

# **ANNUAL REPORT**

## **2004**

### **DIVISION OF DEVELOPMENTAL SERVICES**



**DIVISION OF DEVELOPMENTAL SERVICES  
DEPARTMENT OF DEVELOPMENTAL AND  
MENTAL HEALTH SERVICES  
AGENCY OF HUMAN SERVICES  
STATE OF VERMONT**

**JANUARY 2004**

Cover photo:

Self-advocates toast in celebration of the  
10<sup>th</sup>-year anniversary of the closing of  
Brandon Training School.

# **Annual Report 2004**

## **Division of Developmental Services**

**Division of Developmental Services  
Department of Developmental and Mental Health Services  
Agency of Human Services  
State of Vermont**

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**January 2004**

**This issue of the Annual Report  
is dedicated to all the people who made possible  
the closing of the Brandon Training School  
on November 17, 1993.**

**Notes:**

All data represented in this report are for FY 2003 unless otherwise stated.

See **Attachment A** for a list of *Developmental Services 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.

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# INTRODUCTION

## BTS Closure 10<sup>th</sup> Year Anniversary

It was a joyous celebration! People from all over the State joined together on a beautiful day in August 2003 to celebrate the 10<sup>th</sup> anniversary of the closing of Brandon Training School. Horse-drawn wagon tours of the old campus were enjoyed along with refreshments in the “Old Laundry Building”. Over 200 people climbed aboard the “Spirit of Ethan Allen” for an afternoon cruise on Lake Champlain – complete with a gourmet buffet, dancing, a slide show and people sharing memories. There wasn’t a person who didn’t have an enormous smile on his or her face.

The chaos was unbelievable at times, but it was a delightful experience; people coming together – meeting old friends, dancing with new ones. Enjoying life! For those who used to live at Brandon, enjoying a life that has changed so dramatically. For those who never lived at Brandon, valuing the freedom from institutionalization they’ve known since birth. And everyone, each and every person, appreciating a state where the fear of being removed from everything familiar in one’s life – home, family, community – to an institution far away, doesn’t exist.

For some it was a step back in time, seeing the old buildings where many spent such a large part of their lives. Meeting up with people they thought they recognized, but weren’t quite sure. Taking photos of people and places and collecting memories. To celebrate means to rejoice, commemorate, make merry, have fun. All of these things and more happened for the people who participated in the day-long festivities. As the day drew to a close, people who used to live at Brandon and some of their friends joined together for a champagne toast after leaving the ferry. A toast to life – past, present and future. For remembering our past and considering our present will undoubtedly make for a better, brighter future.

*TERESA WOOD*

Director, Division of Developmental Services  
February 2004



## Are Our Principles at Risk?

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 period of 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 in much the same fashion as do people without disabilities. These changes, along with increased knowledge, skill, and practice standards has resulted in an unmeasurable improvement in the life quality of the people who depend upon the community system for their daily support.

With the passage of the Developmental Disabilities Act of 1996, the citizens of Vermont, through the actions of their elected representatives, wrote into Vermont Law twelve principles of service that established standards and articulated expectations intended to 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, and they have formed the basis for how services within Vermont have been evaluated and improved over time. 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 the 2005 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 legacy's being formed by the decisions made and the actions taken during such times.

Vermont should rightfully take great pride in its accomplishments when reflecting upon the opportunities that are available to many people who are developmentally disabled. 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  
February 2004

## Memories from the Brandon Training School 10<sup>th</sup> Reunion – BTS Tour



## Memories from the Brandon Training School 10<sup>th</sup> Reunion – Celebration



# THE DEVELOPMENTAL SERVICE SYSTEM

The Developmental Disabilities Act of 1996 requires the Department of Developmental and Mental Health Services (DDMHS), 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 People with Developmental Disabilities*, 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.
- ★ **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.

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<sup>1</sup> Developmental Disabilities Act of 1996, 18 V.S.A. § 8724

- ★ **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 guardianship services. See **Attachment B: *Division of Developmental Services Staff***.

The Division of Developmental Services contracts directly with fifteen (15) private, nonprofit developmental services providers who provide services to people with disabilities and their families. Services and supports offered emphasize the development of community capacities to meet the needs of all individuals regardless of severity of disability. The Division works with all people concerned with the delivery of services: people with disabilities, families, guardians, advocates, service providers, the State Program Standing Committee for Developmental Services, and state and federal governments to ensure that programs continue to meet the changing needs of people with developmental disabilities and their families. See **Attachment C: *Vermont Developmental Services Providers***; and **Attachment D: *Members of the State Program Standing Committee for Developmental Services***.

## Developmental Services Providers

### Designated Agencies

The Department of Developmental and Mental Health Services designates 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>2</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 DDMHS. It must be an organization that either: 1) provides a distinctive approach to service delivery and coordination; 2) provides services to meet distinctive individual needs; or 3) had a contract with DDMHS developed originally to meet the above requirements prior to January 1, 1998. There are five Specialized Service Agencies who serve people with developmental disabilities.

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<sup>2</sup> For developmental services, geographic regions are defined along county lines.

## Contracted Providers

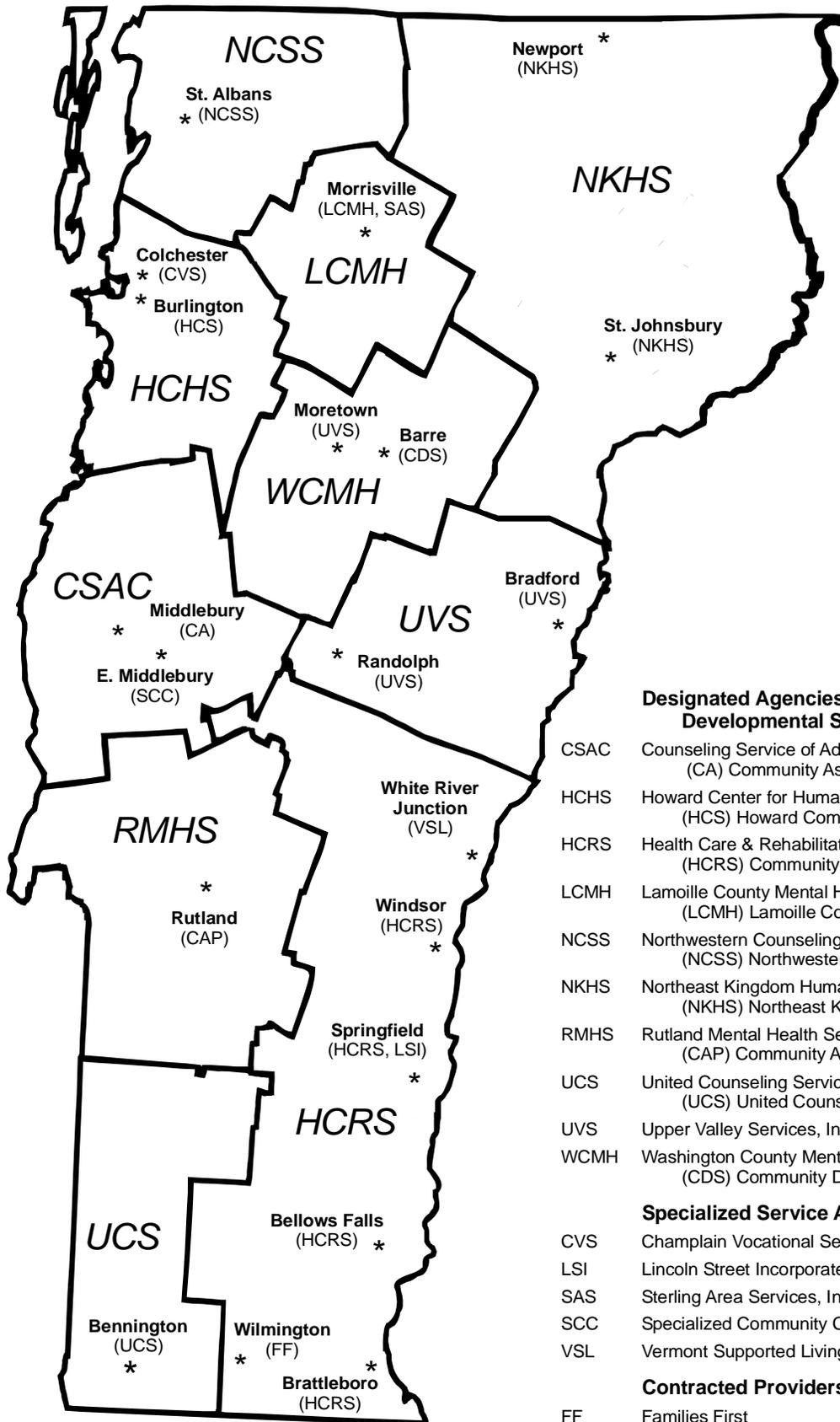
Contracted providers are providers who do not have a direct contract with DDMHS but are non-profit agencies subcontracted through DAs and SSAs to provide supports to people in the region. Any organization that wishes to provide direct services to people with developmental disabilities and receives state 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 the Division of Developmental Services on behalf of people with disabilities and their families. Today, people have a choice of who will manage their services. There are four options available to people who receive services:

- **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 and will do many of the bookkeeping and reporting responsibilities of the employer. A person may also choose to hire or contract with an Independent Support Broker (ISB) to assist in self-management responsibilities. A guide to people who are self/family managing their service has been developed by DDS to assist individuals, families and service providers with the development and maintenance of these arrangements.
- **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.

# 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
- VSL Vermont Supported Living

**Contracted Providers**

- FF Families First

## Quality Assurance & Quality Improvement

Quality Service Reviews – 2003	
Number of agencies reviewed	16
Number of people reviewed	406
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 2003:

- Individual Support Agreements
- Staff Training
- Behavior Support Plans
- Quality Assurance
- Employment
- Individual Budgets

The annual service reviews also informs the designation process that takes place for each agency every four years. In 2003, four agencies went through the re-designation process. To date, all agencies except two have gone through re-designation at least once<sup>3</sup>.

As part of the agency review process, the Community Alternative Specialists incorporate 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 & Appeals** processes for people applying for or receiving services, their family members, guardians and other interested individuals.
- **Safety & Accessibility Reviews** of all new residential settings funded by DDS were conducted. The Division of Developmental Services contracted separately for 185 home safety reviews and 26 home accessibility reviews in FY '03. Three agencies arranged for their own safety and accessibility reviews.
- **Consumer & Family Surveys** to measure the satisfaction of people receiving services and to assess how families feel about services they receive.

<sup>3</sup> CSAC, SCC, CVS and LSI were re-designated in FY '03. SAS goes through re-designation early in 2004. VSL went through the initial designation process to become an SSA in 2002.

- **Ethics Committee** to review any decisions by a Guardianship Services Specialist to abate life-sustaining treatment for a person receiving services.
- **Human Rights Committee** to review behavior support plans which include the use of restraints to safeguard the human rights of people receiving developmental services.

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

**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
  - Positive support strategies & behavior support plans
  - Policies & guidelines
  - Best practices
  - Data and other information reporting
  - 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, PATH, Social and Rehabilitation Services 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** provided in the following areas:
  - Advance directives
  - Leadership skill development for Employment Coordinators
  - Pervasive Developmental Disorders
  - Estate planning
  - Alternatives to guardianship
  - Understanding the Medicaid system
  - Social skills and relationship development
  - Statewide conference on supporting people to communicate
  
- ★ Intensive **nine-day training** series was developed and provided to service coordinators and independent support brokers.
  
- ★ A dozen people were trained and certified as local **Vermont Safety Awareness Training** (VSAT) instructors.
  
- ★ As a **priority goal** for the system, DDS chose 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.*
  
- ★ To help maintain consistent and quality services and supports across the state, the Division of Developmental Services has developed certain **policies**, many of which have been recently updated or are in the process of being revised:
  - *Critical Health Care Decisions* (1996)
  - *Complaint & Appeal Processes* (1998)
  - *Guidelines for Critical Incident Reporting* (Revised: 2002)
  - *Flexible Family Funding Guidelines* (Revised: 2002)
  - *Individual Support Agreement Guidelines* (Revised: 2003)
  - *Background Check Policy* (Revised: 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* (being finalized: 2004)
  - *Guidelines for Quality Services* (being revised: 2004)
  - *Health & Wellness Standards & Guidelines* (being finalized: 2004)
  - *Behavior Support Guidelines for Support Workers Paid with DDS Funds* (being finalized: 2004)

## Highlights from FY 2003

- ★ **Medicaid Waiver Gets High Marks** – The Centers for Medicare & Medicaid Services reviewed Vermont’s home and community-based waiver services in Spring 2003 for individuals with developmental disabilities. They concluded that Vermont “*provides the type of individualized services that people need and want*” and that Vermont “*serves as a model*” for other states.
- ★ **5-year Renewal of Medicaid Waiver Granted** – Vermont was successful in renewing its home and community-based waiver for people with developmental disabilities for another 5 years.
- ★ **10-year Anniversary of the Closing of Brandon Training School Celebrated** – Over 280 people attended festivities marking the 10<sup>th</sup> year anniversary of the closing of Brandon Training School (BTS) and the transition to complete community-based developmental services for people in Vermont. Former residents of the school enjoyed horse-drawn carriage tours of the old BTS campus in the morning and gathered for a special afternoon event with testimony and celebration of the closure of the institution 10 years ago.
- ★ **Service Coordinator Training Developed** – The Division of Developmental Services, in collaboration with service providers and people who receive services, developed and provided a nine-day training for new and experienced service coordinators and Independent Support Brokers. The training covers such topics as funding, support plans, self-management, behavior support, communication, guardianship, self-advocacy, supervision and quality assurance.
- ★ **Nursing Facility Use at an All-Time Low** – People with MR/DD who live in nursing facilities reached an all-time low of 29 people as of December 31, 2003. 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 34% decrease since just last year.
- ★ **Vermont Voices and Choices Conference a Huge Success** – A record 380 people attended this year’s Voices and Choices self-advocacy conference. Most of the participants were self-advocates and each presentation included presenters who were self-advocates. This was the first year Voices & Choices was a two-day event with 165 self-advocates participating in evening activities and over 100 staying overnight. Green Mountain Self-Advocates organized the conference.
- ★ **Individual Support Agreement Guidelines Finalized** – After incorporating feedback from stakeholders and careful review, the Division of Developmental Service’s Individual Support Agreement Guidelines were revised and distributed. In addition, DDS’s Background Check Policy was updated.

