.

PO Box 588, 100 Ledge Hill Drive
Bennington, VT 05201
Phone: 442-5491 FAX: 442-3363

Director: Kathy Hamilton
County: Bennington

(UVS) UPPER VALLEY SERVICES, INC.

267 Waits River Road
Bradford, VT 05033
Phone: 222-9235 FAX: 222-5864

Executive Director: William Ashe
Counties: Orange and Washington

Regional Offices:

12 Prince Street, Randolph, VT 05060
Phone: 728-4476 FAX: 728-6741

PO Box 719, Moretown, VT 05660
Phone: 496-7830 FAX: 496-7833

**MEMBERS OF THE STATE PROGRAM
STANDING COMMITTEE FOR DEVELOPMENTAL SERVICES
January 2006**

Name	Address, Phone and Fax	Represents	Term Expires (July 1)
Arsenault, Dawn	54 Jalbert Road Barre, VT 05641 Phone: 476-0624 e-mail: da102473@hotmail.com	Professionals/Advocates	2007
Bakeman, Anne	3 Bedford Green South Burlington, VT 05403 Phone: 658-3374 Fax: 658-8061 e-mail: abakeman@zoo.uvm.edu	Family Members	2006
Breiden, Nancy	Disability Law Project 57 N. Main Street Rutland, VT 05701 Phone: 775-1122 Fax: 775-0022 e-mail: nbreiden@vtlegalaid.org	Professionals/Advocates	2006
Bernard, Gerald	Rutland Mental Health Services PO Box 222 Rutland, VT 05702 Phone: 775-0828 Fax: 747-7692 e-mail: jbernard@rmhscn.org	Professionals/Advocates	2007
Cheney, Karen	170 Centerview Terrace St. Johnsbury, VT 05819 Phone: 695-3373 (w) 748-1447 (h) e-mail: kcheney@together.net	Family Members	2006
Compton, Joshua	Health Care and Rehabilitation Services 195 North Main Street White River Jct., VT 05001 Voice: 674-2539 Fax 674-5419 email: jcompton@hcrs.org	Professionals/Advocate	2008
Gilmond, Jean D.	2555 Ballard Road St. Albans, VT 05478 Phone: 524-6555 ext. 608 (w) 524-4377 (h) email: jgilmond@ncssinc.org	Professionals/Advocates	2007
Grassette, Patty	PO Box 867 Morrisville, VT 05661 Phone: 241-2617 (w) 888-8407 (h)	People with Developmental Disabilities	2007
Hathaway, Sarah	c/o Community Developmental Services 50 Granview Drive Barre, VT 05641 Phone: 479-2502 (w)	People with Developmental Disabilities	2006

Name	Address, Phone and Fax	Represents	Term Expires (July 1)
Leavitt, Suzanne F.	109 Lincoln Avenue St. Albans, VT 05478 Phone: 524-4158 e-mail: sleav731@sover.net	Professionals/Advocates	2006
Morse, Janeen A.	14 Village Circle Randolph, VT 05060 Phone: 371-7677 (cell)	Professionals/Advocate	2008
Neron, Steven	PO Box 8 Bethel, VT 05032 Phone: 234-6591	People with Developmental Disabilities	2008
Place, Edwin	Randolph House, Apt. 208 Main Street Randolph, VT 05060 Phone: 728-2021	People with Developmental Disabilities	2008
Woodberry, Connie	103 Partridge Road East Dummerston, VT 05346 Phone: 254-8611 (w) 257-0300 (h) Fax: 254-8611 e-mail: conniewo@sover.net	Family Members	2007
Vacancy		Family Members	2008



State Standing Committee Members: Left to right back row – Steven Neron, Joshua Compton, Gerald Bernard, Suzanne Leavitt, Sarah Hathaway and Karen Cheney. Front row – Dawn Arsenault. Jean Gilmond, Nancy Breiden and Patty Grassette. Missing from photo: Anne Bakeman, Janeen Jarvis-Morse, Edwin Place and Connie Woodbury.

