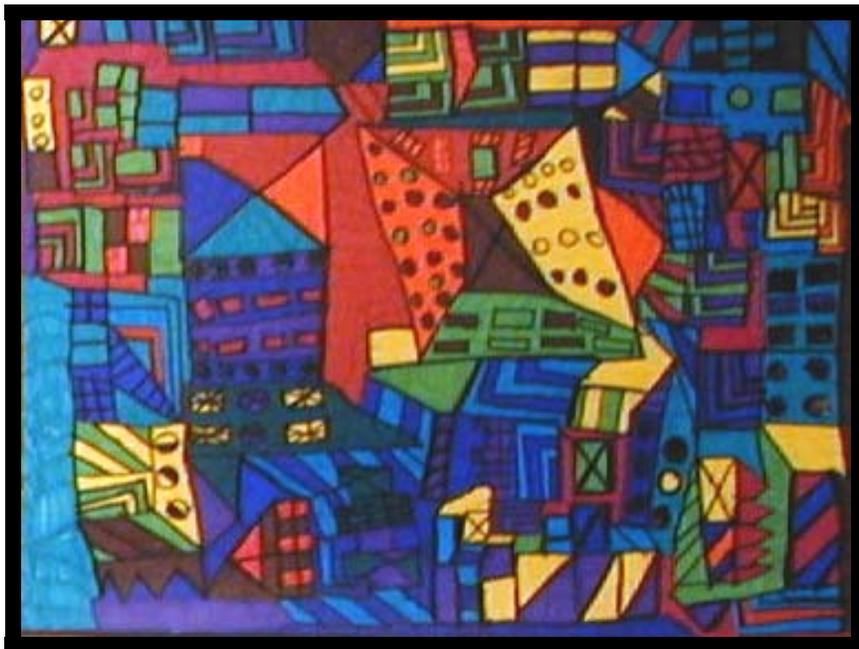


# **ANNUAL REPORT**

## **2005**

### **DIVISION OF DEVELOPMENTAL SERVICES**



**DIVISION OF DEVELOPMENTAL SERVICES  
DEPARTMENT OF AGING AND INDEPENDENT LIVING  
AGENCY OF HUMAN SERVICES  
STATE OF VERMONT**

**JANUARY 2005**

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of Colchester, VT



# **Annual Report 2005**

## **Division of Developmental Services**

**Division of Developmental Services  
Department of Aging and Independent Living  
Agency of Human Services  
State of Vermont**

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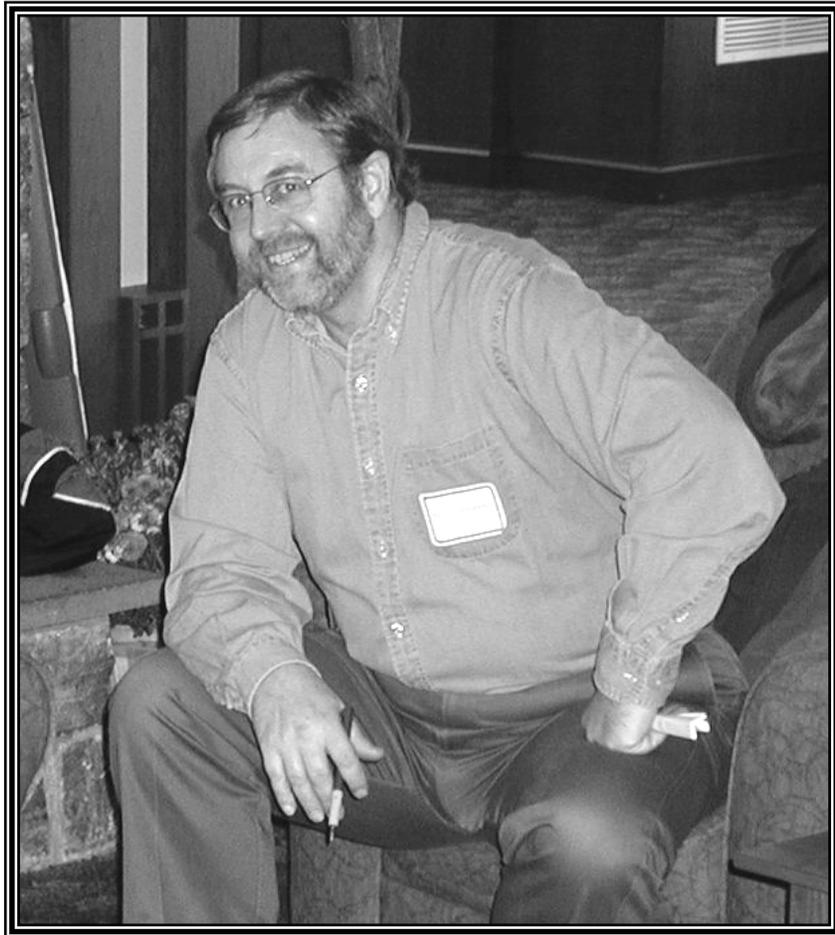
**Notes:**

All data represented in this report are for FY 2004 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.



**This issue of the Annual Report  
is dedicated to  
PETER YOUNGBAER  
for  
his many years of committed advocacy  
to the well being of the people of Vermont.**



# TABLE OF CONTENTS

<b>INTRODUCTION.....</b>	<b>1</b>
Agency of Human Services Reorganization.....	1
Are Our Principles at Risk? .....	2
Memories from the Vermont Voices and Choices Conference .....	3
More Memories from the Vermont Voices and Choices Conference.....	4
<b>THE DEVELOPMENTAL SERVICE SYSTEM.....</b>	<b>5</b>
Principles of Developmental Services .....	5
Division of Developmental Services .....	7
Developmental Services Providers .....	7
<i>Designated Agencies</i> .....	7
<i>Specialized Service Agencies</i> .....	7
<i>Contracted Providers</i> .....	8
<i>Management Options for Services</i> .....	8
Quality Assurance and Quality Improvement.....	10
Highlights from FY 2004.....	14
Pressures on Community Services.....	17
New Caseload Funding – FY 2004.....	19
Financial Summary .....	20
<b>SERVICES &amp; FUNDING.....</b>	<b>23</b>
Funding Sources.....	23
Types of Services Provided .....	24
Total Served.....	25
<b>SERVICES &amp; SUPPORTS .....</b>	<b>27</b>
Service Planning and Coordination .....	27
Home Supports.....	29
Employment Services .....	37
Community Supports .....	40
Family Supports.....	44
Children’s Services .....	47
Clinical & Crisis Services.....	50
Nursing Home Reform.....	53
Self-Advocacy.....	56
Office of Public Guardian.....	60
Offenders with Developmental Disabilities.....	62
Real Choices Grant .....	64
Communication.....	68
Consumer Survey.....	72
Children’s Personal Care Survey .....	78
National Comparisons.....	80

**ATTACHMENTS**

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

# INDEX OF TABLES AND FIGURES

## THE DIVISION OF DEVELOPMENTAL SERVICES

Vermont Developmental Services Providers .....	9
Quality Service Reviews – 2004.....	10
Reasons for Receiving New Caseload Resources – FY 2004.....	19
New Caseload Numbers Over Time 2000 – 2004 .....	19
Average Waiver Cost per Person / Average Cost per Person – All Services: FY '92 – FY '04.....	20
Total Agency Administration Costs: FY '93 – FY '04.....	21
Per Person Service Rates of Individuals Served: FY 2004.....	21
Comparative Annual Cost of Services: Institution (1994) vs. Community (2004) .....	22
Percentage for Funding & Percentage for People by DS Funding Type: FY 2004.....	22

## SERVICES & FUNDING

Funding Sources – Numbers Served: FY 2004.....	23
Home and Community-Based Waiver Services Over Time .....	23
Flexible Family Funding Over Time .....	23
Total Number of People Supported by Service Provider: June 30, 2004 .....	25
Total Number of People Served: FY 1992 – FY 2004 .....	25
Age Breakout of People with Developmental Disabilities Served Over Time.....	26

## SERVICES & SUPPORTS

Service Planning and Coordination – Numbers Served: FY 2004 .....	27
Home Supports – Numbers Served: FY 2004.....	29
People Supported by Type of Living Arrangement: June 30 2004 .....	30
Number of People in Residential Settings by Size of Setting Over Time .....	30
Percentage of People in Residential Settings of 1-3 People: FY 2003 .....	31
Residential Care Home Use by People with Developmental Disabilities Over Time .....	31
Number of Residences by Size of Residential Setting: FY 2004 .....	31
Total Number of People Receiving Home Supports Over Time .....	32
Cost per Person (Waiver Funding) by Type of Home Compared to Numbers Served: FY 2004.....	32
Population Change by Type of Home Setting: FY '92 – FY '04 .....	33
Average Cost per Person by Type of Home: FY '95 – FY '04 .....	34
Employment Services – Numbers Served: FY 2004 .....	37
People with Developmental Disabilities Receiving Supported Employment to Work Over Time .....	37
Community Supports – Numbers Served: FY 2004 .....	40
Number of People Receiving Community Supports Over Time .....	40
Family Supports – Numbers Served: FY 2004 .....	44
Family Support vs. Home Support Over Time .....	44
Family Support to People Living at Home (Flexible Family Funding and Waiver): FY 2004 – Total People Served & People Served per 1,000 Population .....	45
Children's Services – Numbers Served: FY 2004 .....	47
Children (under 18) on Medicaid Waiver Over Time .....	47
Clinical & Crisis Services – Numbers Served: FY 2004 – Vermont Crisis Intervention Network .....	50

Vermont State Hospital Utilization by People with Mental Retardation:	
FY 1988 – FY 2004 .....	51
Nursing Home Reform – Numbers Served: December 31, 2004 .....	53
People with MR/DD who Reside in Nursing Facilities: 1991 – 2004.....	53
People with MR/DD as a Percentage of All People who Reside in Nursing Facilities: 1991 – 2004.....	54
People with MR/DD in Nursing Facilities as a Percentage of All People with MR/DD Receiving Residential Supports: June 30, 2003 .....	54
Guardianship Services – Caseload: June 30, 2004 .....	60
Consumer Survey – Numbers Surveyed: 2004.....	72
Consumer Survey Results: 2004.....	72
Demographic Summary: Vermont’s 2004 Consumer Survey Results .....	74
National Comparison of Vermont’s 2003 Consumer Survey Results .....	75
Comparison of Vermont’s 2001 and 2004 Consumer Survey Results .....	77
Children’s Personal Care Survey – Number Surveyed: 2004.....	78
Children’s Personal Care Survey Demographics: 2004 – Age of Family Member with a Disability, Caregiver’s Age, Caregiver’s Health, Length of Time getting PCS, Other Funding Source from DDS .....	78
MR/DD State Spending per Capita: FY 2002.....	80
State Fiscal Effort – Total MR/DD Spending per \$1,000 in Personal Income: FY 2002.....	80
Percent of State MR/DD Budget Paid by State Funds: FY 2002 .....	81
Number of People in MR/DD Residential Services & Nursing Facilities per 100,000 Population: FY 2002.....	81
Family Support Fiscal Effort – Total Spending per \$100,000 Personal Income: FY 2002 .....	82
Family Support Spending as Percent of Total MR/DD Budget: FY 2002 .....	82
Total Amount of Spending per Family: FY 2002.....	83

**ATTACHMENTS**

Acronyms.....	Attachment A
Organizational Chart: Agency of Human Services.....	Attachment B
Division of Developmental Services Staff:	
Waterbury Office Staff	
Community Alternative Specialists: Red and Blue Teams	
Office of Public Guardian Offices and Map	
Community Alternative Specialists: Blue and Red Team Structure and Map....	Attachment C
Vermont Developmental Services Providers .....	Attachment D
Members of the State Program Standing Committee for Developmental Services.....	Attachment E
Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities.....	Attachment F
System of Care Plan Funding Priorities.....	Attachment G
Division of Developmental Services FY 2005 Fiscal Resources .....	Attachment H
Green Mountain Self-Advocates: Local Chapters and Map.....	Attachment I

# INTRODUCTION

The Agency of Human Services' (AHS) reorganization has touched or will touch almost half of the population of the State of Vermont. Included among those affected are people with developmental disabilities and their families, and those who assist them. Effective July 1, 2004 the Department of Developmental and Mental Health Services was abolished. At the same time, the Division of Developmental Services, along with the Children's Personal Care Program and the High Technology Home Care Program joined with the former Department of Aging and Disabilities to form a new department – *the Department of Aging and Independent Living*. The reconfigured Agency of Human Services now has four departments. (See **Attachment B: AHS Organizational Chart**).

Among the many changes occurring, it is easy to lose track of the main reason for making them. For the first time since AHS was formed more than thirty years ago, almost all services for children and adults who will require long term supports are within one department. There will be an enhanced focus on services for people with autism through the creation of an Autism Specialist. The integration of services for elders, people with physical disabilities, people who have experienced a traumatic brain injury and people with developmental disabilities will afford opportunities for collaboration that have never existed before. It will take years to realize all of the promises that reorganization holds, but that should not deter us from taking the steps, person by person, to make them a reality. Struggles and challenges exist, but opportunities do as well.

The financial climate of the overall Medicaid program will continue to be a primary focus. The “global commitment” – a new way of partnering with the federal government for Medicaid services – is in development and many questions still exist. However, while we must have our eyes open for any problems that could develop, we must also be open to new opportunities for flexibility; flexibility to think about supporting Vermonters based on functional needs, not on labels or ages; flexibility to think about approaches to services that we have yet to tap into.

Another activity that has had an impact on Vermont's system of services for people with developmental disabilities and their families is the provider sustainability study commissioned by the Legislature. The consultants hired to perform the study interviewed countless individuals and held public hearings; they researched national and regional data; they looked at Vermont's own reports. Their conclusion – Vermont has an excellent developmental services system that people value and we have almost fully maximized Medicaid. That doesn't mean that there aren't improvements to be made, but the conclusion that this system is built upon a common set of values was very important. The study also recommended three potential financing models. The model that has been agreed to includes a 7.5% increase per year for the next three years. Of that, 3.75% is for caseload increases. Unfortunately, this is significantly less than recent years, so changes will need to be made to existing services and those who receive new funding. Identifying different strategies to meet the ever-growing needs of people with disabilities will, indeed, be a significant challenge for the system and for individuals and families.

***Theresa Wood***

Deputy Commissioner, DDS

## Are Our Principles at Risk?

*As we move toward FY 2006, the developmental services system is faced with many challenges within the context of overall State pressures in the Medicaid program. Given the uncertainties of the future, it seems appropriate to repeat the following words from last year's report.*

Certainly the past quarter century has been witness to remarkable changes in the ways people with developmental disabilities have been supported within Vermont communities. Over this time, there has been a tremendous influx of knowledge throughout the entire system. However, there has been no greater a change than in the growth in attitude and philosophy about how people with developmental disabilities should and can be incorporated within typical Vermont communities. The entire system is developing a better understanding of the power and importance of caring and individualized relationships in the lives of people with disabilities. The community system today has an increased recognition that people with disabilities can participate in the control of their own lives. These changes, along with increased knowledge, skill, and practice standards have resulted in an immeasurable improvement in the life quality of the people who depend upon the community system for their daily support.

The Developmental Disabilities Act of 1996 highlights twelve principles of service that define and protect the rights of Vermonters who are developmentally disabled (see page five). Since 1996, these principles have appropriately served as beacons defining the parameters of acceptable practice. Recently however, Vermont's budgetary challenges have caused a shift in current practice making it more difficult for the system to remain true to the twelve principles contained in the 1996 Act.

As we approach this next fiscal year, it is important that we reflect upon the twelve guiding principles that were adopted in the State of Vermont less than a decade ago. There are warning signs emerging indicating that the optimism and promises of the mid-1990's are being eroded by budgetary constraints and competing priorities. Staying true to guiding principles during relatively good financial times is easy. The strength of ones convictions, however, is measured most meaningfully during times of difficulty. It is during difficult times that an individual, an organization, or a State will have the strength of its convictions tested most harshly, with memories and legacies being formed by the decisions made and the actions taken during such times.

Vermont should rightfully take great pride in its accomplishments. Unfortunately, however, resource limitations are making it increasingly difficult for individuals with such disabilities, and their families, to access services and supports that are essential for their well-being. The Developmental Disability Act of 1996 offered optimism for all Vermonters who have a significant developmental disability by establishing its twelve guiding principles. The extent to which Vermont will assure that these principles of optimism become a reality for all of Vermont's neediest citizens still remains to be seen.

***William Ashe***

Executive Director, Upper Valley Services

## Memories from the Vermont Voices and Choices Conference



## More Memories from the Vermont Voices and Choices Conference



# THE DEVELOPMENTAL SERVICE SYSTEM

The Developmental Disabilities Act of 1996 requires the Department of Aging and Independent Living (DAIL), Division of Developmental Services (DDS), 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 Developmental Services *Annual Report*, together with the *Vermont State System of Care Plan for Developmental Services Three Year Plan (FY 2005 – FY 2007)*, covers all requirements outlined in the developmental disabilities statute<sup>1</sup>.

## 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.

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<sup>1</sup> 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 the Division of Developmental Services under the newly formed Department of 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 Developmental Services

The Division of Developmental Services 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 C: *Division of Developmental Services Staff***.

The Division of Developmental Services contracts directly with fourteen (14) private, nonprofit developmental services providers who provide services to people with disabilities and their families<sup>2</sup>. 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 D: *Vermont Developmental Services Providers***; and **Attachment E: *Members of the State Program Standing Committee for Developmental Services***.

## Developmental Services Providers

### Designated Agencies

The Department of Aging and Independent Living 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 region<sup>3</sup>. 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

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<sup>2</sup> There were 15 developmental service providers in FY '04, but one of the DS agencies (Vermont Supported Living, a Specialized Service Agency) discontinued providing services as of June 30, 2004. There are currently 14 private, non-profit developmental service providers, four of whom are Specialized Services Agencies.

<sup>3</sup> For developmental services, geographic regions are defined along county lines.

(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.

## 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 DDS 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

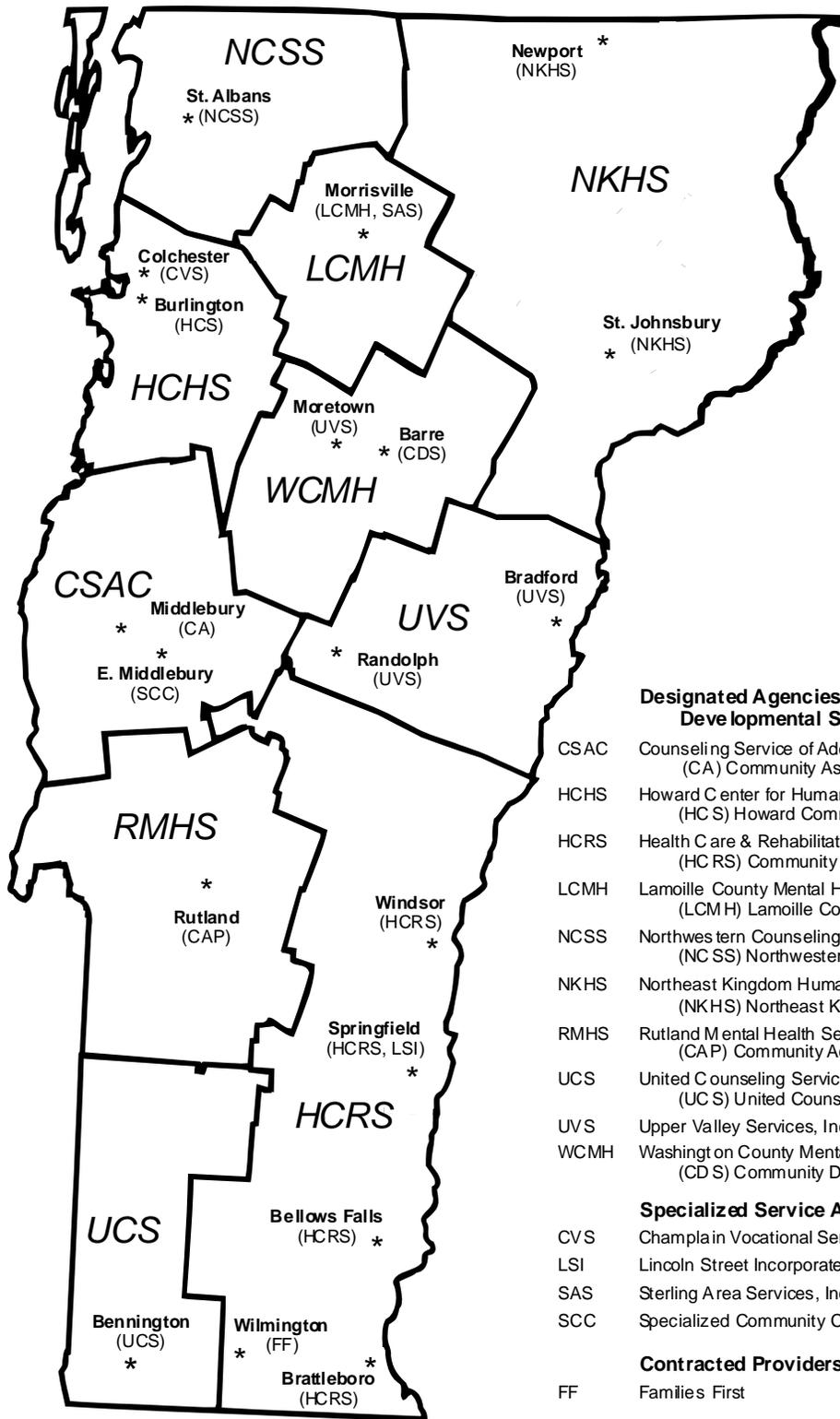
Traditionally, developmental service providers have managed all the services funded through DDS on behalf of people with disabilities and their families. Today, people have a choice of who will manage their services<sup>4</sup>. There are four options available to people:

- **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. An Intermediary Service Organization (ISO) is 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.

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<sup>4</sup> A guide for people who are self-/family-managing or shared-managing their services has been developed by DDS.

# 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 (as of 7/1/04)

Note: Vermont Supported Living was an SSA in FY '04, but as of June 30, 2004, all people served by the agency were transferred to other providers.

## Quality Assurance & Quality Improvement

Quality Service Reviews – 2004	
Agencies reviewed	16
People reviewed	407
Percentage of people reviewed getting Medicaid-funded services	19%

**Assessment, assurance and improvement of service quality** are critical functions of the Division of Developmental 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 Developmental 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 2004:

- Individual Support Agreements
- Medical Services, Documentation and Oversight
- Staff Training and Supervision
- Employment Services
- Behavior Support and Psychiatric Medication Support Plans

The annual quality reviews also inform the designation process that takes place for each agency every four years. In 2004, two agencies went through the re-designation process. Because of changes during the Agency of Human Services reorganization, designations have been extended until June 30, 2005<sup>5</sup>. 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 DDS 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** of all new unlicensed residential settings funded by DDS were conducted. The Division of Developmental Services contracted separately for 168 home safety reviews and 13 home accessibility reviews in FY '04. Three agencies<sup>6</sup> arranged for their own safety and accessibility reviews.

<sup>5</sup> SAS was re-designated and VSL was de-designated in FY '04. It is anticipated the temporary suspension of the designation process will extend through June 30, 2005.

<sup>6</sup> HCS, NKHS and UCS.

- **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 F: Sources of Quality Assurance and Protection for Citizens with Developmental Disabilities**.