- ★ **Communication Conference Kicks-off Statewide Communication Initiative** – The Vermont Communication Task Force (VCTF) organized *Making Communication Happen*, a one-day conference that provided practical information to people on how best to support people to communicate. This event marked the start of a statewide initiative focusing on opportunities and supports for people to improve their communication. Three helpful guides on communication funding, planning and resources were developed by VCTF.
  
- ★ **Green Mountain Speaker's Bureau Formed** – The Division of Developmental Services, in partnership with Green Mountain Self-Advocates, created a Speaker's Bureau of interested self-advocates to assist with presentations and training. A helpful pamphlet, *Creating New Partnerships: Including Self-Advocates in Training* was developed to help ensure people get the necessary supports in preparing for and providing presentations.
  
- ★ **Sex Offender Treatment Progress Scale Developed and Piloted** – With funds from a Department of Justice grant, the Division of Developmental Services sponsored the development of a treatment progress scale specifically for sex offenders with developmental disabilities. The validity and usefulness of the scale will be measured in the coming year. The scale is designed to document an offender's progress and treatment and to identify areas where the offender still needs treatment. Once its validity is established, the scale will be used in programs throughout Vermont and will be publicized nationally.
  
- ★ **Two-day Conference on Pervasive Developmental Disorders Organized** – The Division of Developmental Services and the University of Vermont's Department of Communication Sciences co-sponsored *Enhancing Diagnostic Precision in the Assessment of Autism Spectrum Disorders*. National experts in the field of Autism presented workshops to psychologists in Vermont who are responsible for conducting evaluations of people applying for developmental services.
  
- ★ **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>4</sup>.
  
- ★ **Vermont #1 in Supported Employment** – Thirty-six percent (36%) of working age adults receiving developmental services are supported to work; considerably higher than the national average<sup>5</sup>.

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<sup>4</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*.

<sup>5</sup> The national average in FY '01 was 24%. *National Survey of State MR/DD Agencies* (FY 2001), Community Inclusion, University of Massachusetts Boston.

## Memories from the Making Communication Happen Conference



## Pressures on Community Services

In FY 2003, the Division of Developmental Services provided supports to 2,889 people with developmental disabilities in Vermont, approximately 25% of the eligible population. However, the population is constantly growing with an estimated 110 children born each year with developmental disabilities<sup>6</sup>, with advances in technology increasing the rate of survival of many infants who would not have survived in the past. The need for developmental services is generally life-long and only an average of 32 people who are currently receiving services die each year<sup>7</sup>. The demand for supports continues to outpace the available resources. The following are some of the many factors influencing this.

- ⊙ **Services to new children have been suspended due to financial constraints** – 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>8</sup>. The continuation of this moratorium has created a backlog of cases that would cost between \$1.2 and \$1.5 million annually.
- ⊙ **Waiting list continues** – At the end of FY 2003, the waiting list included 44 people who are eligible for developmental services. Those people were funded starting in July 2003. As of December 2003, there were already another 28 people on the waiting list.
- ⊙ **Special education graduates need supports to keep them employed and living at home<sup>9</sup>** – There are an estimated 75 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 75, only 58 people will be expected to be eligible under current funding priorities for home and community-based waiver funding and 13 for Division of Vocational Rehabilitation grant-funded employment services. This leaves four graduates who are eligible for services but do not meet funding priorities.

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<sup>6</sup> Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6,367 live births (State of Vermont 2001 Vital Statistics).

<sup>7</sup> Based on an average of the past six years (*Mortality Among People Receiving Developmental Services in Vermont FY 2003*).

<sup>8</sup> See **Attachment F: System of Care Plan Funding Priorities Changes**.

<sup>9</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.

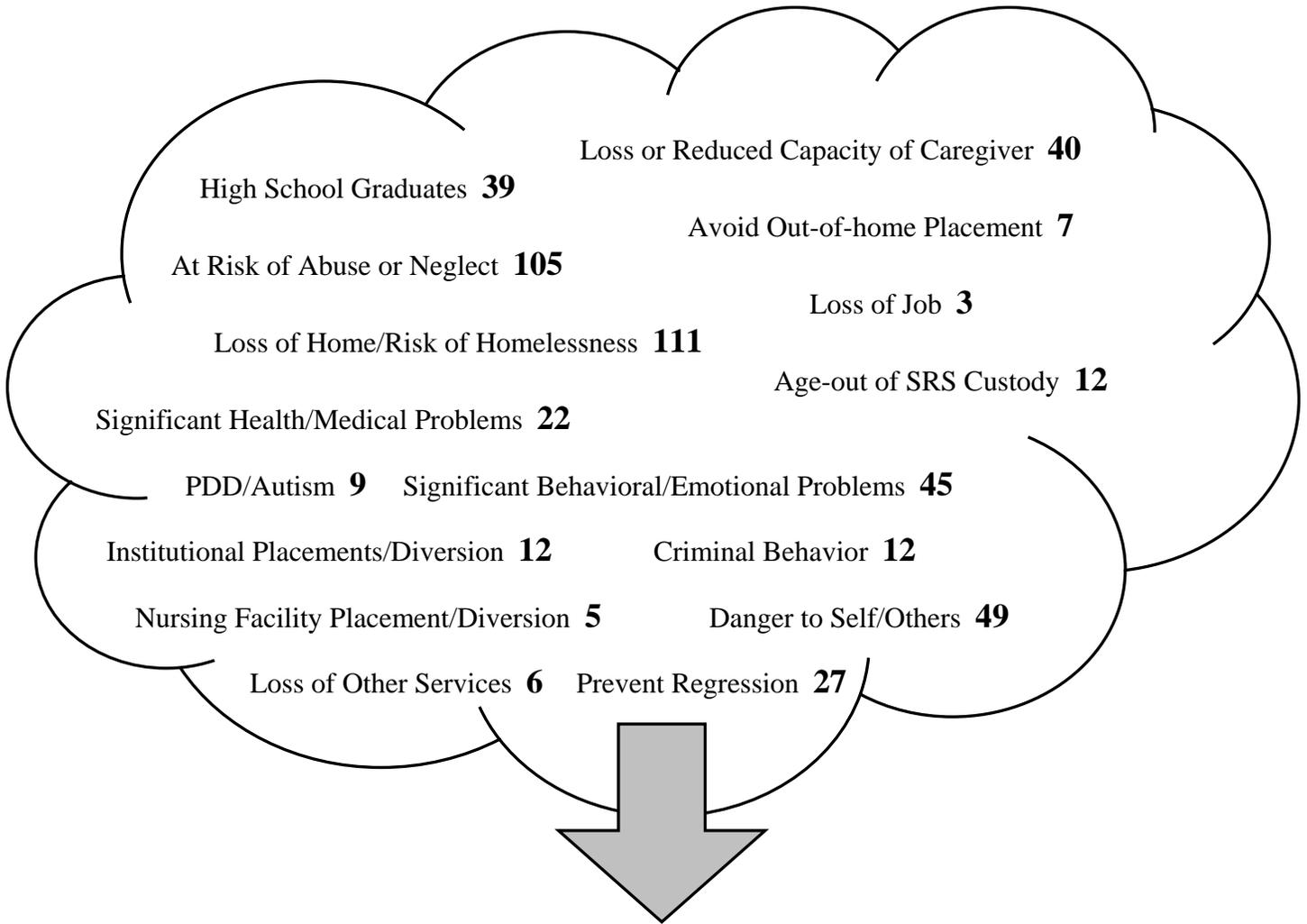
- ◎ **People who live with aging parents often need additional supports** – People often need additional supports as they get older. Aging parents who have never asked for help before are seeking support before they die. It is significant that 22% of family caregivers are age 60 or more<sup>10</sup>.
  
- ◎ **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. More than 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 194 individuals in FY '03 who met the State System of Care Plan funding priorities for developmental services. The diagram on the following page provides a summary of the reasons people received new caseload funding. The majority of people who received new caseload funding had previously not received developmental services or received only “minimal services”<sup>11</sup>.

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<sup>10</sup> Vermont Division of Developmental Services Family Satisfaction Survey – Statewide Results – Fall 2001

<sup>11</sup> “Minimal services” are Flexible Family Funding, Targeted Case Management, or Transition grant-funded employment services.

## New Caseload Funding<sup>12</sup> – FY 2003



**People Served from New Caseload Resources**  
**194**

**Developmental services resources are being successfully managed:**

- New caseload funding goes to those most in need;
- Of the 194 getting new funding, 54% meet the definition of “new consumer;”
- In FY '03, 66 people left services (e.g., move out of state, died, graduated from services).

**However, although we are currently serving only about 25% of the eligible population, many more people with developmental disabilities are born each year, creating *new* demand for services *yearly*.**

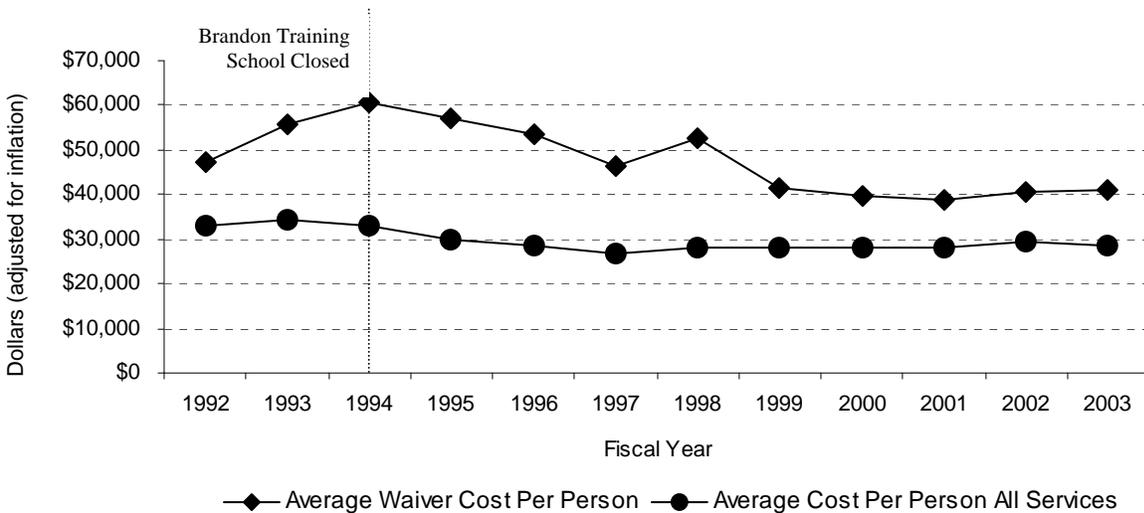
<sup>12</sup> Information is based on Designated Agencies’ intake information as reported to DDS via an annual funding summary. Individuals may be counted in more than one category.

## 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 G: Division of Developmental Services' FY 2003 Budget Summary.**

- ★ The **average waiver cost per person** rose by approximately **9.2%** over the course of the past two years primarily because of the suspension of services to new children in December 2001 (as the average waiver cost for children is generally lower than adults). In addition, the net increase of **113 adults** to 24-hour home supports since FY '01 also contributed to the increase in the average waiver cost per person.
- ★ The **average cost per person** for all services has **remained stable**. An increase over time in the number of individuals supported by less costly (non-residential) family support contributes to the stability of the average cost per person<sup>13</sup>.

**Average Waiver Cost per Person  
Average Cost per Person - All Services  
FY 1992 - FY 2003**



- ★ Fiscal growth for developmental services between 2000 and 2002 grew at an average rate of 17% nationally, while Vermont's fiscal growth was **12%**<sup>14</sup> over that same period of time.