SOURCES OF QUALITY ASSURANCE AND PROTECTION FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

January 2006

Quality assurance activities will not be successful if they are relegated to a single bureaucratic cubbyhole. The Vermont developmental services system has numerous components that impact upon quality assurance. There is great value in having a multi-faceted system of quality assurance, and the participation of numerous people in quality promotion activities is a strength. In Vermont, the overall quality assurance system includes at least the following components:

I. **Within the Department of Disabilities, Aging and Independent Living:**

- A. **Designation Process.** The Department of Aging and Independent Living (DAIL) designated one agency in each region of the state to ensure needed services are available through local planning, service coordination, and monitoring outcomes within their geographic region. The Designated Agency must either provide directly or contract with providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines.
- B. **Agency Reviews.** Twelve (12) full-time staff, including two registered nurses, conduct on-site reviews to assess the quality of services provided. The Community Alternative Specialist staff assess all Medicaid funded services to assure compliance with state and federal Medicaid standards and the outcomes detailed in the *Guidelines for Quality Services*. Site visits are conducted annually with follow-up as appropriate.
- C. **Office of Public Guardian.** Twenty-five (25) staff provide guardianship services as specified by law to about 650 adults with developmental disabilities and/or who are aging. Public Guardians play distinct quality assurance functions, including on-going monitoring of people's welfare, assessment of quality of life and functional accessibility, participation in individual support plans, and advocacy for appropriate services. Public Guardians are expected to have face-to-face contact with people for whom they are guardian at least once a month, and are available for emergencies 24 hours a day.
- D. **Safety and Accessibility Checks.** All residences of people with developmental disabilities (except those licensed through the Division of Licensing and Protection/DAIL or a public housing entity, such as Section 8) funded by the Division of Disability and Aging Services are inspected for compliance with safety and accessibility standards.
- E. **Consumer and Family Surveys.** The Division of Disability and Aging Services contracts for independent statewide consumer interviews to take place on a regular basis to measure the satisfaction of people receiving services. A confidential family satisfaction mail-in survey is also conducted periodically to assess how families feel about services that they receive to support their family members who live at home.

- F. **Critical Incident Reporting Process.** Developmental service providers provide critical incident reports to the Division of Disability and Aging Services when certain incidents take place, such as the death of someone receiving services; use of restrictive procedures; allegations of abuse, neglect or exploitation; or criminal behavior by or against someone receiving services.
- G. **Complaint and Appeals.** Each developmental service provider must have a written complaint and appeals procedure and inform applicants and service recipients of that process. Both informal and formal complaint and appeal processes are available to people applying for or receiving developmental services, their family members, guardians and other interested individuals.
- H. **Ethics Committee.** An Ethics Committee convenes bimonthly as needed, or on an emergency basis, to review any decisions by a Public Guardian or other developmental services staff to abate life-sustaining treatment for a person receiving services. In addition, any individual who wants advice about the ethical aspects of a decision, or is dissatisfied with a critical care decision made for a non-consenting person with developmental disabilities, may request the Ethics Committee to review the decision.
- I. **Human Rights Committee.** A Human Rights Committee meets monthly to review policies, procedures, trends and patterns, individual situations and positive behavior support plans to safeguard the human rights of Vermonters receiving developmental services. The committee provides an independent review of any restrictive procedures while assisting individuals and agencies to develop alternatives to restrictive procedures.
- J. **Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD).** ICF/DDs are licensed and monitored under federally specified guidelines by nursing staff of the Division of Licensing and Protection/DAIL. The Division of Disability and Aging Services conducts Utilization Reviews once every six months to determine whether continued stay is appropriate and necessary for each person residing in an ICF/DD.
- K. **Residential Care Home Licensure.** The Department of Disabilities, Aging and Independent Living licenses residences where three or more unrelated people with disabilities live.
- L. **Vocational Rehabilitation (VR) Services.** Vocational rehabilitation services, (as opposed to Medicaid-funded work supports), are provided and reviewed by the Division of VR/DAIL.

II. Elsewhere in State Government:

- A. **Abuse Complaints.** The Department for Children and Families and the Department of Disabilities, Aging and Independent Living handle complaints of abuse and neglect for children and adults, respectively. Any human service worker, including Division of Disability and Aging Services staff, is legally mandated to file an immediate report of any suspected abuse, neglect or exploitation of a person with a disability. For adults with disabilities, Adult Protective Services staff conduct independent investigations of each complaint and pursues legal or other recourse as indicated by the needs of the individual.
- B. **Fire Safety Regulation.** Staff of the Department of Labor and Industry must approve all Level III Residential Care Homes and ICF/DD facilities. Facilities must meet appropriate standards of the National Fire Safety Code.