**Training and technical assistance** are provided as part of the Division of Developmental 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 DDS 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 DDS 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 Developmental 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 Developmental 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

## 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:
  - Advance directives
  - Leadership skill development for Employment Coordinators
  - Estate planning
  - Inclusion and developing community presence
  - MAPS and PATHS
  - Alternatives to Guardianship
  - Social skills and relationship development
  - Ongoing support and training for local communication resource people
  
- ★ Intensive **nine-day training series** for service coordinators and independent support brokers was completed and work began on an accompanying reference manual.
  
- ★ 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 Developmental 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
  - Contenance 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 Developmental 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: 2005)

## Highlights from FY 2004

- ★ **New 3-year State System of Care Plan Adopted** – The Division of Developmental 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.
- ★ **Preparation for Agency of Human Services Reorganization Effort** – The Agency of Human Services and all associated departments began planning and taking preliminary steps toward a comprehensive reorganization effort of human services within the State of Vermont.
- ★ **Children’s Personal Care Services and High Tech Home Care Shifted to Developmental Services** – The Division of Developmental Services started preliminary work toward taking on the 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.
- ★ **Nursing Facility Use at an All-Time Low** – People with MR/DD who live in nursing facilities reached an all-time low of 27 people as of December 31, 2004. There has been a steady decline in this number since the inception of PASARR (pre-admission screening and resident review) services in 1988, including a dramatic 31% decrease in the last two years.
- ★ **Qualified Developmental Disability Professionals Rules Finalized** – The Division of Developmental Services updated the *Qualified Developmental Disability Professionals Definition, Qualifications, and Roles* as well as defined the *Endorsement of Individuals Acting Independently as Qualified Developmental Disability Professionals*. These two documents were incorporated into the Guide for People who are Self- or Family-Managing.
- ★ **Guide for People who are Self- or Family-Managing Developed** – The Division of Developmental Services released a guide to help individuals who are self- or family-managing developmental services that are funded through Medicaid. The guide incorporates the Qualified Developmental Disability Professionals rules and the Endorsement protocol.
- ★ **Guide for New Members of Boards and Committees Developed** – Green Mountain Self-Advocates, in partnership with the ARC of Vermont, created *Get on Board and Make a Difference! Effective Practices for Including People with Developmental Disabilities and New Members on Boards and Committees*.

- ★ **Health and Wellness Guidelines Finalized** – After lengthy discussions and incorporation of feedback, the Division of Developmental Services' *Health and Wellness Guidelines* were revised and finalized.
- ★ **Vermont Voices and Choices Conference a Huge Success** – An impressive 370 people attended this year's Voices and Choices self-advocacy conference. The event served as an opportunity to celebrate GMSA's 10-year anniversary. Most of the participants were self-advocates and each presentation included presenters who were self-advocates. Once again it was a two-day event with a record 225 staying overnight. Green Mountain Self-Advocates organized the event.
- ★ **New Policy of Education and Support of Sexuality Introduced** – The Division of Developmental Services, in collaboration with Social and Sexuality Education Resource Network and others, adopted a policy that identified the best way for agencies to provide education and support so that individuals receiving services may learn about the risks and responsibilities of expressing their sexuality.
- ★ **Network of Local Communication Resource People Supported** – Representatives from all developmental service agencies formed into a statewide communication network. The group participates in ongoing training sessions that offer tools, skills and resources for working with others at their agencies to better support people to communicate more effectively.
- ★ **Sex Offender Treatment Progress Scale Piloted** – Responding to the lack of objective measurements to help programs assess progress and treatment needs of sex offenders with developmental disabilities, DDS contracted with nationally known and respected expert Robert McGrath to create a treatment progress scale. Agencies throughout the state piloted the program in FY '04, and are completing it again in FY '05. Results will be analyzed and a revised version of the scale will be completed by the end of 2005.
- ★ **Crisis and Respite Program Established for Sex Offenders.** A specialized crisis bed and a specialized respite bed started operations. Staff are specially trained to work with and supervise sex offenders and the building is secured with alarms. Operated by NKHS, the program works in cooperation with DDS to prioritize referrals from around the state and provide individualized programs for those who use this resource.
- ★ **National Consumer Survey Results Rank Vermont Highest** – Vermont is listed #1 in a national comparison of consumer survey results in the areas of personal choice, community inclusion and choice related to supports<sup>7</sup>.

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<sup>7</sup> Data based on results from eighteen states that participated in the 2002 consumer surveys as part of the National Core Indicators. Results published in *Consumer Outcomes – Phase V Final Report – Fiscal Year 2002-2003 Data*.

- ★ **10-year Anniversary of Green Mountain Self-Advocates** – Ten years ago, the fledgling Vermont Peer Support Network made its debut as Vermont’s first self-advocacy organization for people with developmental disabilities. A decade later and under a different name, Green Mountain Self-Advocates has spawned upwards of two dozen different local self-advocacy groups, assured there are self-advocates on local and state advisory boards, and expanded training by and for people with disabilities to all corners of the state.
  
- ★ **“Our Bill of Rights” Video Produced by Self-Advocates** – Green Mountain Self-Advocates worked with the Awareness Theater Company, an acting troupe comprised of actors with developmental disabilities, to create an entertaining and educational video that helps people with developmental disabilities understand their rights and learn how to speak up about them.
  
- ★ **New Website Provides Helpful Resource** – Considerable effort and time went into creating a new website for the Division of Developmental Services. It is anticipated that more changes will be made to accommodate recent reorganization of the Vermont Agency of Human Services. In the meantime, <http://www.dail.state.vt.us> provides a link to a wide-range of information about services and supports provided through the Division of Developmental Services.
  
- ★ **Vermont Art on Display at the United States Capitol** – Support from developmental services and the hard work of Health Care and Rehabilitation Services of Southeastern Vermont, launched the “Painting One’s Dreams” (P.O.D.) Project from a fledgling art class of five students to multiple classes in watercolor and drawing for both adults and children in two different towns. During 2004, artists from P.O.D. had an exhibition at the U.S. Capitol in Washington D.C. The opportunity to create and show one’s work of art provides participants with a sense of community and accomplishment.

## Pressures on Community Services

In FY 2004, the Division of Developmental Services provided supports to **3,024** people with developmental disabilities in Vermont, approximately 28% of the eligible population<sup>8</sup>. However, the population is constantly growing with an estimated 110 children born each year with developmental disabilities<sup>9</sup>. The need for developmental services is generally life-long and only an average of 33 people who are currently receiving services die each year<sup>10</sup>. 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. A moratorium on funding to serve newly identified children with comprehensive services was implemented 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 time<sup>11</sup>.
- ⊙ **Waiting list continues** – At the end of FY 2004, the waiting list included 65 people who are eligible for developmental services. Those people were funded and began receiving services starting in July 2004. As of November 2004, there were 9 people on the waiting list.
- ⊙ **Special education graduates need supports to keep them employed and living at home**<sup>12</sup> – There are an estimated **106** graduates from Special Education programs expected to exit the educational system in FY '04. These young adults will look 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 is expected that **96** people will be eligible under current 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 (at age 18 and 19 years old).

<sup>8</sup> Based on National Census figures (7/1/03) obtained from the Vermont Department of Health.

<sup>9</sup> Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6,386 live births (State of Vermont 2002 Vital Statistics).

<sup>10</sup> Based on an average of the past six years (*NCI Mortality Data*).

<sup>11</sup> See **Attachment G: System of Care Plan Funding Priorities**.

<sup>12</sup> Designated Agencies survey local schools each year to find out exactly how many students with developmental disabilities are expected to graduate 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. It is significant that 22% of family caregivers are age 60 or more<sup>13</sup>.
  
- ◎ **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 150 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 247 individuals in FY '04 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. About 50% of people who received new caseload funding had previously not received developmental services or received only “minimal services”<sup>14</sup>.

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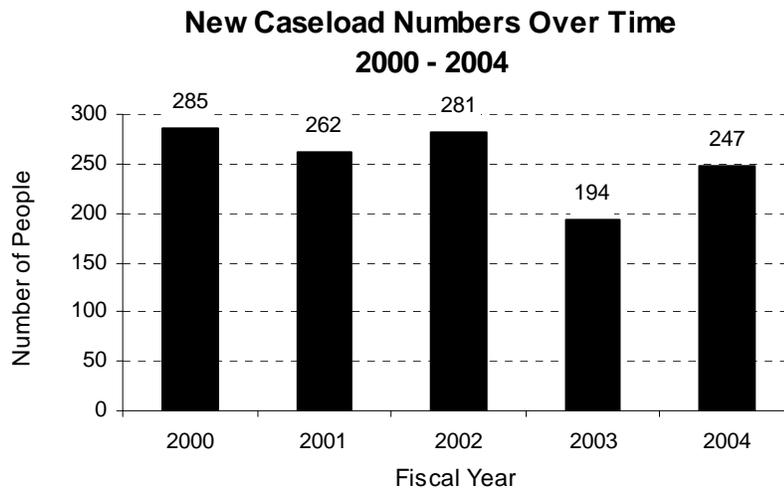
<sup>13</sup> Vermont Division of Developmental Services Family Satisfaction Survey – Statewide Results – Fall 2001.

<sup>14</sup> “Minimal services” are Flexible Family Funding, Targeted Case Management, or Transition grant-funded employment services.

## New Caseload Funding<sup>15</sup> – FY 2004

<b>Reasons for Receiving New Caseload Resources<sup>16</sup> - FY 2004</b>	
Imminent risk to person’s health or safety – for adults	131
Loss of home / imminent risk of homelessness – for adults	119
Risk of abuse, neglect or exploitation – for adults	100
Loss or reduced capacity of caregiver – for adults	30
High school graduation and job loss prevention	26
Risk to public safety	22
Risk of institutional placements or diversion from institutional Placement – for children and adults	18
Criminal behavior (Act 248) – for adults	22
<b>Total people served from new caseload resources (unduplicated)</b>	<b>247</b>

The Division of Developmental Services manages its resources each year by making sure new caseload funding goes to those most in need. Anyone getting new caseload resources must meet the State System of Care Plan funding priorities. Of the 247 getting new caseload funding, about half goes to people who meet the definition of “new consumer.” 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. For example, 72 people left waiver-funded services in FY '04; of whom 34 died, 11 moved out of state, five became ineligible for Medicaid or declined services, and 19 terminated for some other reason. Only three were known to leave services because they no longer needed the support.

<sup>15</sup> “New Caseload” funding includes all newly appropriated caseload, Equity Fund, High School Graduate Fund, and Public Safety Fund. Information is based on Designated Agencies’ intake information as reported to DDS via an annual funding summary. Individuals may be counted in more than one category.

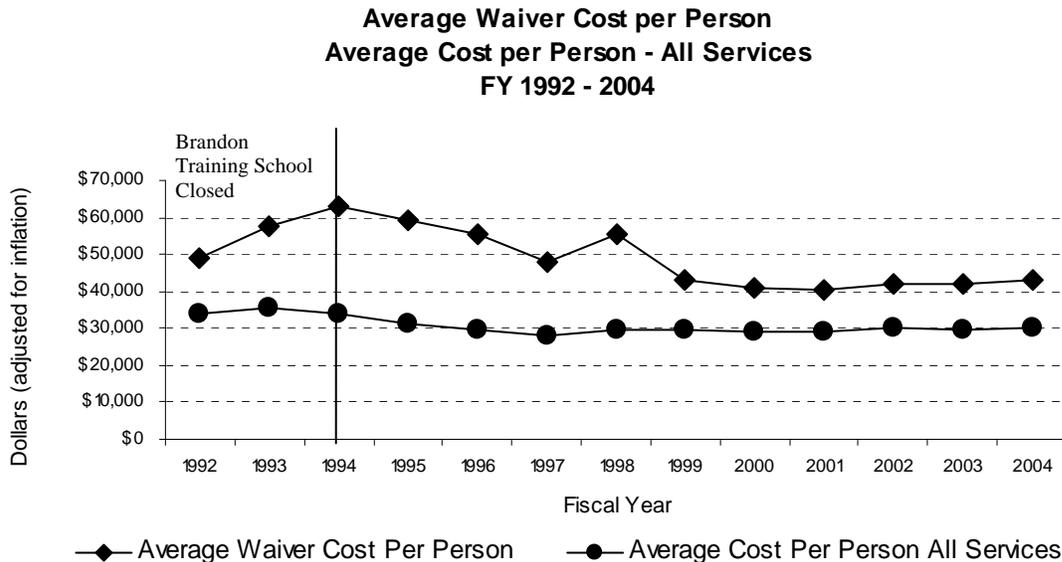
<sup>16</sup> See the *Vermont State System of Care Plan for Developmental Services Three-Year Plan FY 2005 – FY 2007* for a complete listing of funding priorities.

## 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. Yet state funds are limited. To capitalize on the resources available, the Division of Developmental Services emphasizes cost effective models and maximization of federal funds. See **Attachment H: Division of Developmental Services FY 2005 Fiscal Resources**.

- ★ The **average waiver cost per person (\$43,198)** rose by approximately 15.5% over the course of the past three years for the following reasons:
  - Suspension of services to new children,
  - Increase of almost 150 adults to 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 (\$30,386)** 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 person<sup>17</sup>.



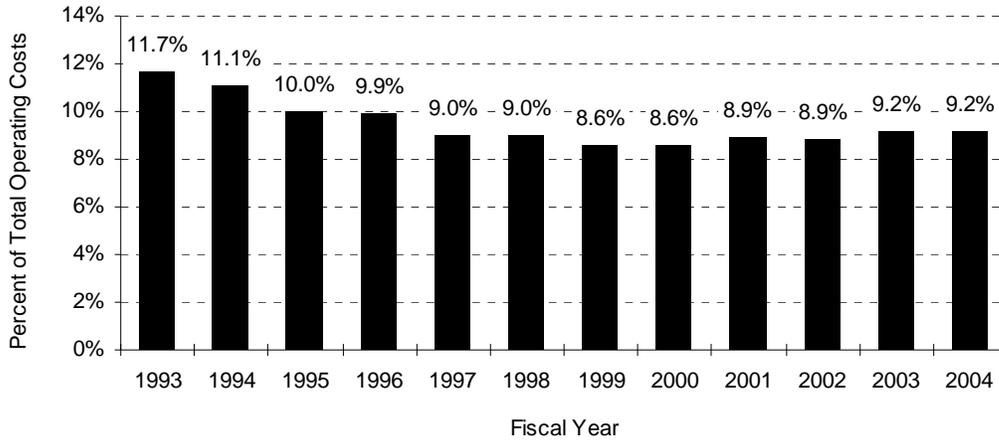
- ★ Nationally, fiscal growth for developmental services between 2000 and 2002 grew at an average rate of 17%; while Vermont’s **fiscal growth** during that same period was **12%**<sup>18</sup>.

<sup>17</sup> 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.

<sup>18</sup> The State of the States in Developmental Disabilities: 2002 Study Summary, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January, 2004.

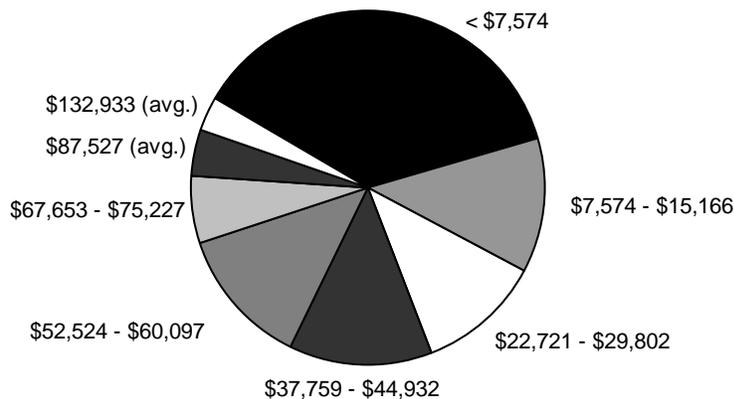
★ **Administrative expenses** include those that are required to run the total agency<sup>19</sup>. These costs have **remained stable** over time.

**Total Agency Administration Costs  
FY 1993 - FY 2004**



★ The **average cost of all services per person** in FY '04 was **\$30,386**. Almost one-half of all individuals served (**49%**) are funded for **less than \$20,000** per person per year. The average per person cost of supports in the most intensive community services category<sup>20</sup> is **\$132,933** per year, which is still almost **60%** less than what the estimated annual per person cost would have been at Brandon Training School in today's dollars (\$224,165). Sixty percent (**60%**) 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 2004  
(N=3,024)**

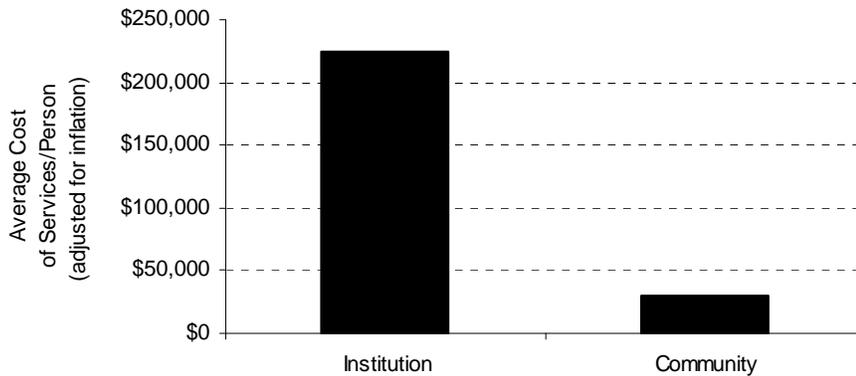


<sup>19</sup> Management expenses (e.g., developmental service director, buildings) relating to major program areas (e.g., developmental services) are considered program expenses, not administration.

<sup>20</sup> The highest rate category includes 6 people with intensive medical needs in an 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 **\$224,165** per year for each person served. In current dollars, **9** families can be supported with intensive in-home support, or **200** families can be supported with respite support, for the same amount of money (adjusted for inflation).

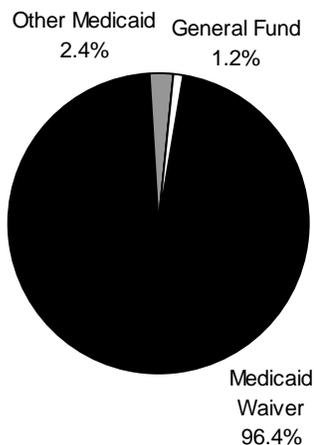
**Comparative Annual Cost of Services:  
Institution (1994) vs. Community (2004)**



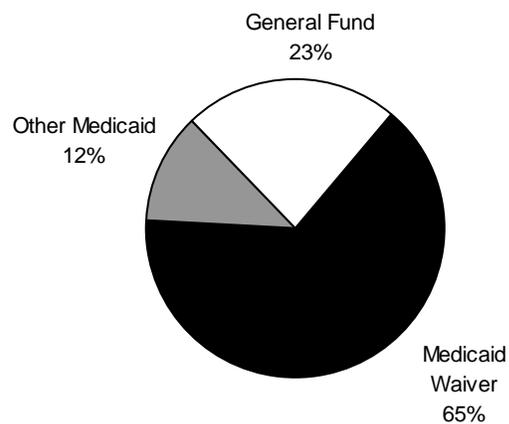
★ Flexible Family Funding, a cost-effective, family-directed support, is provided through general funds (GF) resources at DDS. It accounts for the significant difference in the number of people served through GF versus the percent of GF funding to the total. Almost **99%** of developmental service funding is from **Medicaid**, making Vermont’s developmental service system the top user of federal funds nationally.

**Percentage of Funding & Percentage for People<sup>21</sup> by DS Funding Type<sup>22</sup>  
FY 2004**

**Percent of Funding by Funding Type**



**Percent of People by Funding Type**



<sup>21</sup> 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.

<sup>22</sup> “Other Medicaid” = Targeted Case Management, Rehabilitation, Transportation, Clinic, ICF/MR and Social Services Block Grant. General Fund (GF) = Flexible Family Funding.

# SERVICES & FUNDING

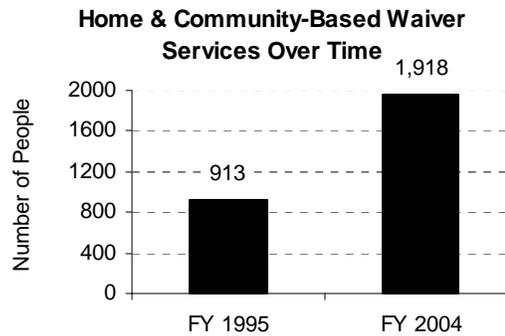
## Funding Sources

Numbers Served – FY 2004	
Home and community-based waiver recipients	1,961
Flexible Family Funding recipients (some dups. with waiver)	808
Other	361
<b>Total people served (unduplicated)</b>	<b>3,024</b>

**Medicaid** (waiver, fee-for-service and ICF/MR) accounts for **98.8%** of all DDS funding (including the state match). The remaining **1.2%** is paid by **state general funds**.

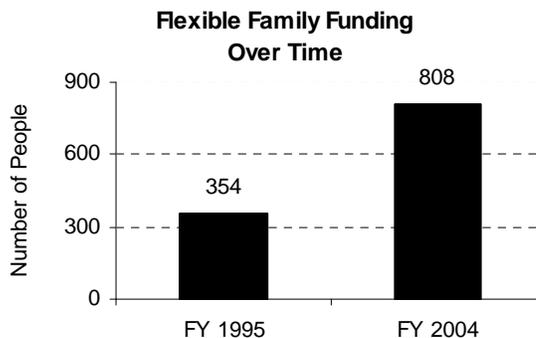
- **Home and Community-Based Waiver (HCBW) – 1,961 people**

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 **96.4%** of all funding for people served through DDS.



- **Flexible Family Funding (FFF) – 808 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 **1.2%** of all funding for people served through DDS.



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

## 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.

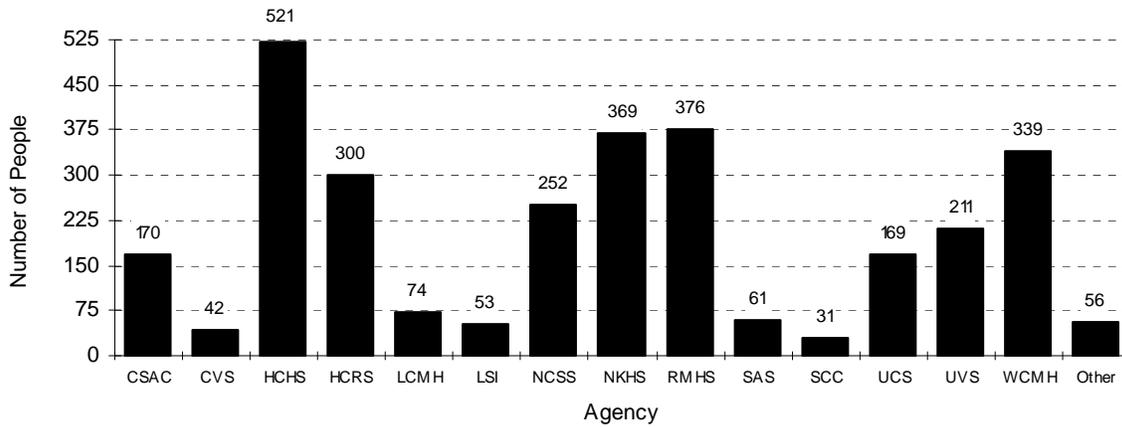
**Home Providers** – Individualized shared-living arrangements offered within a contracted home provider's home.