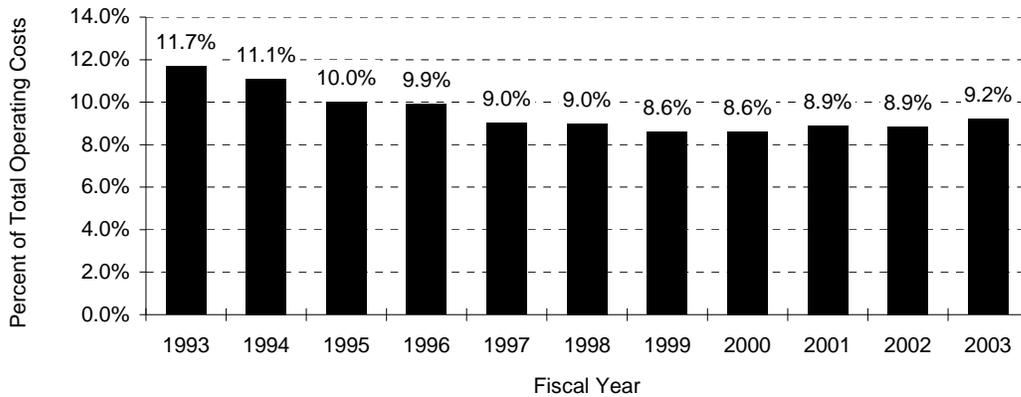
<sup>13</sup> For "Average Waiver Cost", waiver years 1992 – 1997 ended on 3/31. From 1998 on, waiver years ended on 6/30. Due to this change over, waiver year 1998 reflects costs for a 15-month period. For "Average Cost per Person – All Services", year-end numbers are used for waiver years ending on 6/30.

<sup>14</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.



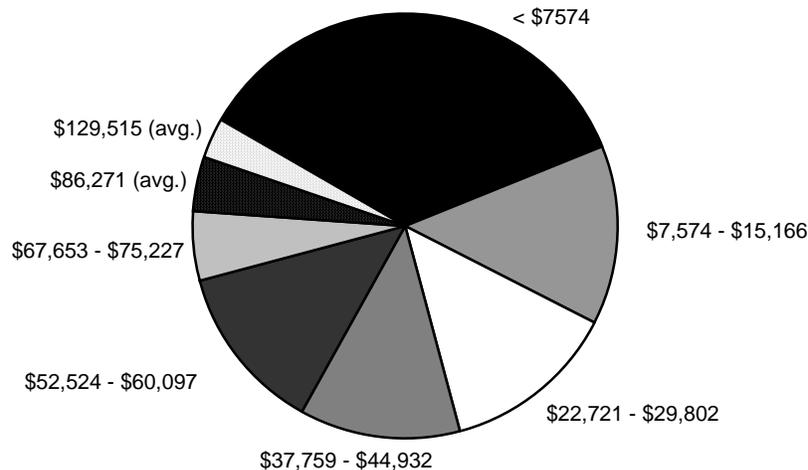
**Administrative expenses** include those that are required to run the total agency. Management expenses (e.g., developmental service director, building, etc.) relating to major program areas (e.g., developmental services) are considered program expenses, not administration.

**Total Agency Administration Costs  
FY 1993 - FY 2003**



The **average cost of all services per person** in FY '03 is **\$28,658**. One-half of all individuals served (**50%**) 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>15</sup> is **\$129,515** per year, which is still **60%** less than what the estimated annual per person cost would have been at Brandon Training School in today's dollars (\$216,802). 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.

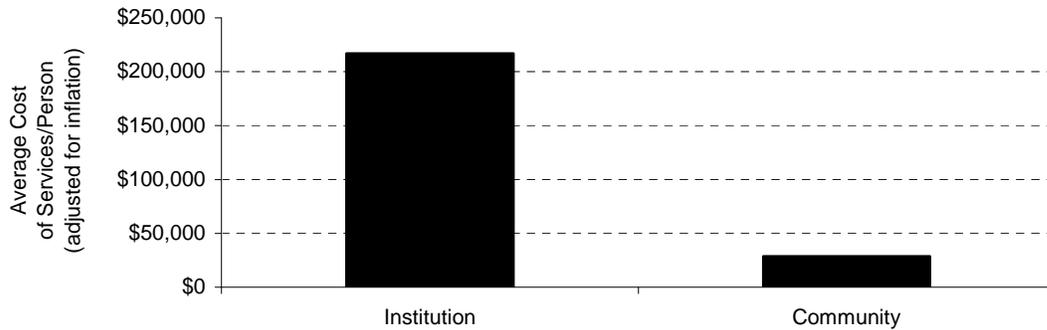
**Per Person Service Rates of Individuals Served  
FY 2003  
(N=2889)**



<sup>15</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 **\$216,802** per year for each person served. In current dollars, **9** families can be supported with intensive in-home support, or **193** families can be supported with respite support, for the same amount of money (adjusted for inflation).

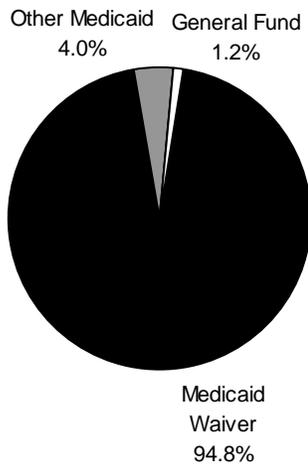
**Comparative Annual Cost of Services:  
Institution (1994) vs. Community (2003)**



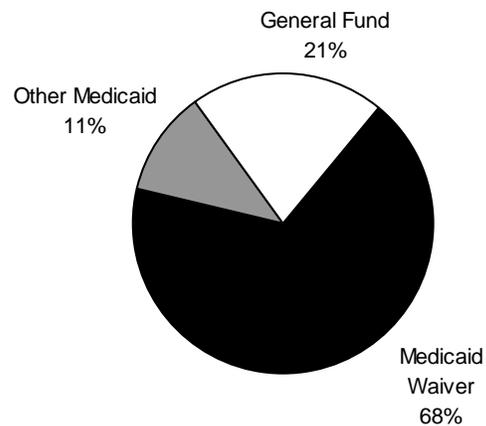
- ★ Flexible Family Funding, a cost-effective, family-directed support, is provided through general funds (GF) resources at DDS. It accounts for the significant difference in the number of people served through GF versus the percent of GF funding to the total. Almost 99% of developmental service funding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

**Percentage of Funding & Percentage for People<sup>16</sup> by DS Funding Type<sup>17</sup>  
FY 2003**

**Percent of Funding by Funding Type**



**Percent of People by Funding Type**



<sup>16</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>17</sup> “Other Medicaid” = Targeted Case Management, Rehabilitation, Transportation, Clinic, ICF/MR & Social Services Block Grant. General Fund (GF) = Flexible Family Funding

# SERVICES & FUNDING

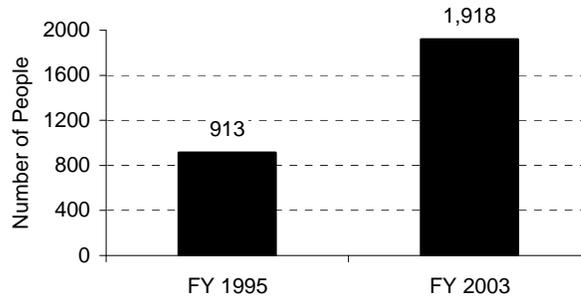
## Funding Sources

Numbers Served – FY 2003	
<b>Total people served</b>	<b>2,889</b>
Home and community-based waiver recipients	1,918
Flexible Family Funding recipients (some dups. with waiver)	737
Other	361

**Medicaid** (including 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**.

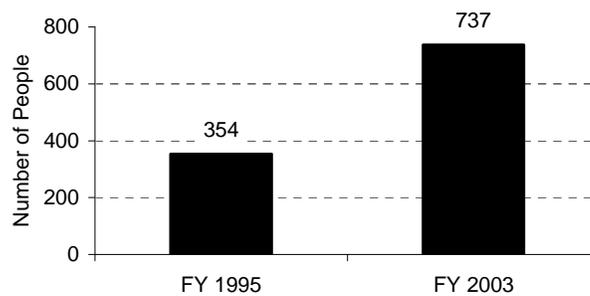
- Home and Community-Based Waiver (HCBW) – 1,918 people funded**  
 The home and community-based waiver, often referred to as “the waiver”, is the primary funding source for people receiving developmental services in Vermont. The waiver accounts for **94.8%** of all funding for people served through DDS.

**HCB Waiver Services Over Time**



- Flexible Family Funding (FFF) – 737 people funded**  
 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 Over Time**



- Other** – Other funding sources are Medicaid fee-for-service (i.e., targeted case management, rehabilitation, transportation and clinic services), Intermediate Care Facility (ICF/MR), vocational grants in partnership with the Department of Aging and Disabilities, Medicare and other 3<sup>rd</sup> party insurance.

## 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 & 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.

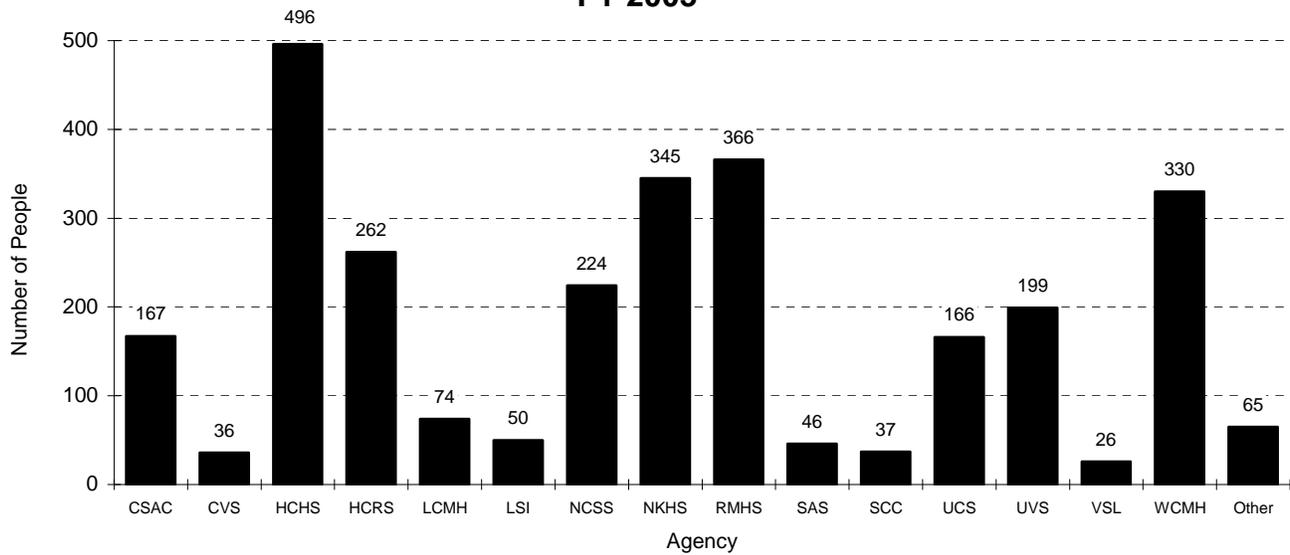
**Home Providers** – Individualized shared-living arrangements offered within a contracted home provider's home.

**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.

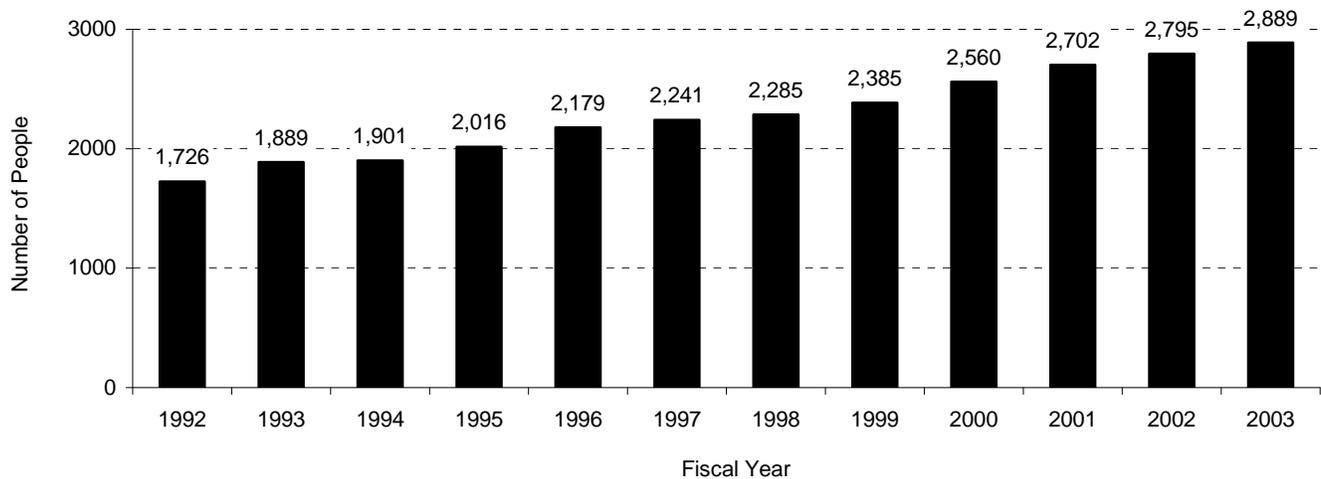
# Total Served

## Total Number of People Supported by Service Provider FY 2003



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.	VSL	Vermont Supported Living
LSI	Lincoln Street Incorporated	WCMH	Washington County Mental Health Services, Inc.
NCSS	Northwestern Counseling & Support Svs., Inc.	Other	Includes people supported by Transition II Employment Services, Families First or Guardianship Services Specialists who are not served by any other DS agency.
NKHS	Northeast Kingdom Human Services, Inc.		
RMHS	Rutland Mental Health Services		

## Total Number of People Served FY 1992 - FY 2003



## Highlights

- ★ What **consumers** said about their agency<sup>18</sup>:
  - **82%** said they are happy with their agency.
  - **96%** said they are listened to at their support plan meetings.
  - **87%** said they got what they wanted in their support plan.
  - **90%** said things in their support plan are important to them.
  - **88%** said people at their agency listen to them.
  - **92%** said people at their agency help them change things they don't like.
  - **94%** said they get the help they need.
  - **89%** said they are happy with the help they get from their agency.
  