- C. **Medicaid Fraud Unit.** This Unit investigates allegations of criminal activity, including abuse, neglect or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports. The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General.

III. Within Developmental Services Agencies:

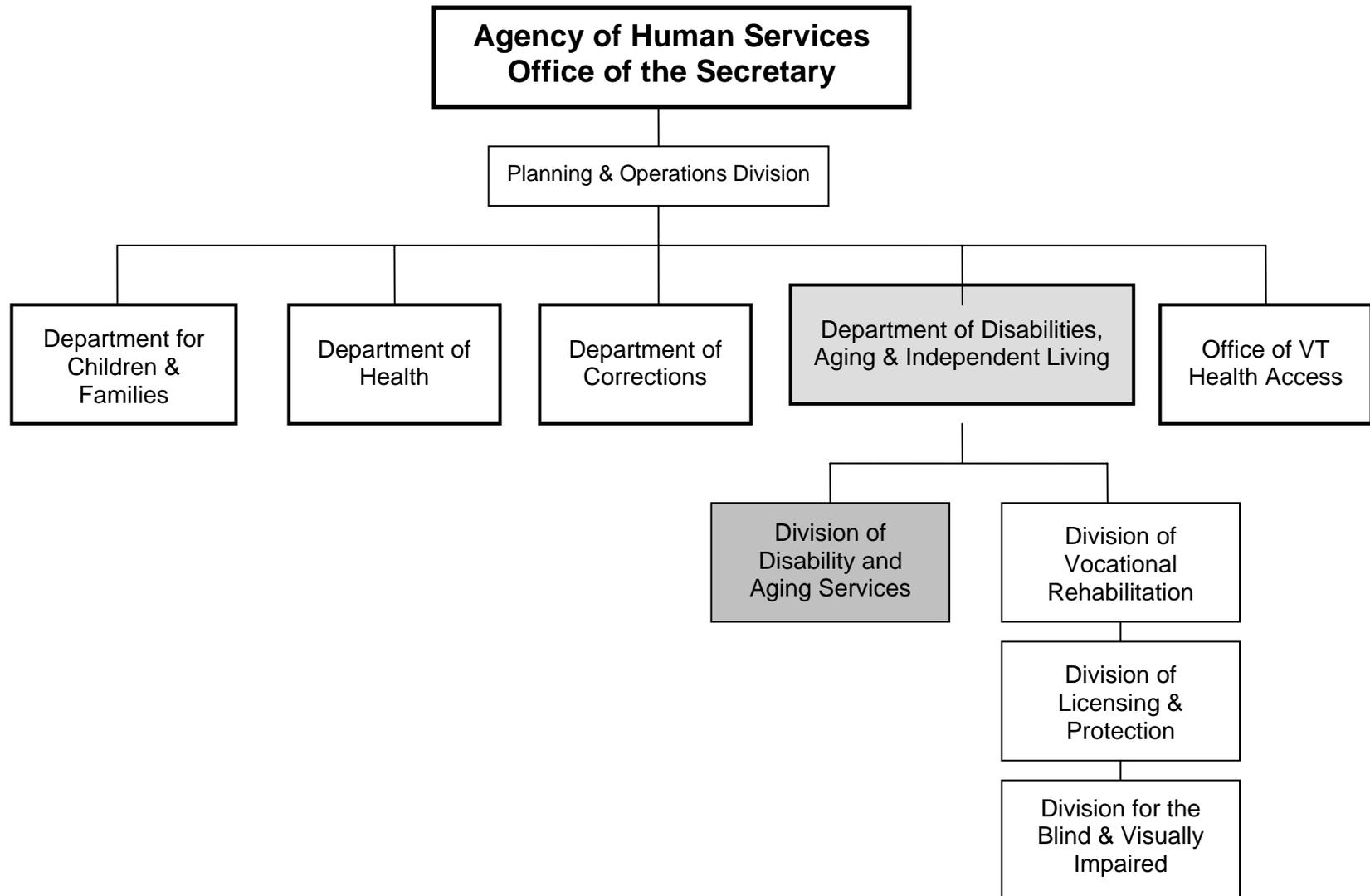
- A. **The Individual's Circle of Support.** Each person applying for or receiving services is encouraged to develop a circle of support. If they do not already have a circle, the service provider can help them form one. The circle is a group of people who helps the individual identify his/her dreams, takes responsibility to help the person create his/her plans and budgets, and determine the quality of his/her life. The primary focus of the circle is on the individual and what that person wants and needs. A circle of support is the ultimate safety net for that person.
- B. **Local Program Standing Committee.** Each designated agency and service provider has a local standing committee that is made up of at least 51% consumer and families, of which 25% must be direct consumers. The purpose of the Local Program Standing Committee is to involve people receiving services in planning and decision-making regarding policies in order to increase consumer satisfaction, service and support quality, and organizational responsiveness.
- C. **Internal Mechanisms.** All developmental service agencies have some level of an ongoing quality improvement process as well as internal quality assurance, such as a Human Rights Committee, peer review, and Local Program Standing Committee oversight. The specific design and intensity of these efforts vary from agency to agency.
- D. **Service Coordination.** Service coordination often includes the functions of "monitoring" and "advocacy." For some people, the service coordinator is the focal point for individual-based quality assurance at the local level.