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

- **Respite** – Services (hourly or daily) 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.

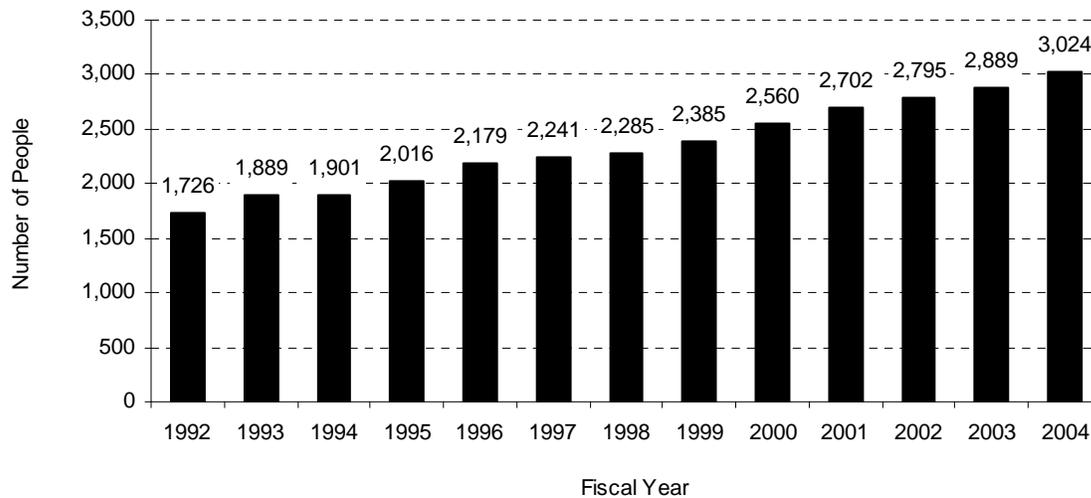
## Total Served

**Total Number of People Supported by Service Provider  
June 30, 2004**

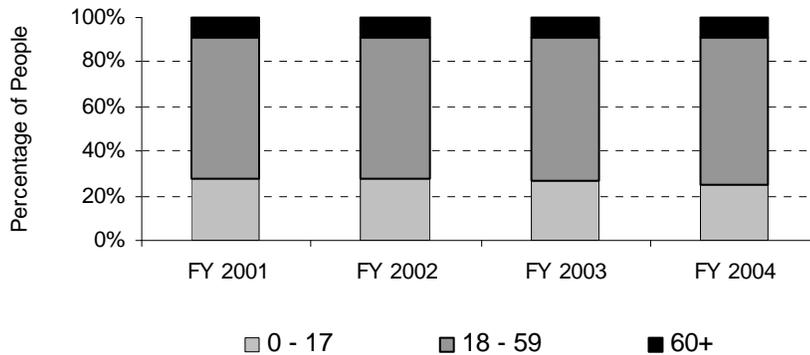


CSAC	Counseling Service of Addison County	SAS	Sterling Area Services, Inc.
CVS	Champlain Vocational Services, Inc.	SCC	Specialized Community Care
HCHS	Howard Center for Human Services	UCS	United Counseling Services, Inc.
HCRS	Health Care and Rehabilitation Services of SE Vt.	UVS	Upper Valley Services, Inc.
LCMH	Lamoille County Mental Health Services, Inc.	WCMH	Washington County Mental Health Services, Inc.
LSI	Lincoln Street Incorporated	Other	Includes people supported by Transition II Employment Services, Families First or Public Guardians who are not served by any other DS agency.
NCSS	Northwestern Counseling and Support Svs., Inc.		
NKHS	Northeast Kingdom Human Services, Inc.		
RMHS	Rutland Mental Health Services		
Note: VSL provided services during FY '04, but as of 6/30/04, all people served had been transferred to other providers.			

**Total Number of People Served  
FY 1992 - FY 2004**



**Age Breakout of  
People with Developmental Disabilities  
Served Over Time**



### Highlights



What **consumers** said about their agency<sup>23</sup>:

- **83%** said they are happy with their agency.
- **94%** said they are listened to at their support plan meetings.
- **88%** said things in their support plan are important to them.
- **89%** said people at their agency listen to them.
- **87%** 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.



What **families** said about their agency<sup>24</sup>:

- **75%** said staff respect their choices and opinions; an additional **20%** said staff sometimes respect their choices and opinions.

### Areas of Focus



What **consumers** said about their agency:

- **43%** said they are not told how much money is in their budget.
- **67%** said they have not been told about their agency’s appeal process.



What **families** said about their agency:

- **62%** said staff are generally knowledgeable and effective.
- **58%** said they chose the agency that works with their family.
- **51%** said they had been informed of their agency’s complaint and appeal process.
- **46%** said they are satisfied with how complaints and appeals are handled.

<sup>23</sup> This data and other references to the consumer survey throughout this report refer to the *Survey of Adult Consumers of Developmental Services – State of Vermont – 2004 Report (in draft)*.

<sup>24</sup> This data and other references to the family satisfaction survey throughout this report refer to the *Vermont Division of Developmental Services Family Satisfaction Survey – Statewide Results – Fall 2001*.

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

## Service Planning & Coordination

Numbers Served – FY 2004	
Waiver-funded Service Coordination	1,961
Fee-for-service Service Coordination	177
<b>Total Service Coordination</b>	<b>2,138</b>

**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

### Highlights

- ★ Service coordinators assist virtually **all people** receiving developmental services<sup>25</sup>.
- ★ What **consumers** said about service coordination:
  - **90%** said they were happy with their service coordinator.
  - **85%** said they got to see their case manager when they wanted.
  - **91%** said they got what they needed when they ask their service coordinator for something.
- ★ What **families** said about service coordination:
  - **76%** said they could contact their family member’s service coordinator whenever they wanted.
  - **71%** said they knew who to contact for information.
  - **77%** said the service plan had things that are important to their family member.

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<sup>25</sup> 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.

## Areas of Focus



What **consumers** said about service coordination:

- **42%** said someone else chose their case manager.
- **21%** said that they have had too many different case managers.

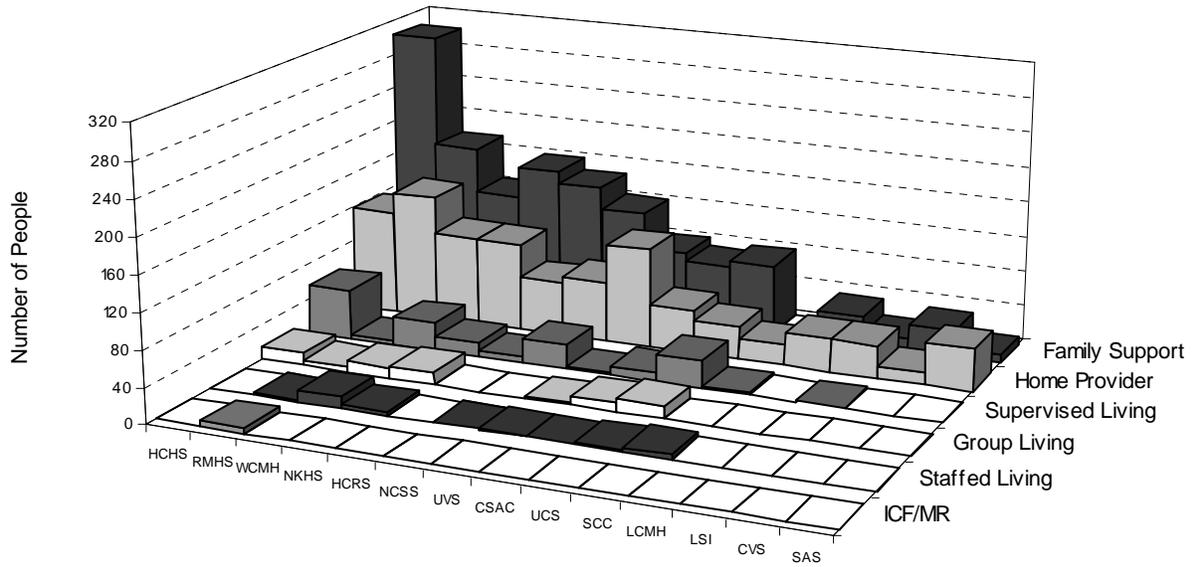


What **families** said about service coordination:

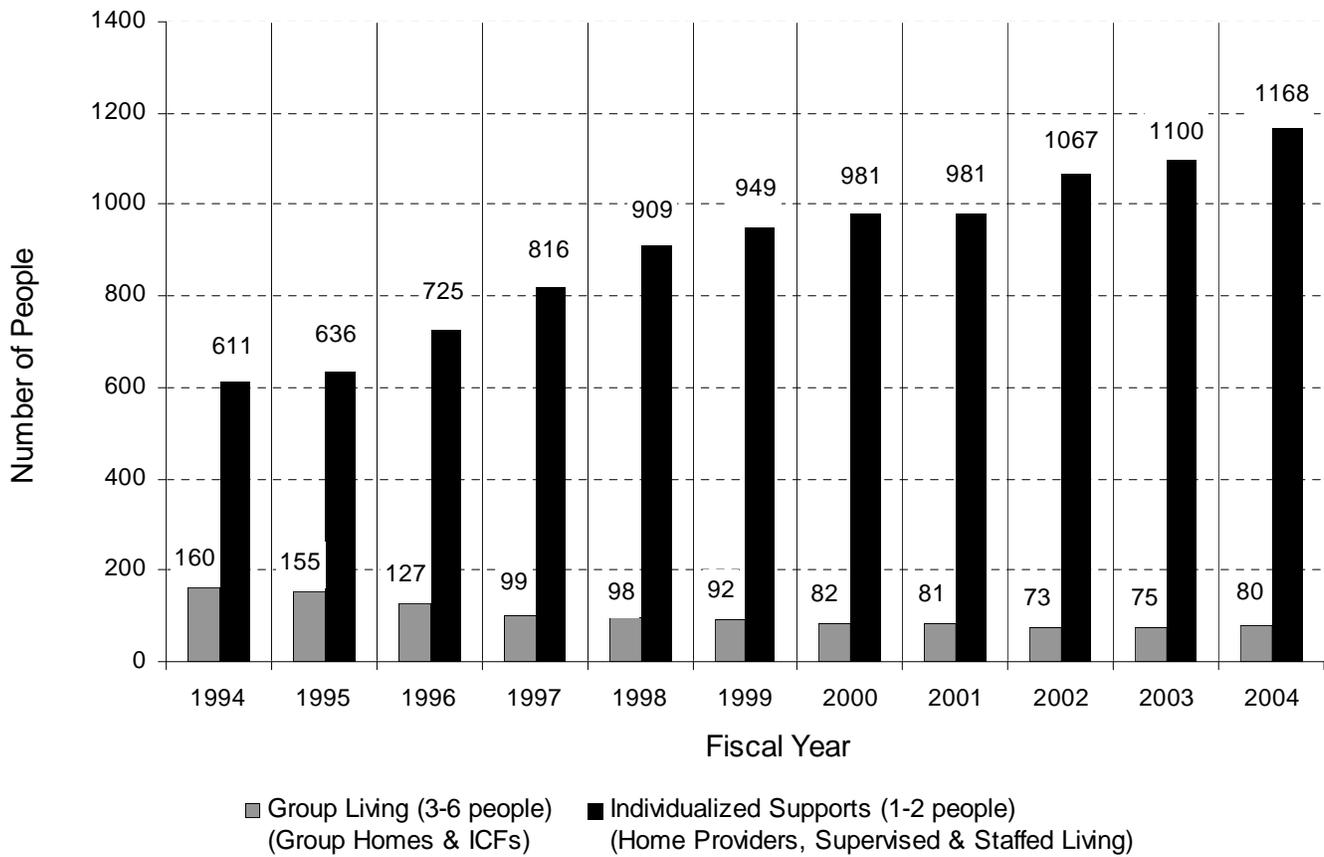
- **66%** got what they needed when they asked the case manager for assistance.
- **50%** got information about services and supports that are available to their family.
- **32%** said no one talks to them about public benefits that are available.
- **41%** know how much money is spent by the agency on behalf of their family member.



### People Supported by Type of Living Arrangement 6/30/04



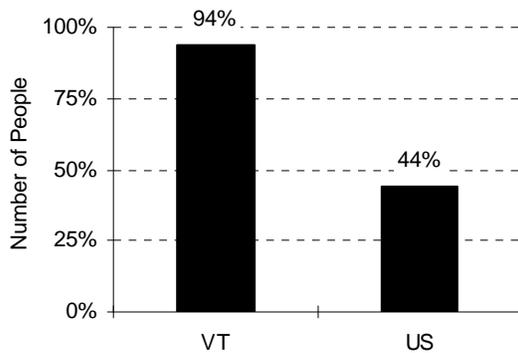
### Number of People in Residential Settings by Size of Setting Over Time



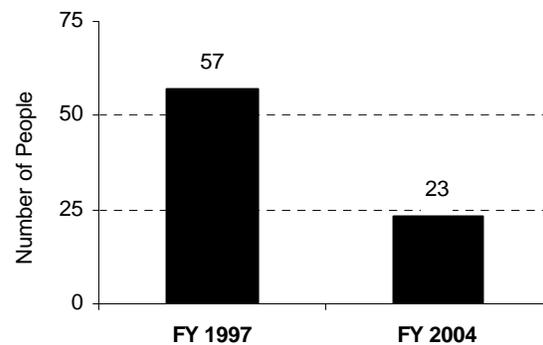
## Highlights

- ★ 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 People<sup>26</sup> FY 2003

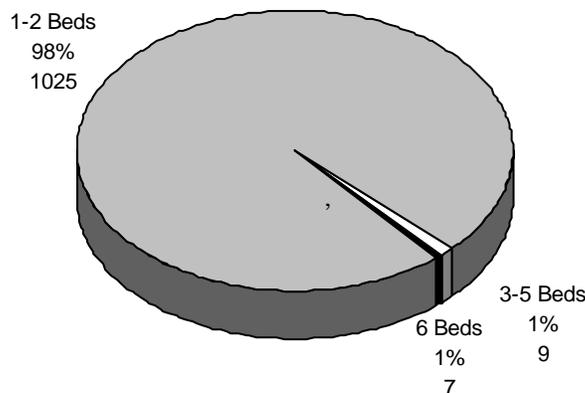


### Residential Care Home Use by People with Developmental Disabilities Over Time



- ★ There are **no** large congregate settings for people with developmental disabilities funded by DDS. 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 consumers<sup>27</sup>.

### Number of Residences by Size of Residential Setting FY 2004

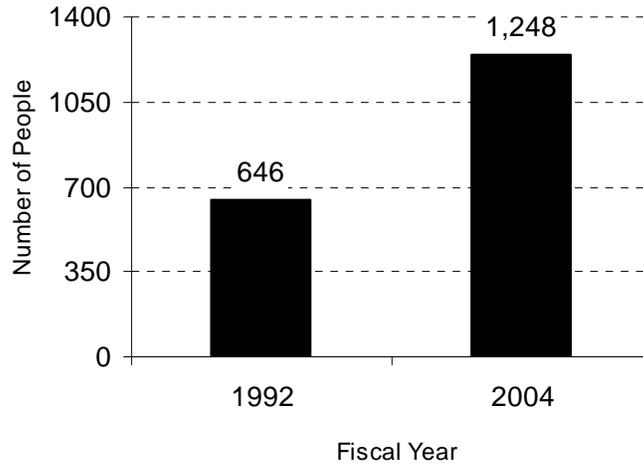


<sup>26</sup> Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2004.

<sup>27</sup> Ibid.

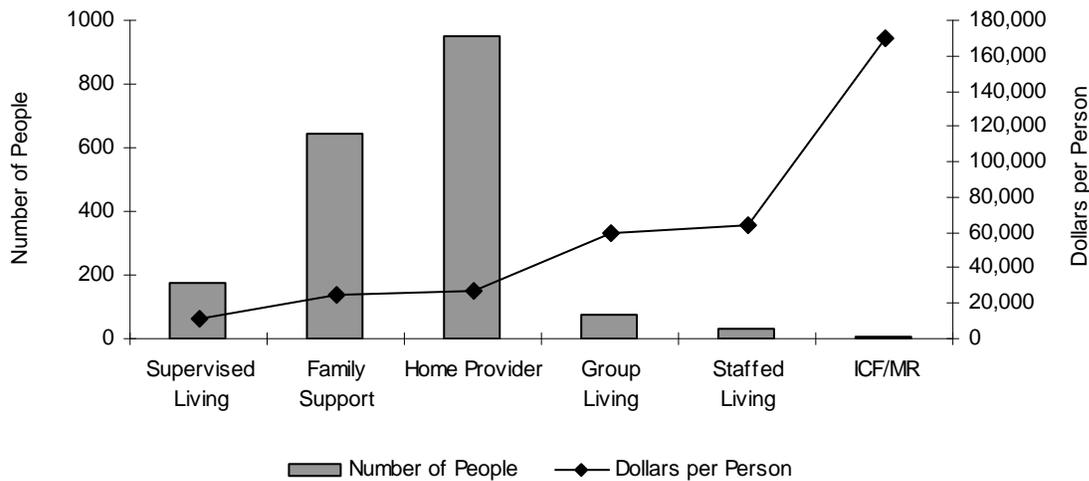
★ Although the need for home supports has steadily increased, Vermont has maintained an average of **1.2** number of people supported per residential setting; still the lowest rate in the country compared with the national average of 2.8<sup>28</sup>.

**Total Number of People Receiving Home Supports Over Time**



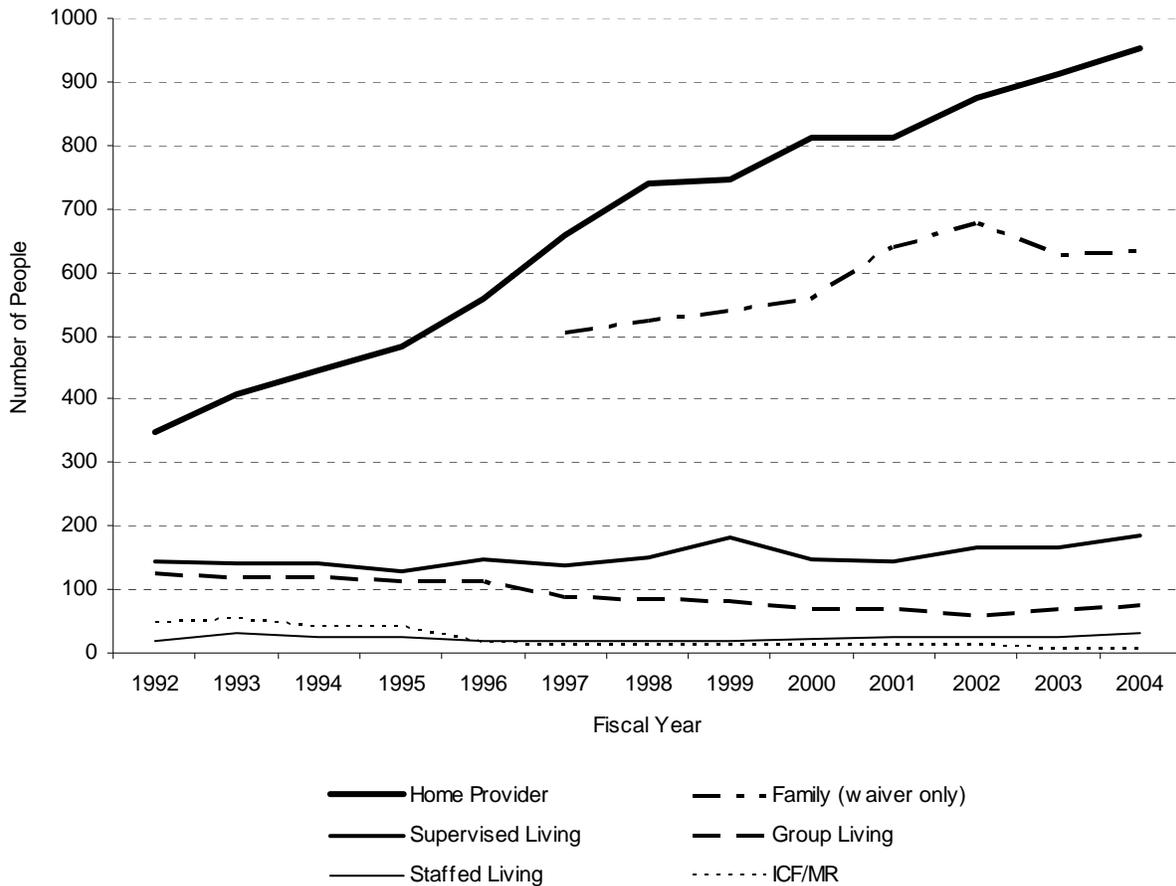
★ Vermont continues to focus on using less costly **in-home family support and individualized home support** options (e.g., home provider and supervised living) as compared to more costly congregate, staff intensive settings (e.g., group living, staffed living and ICF/MRs).

**Cost per Person (Waiver Funding) by Type of Home Compared to Numbers Served FY 2004**



<sup>28</sup> Ibid.

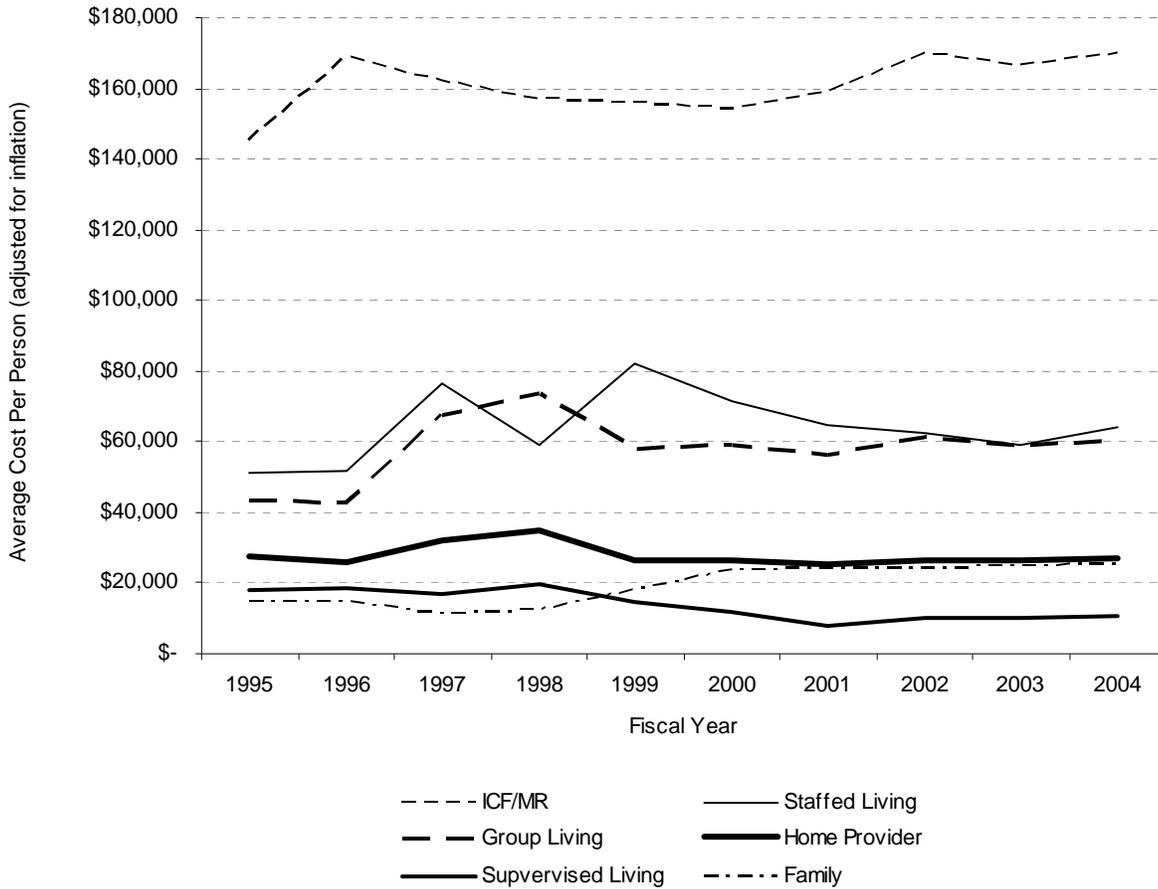
### Population Change by Type of Home Setting FY 1992 – FY 2004



- **Home Provider** residential settings have **steadily increased** throughout the past decade. They make up **76%** of all residential support options.
- **Families** whose family member lives at home and receives waiver-funded supports have **steadily risen** over time. A recent drop in FY '03 reflects the elimination of waiver funding for newly identified children (under age 18)<sup>29</sup>.
- **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) and FY '04 (opening of new home 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** have **steadily decreased** over time; only one remains open as of June 30, 2004.