- ★ What **families** said about their agency<sup>19</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:
  - **27%** said there are supports and services they wish they had that they do not have now.
  - **95%** said they don't know how much money is in their budget.
  - **91%** said they don't know how they can use their money for services.
  - **57%** said they have not been told about their agency's appeal process.
  - **27%** said they never get to learn new things.
  
- ◎ 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.

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<sup>18</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 – 2003 Report*.

<sup>19</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 2003	
Number of people getting waiver-funded service coordination	1,918
Number of people getting fee-for-service service coordination	310
(duplications between waiver & FFS)	(138)
<b>Total Service Coordination (unduplicated)</b>	<b>2,090</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 Plan
- Periodic Review/Assessment of Needs
- Medicaid Billing
- Evaluations & Assessments
- Waiting and Applicant Lists
- Overall Health & 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>20</sup>.
- ★ What **consumers** said about service coordination:
  - **91%** said they were happy with their case manager.
  - **83%** said they got to see their case manager when they wanted.
  - **92%** said they got what they needed when they ask their case manger for help.
- ★ 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>20</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:

  - **35%** said they chose their own case manager.
  - **16%** said that having a lot of different case managers was a problem.
  
- ⊙ 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.

### A Family Reunited: How a Service Coordinator Helped

*The year 1966 was a devastating time for Sally who, at 3 years old, lost both of her parents. Sally was placed in a foster home in Milton and was separated from her six siblings when she moved. This all changed for her though, on March 2, 2002, when she was reunited with her family in Burlington.*

*Sally's search to locate her family began in May 2000, with support from Donna, her case manager at Northeast Kingdom Human Services, and consent from her legal guardian. One of Sally's sibling's names was found in a birth certificate in Colchester. The search continued on the "Net" as Sally's new case manager, Rachael looked at websites for ancestors and genealogy for nearly six months, but came up with nothing. Rachael then decided to try "telephonenumber.com" for Vermont listings. By doing this, she was able to locate one of Sally's sisters. Sally's sister couldn't believe it when she received Rachael's phone call. She was ecstatic to hear from Sally because they had also been trying to locate her.*

*On March 22, 2002, with the support of Rachael, Sally was reunited with her family in Burlington. Sally rejoiced with her two sisters and brother on that special day and has also recently met another brother. She is still hoping to reunite with another sister in New Hampshire.*

*Sally has been overjoyed with the reuniting of her family. She is very happy and looks at their pictures several times a day. What an impact this has had on Sally and her family. They, too, are very interested in getting to know Sally better. If you or someone you know is trying to locate a long lost friend or family member, try searching the "Net". It could change your life forever!*



## HOME SUPPORTS

<b>Numbers Served – FY 2003</b>	
<b>Number of people getting home supports (6/30/03)</b>	<b>1,175</b>
Number of homes (6/30/03)	988
Average number of people per residential setting	1.2

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

### Types of Home Supports

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

**Number of People – 911**

**Number of Homes – 796**

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

**Number of People – 165**

**Number of Homes – 157**

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

**Number of People – 69**

**Number of Homes – 14**

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

**Number of People – 24**

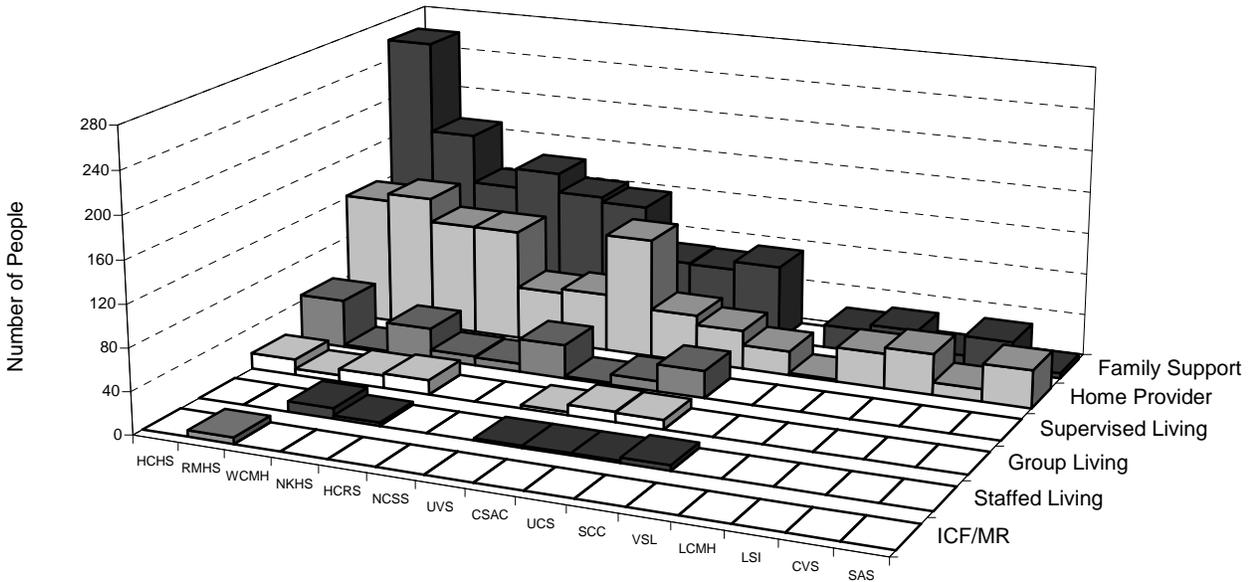
**Number of Homes – 20**

- **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.

**Number of People – 6**

**Number of Homes – 1**

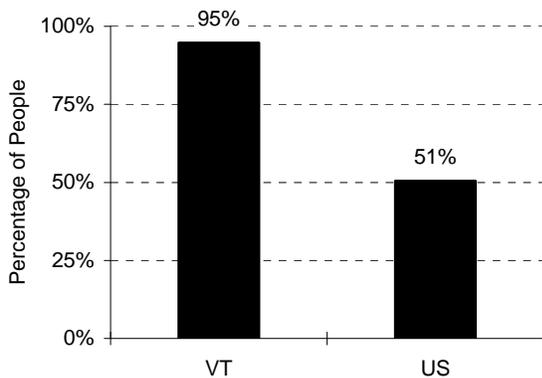
### People Supported by Type of Living Arrangement 6/30/03



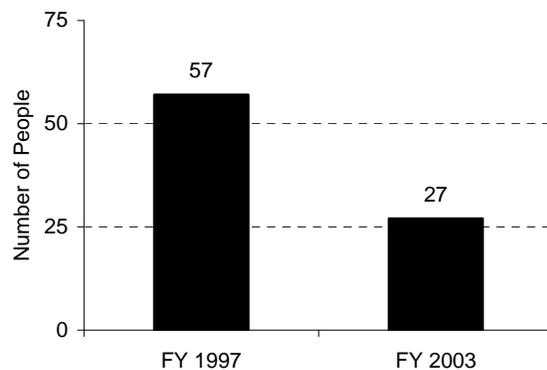
### Highlights

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

### Percentage of People in Residential Settings of 1-3 People<sup>21</sup> FY 2002



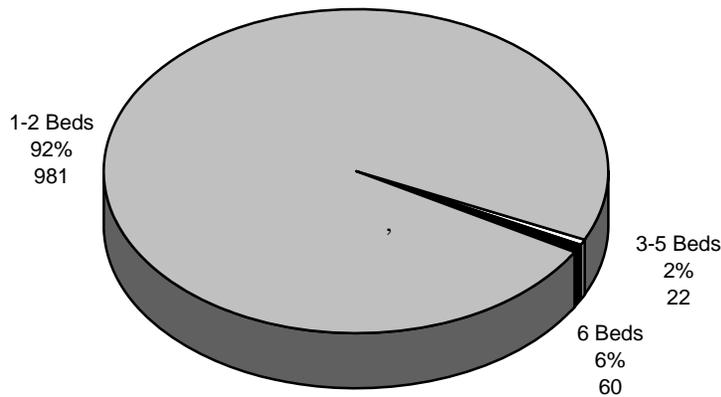
### Residential Care Home Use by People with Developmental Disabilities Over Time



<sup>21</sup> Source: Prouty, R, Smith G. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002*. Research & Training Center on Institute on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2003.

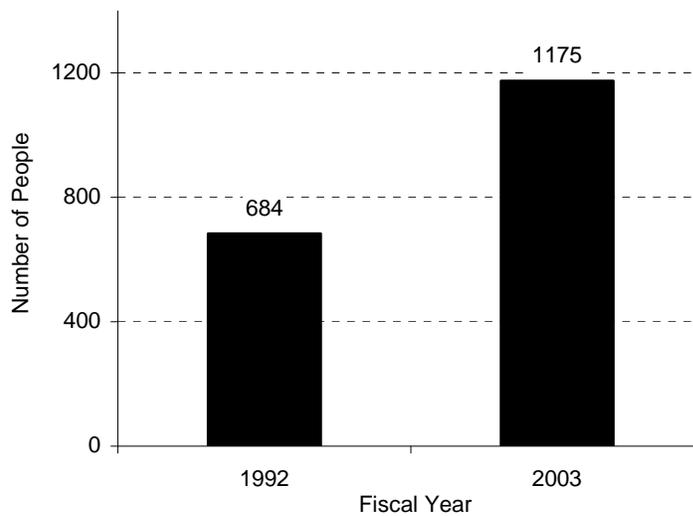
★ There are no large congregate settings for people with developmental disabilities funded by DDS. Vermont is the only state in the country that has **100%** of the people funded for home supports living in residential placements with six or fewer consumers<sup>22</sup>.

**Number of Residences by Size of Residential Setting  
FY 2003**



★ 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 3.1<sup>23</sup>.

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

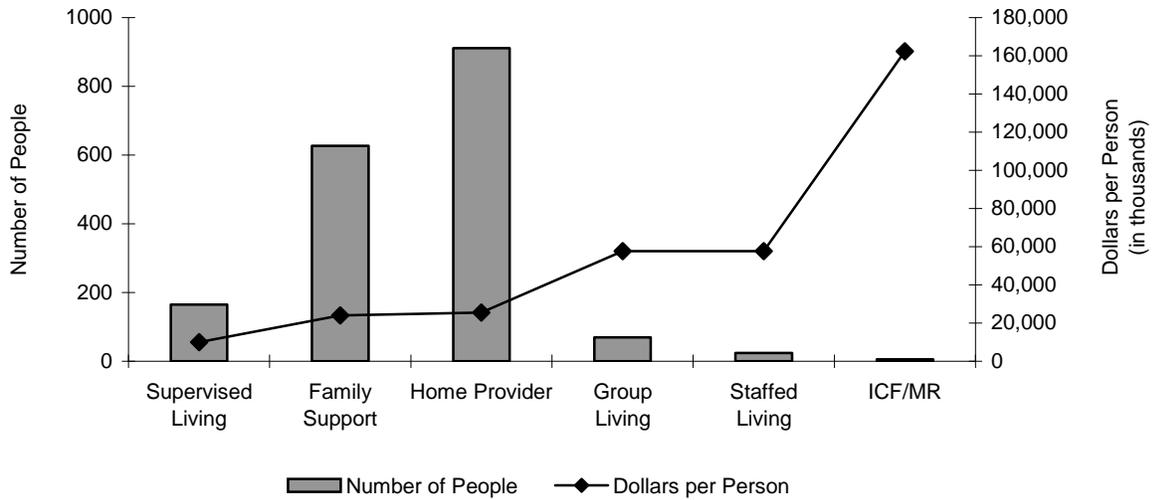


<sup>22</sup> Ibid.