IV. External to the Service System:

- A. **State Program Standing Committee for Developmental Services.** The State Program Standing Committee for Developmental Services was created by statute in 1990, (and updated through regulation in 1998), and is required to have at least 51% of its membership consumer and families. The Governor appoints this committee of people with developmental disabilities, family members, advocates, and people with professional/advocacy expertise in the field of developmental disabilities. The committee meets monthly as a working advisory group to the Division of Disability and Aging Services.
- B. **Vermont Developmental Disabilities Council.** A broad-based, federally mandated board that provides independent oversight and systemic advocacy for the needs of people with developmental disabilities.

- C. **Protection and Advocacy System.** This system has two components: a legal component through the Disability Law Project (DLP) and citizen advocacy. The Disability Law Project is part of Vermont Legal Aid and has offices in Rutland, Burlington, Montpelier, Springfield and St. Johnsbury. They provide protection and advocacy services to individuals with disabilities in a wide variety of forums (e.g., court proceedings, school negotiations, administrative hearings, Social Security Administration).
- D. **ARC of Vermont.** The ARC of Vermont provides a focus for families and concerned members of the public to identify and respond to the needs of people with developmental disabilities. There are four counties with local ARC offices. The Champlain ARC provides information, support and advocacy for individuals with disabilities and their family members in Chittenden County. Central Vermont ARC (Montpelier), Franklin ARC (St. Albans), and the Rutland ARC (Rutland) also share this mission.
- E. **Self-Advocacy.** Green Mountain Self-Advocates, a statewide self-advocacy group, works to empower people with disabilities to learn to make decisions, solve problems, speak for themselves, and to exert control over their own lives. It is committed to educating and making the general public aware of the strengths, rights and desires of people with disabilities. There are presently about 16 local chapters in various stages of development around the state.
- F. **Other Advocacy Groups.** There are other locally based groups of concerned families and advocates. For example, Guardianship Trust provides regular, structured individually-based citizen monitoring of residential services provided by WCMH in Barre. Brandon Training School Association is an alliance of parents and other people concerned with the well being of former residents of Brandon Training School.
- G. **Law Enforcement Agencies.** In recent years, many local and state police have received training in the techniques of interviewing people with developmental disabilities who are victims of crime. The traditional sources of citizen law enforcement—the police, State's Attorney's, and Attorney General's offices—have played an increasingly effective role in protecting citizens with developmental disabilities who may become victims of crime.
- H. **Criminal Penalties.** Vermont law makes it a crime to abuse, neglect or exploit a person with a disability. The Office of Attorney General will prosecute for violations of this law.
- I. **The Federal Government.** Through Medicaid audits and look-behind surveys, the federal government provides a back-up system of quality assurance.
- J. **Concerned Members of the Public.** These include interested professionals (e.g., physicians, psychologists), members of the academic community, legislators, etc., who express their concerns through traditional channels of professional, administrative and legislative communication.
- K. **Above all, individual friends, family members, guardians, coworkers, neighbors.** Friends, family and neighbors provide for individuals in community settings the most important and dependable source of monitoring and advocacy – someone that will “go to bat” for you if things are not going well.