<sup>29</sup> Data for family (waiver) supports for FY 1998 and FY 1999 are estimated.

### Average Cost per Person by Type of Home FY 1995 – FY 2004



- The cost of **Intermediate Care Facilities** has **steadily increased** over the years, 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, until 2004.
- The cost of **Group Living** has fluctuated some, but overall costs have **remained stable**.
- 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 a very good value.
- The cost of **Supervised Living** has **decreased steadily** over time, though it has been relatively stable these past couple of years.
- 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.
- **82%** of the people who live alone said they like living by themselves.
- **91%** said they like the people they live with<sup>30</sup>.
- **95%** said they like the food where they live.

## Areas of Focus



In FY 2004, an estimated **248** people were reported as living in a home they either **own (34) or rent (214)**. 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**, such as supervised living and innovative shared living arrangements.



**Home safety and accessibility reviews** were conducted on **181** homes in FY '04. Of those, 13% were in compliance within the first 30 days. An additional 46% were in compliance within the maximum 90-day grace period. There were ten homes that had not yet met compliance at the end of the fiscal year.



What **consumers** said about home supports:

- **38%** said someone else chose the place where they live.
- **40%** said someone else chose who lives with them.
- **20%** said they would like to have more chores to do at home.
- **13%** said people don't let them know before coming into their bedroom.
- **34%** said someone else decides when they can have friend or family over to visit.
- **20%** said they cannot be alone with friends when they come to visit.
- **30%** said when people in their house go somewhere they have to go too.
- **34%** said they do not have a key to their house.

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<sup>30</sup> This percentage combines responses for up to three people with whom the person lives (paid and unpaid), and therefore includes multiple answers for many of the respondents.

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## Bernice's Story

*"We are put on earth a little space.  
That we may earn to bear the beams of love."  
– William Blake*

*Bernice was born in Barnet, Vermont on May 4, 1914. She was admitted to Brandon Training School on December 13, 1951. Her parents were deceased at this time.*

*In 1969, Bernice was released from the Training School and was placed in the community. She lived in various Community Care Homes, but none compared to the small farm on York Street Extension in Poultney. Bernice moved in with Elizabeth and her extended family. That was fifteen years ago and life changed dramatically for her. Once she was easily frightened and socially withdrawn, but within this nurturing setting she found a sense of humor and a zest for life. Since she had a great love for animals, the farm was the perfect place for her. She got tremendous pleasure in watching the cows from the kitchen window, and adored the three dogs and two cats that roam around the house. On many occasions Elizabeth's brother brought a new baby calf into the house to surprise Bernice, which was a source of immense delight for her.*

*Although Bernice's communication is limited, she is able to use facial expressions, gestures, and vocal sounds to express her wants and needs. She does an impressive impression of Santa Claus, and is able to use the words "yes" "no" and "bye."*

*In May 2004, Bernice turned 90. Friends gathered at her farm house to celebrate. She received cards from her two nieces who lived in Rhode Island and had recently reconnected with her. They also visited her this summer to continue her 90<sup>th</sup> birthday celebration.*

*On November 4<sup>th</sup>, Bernice passed away after a brief illness. The finest years of her life were spent living on this small farm in Poultney. Bernice brought a special energy and an abundant amount of joy to this home. She made her "family" feel alive and she brought out the best in everyone. Elizabeth and her family gave Bernice back a tremendous amount of love and respect. As far as what truly matters in life, it doesn't get any better.*



*– Timothy Anthony Haley  
Public Guardian*

## Employment Services

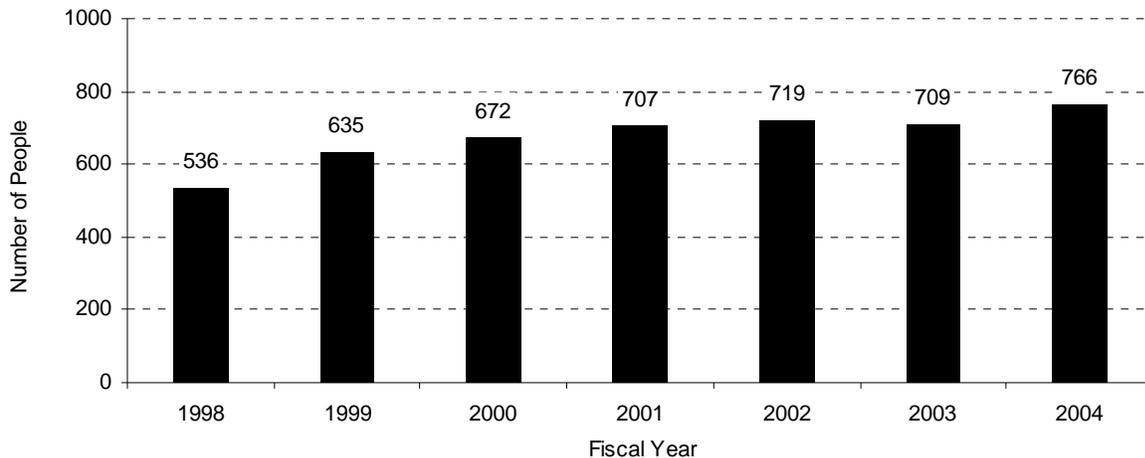
<b>Numbers Served – FY 2004</b>	
<b>People employed</b>	<b>766</b>
Average hourly wage	\$7.35
Average hours worked per week	11 hr./wk.
<b>Estimated public benefits (SSI) saved</b>	<b>\$1,024,464</b>

**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 Developmental 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 **43%** in the past **7 years**<sup>31</sup>.

**People with Developmental Disabilities Receiving Supported Employment to Work Over Time**



<sup>31</sup> The reported number of people receiving supported employment in FY 2004 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.

- ★ **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 employed<sup>32</sup>.
- ★ Vermont is ranked **#1** in the nation (FY '02) in the number of people with developmental disabilities who receive supported employment to work per 100,000 of the state population<sup>33</sup>.
- ★ Vermont is ranked **4<sup>th</sup>** nationally (FY '02) in people in supported employment as a proportion of total people getting community supports and/or work supports<sup>34</sup>; 42% in Vermont compared with the national average of 24%.
- ★ The average wage for people receiving employment services (\$7.35) continues to rise every year and is considerably **higher** than minimum wage in Vermont (\$6.75).
- ★ What **consumers** said about work supports:
  - **97%** said they like their job.
  - **96%** said the work they do is important.
  - **93%** said people respect them at work.
  - **89%** said they get a vacation from work.
- ★ What **families** said about work supports:
  - **84%** said work supports are worthwhile to their family member.

### Areas of Focus

- ◎ National data show that 2 out of 3 unemployed adults with disabilities want to work<sup>35</sup>; yet over **1200** adults with developmental disabilities (ages 18 – 65) in Vermont who receive services are not employed.
- ◎ What **consumers** said about work supports:
  - **34%** of the people who do not work said they want a paid job.
  - **29%** said someone else chose their job coach.
  - **14%** said they have too many different people support them at work.
  - **42%** said they have to go to work; it was not their choice.
  - **30%** said they would like to work more hours.

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<sup>32</sup> 2004 National Organization on Disability, *Harris Survey of Americans with Disabilities*.

<sup>33</sup> *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January 2004.

<sup>34</sup> Ibid.

<sup>35</sup> Ibid.

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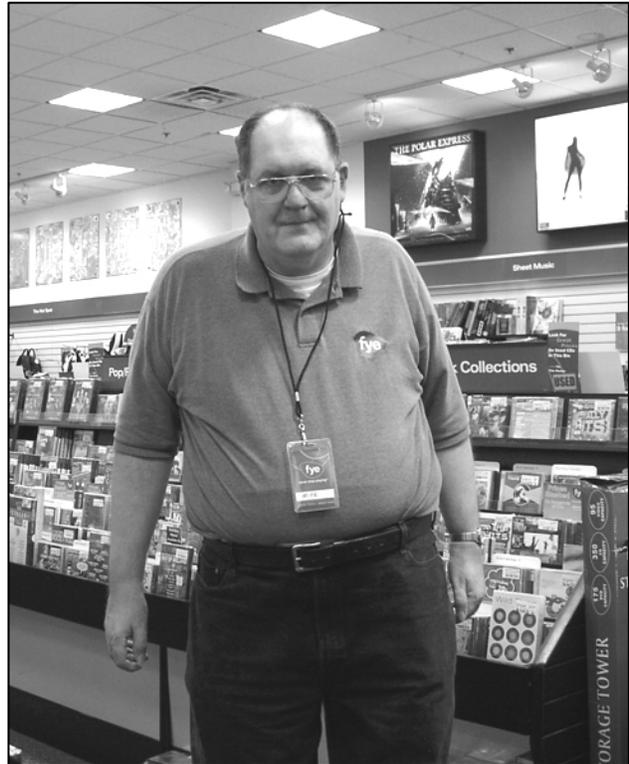
## Michael's Story

*“My name is Michael and I started my first job in September at For Your Entertainment (FYE). I like the boss because he gives me a lot of work to do. I work three hours a week. I wear a FYE shirt and name tag. I also wear black pants and black shoes. I hope I can work at FYE for a long time. “*

*– Michael*

*Mike first approached the Way2Work Program staff with his desire to find a paid position in the spring of 2004. Mike, who had no work experience outside of decades at the now closed sheltered workshop at Champlain Vocational Services (CVS), wanted to find a job in vending, sports, or music.*

*He used the skills that he gained at self-advocacy meetings to voice his true preferences to his support staff, service coordinator, and family members. He practiced creative visualization exercises at the CVS Career Club, which helped him remain focused and hopeful during his job search. Last summer, Michael was hired by the music store FYE as a store assistant. He labels, stocks and organizes the CDs and tapes. He's very proud of the work that he does at the store and has quickly made new friends with his co-workers.*



*– Jodi Hoh, Coordinator, Way2Work Program  
Champlain Vocational Services*

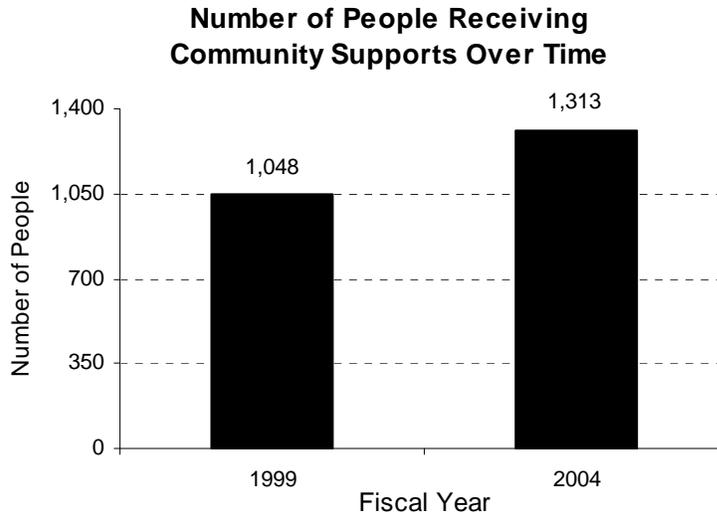
## Community Supports

<b>Numbers Served – FY 2004</b>	
<b>People receiving community supports</b>	<b>1,313</b>
Total annual cost of community supports	\$15,732,921

**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. **Almost all** community supports take place in and around a person’s home and community.
  
- ★ There has been a steady **increase** in people getting community supports over time, yet the average per person cost of community supports decreased in FY ‘04.



- ★ What **consumers** said about community supports:
  - **96%** said they like their community supports<sup>36</sup>.
  - **97%** said people who they spend time with during the day respect them<sup>37</sup>.
  - **95%** said they go shopping; of whom **62%** go as often as they want.
  - **95%** said they go out on errands, of whom **84%** go as often as they want.
  - **85%** said they go out to eat; of whom **67%** go as often as they want.

<sup>36</sup> This percentage takes into consideration responses for individual and group community supports, and therefore includes some duplication across types of community support.

<sup>37</sup> Ibid.



What **families** said about community supports:

- **86%** said community supports are worthwhile to their family member.

## 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 community supports:

- **38%** said they would like more hours of community supports<sup>38</sup>.
- **32%** said they do not make the choice to go to their community activities<sup>39</sup>.
- **28%** said there is something else they would rather do doing the day<sup>40</sup>.
- **40%** said they wish they had more friends.
- **78%** said they play sports; of whom **56%** play as often as they want.
- **65%** said they don't ever go to church, of whom **27%** would like to.
- **29%** said they don't ever go out for entertainment, of whom **44%** would like to.

## Jay's Story

*Around March of 2001 Jay moved into a temporary respite home in Rutland Town with Tom and Karen and their children. Karen remembers that Jay visited for only two days before deciding that this was where he wanted to make his new life. Karen says Jay became a part of the family immediately and that he put his complete trust in them to help him on his way to adulthood and to make his own decisions. He was 20 years old at the time. Since his mother passed away this has become his permanent home.*

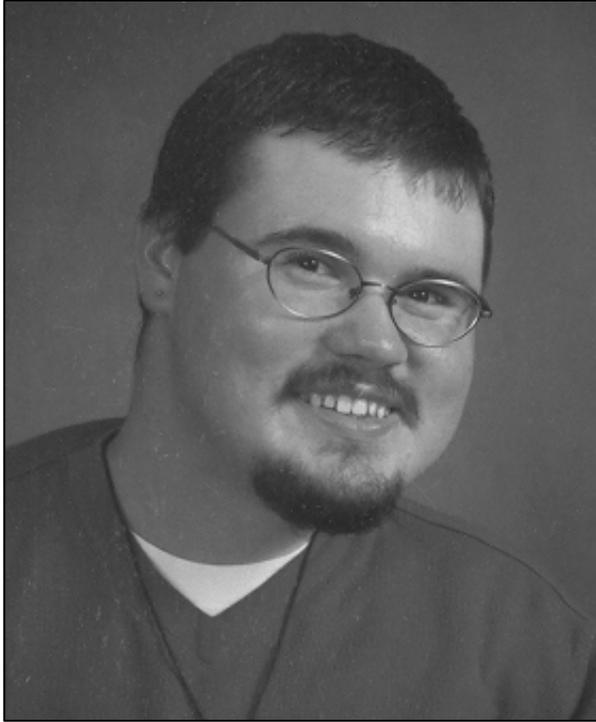
*Jay was still in school and he was receiving support for a full day of activities. He thrived. Jay has a form of muscular dystrophy (MD) that severely limits his physical abilities. He uses an electric wheelchair and steers it with a joystick. After the Young's started caring for him his health improved. His physical abilities also improved. He obtained a van, which has made a vast difference in his life.*

<sup>38</sup> Ibid.

<sup>39</sup> Ibid.

<sup>40</sup> Ibid.

*After graduation in June of 2002, Jay found a volunteer position at Rutland Regional Medical Center (RRMC). He finally was a part of the larger world in which he had been waiting to participate. Jay met many new friends at RRMC. He was out and about five days a week and was as active as possible. He always looked forward to it. Every night Jay shared his entire day with the Youngs, expressing pride in his accomplishments and responsibilities.*



*Jay's MD leaves him susceptible to various systemic problems. In April 2004, Jay came down with aspiration pneumonia and ended up in the Intensive Care Unit (ICU) at the RRMC. He was supported in the hospital by direct support staff, his service coordinator, home providers and friends.*

*Anne has been with Jay as his Community Access Program (CAP) nurse for many years. Although his medical issues have always been at the forefront of Anne's relationship with him, his personality and advocacy for his own needs have impressed her. Anne says his relationships with all of his caregivers, especially Karen and Tom, are wonderful. One event that stands out in Anne's memory is the time late one evening when Karen and Anne were "fretting" about his discharge plans from the ICU.*

*Jay, surrounded by tubes, looked up at Anne from his bed and said, "Oh, Anne, stop worrying. Everything will be OK!" Anne now says, "It was – and is."*

*Jay wanted very badly to come back home to the Young's but he needed a great deal of ongoing medical attention and Karen and Tom were feeling overwhelmed with the idea of providing the level of care necessary. Jay insisted that with the right help at home Karen and Tom could do it. In fact, Jay insisted that this had to happen. Once Jay had commitments from everyone on his team his strength somehow multiplied.*

*Jay's doctors insisted that he needed oxygen 24 hours a day, which would have restricted him to his bedroom. Jay did not want that. He convinced his doctors to reconsider. After more than a month in the ICU, Jay came back home with a portable ventilator, a tracheotomy, a feeding tube and professional nursing staff ... and a more positive attitude than ever before. The portable technology greatly enhanced Jay's quality of life and he can now speak louder and clearer due to the ventilator providing more air. Jay decided he wanted to eat solid food again and his doctor finally gave in. In typical fashion he progressed at a much faster rate than anyone thought he could. He has determinedly strived to eat normally and has succeeded. At this point he's eating full meals.*

*Karen says that as she looks back on the transition from the hospital to home it takes her breath away. "It was simply amazing." Karen credits CAP and Gary from the hi-tech program with addressing service system issues. She says CAPs attitude was "whatever it takes to make this happen, go for it." Karen says that Jay's trust was unreal. "He saw us as being able to do anything. He wanted his life back and he knew, even if we didn't, that we could make it happen. Jay did his part in getting better and his confidence in us made us decide to bring him home.*

*Jay has been back home for almost nine months. He receives Professional Nursing Services as well as community support and respite. Jay designs his own very busy daily schedule. He is back working at the hospital. He goes to concerts and shopping at malls. He visits his old high school frequently and maintains contact with the staff there. He has recently become a mentor for another man with MD. This relationship has given Jay a valued role in yet another person's life.*

*Jay's guardian, Rodger, feels that without the large, talented circle of support around Jay it is likely that he would not be alive today. "Unfortunately, he remains a New York Yankees fan in spite of continued efforts to influence him toward the Red Sox."*

*Carolyn, Jay's new service coordinator, initially met Jay when they were in school together in 6th grade. Back then Jay was still walking with some assistance. He would come into the nurse's office at school to rest and do his physical therapy. Jay would kid and make jokes the whole time he was there. Carolyn had seen Jay only a few times in the last few years, but every time he'd start with his usual bantering. She believes we should take a lesson from Jay and always keep a positive attitude. "You never know what obstacles you can overcome."*

*Jay says he knows his decisions are important and he has looked to Tom and Karen for support in making them. He has a voice. He accomplishes what he sets his mind to accomplish. Love and compassion have strengthened him and he is proud of who he has become. He's figured out what is really important in life.*

*Karen says she knows everyone in her family is a better person because of Jay. "Jay has changed our lives forever."*

## Family Supports

<b>Numbers Served – FY 2004</b>			
<b>Funding/Supports for Families</b>	<b>Adults (22 and over)</b>	<b>Children (under 22)</b>	<b>Total</b>
Flexible Family Funding recipients	149	659	<b>808</b>
Home and community-based waiver recipients	364	269	<b>633</b>
Respite/In-home supports	239	254	493
Other Supports (Employment/Community Supports)	328	101	429
(duplications between FFF and HCBW)	(64)	(34)	(98)
<b>Total family supports</b> (unduplicated)	<b>449</b>	<b>894</b>	<b>1,343</b>

**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.

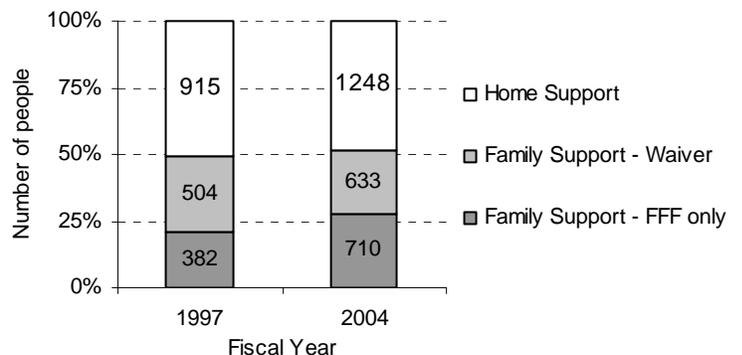
- **Flexible Family Funding (FFF):** Money provided to eligible families with children or adult family members with disabilities living at home used at their discretion toward services and supports that are in the person’s/family’s best interest. Examples of what may be purchased with the funding include, 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 Flexible Family Funding grew by **86%** in the past 7 years, versus 26% growth in waiver-funded family support and 36% growth in home supports.

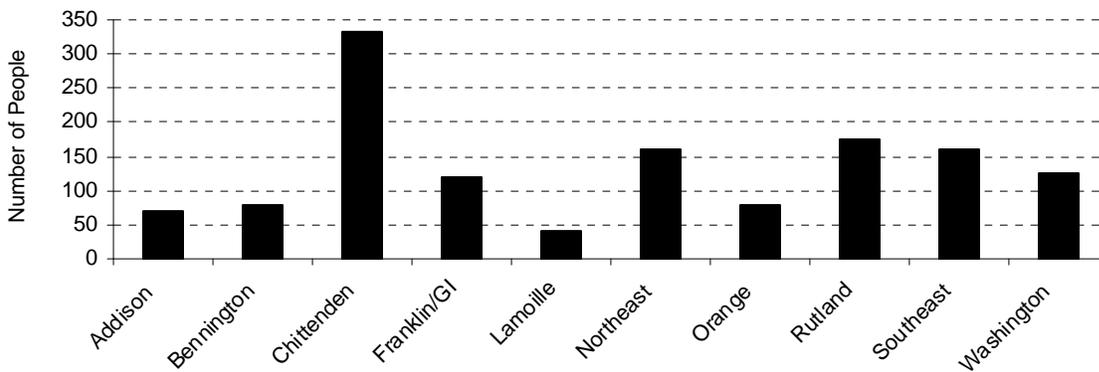
**Family Support vs. Home Support Over Time**



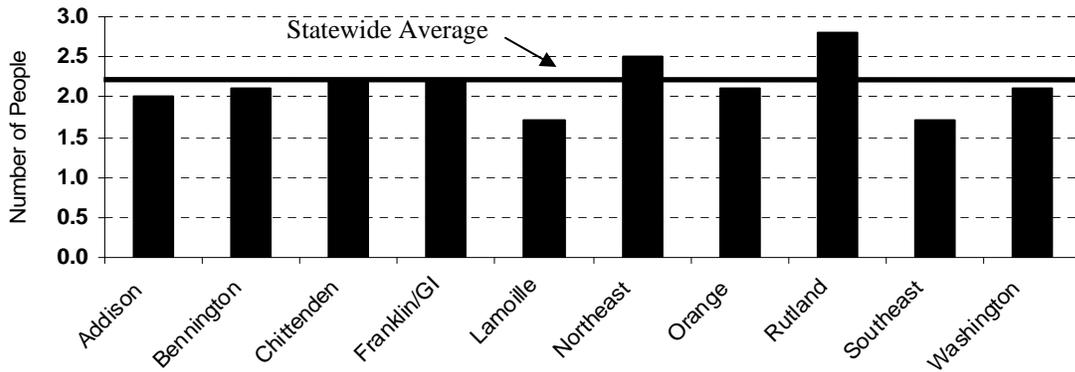
- ★ People receiving family support represents **44%** of all people served. This is up from 30% back in FY '96.
- ★ Family supports are provided statewide to an average of **two people per 1000 residents**<sup>41</sup>.