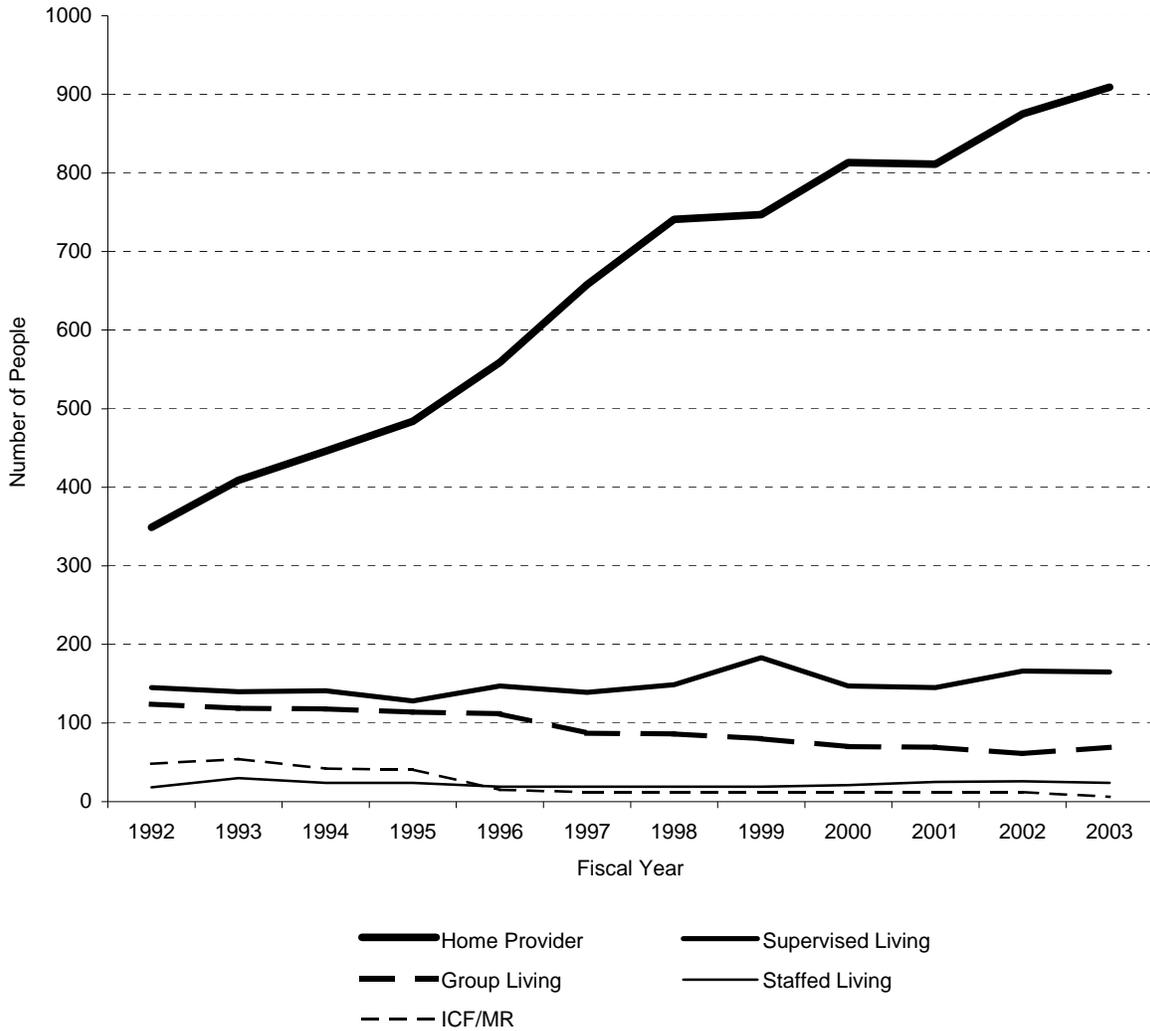
<sup>23</sup> Ibid.

★ Vermont continues to increase less costly **in-home family support and individualized home support** options (e.g., home provider and supervised living) while decreasing the use of 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 2003**

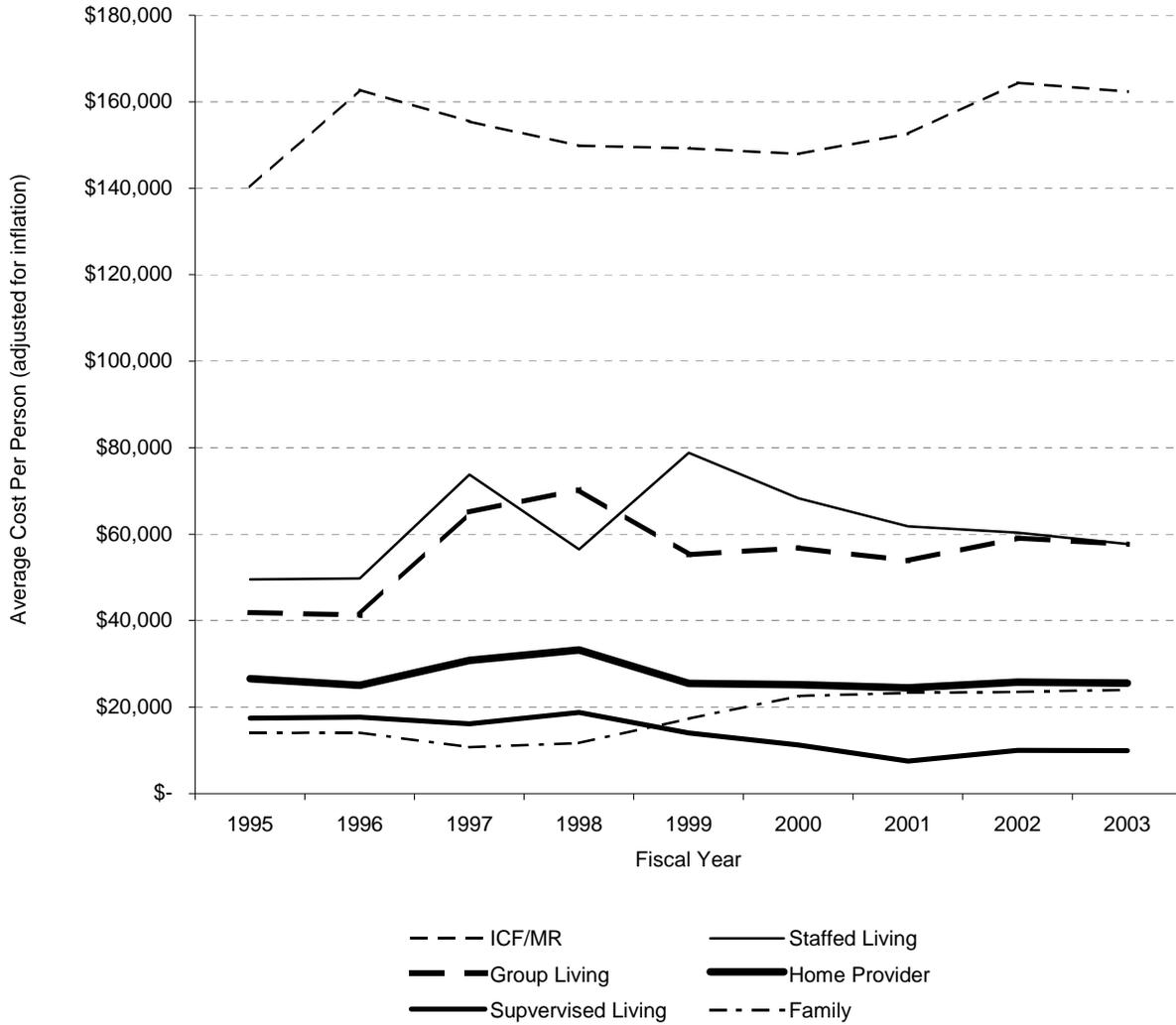


### Residential Population Change by Setting FY 1992 – FY 2003



- **Home Provider** residential settings have steadily increased throughout the past decade. They make up **77%** of all residential support options.
- **Supervised Living** has fluctuated over time, but the numbers have **increased slightly** overall.
- **Group Living** has **steadily decreased** over time despite a slight increase in FY '03.
- **Staffed Living** reached an all time high of 30 in FY '93, dropped down to a low of 19 in the late 1990s. There has been a **slow rise** the past few years.
- **Intermediate Care Facilities** have **steadily decreased** over time; only one remains open as of June 30, 2003.

### Average Cost per Person by Type of Home FY 1995 – FY 2003



- 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 also **declined** the past few years.
- The cost of **Group Living** has fluctuated, but there has been a general **decrease** in the average cost over time as the numbers served in this setting have declined.
- The cost of **Home Provider** residential 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.

What **consumers** said about home supports:

- **81%** said they were happy with where they live.
- **100%** of the people who live alone said they liked living by themselves.
- **89%** said they like the people they live with<sup>24</sup>.
- **92%** said they like the food where they live.

## Areas of Focus

- ⊙ In FY 2003, an estimated **248** people were reported as living in a home they either **own (29) or rent (219)**. 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.
- ⊙ What **consumers** said about home supports:

  - **50%** said they had no choice in deciding where they live.
  - **79%** said they had no choice in deciding who lives with them.
  - **29%** said they would like to have more chores to do at home.
  - **18%** said people come into their bedroom without asking.
  - **29%** said they cannot be alone with friends when they come to visit.
  - **64%** have to wait for someone to take them if they want to go out.
  - **48%** do not have a key to their house.
- ⊙ Compliance and follow-up to **home safety reviews** within the first 30 days has dropped considerably since last year. Although the majority of homes were in compliance within the maximum 90-day grace period, there were still 31 homes (17%) not in compliance at the end of the fiscal year.

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<sup>24</sup> This percentage combines responses for up to 3 people with whom the person lives, and therefore includes multiple answers for many of the respondents.

## Employment Services

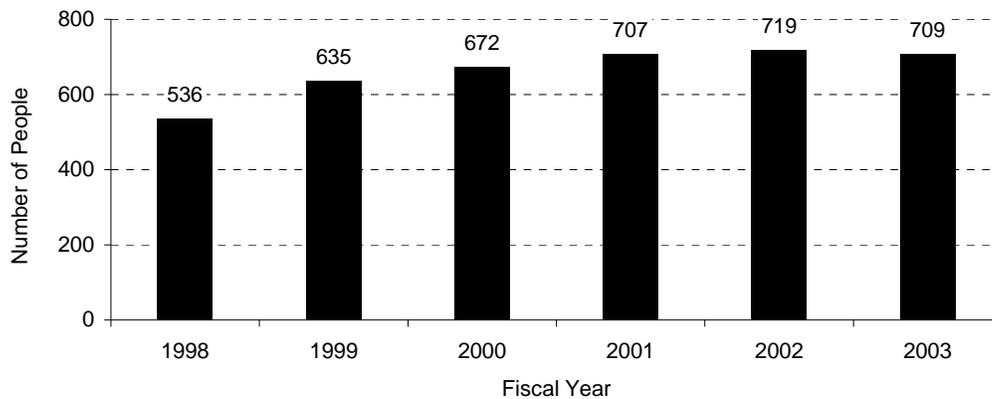
<b>Numbers Served – FY 2003</b>	
<b>Number of people employed</b>	<b>702</b>
Average hourly wage	\$7.08
Average hours worked per week	14 hr./wk.
Estimated public benefits (SSI) saved	\$1,056,375

**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 work force 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, and has gone up **32%** in the past **5 years**.

**People with Developmental Disabilities  
Receiving Supported Employment to Work  
FY 1998 - FY 2003**



Note: The total number of people receiving supported employment in FY 2003 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.

- ★ **36%** of working age adults receiving developmental services are supported to work; much higher than the national average<sup>25</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>26</sup>.
- ★ Vermont is ranked **4<sup>th</sup>** nationally in people in supported employment as a proportion of total people getting community supports and/or work supports<sup>27</sup>; 42% compared with the national average of 24%.
- ★ The average wage for people receiving employment services continues to rise every year and is considerably **higher** than minimum wage in Vermont.
- ★ What **consumers** said about work supports:
  - **91%** said they like their job.
  - **91%** said the work they do is important.
  - **94%** said people respect them at work.
  - **94%** said they get a vacation from work.
  - **97%** said that having a lot of different job coaches was not a problem for them.
- ★ 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>28</sup>; yet over **1200** adults with developmental disabilities (ages 18 – 65) who receive services are not employed.
- ◎ What **consumers** said about work supports:
  - **79%** of the people who do not work said they wanted a paid job.
  - **26%** said they did not choose where they work.
  - **46%** said they did not choose their job coach.
  - **38%** said they would like to work more hours.
  - **34%** said they would like to do something else during the day.

<sup>25</sup> The national average in FY '01 was 24%. National Survey of State MR/DD Agencies (FY 2001), Community Inclusion, University of Massachusetts, Boston.

<sup>26</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>27</sup> Ibid.

<sup>28</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.