ORGANIZATIONAL CHART AGENCY OF HUMAN SERVICES



SYSTEM OF CARE PLAN FUNDING PRIORITIES FY 2005

	Age	Priority	Approval	Comments
A.	Children & Youth under age 21	Support needed by families to assist them with personal care tasks as defined in the Personal Care Program	Eligibility & support level determined via Personal Care Program process	Entitled Medicaid state plan service for eligible children & youth
B.	Children & Adults	Support for respite and items through Flexible Family Funding that will help the biological or adopted family or legal guardian support the person at home	Determined by the designated agency; does not need to go through local funding committee	Sliding service scale in <i>Flexible Family Funding Guidelines</i> ; maximum \$1,122/person; effective 07/01/05 requires Medicaid eligibility
C.	Children & Adults	Support needed to prevent or end institutionalization in inpatient public or private psychiatric hospitals or nursing facilities or end institutionalization in Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD)	Reviewed by local funding committee & forwarded to Equity Committee	Money from PASARR Fund is approved by PASARR manager; legally mandated
D.	Adults 18 & over	Support needed to prevent or respond to an adult being abused, neglected or exploited	Reviewed by local funding committee & forwarded to Equity Committee	
E.	Adults 19 & over	Support needed by an adult to prevent an imminent risk to the person's health or safety	Reviewed by local funding committee & forwarded to Equity Committee	
F.	Adults 18 & over	Support needed for parents with developmental disabilities to provide training in parenting skills to help keep a child under 18 at home.	Reviewed by local funding committee & forwarded to Equity Committee	Services may not substitute for regular role & expenses of parenting; maximum amount of \$5,000/ year
G.	Adults 18 & over	Support needed to respond to an adult who is homeless or at imminent risk of being homeless	Reviewed by local funding committee & forwarded to Equity Committee	
H.	Adults 18 & over	Support needed by an adult who is experiencing the death or loss of an unpaid or minimally paid (e.g., residential care home) caregiver	Reviewed by local funding committee & forwarded to Equity Committee	
I.	Adults 18 & over	Support needed for specialized services in a nursing facility	PASARR fund manager	Limited to 5 hours per week; legally mandated
J.	Adults 19 & over	Support needed for a high school graduate to maintain an employer-paid job	Reviewed by local funding committee & forwarded to Equity Committee	Maximum of 25 hours/week
K.	Adults 18 & over	Support needed by an adult who has been committed to the custody of the Department of Disabilities, Aging & Independent Living pursuant to Act 248	Reviewed by local funding committee & forwarded to Public Safety Funding Committee	Services may be legally mandated
L.	Adults 18 & over	Support needed to prevent an adult who poses a risk to public safety from endangering others	Reviewed by local funding committee & forwarded to Public Safety Funding Committee	Does not substitute/ replace DOC supervision; see add'l. requirements under Public Safety Fund

**DIVISION OF DISABILITY AND AGING SERVICES
FY 2006 FISCAL RESOURCES**

The legislatively mandated study of the designated provider system for developmental services, mental health and substance abuse resulted in a negotiated increase of 7.5% per year for three years (FY 06, FY 07, and FY 08). In FY 06 for developmental services, one-half of that increase (3.75%) is allocated for cost of living increases for the community system. This is intended to cover the increased costs of any salary or contracted worker increases, higher insurance and fuel expenses, annualization of FY 05 worker's compensation coverage, etc. The remaining 3.75% is allocated to increased caseload needs. A summary of the available caseload funding is provided below:

FY 05 Caseload Annualization

Fully Funded in Base FY 06 Budget	<u>\$760,629</u>	<u>\$1,850,679</u>
-----------------------------------	-------------------------	---------------------------

FY 06 Caseload Need

Total needed for estimated 338 individuals	\$3,922,214	\$9,543,100
-- 219 emergency caseload		
-- 23 public safety		
-- 96 high school graduates		