### Family Support to People Living at Home (Flexible Family Funding and Waiver) FY 2004

Total People Served  
(unduplicated)



People Served Per 1,000 Population  
(unduplicated)



<sup>41</sup> Source: US Census Bureau, Census 2003 estimates from the Vermont Department of Health, Vermont Population and Housing Estimates.

- ★ The Division of Developmental Services funded **four** respite homes around the state to provide planned out-of-home respite support to eligible individuals. In FY '04, **22 adults** and **20 children** received out-of-home respite for a total of **486 days**.
- ★ Vermont is **4<sup>th</sup>** in the country in terms of total family support spending per family<sup>42</sup>.
- ★ One third, or **33%**, of people who receive home and community-based waiver services live with their family.
- ★ What **families** said about family supports:
  - **72%** said family supports make a positive difference in the life of their family member.
  - **70%** said they choose the support/respite workers that work with their family.
  - **76%** said they want to have control over the hiring and management of their support/respite workers; **71%** said they do have control and/or input.

### 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.
- ◎ What **families** said about family supports:
  - **49%** said supports are available when their family needs them.
  - **26%** said frequent changes in support staff are a problem for their family.

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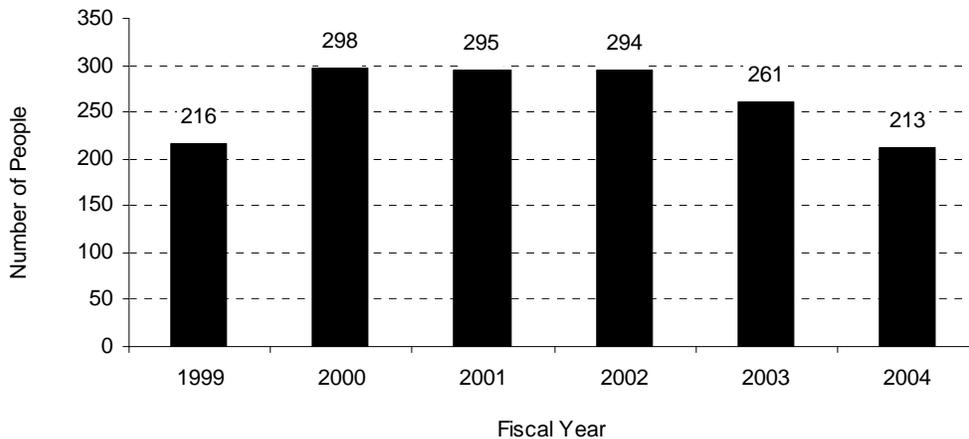
<sup>42</sup> *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January 2004.

## Children's Services

<b>Numbers Served – FY 2004</b>				
<b>Funding/Support for Children</b>	<b>Birth – 6</b>	<b>7 – 18</b>	<b>19 – 21</b>	<b>Total</b>
Flexible Family Funding recipients	137	444	78	<b>659</b>
Home and community-based waiver recipients	8	246	133	<b>387</b>
Lives with family	7	200	62	269
Does not live with family <sup>43</sup>	1	46	71	118 (31 w/DCF)
Other (Medicaid, vocational grant, self/private pay)	2	15	20	<b>37</b>
(duplications between FFF and HCBW)	(2)	(25)	(11)	<b>(38)</b>
<b>Total children services (unduplicated)</b>	<b>145</b>	<b>680</b>	<b>220</b>	<b>1045</b>

**Children's Services** are provided to children and youth 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  
Over Time**



### Highlights

- ★ On July 1, 2004, through the Agency of Human Services reorganization, the following Medicaid-funded services were transferred to the Division of Developmental Services:

<sup>43</sup> The one child under age 7 who is listed as “not living with family” lives in a shared parenting situation and therefore lives with family on a part time basis. Thirty-one (31) of the 46 children ages 7 – 18 who do not live with family receive foster care through the Department for Children and Families (DCF).

- **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 and enhance skill building to achieve greater independence. These services can be family-managed or provided by an agency. The number of recipients in FY '04 was 1040.
- **High Technology Home Care (HTHC)** program is an intensive home care program serving both adults and children. The program provides skilled nursing care 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 '04 was 98, with the majority of these being children.

★ Of the total number of people receiving developmental services in FY 2004, **35%** are children (under age 22). This percentage compares favorably to FY '97 when children made up 26% of the total served.

★ Vermont is ranked **4th** in nation in the amount of funding spent on family support per person<sup>44</sup>.

★ The Division of Developmental Services sent out a **family satisfaction survey** in August 2004 to find out what families had experienced previously with Children's Personal Care Services in order to provide a better quality program in the future.

★ 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.

### 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 has been available to children since the December 2001 moratorium on funding.

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<sup>44</sup> *The State of the States in Developmental Disabilities: 2002 Study Summary*, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January 2004.

◎ Ongoing work will be done to make **positive and effective improvements** to Children's Personal Care Services and High Technology Home Care based on input received from the August 2004 family satisfaction survey.

◎ What **families** said about Children's Personal Care Services:

- **67%** said family member's needs did not change enough to make a 6-month assessment necessary.
- **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.

## Clinical & Crisis Services

<b>Numbers Served – FY 2004</b>	
<b>Vermont Crisis Intervention Network</b>	
Level II – Technical assistance Number of people supported (est.)	89
Level III – Crisis beds	
Number of stays	35
Number of total days	575
Avg. length of stay (range 3-50 days)	16 days
Institutional diversions (est.)	31

**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.

The Vermont Crisis Intervention Network operates on a three-tiered system:

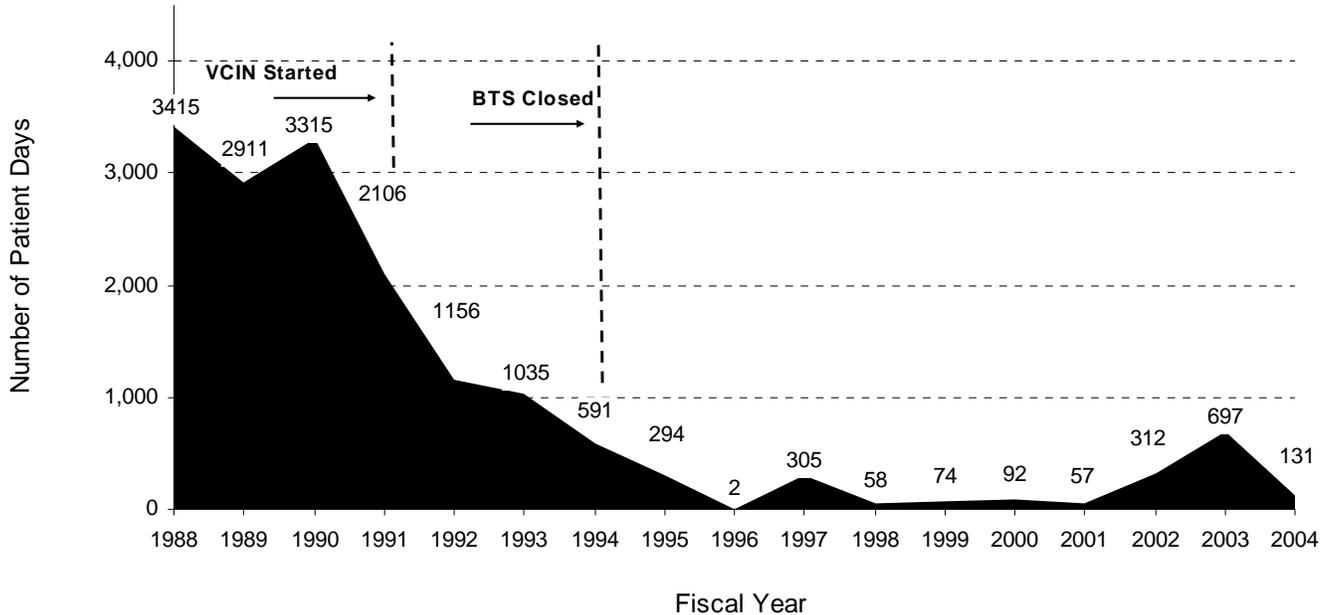
- **Level I: The Clinical Network** provides consultation on individual situations and professional techniques through a statewide network of agency clinical providers (prevention orientation, quarterly meetings, training)
- **Level II: On-site Consultation** and support to individuals, families and agency staff (early intervention, assessment, staff training, consultation, psychiatric consultation)
- **Level III: Crisis Residential Services** offers emergency, short-term, back-up residential services at two crisis homes or through a mobile emergency team (clinical evaluation, treatment, direct staffing).

### Highlights

- ★ **Roy Mountain**, a specialized crisis and respite program for sex offenders, started operations. Staff are specially trained to work with and supervise sex offenders. The program works in cooperation with DDS to prioritize referrals from around the state.

- ★ The inception of the **Vermont Crisis Intervention Network** in March 1991 greatly reduced use of the Vermont State Hospital by people 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. All ten designated agencies are required to have a local crisis capacity.

**Vermont State Hospital Utilization<sup>45</sup>  
by People with Mental Retardation  
FY 1988 – FY 2004**



- ★ 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.
- ★ Future collaboration is being developed with the Department of Psychiatry at the Dartmouth Hitchcock Medical Center to **increase psychiatric services** to people with developmental disabilities.
- ★ The **Personal and Community Safety Plan/Behavior Support Plan** for use with offenders was incorporated into the Behavior Support Guidelines.

<sup>45</sup> 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 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). One person who was at VSH in FY'97 (130 days) and three people who were at VSH in FY '03 (158 days) were not known to DDS during their stays. In FY 2003, one person accounted for 365 of the 697 days.

## 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.
  
  - ◎ What **families** said about crisis services:
    - **58%** said they received help right away when they were in crisis and asked for the agency's assistance.
- 
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### Tasha's Story

*When I first came to UCS I was suicidal and did not have any belongings. UCS helped me feel important by helping me get an apartment, help me with my budget, get a phone and cable TV. UCS helped me learn DBT counseling and how to be in a group.*

*My staff helps me with finishing school, I want to graduate this year, keeping my apartment clean and learning to live by my self. They also remind me that personal hygiene is important.*

*I know (sic) feel happy, glad and surprised of what I can do on my own. I am no longer suicidal.*

– Tasha



## Nursing Home Reform

<b>Numbers Served – December 31, 2004</b>	
<b>People living in nursing facilities<sup>46</sup></b>	<b>27</b>
People receiving specialized services	16
PASARR screenings	22
Diversions to keep people out of nursing facilities	7
Community placement of people from nursing facilities	2

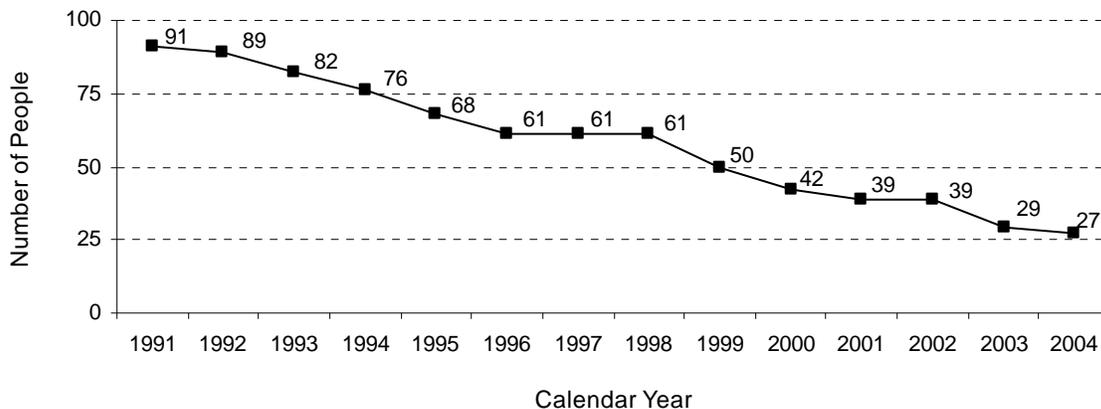
**Pre-Admission Screening and Resident Review (PASARR):** The Omnibus Budget Reconciliation Act of 1987 established PASARR which mandates the screening of all nursing facility residents and new referrals to determine the presence of mental retardation and/or related conditions and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services<sup>47</sup>.

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.

### Highlights

- ★ The number of people with MR/DD living in nursing facilities has steadily declined (**78% overall**) since 1988<sup>48</sup>. There has been a **31%** decline in the last two years. It reached an all time low of 27 as of December 31, 2004.

**People with MR/DD who Reside in  
Nursing Facilities 1991-2004**



<sup>46</sup> PASARR uses the federal definition of “mental retardation or related conditions.”

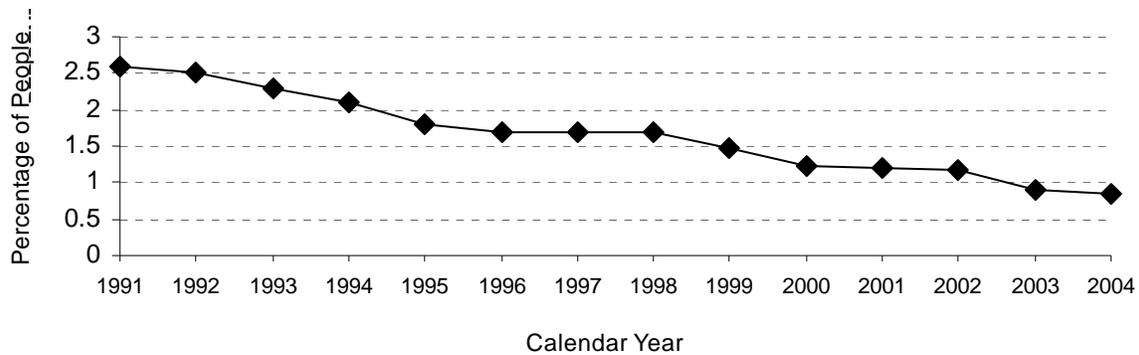
<sup>47</sup> Changes in federal law in 1996 eliminated the requirement for an *annual* resident review.

<sup>48</sup> Based on the initial 1988 screening that found 125 people with MR/DD living in nursing facilities.



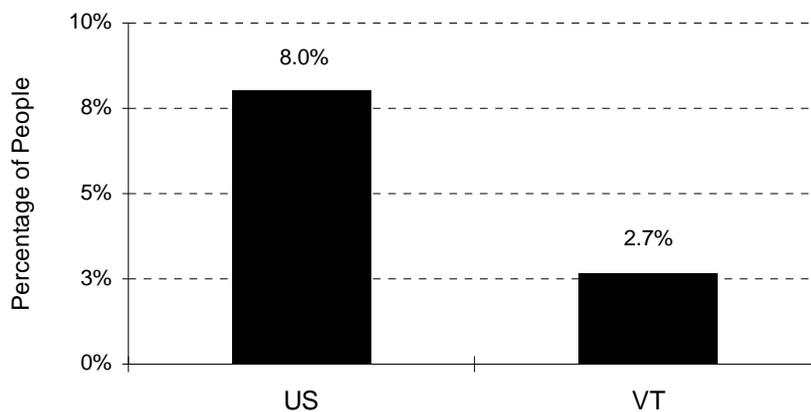
The national prevalence rate for people living in nursing facilities with developmental disabilities is estimated at 2.6% of the general population based on the federal definition of developmental disability<sup>49</sup>. The Vermont rate of occurrence for people with MR/DD living in nursing facilities was **0.8%** in December 2004, **well below the national average**.

**People with MR/DD as a Percentage of All People who Reside in Nursing Facilities  
1991 - 2004**



The number of people in Vermont with MR/DD in nursing facilities compared to all residential services for people with developmental disabilities in Vermont – **2.7%** – is **well below the national average (8.1%)**<sup>50</sup>.

**People with MR/DD in Nursing Facilities as a Percent of All People with MR/DD Receiving Residential Supports<sup>51</sup>  
June 30, 2003**



<sup>49</sup> Based on 2002 Kaiser Family Foundation – [www.statehealthfacts.com](http://www.statehealthfacts.com).

<sup>50</sup> Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2003*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2004

<sup>51</sup> Residential services include those provided under home and community-based waiver, ICF/MRs, and nursing facilities.

**Specialized Services:** The Division of Developmental 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 individuals to address their social and recreational needs as well as their overall well being. The following story tells of one person's experience with specialized services and how these supports made a difference in her life.

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### Marie's Story

*Marie lived a very protected life with her family for many years, with no opportunity to work, socialize or make friends outside a very small circle. She and her mother were alone after her father died and both had numerous health problems. Marie and her mother both entered an Addison County nursing home when her mother's health failed and her siblings were unable to care for her. Marie's mother passed away in the nursing home. Marie was overweight, had a severe knee injury and was unable to walk. Marie was sometimes fearful and lashed out at people in the nursing home. Community Associates became involved and provided specialized services to her while she was in the nursing home.*

*The social supports offered by Community Associates enabled Marie to participate in activities in the nursing home and out in the local community. These supports kept Marie connected to the outside world. Marie's knee healed and she began to lose weight, but she was still unable to walk unassisted and relied on the safety and security of a wheelchair. Community Associates began to look for a home for Marie so she could leave the nursing home. In October 2003, Marie moved into the Paquin family home in Panton.*

*Since the spring of 2004, Marie has lost over 150 pounds. With support from the Paquins, Marie eats a healthy diet and has continued to lose weight. She now gets around without a walker and her health has improved enormously. Most importantly, with support and devotion from the Paquins, Marie has acquired a great zest for life. She is eager to communicate, loves to laugh, and the anger and fear she displayed at the nursing home are a thing of the past. Community supports allow Marie to enjoy getting to know her surrounding communities. She loves purchasing items for herself at local stores and garage sales. She attends Together Arts workshops and has discovered an interest in drawing and painting. She is proud of doing her part around the house, and is consistently encouraged to do things independently.*

*The Paquins also support Marie to maintain contact with her brothers and an aging aunt in northern Vermont. The Paquins have a large extended family and Marie is happily included in many events and outings. At the age of 53, Marie now has both physical and emotional health, a family and home to call her own, and a great eagerness to be an active participant in her community.*

## 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 17 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*, 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



We successfully completed the second year of our grant with the Division of Developmental 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 13 agency boards and standing committees. Approximately 180 people participated.
- Local teams consisting of people with and without developmental disabilities completed a 2-day **Train-the-Trainers Retreat**. Many existing teams returned to get training for additional team members and three agencies sent newly formed teams. This increases the number of local training teams to eleven who are able to teach our series of six 2-hour self-advocacy workshops. In 2004, over 700 people participated in 52 self-advocacy workshops.
- GMSA staff are certified to teach Steven Covey's **7 Habits Of Highly Effective People**. Four different 3-day leadership retreats were held throughout the year to teach the 7 Habits to a total of 160 people. One of the retreats was specifically designed for high school students with disabilities.

- Two **Home Ownership Forums** were held with representatives from Vermont State Housing Authority, Burlington and Springfield Land Trusts, and Housing and Urban Development (HUD), as well as a 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.



This year's theme for our annual statewide **Voices and Choices Conference** was celebrating our 10-year anniversary. The two-day self-advocacy conference featured 14 workshops including: *Safety Awareness for Everyone*; *Learn Self-Defense with Police Officer Chris*; *Is your Love Life in JEOPARDY?*; *Have Something Important To Say? Learning How to Tell Our Stories*; *Choosing a Career*; and *How to Get Your Self-Advocacy Group Going*. A total of 370 people attended the conference, with 225 staying overnight for dinner and dancing and participation in a group art project the next day.



A team of poets and writers was recruited to publish our first newsletter, *Speaking for Ourselves*.



A voter education grant was received from the Vermont Secretary of State to develop a **2-hour voter workshop/toolkit** and conduct a training of trainers. Twelve local teams participated and went back to their communities to teach over 180 people about voting.



With the help of the Awareness Theater Company and Green Mountain Video, copies of our video *Green Mountain Self-Advocates: Our Bill of Rights* were ready for distribution in January of 2004. The video has been presented locally, at state functions, as well as at national conferences and meetings.



We worked with special educators to adapt and expand our existing curriculum, *Stay Safe and Know Your Legal Rights*. This tool was used to teach high school students how to live and work safely in the community and protect their constitutional rights as US citizens. We made this a "real life" tool that deals with "real life" situations creating additional activities, role plays, and picture cues to adapt the curriculum to life as we know it in Vermont. In November, we presented a 1-day training of trainers for 37 special educators and providers. Each participant received a free copy of the curriculum plus student materials.



Thirty (30) Vermonters raised money to attend the national self-advocacy conference of SABE, Self-Advocates Becoming Empowered, held in California. GMSA presented two workshops: *It's not Just about Buses! How to Organize for Better Transportation and Sheltered Workshops: Shut 'em Down*.



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.



Continued to organize with ROVER (Riders of Vermont) to **improve existing public transportation** for people with disabilities and advocate for other transportation options to meet the needs of people living in rural areas.

★ Collaborated with the Vermont Center for Crime Victim Services to organize three regional trainings and one statewide conference on *Working towards Ending Abuse of the Elderly, People with Disabilities and Deaf Individuals*. GMSA presented information on effective communication strategies to use when working with people with developmental disabilities. The audience included police officers, first responders and social workers.

★ What **consumers** said about self-advocacy:

- **39%** said they went to a self-advocacy meeting, conference or event.
- **76%** of those who went to a self-advocacy meeting, wanted to go.
- **82%** said they see themselves as being a self-advocate.
- **85%** said they have a group of friends or family to help them make decisions.
- **82%** said they think they have enough control over their life.