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## Welcome To Our House: How Work Supports Make a Difference

*So reads the sign at the front entrance to “American Flatbread,” a bakery and restaurant serving oven-baked pizza. Located among the historic stone buildings of the renovated Marble Works, American Flatbread is truly a welcoming place to all that enter.*



*While weekends find standing-room only crowds, weekdays at American Flatbread are less hectic, as a crew of roughly twenty workers prepares a variety of favorite pizzas. The voices of co-workers welcome you to a warm and creative work environment.*

*Among those welcoming voices is one belonging to Bob, a worker who is most often found peeling garlic, in bulk, with a three-pound sledge! Seated at a specially adapted worktable, Bob prepares garlic that is used in almost every offering at Flatbread. Bob’s warm smile and deep voice greet co-workers as they return from their lunch break. Conversation ranges from a simple “Hi!” to commentary on the music, or information on the week’s happenings. This time of the workday is among Bob’s favorite. It kicks off an afternoon of work and community building as Bob and his fellow employees share in the tasks of preparing a “whole lot of pizzas.”*



*Bob is one of three employees receiving work supports from developmental services who work for American Flatbread in Middlebury. Bob’s supports represent a team effort carried out by a partnership of services – all pulled together and held together by Bob himself. Through his own initiative, patience, and tenacity, Bob has seen his job at American Flatbread become an important part of his life – and the life of the community.*

*Early last year, Bob told his service coordinator at Specialized Community Care (SCC), that he wanted to be employed. Bob then contacted the local Division of Vocational Rehabilitation (DVR) to ask about resources and supports to find and succeed at a job. It was through DVR that Bob learned about Employment Associates (EA), the supported employment program of Community Associates in Middlebury. Bob’s phone call to EA set in motion a journey that began in his apartment in Vergennes on a cold, snowy afternoon, and brought him to the warm fireplace of American Flatbread; garlic and hammer in hand.*

*Bob led his team from brainstorming about interests and skills to exploration of work opportunities, including self-employment. Bob remained true to his dream every step of the way – to work and to work independently. Bob steered his EA Employment Representative through his web of supports, all of which enable Bob to contribute his skills and gifts in the work place. With minimal assistance, Bob even arranged for access to public transportation for himself and his motorized wheelchair. Each work day, Bob boards the bus in Vergennes with the help of his SCC support worker. When he arrives at Flatbread, Bob is greeted by his Employment Representative whose primary assistance these days is to help set up and clean up. Bob then catches the bus for the return trip home.*

*Bob’s co-workers at Flatbread speak highly of his work. The prepared garlic, his enthusiasm for life and the job, his warm greetings, and his great personality all “add a lot to this place” says John, the bakery manager. “Bob loves to work, and we have learned a lot from each other in the process.”*

*Everyone involved in this partnership has “learned a lot” about each other, about the many details that go into working independently, about persistence when other details get in the way, but most of all about drawing strength from each person’s efforts – a strength that has resulted in a very “Welcoming House” for all who enter.*



## Community Supports

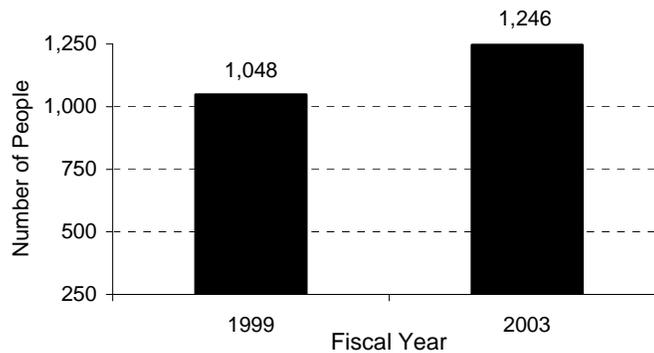
<b>Numbers Served – FY 2003</b>	
<b>Number of people receiving community supports</b>	<b>1,246</b>
Total annual cost of community supports	\$14,683,111

**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.
- ★ There has been a steady **increase** in people getting community supports over time, yet the average per person cost of community services decreased in FY ‘03.

**Number of People Receiving  
Community Supports Over Time**



- ★ What **consumers** said about community supports:
  - **96%** said they like their community supports<sup>29</sup>.
  - **84%** said they have a way to get there if they want to go somewhere.
  - **93%** said people who they spend time with during the day respect them<sup>30</sup>.
  - **81%** said they got to go shopping as much as they wanted.
  - **75%** said they got to go out to eat whenever they wanted.
  - **70%** said they got to play sports as much as they wanted.

<sup>29</sup> This percentage takes into consideration responses for individual, group and volunteer community supports. The count includes some duplication across types of community support.

<sup>30</sup> Ibid.



What **families** said about community supports:

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

### Areas of Focus



The percentage of people receiving community supports as a proportion of the total number getting work and community supports **increased**. 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 be supported to get a job.



Creative development of activities and community connections are needed to strengthen supports allowing adults to pursue their interests and achieve their personal and educational goals.



What **consumers** said about community supports:

- **41%** said they would like more hours of community supports<sup>31</sup>.
- **53%** said they did not choose who supports them during the day<sup>32</sup>.
- **52%** said they do not make the choice to go to their community activities<sup>33</sup>.
- **34%** said there is something else they would rather do during the day<sup>34</sup>.
- **73%** said they want to learn new things or new skills.
- **34%** of those who said they don't ever go to church would like to.
- **42%** of those who said they don't ever play sports would like to.
- **70%** of those who said they don't ever go out for entertainment would like to.
- **75%** of those who said they don't ever go shopping would like to.
- **85%** of those who said they don't ever go out to eat would like to.

### Mary's Story: How Community Supports can Truly Support Community

*My name is Mary and I live in my own apartment in Middlebury. I've lived there for four or five years and I've had some good neighbors there. Before I lived at this apartment, I've shared an apartment with some other people. Community Associates helped me to meet new people and they helped me to find an apartment and roommates. They helped me to buy things I needed for my apartment and to talk to my landlord if there was a problem.*

*Employment Associates (EA) helped me to get my job and I've been working at the same job for 13 years. They come visit me at my job once in a while and I stop by the office if I need to talk to my EA staff. I get back and forth to work on my own, either walking or taking the bus.*

<sup>31</sup> Ibid.

<sup>32</sup> Ibid.

<sup>33</sup> This percentage takes into consideration responses for individual and group community supports.

<sup>34</sup> Ibid.

*I used to have a rep payee who had worked for EA and then I became my own payee. If I have questions, I ask for someone's help. I take care of my own apartment and whenever [someone] comes for a safety check, everything looks great.*

*In my free time, I go to Special Olympics all year round. I play soccer and basketball and I swim and ski. I've gone to the World Games in Indiana and North Carolina. I've been to training for public speaking for Special Olympics and I've talked to people at the bank and I made a speech at the Penguin Plunge. I raise money, too.*

*I volunteer with Equestrian Challenges every week and now I volunteer at the Bristol Family Center every Wednesday. I help the kids be safe and I play with them.*

*I'm a member of the self-advocacy group called Speak-Up Addison County and we give workshops on how to work out problems at your job or when you're around town. We meet about every week and there may be an article about us in the local newspaper.*

*I go to Reading Group every week and we just read books together and we talk about our weekends and the trips we go on. We've read stories and then went to see the plays. We went on a Lake Champlain cruise and every year we have a party before our summer break.*

*There are classes at Birchard Park and they're fun to go to. I liked the cooking classes, the makeover class, the yoga class, the self-defense class and the relationship group. EA had a Good Choices class and we danced around and watched Richard Simmons and did the routine. It was crazy.*



*On holidays I go to my friend's parent's house. Every holiday I have two or three invitations. One of my best friends and her seven year old daughter live in Rutland and I hang out at their house and help her out.*

*Last summer I invited CA staff and my crazy guardian for lunch at Mr. Up's and we were celebrating how well I'm doing. If I need help from CA, I can call.*

## Family Supports

<b>Numbers Served – FY 2003</b>			
<b>Funding/Supports for Families</b>	<b>Adults (22 &amp; over)</b>	<b>Children (under 22)</b>	<b>Total</b>
Flexible Family Funding recipients	150	587	<b>737</b>
Home & community-based waiver recipients	349	278	<b>627</b>
Respite/In-home Supports	225	265	490
Other Supports (Employment & Community Supports)	294	50	344
(duplications between FFF & HCBW)	(77)	(49)	(126)
<b>Total Family Supports (unduplicated)</b>	<b>422</b>	<b>816</b>	<b>1,238</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/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

- ★ People receiving family support represents **43%** of all people served. This is up from 30% back in FY '96.
- ★ Vermont is **4<sup>th</sup>** in the country in terms of total family support spending per family<sup>35</sup>.

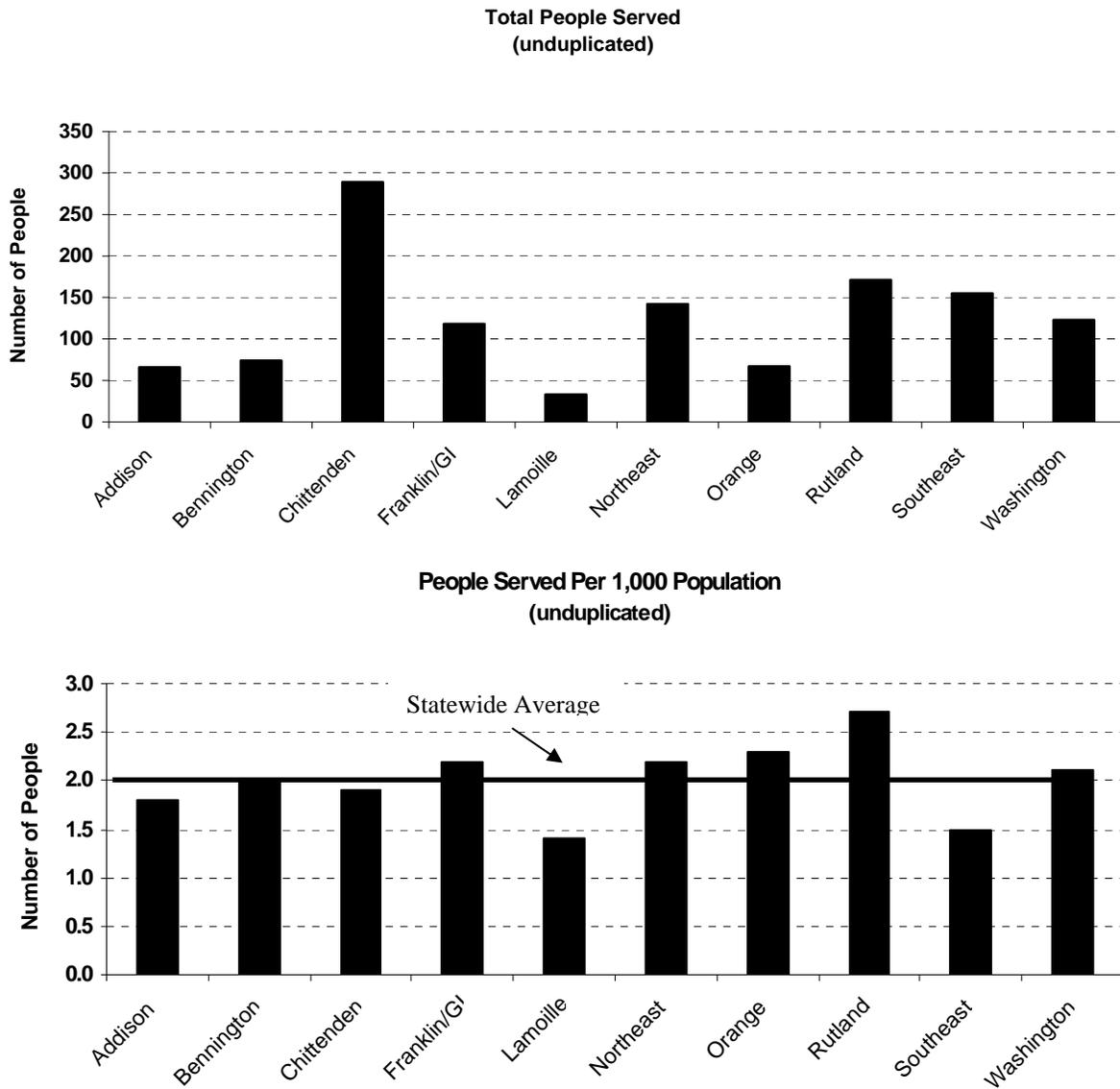
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<sup>35</sup> The State of the States in Developmental Disabilities: 2002 Study Summary, Coleman Institute for Cognitive Disabilities & Department of Psychiatry, University of Colorado, January 2004.

★ 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 '03, **32 adults** and **17 children** received out-of-home respite for a total of **608 days**.

★ Family supports are provided statewide to an average of **two people per 1000 residents**<sup>36</sup>.

### Family Support to People Living at Home (Flexible Family Funding & Waiver) FY 2003



<sup>36</sup> Source: US Census Bureau, Census 2002 estimates from the Vermont Department of Health, Vermont Population and Housing Estimates.

★ 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/respice workers that work with their family.
- **76%** said they want to have control over the hiring and management of their support/respice 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.