Available

3.75% increase in appropriation	\$1,245,456	\$3,030,307
Estimated Equity Fund	805,055	1,958,771
Balance from Flexible Family Funding Program after conversion to Medicaid under Global Commitment	640,178	1,557,611
Conversion of state-funded services coordination to Medicaid	159,151	387,229
2.0% cut in existing Medicaid waiver services	<u>750,000</u>	<u>1,824,818</u>

Total Available for Caseload

	<u>\$3,599,840</u>	<u>\$8,758,736</u>
--	---------------------------	---------------------------

Difference

	<u>(\$322,374)</u>	<u>(\$784,364)</u>
--	---------------------------	---------------------------

Other Funding Increases in FY 06

Cost of living increase @ 3.75%	\$1,441,855	\$3,508,163
Funds needed to replace lost federal funds	\$1,446,857	\$0

GREEN MOUNTAIN SELF-ADVOCATES

January 2006

Green Mountain Self-Advocates (GMSA)

73 Main Street, Suite 401

Montpelier, VT 05602

gmsa@sover.net

802-229-2600

Contact: Ryan Whipple and Karen Topper

Toll Free (in VT): 1-800-564-9990

LOCAL CHAPTERS:

Advocates For Action

12 Church St,
Bellows Falls, VT 05101
257-5537 – Felicia Rumrill
463-3962 – Kate Berge-Charter
Board Rep: Donna Bennett

Bennington Peer Support

United Counseling Services, Inc.
PO Box 588
Bennington, VT 05201
442-5491 – Melanie Brunina
Board Rep: Holly Colvin

B-SAC

Burlington Self-Advocacy Club

Howard Community Services
102 South Winooski Ave.
Burlington, VT 05401
658-1914 – Kathy Kretz and
Tracy Drake
Board Rep: Dan Denis

Capital City Self-Advocates

Montpelier and U-32 High Schools
5 High School Drive
Montpelier, VT 05602
262-1236 – Karen Noone
Board Rep: JT

Champlain Voices

Champlain Vocational Services, Inc.
512 Troy Ave., Suite 1
Colchester, VT 05446
655-0511 – Pricilla Thomas
Board Rep: Paul Nichols

COPS – Connections of Peer Support of White River Jct.

PO Box 678
Springfield, VT 05156
885-9533 – Karen Daley-Regan
Board Rep: Helen George

Friends Helping Friends

Community Developmental Services
50 Grandview Drive
Barre, VT 05641
479-2502 – Wendy Faery
Board Rep: Margaret Pearlstein

Next Step of St. Albans

Northwestern Counseling and Support
Services, Inc.
156 North Main Street
St. Albans, VT 05478
524-6561 – Syd Boyd
Board Reps: Katie Fairchild and
Rodney Farmer

Our Drop In Center

153 Main Street
Newport, VT 05855
344-8378 Diane Blais
Board Reps: Gail Rowe and
Roland Maurais

Peer Party Based in Springfield

HCRS – DS
118 Park Street
Springfield, VT 05156
885-5171 – Marilyn Comstock

RAPS - Randolph Area Peer Support

Upper Valley Services, Inc.
12 Prince Street, Suite #2
Randolph, VT 05060
728-4476 – Sue Stone
Board Rep: Edwin Place

Rutland High School Self-Advocates

22 Stratton Rd
Rutland, 05701
770-1012 – Maggie Rafter

Self-Advocates Becoming Empowered of Rutland

Rutland ARC
128 Merchants Row
Rutland, VT 05701
775-1370 – Lisa Lynch
Board Reps: Patty Derouchie and
Herman Goldberg

SAMS - Self Advocates Meeting of Springfield

PO Box 678
Springfield, VT 05156
885-9533 – Ki Tornquist
Board Rep: Mel Hill

Speak Up Addison County

61 Court Street
Middlebury, VT 05753
388-0168 – Lindsey Hescocock. Board
Rep: Randy Lizotte

Vermont Choices

Northeast Kingdom Human Svcs., Inc.
PO Box 368
St. Johnsbury, VT 05819
748-3181 – Robin Burnash
Board Rep: Lori Gervais

Green Mountain Self-Advocates

Local Self-Advocacy Chapters