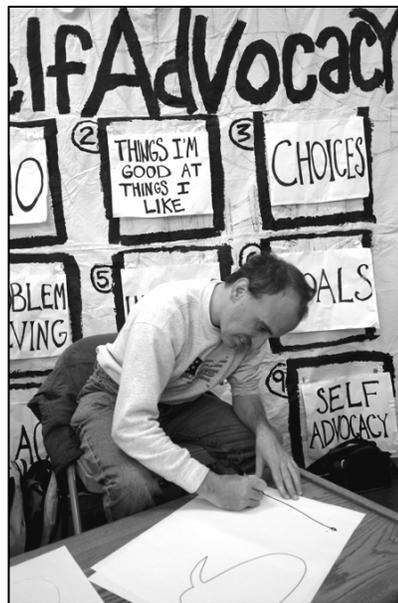
### Areas of Focus

- ◎ Organize one-day **mini-conferences** in the northern and southern parts of the state.
- ◎ Complete a toolkit on *Alternatives to Guardianship*.
- ◎ Complete the **website** for Green Mountain Self-Advocates.
- ◎ Train local teams working with the Real Choices project on how to do workshops for **orientation training** for new support workers.
- ◎ Sponsor workshops about **relationships and sexuality** with Kathleen McGlaughlin from Planned Parenthood of Northern New England.
- ◎ Design and provide training on **how to be an officer** of a local group or board.
- ◎ Increase **public awareness** about self-advocacy.
- ◎ Design and offer workshops on how to include people who use **alternative communication** to participate in self-advocacy activities.
- ◎ What **consumers** said about self-advocacy:
  - **62%** of those who did not go to a self-advocacy meeting wanted to go.
  - **40%** 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.
  - **54%** said they want to know more about self-advocacy.
  - **34%** of those who did not vote in an election said they wanted to vote.
  - **36%** said there are choices they wish they could make that they don't make now.
  - **41%** said they need to know more about how to interview their support workers.

## A Story of Theater and Self-Advocacy

*The Adult Self Advocacy Theater Program (A-SAT) is a theater class designed by VSA Arts of Vermont and taught by Emily Anderson. Its goal is to use theater to support the participants involved to cultivate and practice their self-advocacy skills. Some of the self-advocacy skills include assessment, goal setting, achieving goals and communication.*

*VSA Arts of Vermont's Adult Self Advocacy Theater Project was born out of the success of the High School Self Advocacy Theater Project that has been conducted in eight schools throughout Vermont over the past two years. This project uses an exciting and innovative approach to promoting self-advocacy for students with developmental disabilities. The goal is to reinforce concepts of self-advocacy to further advance students in successfully implementing the "transition from school to adulthood" portion of their education plan.*



*The Adult Self Advocacy Theater Project is a 24-week program that is open to people with a variety of learning and communication styles. There are no prerequisite skills required to participate in this program. The real value comes from presenting the concept of self-advocacy in a manner that draws directly on peoples' life experiences, giving a safe place in which people can practice the various outcomes of self-advocacy in situations recreated from real life and culminating in a performance for families, peers and the general public to entertain, enlighten and reinforce this important concept.*



*The Adult Self Advocacy Theater Project has expanded its program into two developmental service agencies, Champlain Vocational Services where it was first piloted, and more recently to Howard Community Services (HCS). Pascal Cravedi-Cheng from HCS is excited about the opportunity for consumers to have a chance to reinforce self-advocacy concepts as well as have the chance to practice them. He said that while there is a great emphasis on the importance of self-advocacy in the lives of adults with developmental disabilities, there are few places in which to practice it.*

*This program's success is in doing just that.*



## Office of Public Guardian

<b>Caseload – June 30, 2004</b>	
Guardianship services (developmental disability specialty)	541
Guardianship services (aging specialty)	54
Case management (developmental disability specialty)	27
Guardianship services – pending (developmental disability specialty)	10
Commitment order – Act 248 (developmental disability specialty)	22
Commitment order – pending (developmental disability specialty)	2
<b>Total Office of Public Guardian program</b> (unduplicated)	<b>648</b>
<b>Representative payee services</b> (developmental disability specialty)	<b>318</b>

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 C: Division of Developmental Services Staff**.

The program's 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, Public Guardians 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

- ★ Developed materials and training on **alternatives to guardianship**
- ★ Developed **website resources** on guardianship in Vermont
- ★ What **consumers** with developmental disabilities said about guardianship:
  - **82%** said they were happy about their guardian.
  - **90%** said they got to see or talk to their guardian whenever they wanted.

## Areas of Focus

- ◎ Continue work on integrating Vermont's two public guardianship programs into a **unified Office of Public Guardian**.
- ◎ Develop written **procedures for review** of certain Public Guardian decisions.
- ◎ Continue to expand and improve training and materials on **Alternatives to Guardianship**.
- ◎ What **consumers** with developmental disabilities said about guardianship:
  - **48%** said someone else chose their guardian.
  - **31%** said their guardian let them make some decisions for themselves.

## Offenders with Developmental Disabilities

The Division of Developmental 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, DDS has undertaken the following initiatives in the past two years.

### Highlights

- ★ The Division of Developmental Services sought and obtained funding from the legislature to develop **planned and crisis respite** for offenders. Sometimes offenders are remanded directly from the court, and need an immediate placement. Others who may be in crisis may need intensive supports in a secure setting.
- ★ 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 System of Care Plan for FY 2005. Monitoring the use of this fund provides an effective way to document and analyze the new fiscal needs of this group.
- ★ Using grant funds from the U.S. Department of Justice, DDS sponsored the development of a **Treatment Progress Scale** for sex offenders with developmental disabilities. Based on international research regarding the factors that best promote treatment of sex offenders, the scale was developed to be used by Vermont providers. Robert McGrath, Clinical Director of the Vermont Treatment Program for Sexual Abusers, in conjunction with Vermont developmental services providers and Department of Corrections staff, developed this assessment tool. The tool was piloted in FY 2004 and will be analyzed for validity and reliability in 2005.
- ★ The Division of Developmental Services collected **data** regarding all sex offenders served through the developmental services system in order to track the efficacy and cost of treatment and support of offenders. Information collected and analyzed on an annual basis contributes to our understanding about best practices in serving this group.

- ★ Green Mountain Self Advocates, in collaboration with special education staff in Rutland, developed a **prevention curriculum** to teach youth with developmental disabilities about their rights and about how to live as law-abiding citizens. The curriculum is designed for use in classrooms and in developmental services programs. It is called *Stay Safe; Know Your Rights*.

### Areas of Focus

- ◎ Analyze the results from the first two years of using the **Treatment Progress Scale** and provide additional training to program staff, as needed.
- ◎ Collaborate with staff at Northeast Kingdom Human Services to develop workable **procedures and practices** for the crisis bed and respite bed. **Analyze usage** of the crisis and planned respite beds.
- ◎ Finalize the editing and distribution of the *Best Practices Manual for Sex Offenders with Developmental Disabilities*.
- ◎ Analyze first year data from the statewide **Sexual Risk Management Information System** questionnaire. Make adjustments in the data collection methodology. Begin to use data collected through this information and monitoring process to assess program efficacy.
- ◎ Develop **alternative residential options** for offenders within the developmental services system, such as staffed and supervised apartments.

## Real Choices Grant

Vermont was awarded a three-year **Real Choice 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 Developmental 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 DDS 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 2004, grants were awarded to the Green Mountain Self-Advocates and the I-Team from the Center on Disability and Community Inclusion at the University of Vermont to carry out the Division of Developmental Services' objectives to provide training in self-advocacy skills to people with developmental disabilities, their families, and DDS and service provider staff. Resources were developed and numerous workshops and training opportunities were presented in 2004.

### Highlights



A two-day **train-the-trainers workshop** for local teams consisting of people with and without developmental disabilities was held for 36 participants from nine different agencies. Six teams were returning to get training for additional team members and three new agencies sent teams to be trained.

- ★ 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*
  
- ★ The ***Get on Board and Make a Difference* manual** was presented to 13 agency boards and standing committees. Approximately 180 people participated in activities on effective strategies for including people with developmental disabilities on boards and committees.
  
- ★ Four different 3-day leadership retreats were held to teach the **7 Habits of Highly Effective People**. A total of 160 people participated. One of the retreats was designed specifically for high school students.
  
- ★ 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.
  
- ★ **Two series of six workshops** for family members of individuals with developmental disabilities were held in Rutland and St. Johnsbury. 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 Developmental 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 ISO Request for Proposal (RFP)** was developed and issued. The response to the Supportive ISO RFP was limited. A decision was made to reconsider options including collaboration with other self- and family-managed services within the Department of Aging and Independent Living. Work continues on developing a support organization to assist individuals and family who manage their services.

## The Invisible Eye – Visions of Self-Taught Artists

*In September 2004, the Helen Day Art Center in Stowe celebrated the works of a number of grassroots artists from Vermont in a rich and diverse exhibit whose common theme was “self-taught artists.” As noted in a review of the show, *The Invisible Eye* is work done by “ordinary people who have turned to art as a means of self-expression late in life. Some of the artists are elderly, others [have disabilities]. None of them have been schooled in the arts; they are all self-taught.”*

*The compelling results are outside mainstream culture; what is sometimes called “outsider art.” A number of Larry Bissonette’s oil paintings were shown,*

*including his trademark buildings from Brandon Training School. Joel Bertelson’s paintings were brilliant, geometric images that captured the viewer’s attention. The landscapes by Eugene Chase clearly reflected his memories from earlier years. Other Vermont artists also had captivating pieces on display.*



*Many of these artists, although self-taught, were fortunate to have exposure to guidance from a unique community resource. Grass Roots Art and Community Effort, better known simply as GRACE, offers workshops and creates an environment that supports adults to make art. GRACE focuses on access to art by people who are elderly or have disabilities and may not otherwise have the exposure or resources to explore art. GRACE “art guides” give participants “the opportunity to parade through the visual language on their own terms.” This extraordinary program has indeed graced Vermont with beautiful and personal pieces of art by “outside artists” who are given the space and materials to create pieces that are uniquely their own.*



## Communication

In July 2003, the Division of Developmental Services developed a system-wide communication initiative with the 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.*

A working **action plan** with outcomes address the issue 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 Developmental 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 DDS, 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 teams (e.g., incorporating communication supports into ISAs, facilitated communication workshops). Incorporated a full-day communication module as part of the service coordination training series.
- ★ Developed a communication resource packet and provided a training series for **local communication resource people** from each agency.
- ★ Developed **annotated bibliography** of communication resources.
- ★ What we learned about people’s ability to communicate from the **Consumer Survey**<sup>52</sup>:
  - **66%** have adequate, reliable speech which allows them full expression.
  - Of those reported *not* to have adequate, reliable speech:
    - **95%** are *able* to communicate with people who are known and familiar to them.
    - **92%** *have* consistent communication partners.
    - **92%** *have* support from their team.
    - **21%** are believed to be communicating *more* effectively than last year.

<sup>52</sup> Data are from the demographic survey completed by service coordinators for all 373 participants of the 2004 Consumer Survey Project.

## Areas of Focus

- ③ Work with Green Mountain Self-Advocates to **increase participation** of people in self-advocacy activities who have limited communication.
- ③ Continue to provide **training, technical assistance and tools** to local communication resource people.



Local Communication Resource People at November training.

- ③ 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.
- ③ Quality Service Reviews will focus specific attention on **ISA outcomes and support strategies** and developing communication dictionaries and communication plans.
- ③ Organize a second **statewide conference** on supporting people to communicate.
- ③ What we learned about people's ability to communicate from the **Consumer Survey**<sup>53</sup>:
  - **20%** do *not* have spoken language as their primary means to communicate.
  - **33%** do *not* have adequate, reliable speech which allows them full expression.
  - Of those who do *not* have adequate reliable speech:
    - **41%** do *not* have access to communication aids or devices.
    - **39%** are *not* able to communicate with people who are *unfamiliar* to them.
    - **39%** 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).
    - **31%** do *not* have consultation or support from an SLP or other communication expert.

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<sup>53</sup> Ibid.

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## George's Story

George<sup>54</sup> is a gentleman who is nonverbal, lives in a group home, and has autism. All his life, George has been limited in his ability to make choices about even simple things like meals and outings or to inquire about people in his life. The introduction of communication boards with pictures, picture symbols, and conversation books (6-8 pages of photos in a folder) has changed this.

In his group home, George will now sit through resident meetings and use his boards to express his opinions about meal and event planning. He is able to join in card games, group activities and ask about other residents and staff. When he is missing someone special, he will ask staff to help him call that person. He is even able to use his books to share past and future events.

The boards and books are a helpful tool for new staff. George will use his communication book to indicate what he wants. George's interests are reflected in the conversation books. This makes it easier to understand how to connect with George.

George keeps his communication book nearby and always brings it into the community. He will choose where he wants to eat, shop or visit. He uses it to independently place orders. He refers to his book when selecting gifts for people. He can also indicate when he wants to go home.

The visual supports have helped bridge the gap between the group home and his family home. He and staff now prepare simple conversation books to share with his family about recent events in his life. His family has been so excited by this that they are sending photos back with George to share with the group home.

George is eager to share these photos! This represents a huge shift in George's social interest. In the past, George would "squirrel away" these materials in his room. Experiencing pleasant conversations about people and events in his life has greatly enhanced his social experiences. Staff has remarked that he seems more interested in other people.

George's mom recently told a story about George sharing a conversation book about his volunteer job. "He was so proud and grinning from ear to ear to share this with his brother." She also said, "It is nice for family friends to see that there is more to George than they had thought."

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<sup>54</sup> "George" is an alias.

*Mailing photocopies of these conversation books to his out-of-state sister has helped reestablish a close relationship. "I never thought of using this means of communication with my brother. It is so simple and I am so excited." Her replies to George include photos of her young children, which he then shares with others.*

*George has been so successful with these low-tech tools, the team is moving forward with computer applications. The conversation books have been given voice output on a desktop. George learned proficient use of a mouse in 5 minutes. Introducing George to the digital camera is the next step in this process. In the near future, the team believes George will independently choose events and people he wants recorded. This is a long way from not having a voice!*

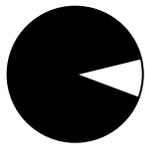
## Consumer Survey

<b>Numbers Surveyed – 2004</b>	
Number of participants – Consumers interviewed	188
Consumers not interviewed	185
<b>Total number of adult participants</b>	<b>373</b>

**Consumer Survey Project:** The Division of Developmental 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. This was the first year in a new survey cycle. In 2004, interviews were conducted at six agencies<sup>55</sup>. The data presented below are aggregate data representing statewide results. This is just a small sampling of the data collected from the survey. For a more complete report, contact the Division of Developmental Services.

### Consumer Survey Results<sup>56</sup> – 2004

#### Highlights



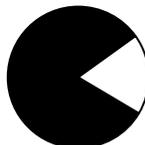
★ **Residential: 91%** said they like where they live.



★ **Work: 97%** said they like their job.



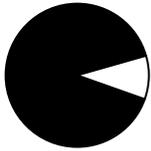
★ **Community Supports: 96%** said they like their community activities.



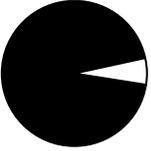
★ **Guardianship: 82%** said they feel happy about their guardian.

<sup>55</sup> The six agencies that took part in the Consumer Survey Project in 2004 were Community Associates, Howard Community Services, Northeast Kingdom Human Services, Specialized Community Care, United Counseling Services, and Champlain Vocational Services.

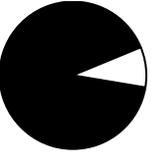
<sup>56</sup> Not all consumers answered all the questions in their interviews. Percentages are based on the total number of consumers who responded to the questions. Consumer survey data needs to be taken in the same context as any study of satisfaction, as a general reflection of a person’s perspective of life. Results from the surveys are anonymous and confidential.



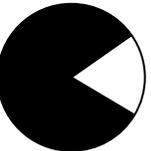
★ **Agency:** 90% said they feel happy with their service coordinator.



★ **Agency:** 94% said they feel listened to at their ISA meetings.

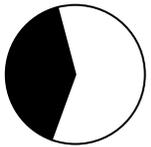


★ **Transportation:** 91% said they had a way to get there if they wanted to go someplace.

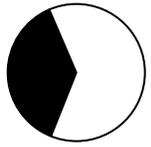


★ **Self-Determination:** 82% said they feel they have enough control over their life.

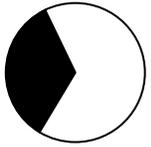
### Areas of Focus



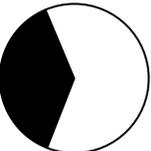
◎ **Residential:** 40% said they did not choose who they live with.



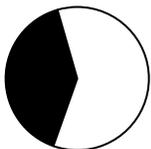
◎ **Residential:** 38% said they did not choose the place where they live.



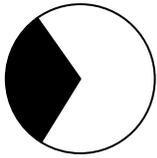
◎ **Work:** 34% of the people who do not work said they wanted a paid job.



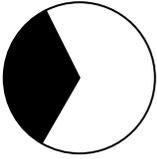
◎ **Community Supports:** 38% said they would like more hours of community supports.



◎ **Friends:** 40% said they wish they had more friends.



**Friends: 32%** said they need to know more about dating.



**Friends: 34%** said someone else decides when they can have friends and family over to visit.

## Demographic Summary: Vermont's 2004 Consumer Survey Results<sup>57</sup>

### Basic Information

<b>Gender</b>		<b>Guardian Status</b>		<b>Representative Payee</b>	
Males	61%	Private	45%	Yes	70%
Females	39%	None	33%	No	30%
		Public	22%		
<b>Marital Status</b>		<b>Court Ordered Restrictions</b>		<b>Family involved in Person's Life</b>	
Never married	90%	No	95%	Yes	85%
Married/Civil Union	5%	Yes	5%	No	13%
Single/Married in past	5%	Unknown		Unknown	2%

### Residential Summary

<b>Residential Type</b>		<b>Household Composition</b>		<b>Paid Residential Support</b>	
Home provider	37%	Non relatives	45%	24-hour	68%
Lives with parents	29%	Parents	24%	Daily	10%
Own home	25%	Lives alone	14%	Less than daily	11%
Group home	7%	Other relatives	9%	As needed	4%
Staffed living	1%	Spouse and/or children	4%	None	5%
Residential Care Home/ Nursing Home/Other	1%	Unknown/Other	4%	Unknown	2%
<b>Who Own/Leases the Home</b>		<b>Residential Location</b>		<b>How Long Living in House</b>	
Family member	30%	Rural/Physically remote	47%	Over 5 years	56%
Unrelated person in home	40%	Walking distance to town/city	35%	3 – 5 years	17%
Provider	11%	Centrally located in town/city	18%	1 – 2 years	16%
Person rents home	13%			Less than 1 year	11%
Person owns home	4%				
Unknown/Other	2%				

### Health Concerns Summary

<b>Is weight a concern?</b>		<b>Does person smoke or chew tobacco?</b>		<b>How physically active is person?</b>	
No	69%	No	87%	Moderately	65%
Yes, overweight	27%	Yes	13%	Inactive	18%
Yes, underweight	4%			Very	17%

<sup>57</sup> Data based on results from *Survey of Adult Consumers of Developmental Services 2004 Report (in draft)*.

## National Comparison of Vermont's 2003 Consumer Survey Results<sup>58</sup>

### Highlights – Individual Questions

- ★ **Choice of where person lives:** Vermont ranked **1<sup>st</sup>**
- ★ **Choice of where person goes during the day:** Vermont ranked **1<sup>st</sup>**
- ★ **Choice of what person buys with spending money:** Vermont ranked **1<sup>st</sup>**
- ★ **Choice of who person lives with:** Vermont ranked **2<sup>nd</sup>**
- ★ **Feel safe in person's home:** Vermont ranked **2<sup>nd</sup>**
- ★ **Feel safe in person's neighborhood:** Vermont ranked **2<sup>nd</sup>**
- ★ **Service coordinator helps get what person needs:** Vermont ranked **2<sup>nd</sup>**
- ★ **Person has friends and caring relationships:** Vermont ranked **3<sup>rd</sup>**

### Areas of Focus – Individual Questions

- ◎ **Likes where person lives:** Vermont ranked **Lowest**
- ◎ **Sees family when person wants:** Vermont ranked **Lowest**
- ◎ **Person has a close friend:** Vermont ranked **Lowest**

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<sup>58</sup> Data is based on results from seventeen states that participated in the 2003 consumer surveys as part of the National Core Indicators. Data presented in this section is outcome adjusted or “risk adjusted” to control for differences in the individual characteristics of people interviewed across states. Results published in *Consumer Outcomes – Phase VI Final Report Fiscal Year 2003-2004 Data (in draft)*, National Core Indicators.

## Highlights – Categories<sup>59</sup>

- ★ **Service Coordinator:** Vermont ranked **highest (98%)**; with a greater proportion of people who say they:
  - Have a service coordinator who helps them get what they need
  
- ★ **Community Inclusion:** Vermont ranked **highest (86%)**; with a greater than average proportion of people who say they:
  - Go shopping
  - Go out on errands or appointments
  - Go out for entertainment
  - Go out to eat
  - Exercise or play sports
  
- ★ **Personal Choices:** Vermont ranked **highest (82%)**; with a greater than average proportion of people who say they:
  - Choose the people they live with
  - Choose their daily schedule
  - Choose how to spend free time
  - Choose what to buy with spending money
  
- ★ **Personal Choices – Supports-Related:** Vermont ranked **highest (67%)**; with a greater proportion of people who say they:
  - Choose the place where they live
  - Choose staff who help them at home
  - Choose their place of work
  - Choose staff who help them at work
  - Choose their case manager

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<sup>59</sup> 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.

## Comparison of Vermont 2001 and 2004 Consumer Survey Results<sup>60</sup>

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 six agencies took part in both the 2001 and 2004 survey. The following are some comparisons of specific survey responses from the two years. The table shows areas where consumer responses were **more positive** in 2004 in regard to their life circumstances and services than they were three years previous in 2001. There were no big changes that showed up as an increase in negative responses.

	2001	2004
<b>Residential</b>		
• You like where you live	82%	91%
• Someone else chose where you live	51%	38%
• You cannot think of a better place to live	71%	62%
• You are bored when at home	20%	9%
• You can invite friends over when you want	82%	89%
<b>Neighborhood</b>		
• You feel afraid in your neighborhood	15%	2%
<b>Work</b>		
• You like your job	88%	97%
• Someone else chose where you work	16%	9%
• You chose who helped you at work	47%	70%
<b>Friends</b>		
• There are times when you feel lonely	24%	11%
• You can see your family when you want to	71%	84%
<b>Service Agency</b>		
• You chose your service coordinator	40%	58%
• You get to learn new things	61%	80%
<b>Self-Determination</b>		
• There are choices you wish you could make that you don't make now	79%	36%

<sup>60</sup> Data based on results from *Survey of Adult Consumers of Developmental Services 2001 Report* and *Survey of Adult Consumers of Developmental Services 2004 Report (in draft)*. The six agencies that took part in the Consumer Survey Project in 2001 and 2004 were Community Associates, Howard Community Services, Northeast Kingdom Human Services, Specialized Community Care, United Counseling Services, and Champlain Vocational Services.

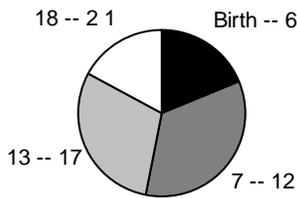
## Children’s Personal Care Survey

Numbers Surveyed – 2004	
<b>Families surveyed</b>	<b>379</b>
Response rate	33%

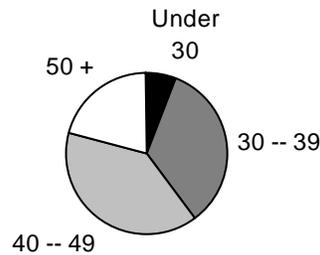
**The Children’s Personal Care Survey:** Personal Care services are provided to children under 21 who are eligible for Medicaid. These services help them with activities of daily living, such as bathing, dressing, feeding, toileting, grooming, positioning, transferring or walking. A confidential statewide family survey was mailed out in August 2004 to ask about satisfaction with Children’s Personal Care services (PCS). The Division of Developmental Services had only just taken over management of the Children’s Personal Care 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 Children’s Personal Care services. The survey covered a number of issues, including the application process, setting up services, personal care workers and services. The survey also offered a number of open-ended questions. This report includes only a sampling of the survey responses. A more complete report will be available through the Division of Developmental Services.