## Children’s Services

<b>Numbers Served – FY 2003</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	125	404	58	<b>587</b>
Home & community-based waiver recipients	15	277	125	<b>417</b>
Lives with family	13	212	53	278
Does not live with family <sup>37</sup>	2	65	72	139 (39 w/SRS)
Other (Medicaid, vocational grant, self/private pay)	3	37	32	<b>72</b>
(duplications between FFF & Waiver)	(5)	(32)	(12)	<b>(49)</b>
<b>Total Children Services</b> (unduplicated)	<b>138</b>	<b>686</b>	<b>203</b>	<b>1027</b>

**Children’s Services** are provided to children and youth who live with their natural 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.

### Highlights

- ★ Of the total number of people receiving developmental services, **36%** are children (under age 22). Although there was no increase in the number of children served in FY ’03, this percentage compares favorably to FY ’97 when children made up 25% of the total served.
  
- ★ Vermont is ranked **4<sup>th</sup>** in nation in the amount of funding spent on family support per person.
  
- ★ What **families** said about children’s services:
  - Families of children expressed **greater satisfaction** than families of adults around control and input over hiring and managing workers and how complaints and appeals are handled.

### 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>37</sup> One of the children age Birth – 6 who is list listed as “not living with family” lives in a shared parenting situation and therefore lives with family on a part time basis.

⊙ There has been a steady rise in children's services over time until this past year when the December 2001 moratorium on funding to serve newly identified children with comprehensive needs went into effect. The total number of children served (under age 22) remained virtually **unchanged** from last year, and the overall percentage of children served dropped.

⊙ What **families** said about children's services:

- Families of children expressed **less satisfaction** than families of adults around receiving information about services, access to services, services meeting family needs and help getting what the family needs, frequent changes in support staff, and overall satisfaction.

## Clinical & Crisis Services

<b>Numbers Served – FY 2003</b>	
<b>Vermont Crisis Intervention Network</b>	
Level II – Technical assistance Number of people supported (est.)	84
Level III – Crisis beds	
Number of stays	27
Number of total days	602
Avg. length of stay (range 5-63 days)	23 days
Institutional diversions (est.)	23

**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:

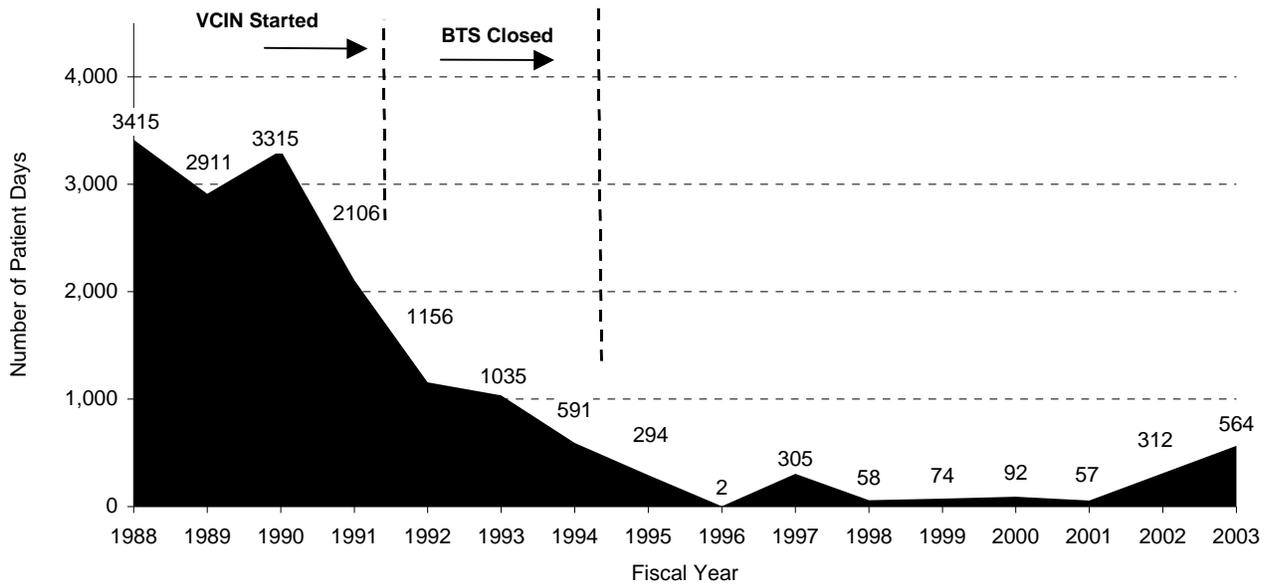
- **Level I: The Clinical Network** provides consultation on individual situations and professional techniques through a statewide network of agency clinical providers (prevention orientation, quarterly meetings, training)
- **Level II: On-site Consultation** and support to individuals, families and 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

- ★ A **Checklist for Crisis Bed Programs** has been developed and is intended to assist service providers and Community Alternative Specialists when considering components and features that are important for a comprehensive crisis bed program.

- ★ 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<sup>38</sup>.
  
- ★ 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.
  
- ★ A sample outline for a **Personal & Community Safety Plan/Behavior Support Plan** has been developed for use with offenders so service providers can incorporate all necessary information in order to better serve offenders in a safe and respectful manner that focuses on positive approaches.

**Vermont State Hospital Utilization  
by People with Mental Retardation  
FY 1988 - FY 2003**



<sup>38</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 was at VSH in FY'97 (130 day stay) who was not known to DDS during her stay. In FY 2003, one person accounted for 365 of the 564 days.

## Areas of Focus

- ⊙ Continued evaluation of **crisis bed** use needed 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.

### Elaine's Story: How A Person's Life can Change with the Right Supports

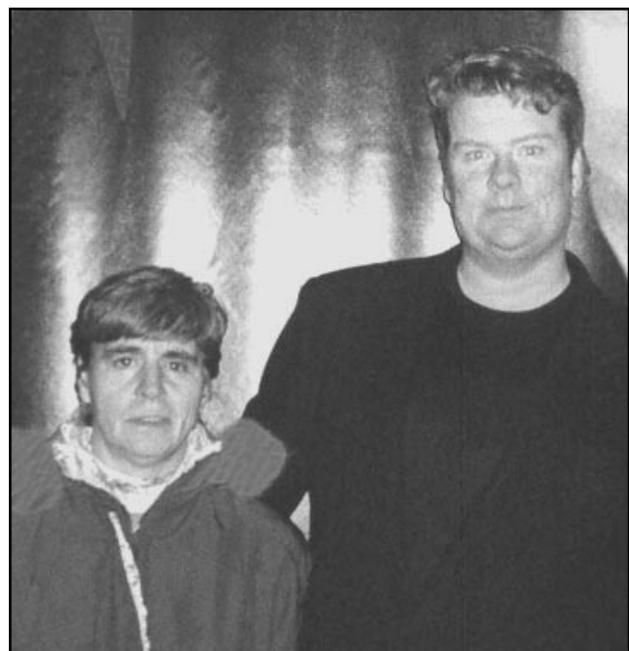
Say hello to Elaine, friend, mother, grandmother and twin. Elaine has made many changes in her life and she is proud of the woman she has become. Having had an agonizing past filled with pain and anguish, Elaine has been able to create a new life for herself.

In July of 1997, Elaine moved to Rutland County after a stay at the Vermont State Hospital and the Vermont Crisis Intervention Network crisis bed. This was a difficult time for Elaine. The Community Access Program of Rutland County embraced the idea of developing a circle of support for Elaine and helping her overcome her many challenges along with her developmental disability. At the core of her circle is Howard; her shared living provider and friend. Their relationship can best be described as honest and open. Together they are a supportive team who has conquered many obstacles. Howard has been able to help Elaine raise her self-esteem and meet a variety of people. He has helped her take pride in her appearance and in her accomplishments, including attending local AA meetings.

With the help of Community Access Program staff, Elaine receives support to maintain employment and develop personal, social and emotional skills. She is learning to become more self-sufficient and she and Howard are saving to take a vacation to Florida, a personal goal for both of them.

Elaine has reunited with her children and enjoys being a grandmother. You can tell how well Elaine is doing by just looking at her.

We are proud of her and all she has accomplished on the road to becoming a happy and productive woman. Thank you, Elaine, for letting us be a part of your life.



## Nursing Home Reform

**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 developmental disabilities (MR/DD) and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services<sup>39</sup>.

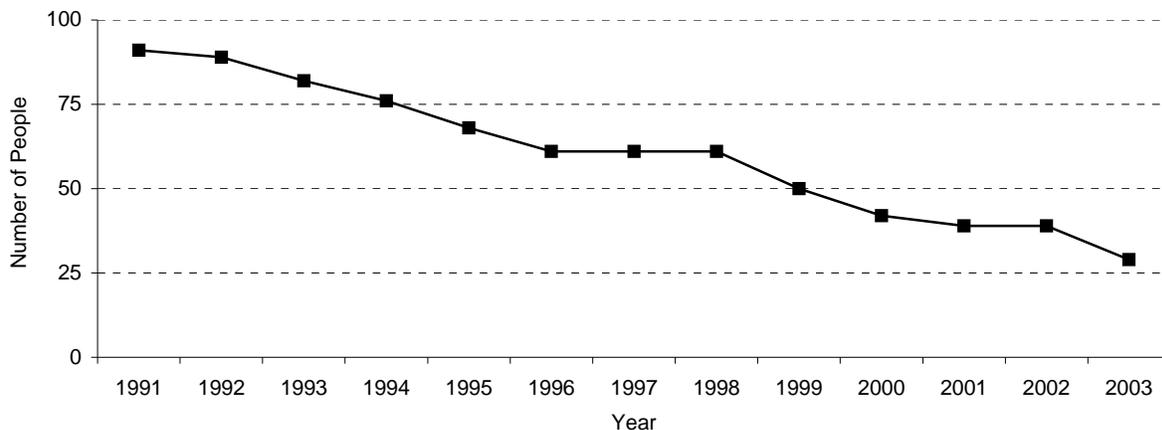
<b>Numbers Served – as of 12/31/03</b>	
<b>People living in nursing facilities<sup>40</sup></b>	<b>29</b>
People receiving specialized services	21
Number of PASARR screenings	21
Number of diversions to keep people out of nursing facilities	10
Number of community placement of people from nursing facilities	2

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 (**77% overall**) since 1988<sup>41</sup>. There has been **34%** decline just since last year. It was at an all time low of 29 as of 12/31/03.

**People with MR/DD who Reside in Nursing Facilities  
1991-2003**



<sup>39</sup> Changes in federal law in 1996 eliminated the requirement for an *annual* resident review.

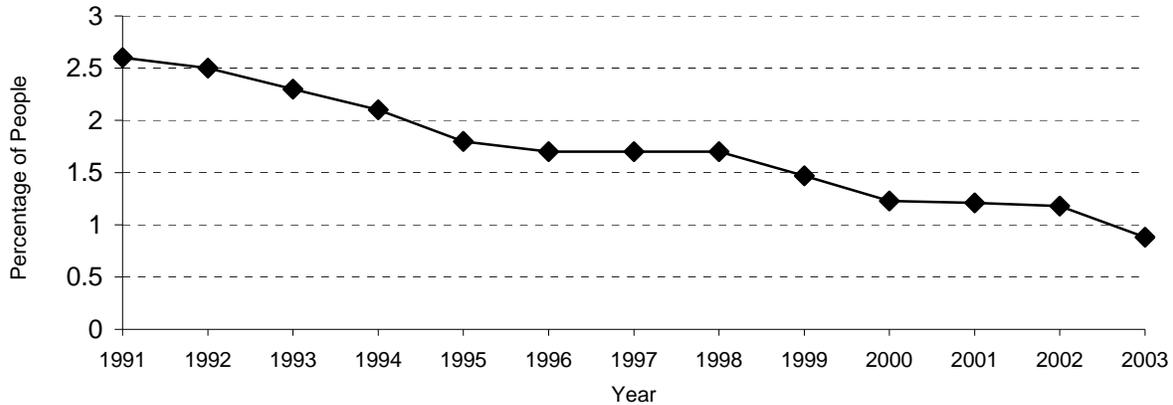
<sup>40</sup> PASARR uses the federal definition of “mental retardation or related conditions”.

<sup>41</sup> Based on the initial 1988 screening that found 125 people with MR/DD living in nursing facilities.



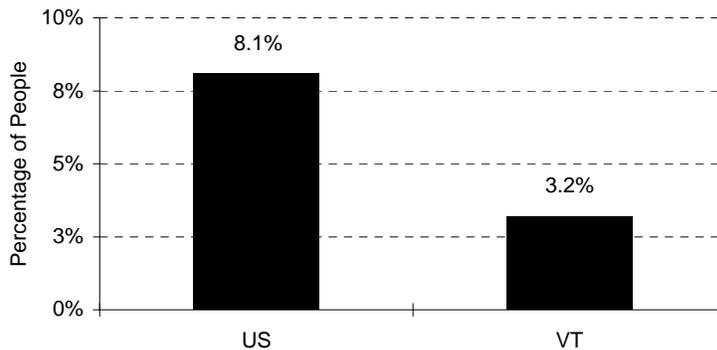
The national prevalence rate for people living in nursing facilities with developmental disabilities is estimated at 2.04% of the general population based on the federal definition of developmental disability<sup>42</sup>. The Vermont rate of occurrence for people with MR/DD living in nursing facilities was **0.9%** in December 2003, well below the national average.