### Children’s Personal Care Survey Demographics – 2004

**Age of Family Member with a Disability**



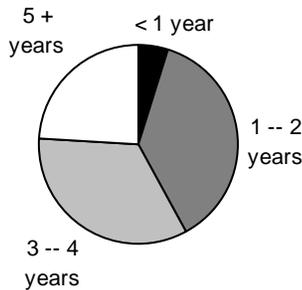
**Caregiver’s Age**



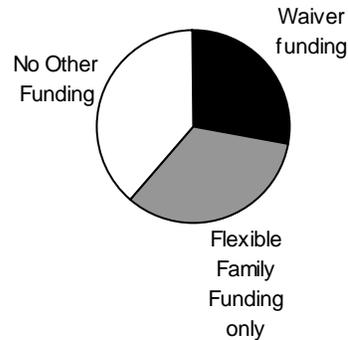
**Caregiver’s Health**



**Length of Time Getting PCS**



**Other Funding Source from DDS**



- **75%** said they used an ISO and hired their own personal care workers.
- **61%** receive some additional developmental services funding (waiver or FFF).
- **55%** said they are the *only* adult in the home who provides care to the family member all or most of the time.

## Highlights

- ★ Personal Care services were said to provide the following **additional benefits**:
  - **89%** said respite
  - **77%** said social and community activities
  - **72%** said supervision
  - **57%** said skill training
  
- ★ **Application process: 78%** said the application process happened in a timely way.
  
- ★ **Notice of decision: 83%** said the Notice of Decision was provided in a timely way.
  
- ★ **A positive difference: 85%** said Personal Care services make a positive difference in the family member's life.
  
- ★ **Available when needed: 95%** said Personal Care services are available when needed some or all of the time.
  
- ★ **Family's well being: 88%** said Personal Care services are helpful overall to their family's well being.

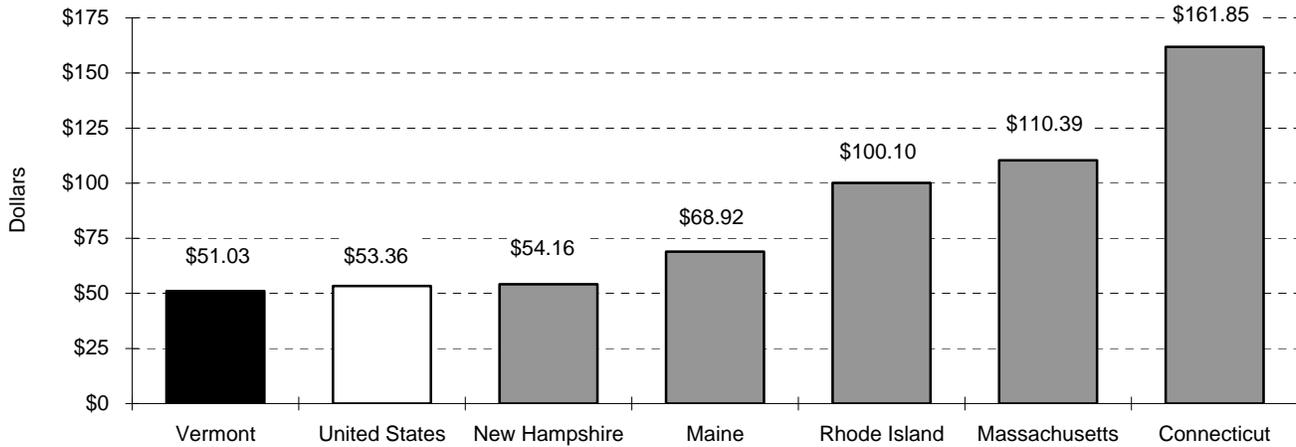
## Areas of Focus

- ◎ Reasons why some or all Personal Care **hours are not used**:
  - **28%** said family can't find workers
  - **11%** said there's too much worker turn-over
  
- ◎ Reason why family/agency **can't find workers**:
  - **35%** said times (e.g., hours and days) when work is needed
  - **34%** said low wages
  - **27%** said lack of benefits
  - **24%** said type and difficulty of work
  
- ◎ **6-month assessment: 67%** said family member's needs did not change enough to make a 6-month assessment necessary.
  
- ◎ **Worker reliability: 45%** said they had problems some or all of the time with workers not showing up or canceling at the last minute.
  
- ◎ **Worker turnover: 55%** said a frequent change in workers was a problem some or all of the time.

## National Comparisons<sup>61</sup>

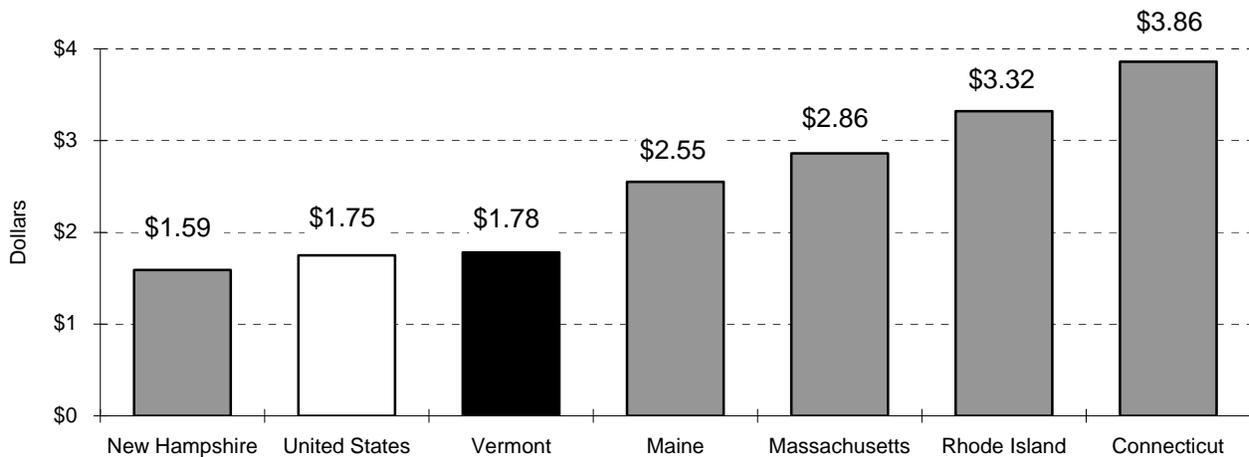
- ★ Vermont spends **fewer state dollars** (including Medicaid match) per state resident for mental retardation/developmental disability (MR/DD) services than any other New England state and **less** than the national average.

**MR/DD State Spending per Capita FY 2002**



- ★ 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 **2<sup>nd</sup>** to New Hampshire as the lowest of all New England states and is **comparable** to the national average.

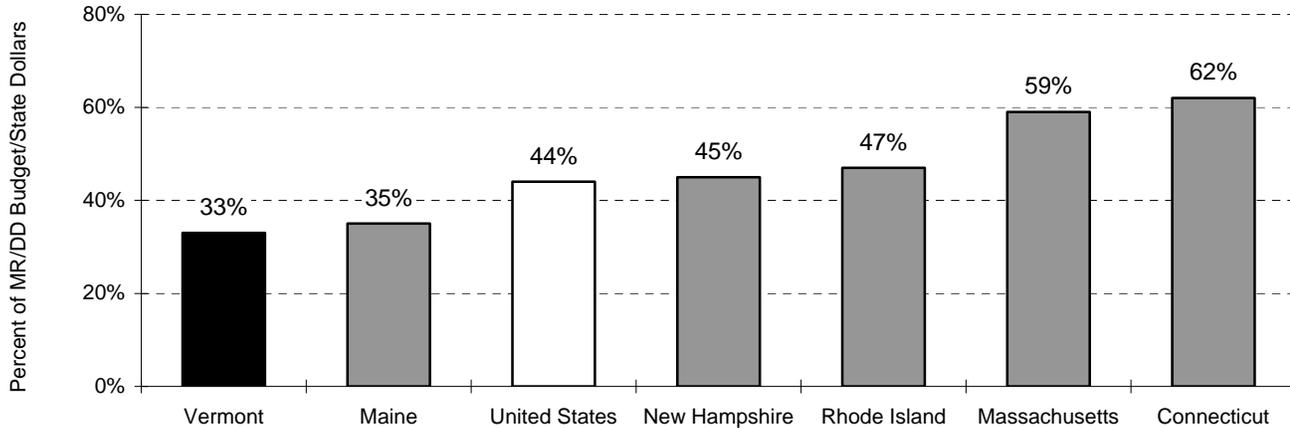
**State Fiscal Effort  
Total MR/DD Spending per \$1,000 in Personal Income  
FY 2002**



<sup>61</sup> The State of the States in Developmental Disabilities: 2002 Study Summary, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January 2004.

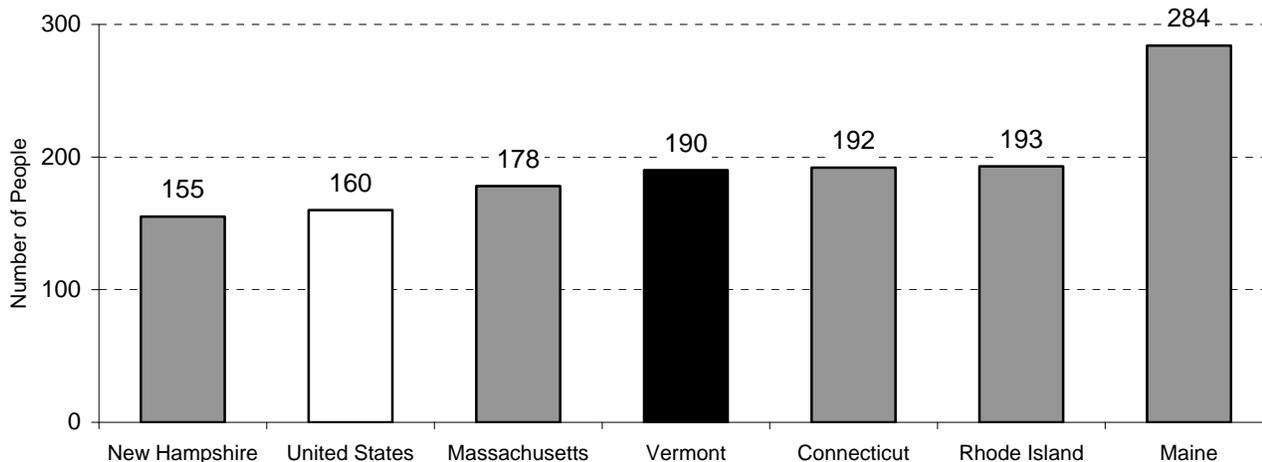
★ **State funds** (including state funds used for Medicaid match) account for a **smaller proportion** of the budget from mental retardation/developmental disability (MR/DD) services in Vermont than in any other New England State. Vermont accesses a **higher** proportion of federal dollars than any other New England state.

**Percent of State MR/DD Budget Paid by State Funds FY 2002**



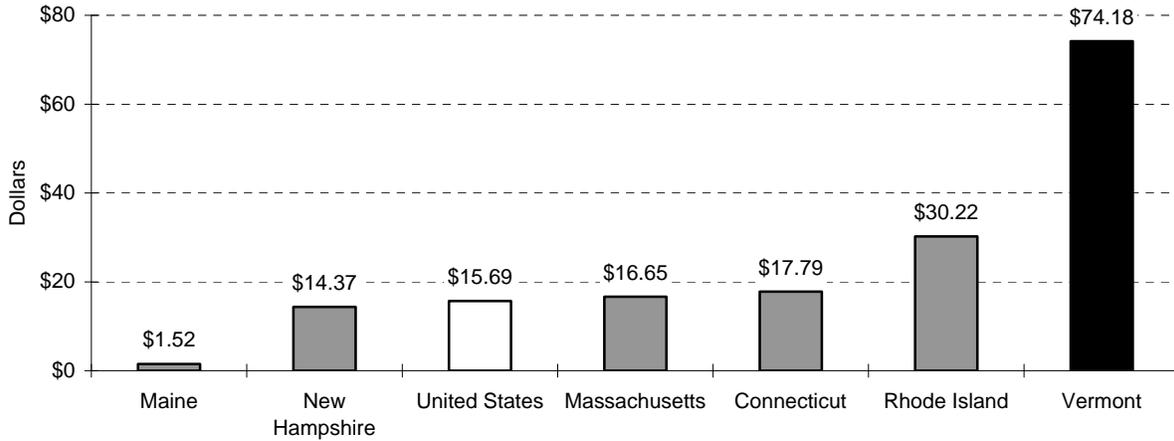
★ The number of people receiving **residential services** in the mental retardation/developmental disability (MR/DD) service system (with the addition of people living in nursing facilities) per 100,000 of the state population is **above** the national average but **on par** with the majority of New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

**Number of People in MR/DD Residential Services & Nursing Facilities per 100,000 Population FY 2002**



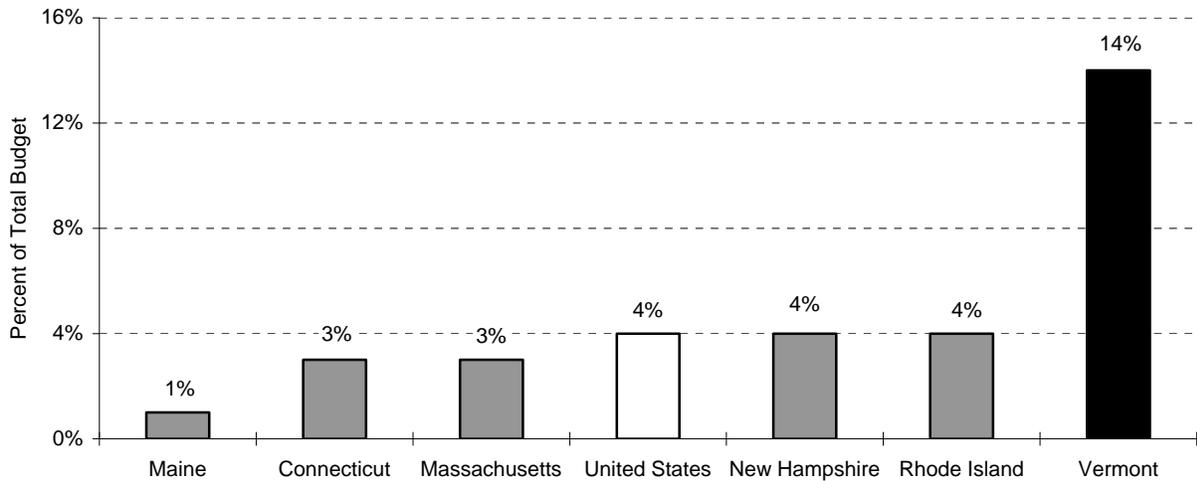
★ Vermont is ranked **1<sup>st</sup>** in New England and **3<sup>rd</sup>** in the nation in total **family support spending** per \$100,000 personal income. Greater support of families' results in lower costs overall.

**Family Support Fiscal Effort  
Total Spending per \$100,000 Personal Income  
FY 2002**



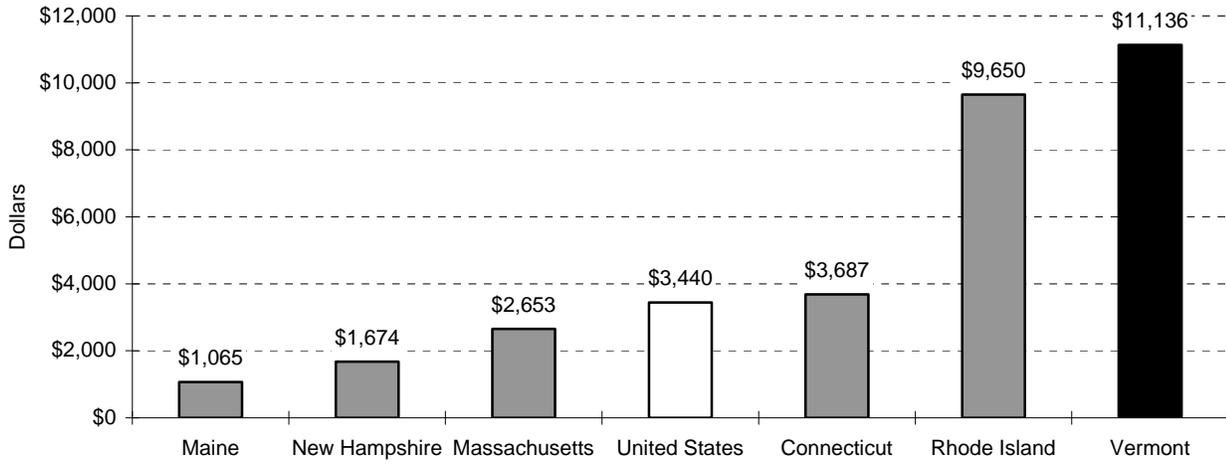
★ Vermont's family supports are ranked **1<sup>st</sup>** in New England and **4<sup>th</sup>** in the nation in **spending of total MR/DD budget**.

**Family Support Spending as Percent of Total MR/DD Budget  
FY 2002**



★ Vermont is ranked **1<sup>st</sup>** in New England and **4<sup>th</sup>** in the nation in the amount of **spending per family** for family support.

### Total Amount of Spending per Family FY 2002





# A T T A C H M E N T S

Acronyms.....	Attachment A
Organizational Chart – Agency of Human Services.....	Attachment B
Division of Developmental Services Staff:	
Waterbury Office Staff	
Community Alternative Specialists: Red and Blue Teams	
Office of Public Guardian	
Office of Pubic Guardian (map)	
Community Alternative Specialists: Blue and Red Team Structure	
Blue and Red Teams (map).....	Attachment C
Vermont Developmental Services Providers.....	Attachment D
Members of the State Program Standing Committee for	
Developmental Services.....	Attachment E
Sources of Quality Assurance and Protection for Citizens with	
Developmental Disabilities.....	Attachment F
System of Care Plan Funding Priorities.....	Attachment G
Division of Developmental Services FY 2005 Fiscal Resources .....	Attachment H
Green Mountain Self-Advocates.....	Attachment I



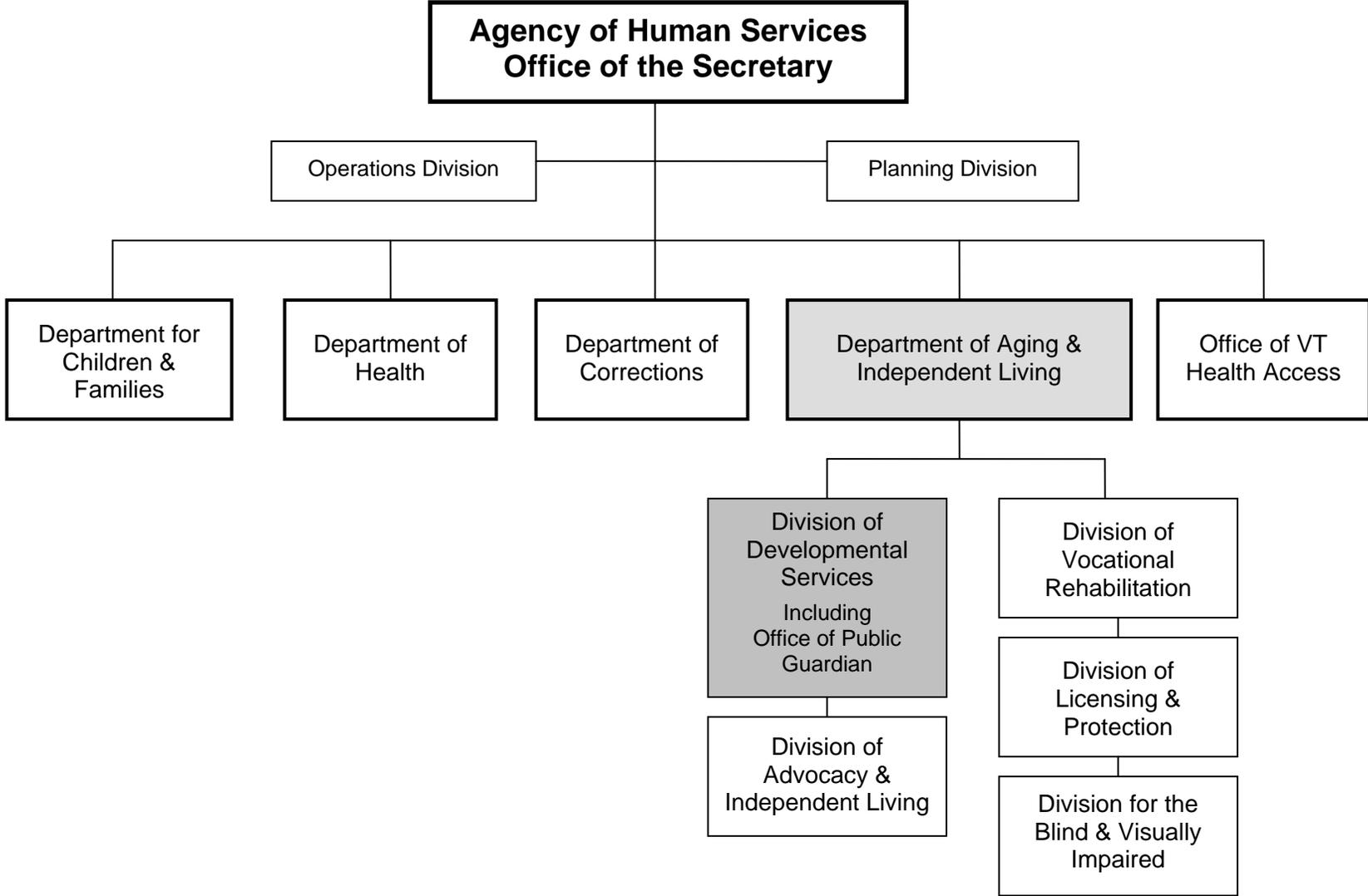
## ACRONYMS

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

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

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







**DIVISION OF DEVELOPMENTAL SERVICES STAFF**

January 2005

103 South Main Street  
 Waterbury, VT 05671-1601  
 Phone: (802) 241-2614  
 FAX: (802) 241-4224  
 (888) 268-4860 (toll free in VT)

**Waterbury Office Staff**

<b>Staff Name</b>	<b>Title</b>	<b>Phone (802)</b>	<b>E-mail Address</b>
Bascom, June	Program Development & Policy Analyst	241-2644	june.bascom@dail.state.vt.us
Boyce, Gary	High Tech. Home Care Coordinator	241-4639	gary.boyce@dail.state.vt.us
Carlomagno, Joe	Associate Director	241-2721	joe.carlomagno@dail.state.vt.us
<i>Temporary Vacancy</i>	Administrative Assistant	241-2663	
Falk, Gail	Program Director Office of Public Guardian	241-2616	gail.falk@dail.state.vt.us
Garabedian, Jennifer	Personal Care Services Coordinator	241-3528	jennifer.garabedian@dail.state.vt.us
Preedom, Lanora	Administrative Assistant	241-2648	lanora.preedom@dail.state.vt.us
Reid, Katie	Administrative Assistant	241-3543	katie.reid@dail.state.vt.us
Rogers, Jackie	Clinical and Children Services Manager	241-3955	jackie.rogers@dail.state.vt.us
Topper, Karen	Consumer Development Coordinator	241-3175	karen.topper@dail.state.vt.us
Wood, Theresa	Deputy Commissioner	241-2648	theresa.wood@dail.state.vt.us

**Community Alternative Specialists  
 Red and Blue Teams**

<b>Staff Name</b>	<b>Title</b>	<b>Phone (802)</b>	<b>E-mail Address</b>
Coy, Jeff	Red Team – Training Specialist	241-2727	jeff.coy@dail.state.vt.us
Freund, Avi	Blue Team – Training Specialist	241-2723	avi.freund@dail.state.vt.us
<i>Temporary Vacancy</i>	Program Services Clerk	241-2678	
Masterson, Jennie	Red Team – Employment Specialist	786-2571	jennie.masterson@dail.state.vt.us
Malone, Ellen	Red Team – Leader	786-5047	ellen.malone@dail.state.vt.us
McFadden, Clare	Blue Team – Children Specialist	241-2863	clare.mcfadden@dail.state.vt.us
Morse, Martin	Blue Team – Generalist	241-4494	martin.morse@dail.state.vt.us
O'Neill, Chris	Blue Team – Employment Specialist	786-8831	chris.oneill@dail.state.vt.us
Parker-Moulton, Janine	Red Team – Children Specialist	786-5081	janine.parkermoulton@dail.state.vt.us
Rappeno, Maureen	Blue Team – Nursing Specialist	786-5052	maureen.rappeno@dail.state.vt.us
Roth, Amy	Red Team – Generalist	241-2675	amy.roth@dail.state.vt.us
Spencer, Kate	Red Team – Nursing Specialist	786-5054	kate.spencer@dail.state.vt.us
Turchin, Robert	Blue Team – Leader	786-5048	bob.turchin@dail.state.vt.us

**Office of Public Guardian  
Public Guardians (Developmental Disability Specialty)**

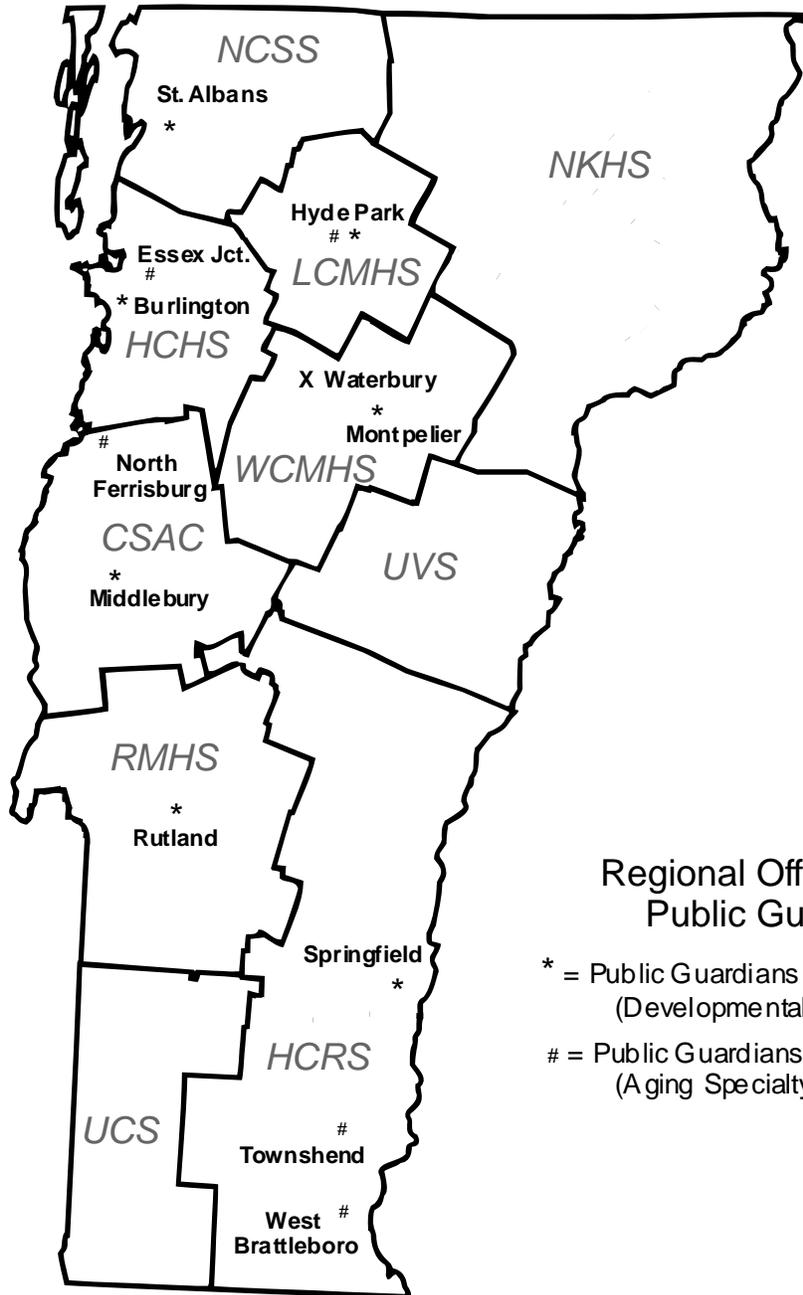
<p><b>Burlington Office</b> 108 Cherry Street Box 205, Suite 205 Burlington, VT 05401 Fax: 951-4036</p>	<p>John Homiller – Public Guardian Ed Wells – Public Guardian</p>	<p>865-7720 865-7721</p>	<p>john.homiller@dail.state.vt.us ed.wells@dail.state.vt.us</p>
<p><b>Hyde Park Office</b> Ken Gar Building 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><b>Middlebury Office</b> 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><b>Montpelier Office</b> 155 Elm Street, Suite 2 Montpelier, VT 05602-2866 Fax: 828-0243</p>	<p>Nancy Collins-Zucca – Public Guardian Becky Guyett – Senior Public Guardian Leslie Pinkham – Public Guardian Lisa Sipsey – Public Guardian</p>	<p>828-3623 828-3622 828-3620 828-3621</p>	<p>nancy.zucca@dail.state.vt.us becky.guyett@dail.state.vt.us leslie.pinkham@dail.state.vt.us lisa.sipsey@dail.state.vt.us</p>
<p><b>Rutland Office</b> One Scale Ave. Suite 109 Rutland, VT 05701-4460 Fax: 786-5055</p>	<p>Michael Fisher – Public Guardian Rodger Goodrich – Public Guardian Timothy Haley – Public Guardian Karen Hawley – Senior Public Guardian Cassandra Torrey – Prog. Svs. Clerk Jan Sherman – Senior Public Guardian Vicki Wetmore – Community Financial Specialist</p>	<p>786-5042 786-5049 786-5040 786-5043 786-5840 786-5041 786-5045</p>	<p>michael.fisher@dail.state.vt.us rodger.goodrich@dail.state.vt.us tim.haley@dail.state.vt.us karen.hawley@dail.state.vt.us cassandra.torrey@dail.state.vt.us jan.sherman@dail.state.vt.us vicki.wetmore@dail.state.vt.us</p>
<p><b>St. Albans Office</b> 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><b>Springfield Office</b> 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>
<p><b>Waterbury Office</b> 103 South Main Street Waterbury, VT 05671-1601 Fax: 241-4224</p>	<p>Gail Falk – Director <i>Temporary Vacancy</i> – Administrative Assistant</p>	<p>241-2616 241-2663</p>	<p>gail.falk@dail.state.vt.us</p>

**Emergency Toll-Free Number: 1-800-642-3100**

**Office of Public Guardian  
Public Guardians (Aging Specialty)**

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

# Division of Developmental Services Office of Public Guardian



## Regional Offices of the Public Guardians

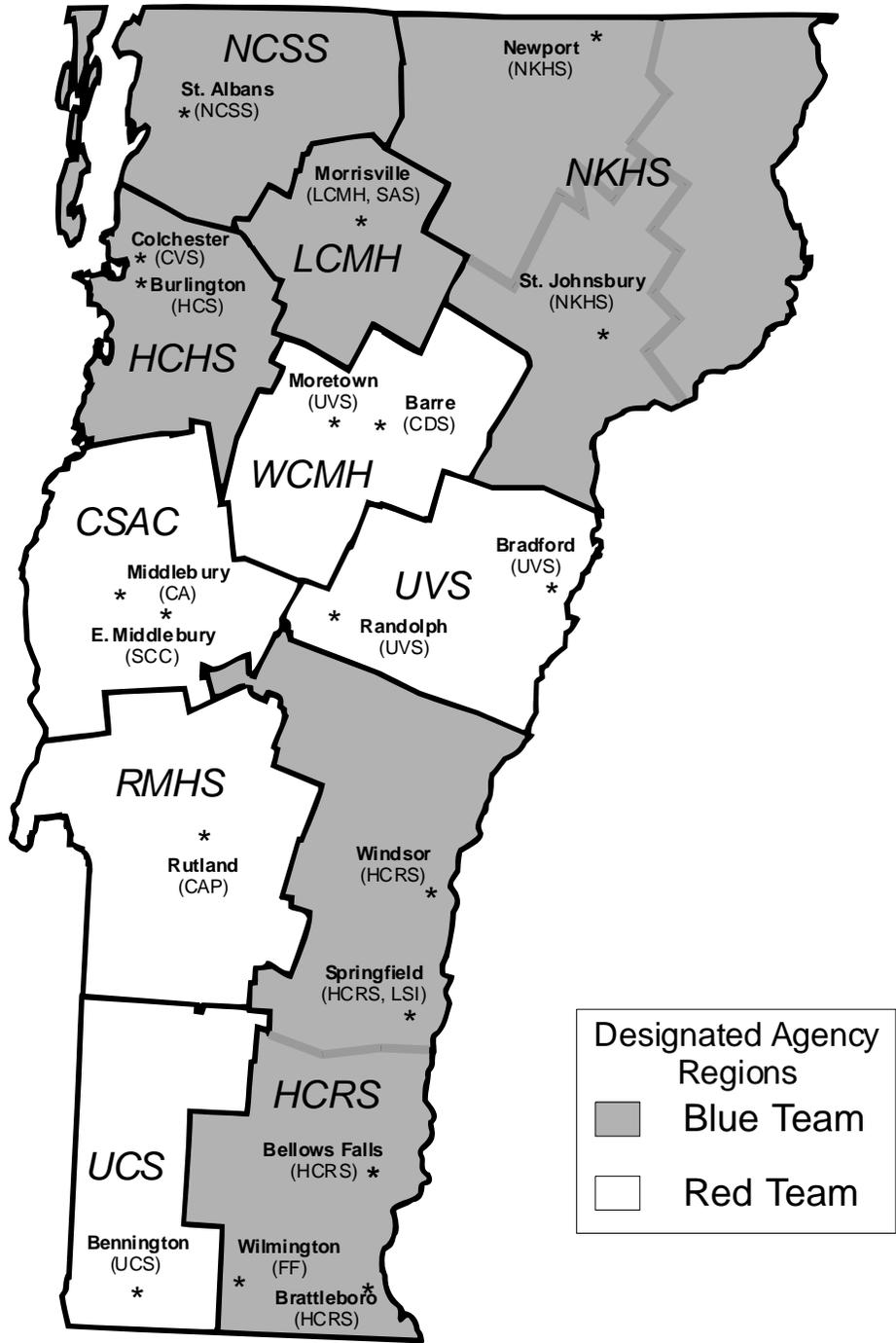
- \* = Public Guardians  
(Developmental Disability Specialty)
- # = Public Guardians  
(Aging Specialty)

**Community Alternative Specialists  
Blue and Red Team Structure**

<b>Blue Team</b>		
<b>Role</b>	<b>Staff Name</b>	<b>Provider Contact</b>
DS Team Leader	Robert Turchin	SCC
Adult Specialist	Martin Morse	HCRS, NKHS, FF
Children Specialist	Clare McFadden	HCS
Employment Specialist	Chris O'Neill	CVS, LCMH
Nursing Specialist	Maureen Rappeno	---
Training Specialist	Avi Freund	NCSS

<b>Red Team</b>		
<b>Role</b>	<b>Staff Name</b>	<b>Provider Contact</b>
DS Team Leader	Ellen Malone	CDS
Adult Specialist	Amy Roth	CAP, LSI, SAS
Children Specialist	Janine Parker-Moulton	CA
Employment Specialist	Jennie Masterson	UCS
Nursing Specialist	Kate Spencer	---
Training Specialist	Jeff Coy	UVS

# Division of Developmental Services Red & Blue Teams



**VERMONT DEVELOPMENTAL SERVICES PROVIDERS**  
**January 2005**

**(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

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

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

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

**(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: Brian Fagan  
County: Lamoille

**(LSI) LINCOLN STREET INCORPORATED**

PO Box 678, 100 River Street, Suite 217  
Springfield, VT 05156  
Phone: 885-9533 FAX: 885-9575

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

Director: Jean Gilmond  
Counties: Franklin and Grand Isle

Regional Office:

14 First Street, Suite 6, Swanton, VT 05488  
Phone: 868-3523 FAX: 868-3524

**(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, 141 Railroad Street  
St. Johnsbury, VT 05819  
Phone: 748-3181 FAX: 748-0704

**(SCC) SPECIALIZED COMMUNITY CARE**

PO Box 578  
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  
PO Box 1207  
Morrisville, VT 05661  
Phone: 888-7602 FAX: 888-1182

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

**(UCS) UNITED COUNSELING SERVICES, INC.**

PO Box 588, 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 2005**

<b>Name</b>	<b>Address, Phone and Fax</b>	<b>Represents</b>	<b>Term Expires (July 1)</b>
<b>Arsenault, Dawn</b>	54 Jalbert Road Barre, VT 05641 Phone: 476-0624	Professionals/Advocates	2007
<b>Bakeman, Anne</b>	3 Bedford Green South Burlington, VT 05403 Phone: 658-3374 Fax: 658-8061 e-mail: abakeman@zoo.uvm.edu	Family Members	2006
<b>Breiden, Nancy</b>	Disability Law Project 57 N. Main Street Rutland, VT 05701 Phone: 775-1122 Fax: 775-0022 e-mail: nbreiden@vtlegalaid.org	Professionals/Advocates	2006
<b>Bernard, Gerald</b>	Rutland Mental Health Services PO Box 222 Rutland, VT 05702 Phone: 775-0828 Fax: 747-7692 e-mail: jbernard@rmhscn.org	Professionals/Advocates	2007
<i>Vacancy</i>		Family Members	2006
<b>Compton, Joshua</b>	Health Care and Rehabilitation Services 14 River Street Windsor, VT 05089 Voice: 674-2539 Fax 674-5419 email: jcompton@hcrs.org	Professionals/Advocate	2005
<b>Daniels, Martin</b>	84 North Street Northfield, VT 05663 Phone: 485-8271 Fax: 485-4596 e-mail: danielism@tds.net	Family Members	2005
<b>Gilmond, Jean</b>	2555 Ballard Road St. Albans, VT 05478 Phone: 524-6555 ext. 608 (w) 524-4377 (h) email: jgilmond@ncssinc.org	Professionals/Advocates	2007
<b>Grassette, Patty</b>	PO Box 867 Morrisville, VT 05661 Phone: 241-2617 (w) 888-8407 (h)	People with Developmental Disabilities	2007

Name	Address, Phone and Fax	Represents	Term Expires (July 1)
<b>Hathaway, Sarah</b>	Community Developmental Services 50 Granview Drive Barre, VT 05641 Phone: 479-2502 (w)	People with Developmental Disabilities	2006
<b>Leavitt, Suzanne</b>	109 Lincoln Avenue St. Albans, VT 05478 Phone: 524-4158 e-mail: sleav731@sover.net	Professionals/Advocates	2006
<b>Jarvis-Morse, Janeen</b>	7 Randolph Avenue Randolph, VT 05060 Phone: 728-5226 (h) 371-8935 (cell) e-mail: roadrner_3@yahoo.com	Professionals/Advocate	2005
<b>Neron, Steven</b>	PO Box 8 Bethel, VT 05032 Phone: 234-6591	People with Developmental Disabilities	2005
<b>Place, Edwin</b>	Randolph House, Apt. 208 Main Street Randolph, VT 05060 Phone: 728-2021	People with Developmental Disabilities	2005
<b>Woodberry, Connie</b>	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



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

## SOURCES OF QUALITY ASSURANCE AND PROTECTION FOR CITIZENS WITH DEVELOPMENTAL DISABILITIES

January 2005

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 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 (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 Developmental Services are inspected for compliance with safety and accessibility standards.
- E. **Consumer and Family Surveys.** The Division of Developmental 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.** Service providers provide critical incident reports to the Division of Developmental 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 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.

## II. Elsewhere in State Government:

- A. **Residential Care Home Licensure.** The Department of Aging and Independent Living licenses residences where three or more unrelated people with disabilities live.
- B. **Abuse Complaints.** The Department for Children and Families and the Department of Aging and Independent Living handle complaints of abuse and neglect for children and adults, respectively. Any human service worker, including Division of Developmental 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.
- C. **Fire Safety Regulation.** Staff of the Department of Labor and Industry must approve all Level III Residential Care Homes and ICF/MR facilities. Facilities must meet appropriate standards of the National Fire Safety Code.
- D. **Vocational Rehabilitation (VR) Services.** Vocational rehabilitation services, (as opposed to Medicaid-funded work supports), are provided and reviewed by the Division of VR/DAIL.
- E. **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.

- F. **Intermediate Care Facilities for People with Mental Retardation (ICF/MR).** ICF/MRs are licensed and monitored under federally specified guidelines by nursing staff of the Division of Licensing and Protection/DAIL. The Division of Developmental Services conducts Utilization Reviews once every six months to determine whether continued stay is appropriate and necessary for each person residing in an ICF/MR.

### 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 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 Developmental 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 17 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.

## SYSTEM OF CARE PLAN FUNDING PRIORITIES

	<b>Age</b>	<b>Priority</b>	<b>Approval</b>	<b>Comments</b>
A.	Children and 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 state plan service for eligible children and youth; no minimum dollar amount
B.	Children and 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
C.	Children and Adults	Support needed to prevent or end institutionalization in inpatient public or private psychiatric hospitals, nursing facilities or Intermediate Care Facilities for People with Mental Retardation (ICF/MR)	Reviewed by local funding committee and forwarded to Equity Committee	Money from PASARR Fund is approved by PASARR manager; legally mandated
D.	Adults 18 and over	Support needed to prevent or respond to an adult being abused, neglected or exploited	Reviewed by local funding committee and forwarded to Equity Committee	
E.	Adults 18 and over	Support needed by an adult to prevent an imminent risk to the person's health or safety	Reviewed by local funding committee and forwarded to Equity Committee	Age requirement of 21 effective July 1, 2006
F.	Adults 18 and 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 and forwarded to Equity Committee	Services may not substitute for regular role and expenses of parenting; maximum amount of \$5,000/ year
G.	Adults 18 and over	Support needed to respond to an adult who is homeless or at imminent risk of being homeless	Reviewed by local funding committee and forwarded to Equity Committee	
H.	Adults 18 and 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 and forwarded to Equity Committee	
I.	Adults 18 and over	Support needed for specialized services in a nursing facility	PASARR fund manager; Equity Committee if PASARR funds are insufficient	Limited to 5 hours per week; legally mandated
J.	Adults 18 and over	Support needed for a high school graduate to maintain an employer-paid job	Reviewed by local funding committee and forwarded to Equity Committee	Maximum of up to 25 hours/week unless public safety issues warrant more
K.	Adults 18 and over	Support needed by an adult who has been committed to the custody of the Department of Aging and Independent Living pursuant to Act 248	Reviewed by local funding committee and forwarded to Public Safety Funding Committee	Services may be legally mandated
L.	Adults 18 and over	Support needed to prevent an adult who poses a risk to public safety from endangering others	Reviewed by local funding committee and forwarded to Public Safety Funding Committee	Does not substitute/ replace Corrections supervision; see add'l. requirements under Public Safety Fund



**DIVISION OF DEVELOPMENTAL SERVICES  
FY 2005 FISCAL RESOURCES**

For FY 2005, the Division of Developmental Services has an appropriated budget of combined state general funds and federal Medicaid funds of **\$99,506,091**. This is allocated as follows:

**Existing Funding**

Existing Community Services (includes \$1,639,189 for annualization of FY 2004 consumers and \$1,055,674 general fund for replacement of lost federal funding due to Medicaid formula change)	\$89,309,649
Salaries and Expenses for Guardianship Services, Quality Assurance and Division Administration	3,694,308
Division of Rate Setting	16,800

**New Funding**

Flexible Family Funding (new funding for 70 families)	85,609
2.75% Cost of Living Increase for Existing Community Services	3,046,350
New Caseload for Consumer Needs (229 people @ \$26,000/person, minus Equity funding, minus adjustment for partial year of services)	1,921,748*
High School Graduates (19 people @ \$26,000/person)	492,001
Public Safety (excess caseload costs for 9-10 people due to public safety risk)	494,000
Worker's Compensation (coverage for 1,150 employees beginning January 2005)	<u>445,626*</u>

<b>TOTAL</b>	<b><u>\$99,506,091</u></b>
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\* Note: The general fund match required to annualize total funding of \$2,367,414 will be required in FY 2006. In FY 2005 dollars that is a minimum of \$937,022 state general funds to continue services started in FY 2005.

**GREEN MOUNTAIN SELF-ADVOCATES**  
**January 2005**

**Green Mountain Self-Advocates (GMSA)**  
**73 Main Street, Suite 401**  
**Montpelier, VT 05602**  
**gmsa@sover.net**  
**802-229-2600**

**Contact: Patty Grassette and Karen Topper**  
**Toll Free (in VT): 1-800-564-9990**

**LOCAL CHAPTERS:**

**Advocates For Action**  
12 Church St,  
Bellows Falls, VT 05101  
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

**Capital City Self-Advocates**  
Montpelier and U-32 High Schools  
5 High School Drive  
Montpelier, VT 05602  
225-8000 – Linda Berger  
229-0321 – Karen Noone

**Champlain Voices**  
Champlain Vocational Services, Inc.  
77 Hedgeman Ave., Fort Ethan Allen  
Colchester, VT 05446  
655-0511 – Jill Allen  
Board Rep: Paul Nichols

**COPS – Connections of Peer  
Support of White River Jct.**  
PO Box 678,  
Springfield, VT 05156  
885-9533 – Tim Shuffleburg  
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 0515  
885-5171 – Marilyn Comstock

**RAPS - Randolph Area  
Peer Support**  
Upper Valley Services, Inc.  
12 Prince Street, Suite #2  
Randolph, VT 05060  
728-4476 – Janeen Morse  
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  
388-0302 – ext. 480 Lindsey Hescock.  
Board Rep: Randy Lizotte

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

**Wildcats**  
PO Box 867  
Morrisville, VT 05661  
888-8407 – Patty Grassette

# Green Mountain Self-Advocates

## Local Self-Advocacy Chapters