**People with MR/DD as a Percentage of All People who Reside in Nursing Facilities 1991 - 2003**



The number of people in Vermont with MR/DD in nursing facilities compared to all developmental disability residential services – **3.2%** – is well below the national average (8.1%)<sup>43</sup>.

**People with MR/DD in Nursing Facilities as a Percent of All People with MR/DD Receiving Residential Supports<sup>44</sup> June 30, 2002**



<sup>42</sup> Based on studies of developmental disability population figures acceptable to the Administration on Developmental Disabilities (Gollay Study) 1978.

<sup>43</sup> Source: Prouty, R., Smith, G. and Lakin, C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002*. Research & Training Center on Institute on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2003.

<sup>44</sup> Residential services include those provided under home and community-based waiver, ICF/MRs, and nursing facilities.

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 his life.

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### **Roland's Story: How Nursing Home Reform Makes a Difference**

*When Roland had a stroke, he needed to go to a nursing home to recuperate. He had been an active member of his community, so it was not easy for him to be in the nursing home. Roland received intensive physical therapy to try and regain some of the movement he lost due to his stroke. It was a long recovery with a yearlong stay in the nursing home.*

*While in the nursing home, Roland received specialized services from Northeast Kingdom Human Services. Support workers provided about 12 hours per week of support both within the nursing home and within the community. These vital services kept him connected to the community that he had been active in before his stroke. His staff helped him to visit his family, especially his brother, with whom he lived with before his stroke. They also helped him stay in touch with familiar places he frequented in his community such as his favorite restaurants. Jackie, his specialized services staff was also crucial in keeping his spirits up during his long rehabilitation. He would often say to his physical therapist, "Let's get this over with as soon as possible. Jackie is coming today."*

*When it became apparent Roland would not regain the skills he lost due to his stroke and would not be able to return to his previous living situation, the agency staff found a developmental home for him in a town near where he use to live, which kept him in his local community. The agency staff helped make the home accessible by securing funding for a ramp and making other accessibility modifications.*

*The home providers happened to know many of the same people Roland knew and had the same interests. During hunting season, it was like "Grand Central Station" at Roland's home, with mutual friends coming and going and telling stories. This was just the thing that Roland enjoyed that was missing from his life when he was in the nursing home. Maple sugaring season provided another gathering of friends who pitched in with the work as well as enjoying each other's company. With his wide screen TV, country music and friends dropping in, this was the perfect fit for Roland.*

*These services and support staff were essential in helping Roland through this difficult transition in his life. Without this support, Roland would have been stuck in the nursing home. Arlene, one of his support workers, described helping Roland out of the nursing home as "the best work I have done". Now, Roland enjoys all that his community has to offer and the Vermont way of life in the Northeast Kingdom.*

## 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 14 local self-advocacy groups. See **Attachment F** for a list 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.

- **Monthly board meetings** are held four times a year on interactive television.
- **Loans and grants** are given to people who used to live 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.
- Facilitate the establishment of **new self-advocacy groups** and support 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



The Division of Developmental Services awarded GMSA a grant to carry out objectives of the **Real Choices Project** by training advocacy skills to people with developmental disabilities, their families, as well as DDS and service provider staff.

- The **Self-Advocacy Series** is made up of six workshops for people with developmental disabilities and their families, friends and providers. The workshops are interactive and involve games, role-plays, videos, art and small group activities that give self-advocates a chance to solve problems. In 2003, teams of people with and without disabilities taught 37 workshops.
- In June 2003, local teams from ten different agencies completed a 2-day **Train-the-Trainers Retreat**. Each local team agreed to teach the series of six self-advocacy workshops by July 2004.
- Four spring workshops focused on **Alternatives to Guardianship** and best practices for supporting people at risk, including individuals with the most significant decision-making support needs. The workshop helped parents, teachers, providers and people with disabilities understand various alternatives to guardianship.

- Green Mountain Self-Advocates collaborated with the ARC of Vermont to publish the manual, *Get On Board and Make a Difference: Effective Practices for Including People with Developmental Disabilities and New Members on Boards and Committees*. This manual includes information about how to include people with different learning styles, tips on how to be a support person, suggestions for other board members and board chairs, an accommodation checklist, and other helpful information about mentoring and running meetings.
- ★ The 6<sup>th</sup> annual statewide **Voices & Choices Conference** was held as a two-day event this year. This self-advocacy conference brings everyone together at the same time, attracts new members, allows parents and staff a chance to participate with self-advocates, and shows Vermonters what people with disabilities want in their lives. This year's conference featured 14 workshops including: *Electricity and the Environment; The Role of Advisors and Supporters in the Self-Advocacy Movement; Just a Little Respect: A Discussion about Healthy Relationships; How to be a Communication Partner; and Tips for Staying Safe and Dealing with Police*. A total of 380 people attended the conference, with 165 staying for a dinner dance.
- ★ The kickoff event to launch our **Speakers' Bureau** included the workshop, *So You Want to be A Public Speaker* taught in Rutland and Barre. Thirty-three (33) self-advocates had an opportunity to refine their public speaking skills and to practice those skills with their peers. We are actively recruiting speakers for our Speaker's Bureau.
- ★ In 2001, David Hingsburger facilitated four regional forums with GMSA to draft a **Bill of Rights**. Since then, GMSA has worked to raise money and produce a video explaining the idea of rights and responsibilities. With the help of the Awareness Theater Company and Green Mountain Video, the video *Green Mountain Self-Advocates: Our Bill of Rights* was completed in 2003.
- ★ What **consumers** said about self-advocacy:
- **30%** said they went to a self-advocacy meeting, conference or event.
  - **71%** said they had a choice about whether they went to a self-advocacy meeting or event<sup>45</sup>.
  - **81%** said they see themselves as being a self-advocate.
  - **83%** said they have a group of friends or family to help them make decisions.
  - **82%** said they had a choice about voting in elections<sup>46</sup>.
  - **81%** said they think they have enough control over their life.

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<sup>45</sup> This percentage includes people who wanted to go to a self-advocacy meeting/event and did go, as well as people who did not want to go and did not go.

<sup>46</sup> This percentage includes people who wanted to vote and did, as well as people who did not want to vote and did not.

## Areas of Focus

- ◎ Adapt **Stay Safe** and **Know Your Legal Rights** curriculums for high schools.
- ◎ Teach **disability awareness workshops** to students and criminal justice personnel.
- ◎ Collaborate with the Vermont Crime Victim Center on **public education projects** concerning crime prevention and support of victims of crime.
- ◎ Develop a **Toolkit on alternatives to guardianship** in collaboration with DDS in follow-up to last year's workshops.
- ◎ Work 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.
- ◎ What **consumers** said about self-advocacy:
  - **56%** 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.
  - **36%** said they want to know more about self-advocacy.
  - **35%** said there are choices they wish they could make that they don't make now.

## Memories from the Vermont Voices & Choices Conference



## Memories from the Vermont Voices & Choices Conference Evening Entertainment



## Guardianship Services

<b>Numbers Served – FY 2003</b>	
Guardianship Services	522
Case management	22
Guardianship Services (Pending)	21
Commitment order (Act 248)	19
Commitment order pending	2
<b>Total Guardianship Services Program (unduplicated)</b>	<b>581</b>
<b>Representative Payee Services</b>	<b>314</b>

**Guardianship Services** are provided to individuals with developmental disabilities who have been determined by Family Court to be in need of supervision, protection and assistance to live safely within the community and to protect them from violations of their human and civil rights.

The program's 20 Guardianship Services Specialists (GSS) work out of eight offices 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 they need to be safe, and work to protect them from abuse 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, GSS staff provide active medical advocacy and coordination and make decisions about medical treatment. GSS staff are available for emergencies 24 hours a day through the program's toll-free phone number.

In addition to guardianship, Guardianship Services Specialists 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 DDMHS 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** assure that people's income from Social Security, SSI and earnings are invested responsibly and accounted for, and that bills are paid on time.

### Highlights



What **consumers** said about guardianship:

- **89%** said they were happy about their guardian.
- **82%** said they got to see or talk to their guardian whenever they wanted.

## Areas of Focus



What **consumers** said about guardianship:

- **63%** said someone else choose their guardian.
- **53%** said their guardian let them make some decisions for themselves.

### A Full Life: How the Role of Supports Can Change Throughout a Person's Life

When Richard Lamphere died from cancer last summer, his friends and family remembered a proud man, who had lived a full life, thanks to his own spirit and the support of family, friends and developmental services.



Richard lived his early years with his family in Calais and attended the local public school. When the school recommended Brandon Training School for Richard's education, his family sent him there so he could "get the best education possible". Richard met Christine at Brandon Training School and they fell in love. The two of them had jobs in Rutland and they eventually married and moved together into an apartment in Rutland. They later moved to Burlington. Richard's family helped him out and helped him live in the apartment.

Richard met Christine at Brandon Training School and they fell in love. The two of them had jobs in Rutland and they eventually married and moved together into an apartment in Rutland. They later moved to Burlington. Richard's family helped him out and helped him live in the apartment.

As Richard developed health problems, his elderly parents asked for assistance in supporting Richard. Howard Community Services stepped in, and provided supports so that Richard and his wife could continue to live together in an apartment. A Guardianship Services Specialist assumed guardianship for Richard, all the while respecting Richard's independence and his decision-making. Richard was a valued, steady employee of Koffee Kup Bakery in Burlington for 15 years, an enthusiastic participant in the arts and an active church member.

When Richard became too ill to live independently, he got support to move to a developmental home. However, his personal and private relationship with his wife continued, as did opportunities to travel out of state to visit family and for vacations.

Last year, when Richard became terminally ill, he made the decisions about what kind of care he wanted to receive. As he wished, he died at home with the support and company through his last days of his wife, home provider, roommate, sister, guardian, and case manager.

## Offenders with Developmental Disabilities

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 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.

The Department of Developmental and Mental Health Services is proud of its public safety record of supporting and treating offenders in non-institutional settings. To serve the unique challenges of this group, DDS has undertaken the following initiatives in the past two years.

### Highlights

- ★ The Department of Developmental and Mental Health 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.
- ★ The Division of Developmental Services sought and obtained funding from the legislature to fund offenders with a **dedicated fund** so as to prevent the costly needs of this group from draining away funds from caseload dollars for law-abiding Vermonters with developmental disabilities. Criteria for access to the fund were developed and included in the System of Care Plan for FY 04. Tracking the use of this fund gives an easy way to document and analyze the new fiscal needs of this group.
- ★ Using funds from a grant from the U.S. Department of Justice, DDS sponsored the development of a **Treatment Progress Scale** for sex offenders with developmental disabilities. Using 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 (DOC) staff, developed this assessment tool. Seventy staff were trained in use of the tool in 2003, and it is now in its first year of use.
- ★ In order to track the efficacy and cost of treatment and support of offenders, DDS has developed a **confidential database** for tracking sex offenders receiving developmental services. This system was developed with funds from the U.S. Department of Justice.

- ★ There is a dearth of literature of the practical aspects of treating sex offenders with developmental disabilities. Last year a broad group of individuals, including attorneys, DOC staff, developmental services staff, and others participated in the drafting of a **Best Practices Manual** for sex offenders with developmental disabilities. This project was developed with funds from the U.S. Department of Justice.
  
- ★ Green Mountain Self Advocates, in collaboration with special education staff in Rutland, are developing 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.

### Areas of Focus

- ◎ Analyze the results from the first year of using the **Treatment Progress Scale** and provide additional training to program staff, as needed.
  
- ◎ Open a **crisis bed and a planned respite bed** with security and staffing levels to accommodate offenders.
  
- ◎ Finalize the editing and distribution of the **Best Practices Manual** for sex offenders with developmental disabilities.
  
- ◎ **Analyze data** from the first year of using the database, and make adjustments in the data collection methodology. **Extend data collection** to all offenders. Begin to use data 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 the Department of Developmental and Mental Health Services and the Department of Aging and Disabilities. 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 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 will be 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 the Division of Developmental Services, Division of Mental Health and the Department of Aging and Disabilities systems.

In May 2002, grants were awarded to the Green Mountain Self-Advocates and the Vermont ARC to carry out the Division of Developmental Services' objectives to provide training in self-advocacy skills for people with developmental disabilities, their families, and DDS and service provider staff. Resources were developed and numerous workshops and training opportunities were presented in 2003.

### Highlights

- ★ A **train-the-trainers workshop** was held for **31 self-advocates** who will provide regional self-advocacy training to other self-advocates and provider agency staff.
- ★ **Ten workshops** on self-advocacy and **Real Choices Grant activities** were presented to service provider staff across the state.

- ★ **Twenty-four (24) workshops on self-advocacy** were presented statewide to people with developmental disabilities. Topics included:
  - How to be a Strong Self-Advocate
  - Knowing Yourself
  - Communication; Rights and Responsibilities
  - Being Part of the Community
  - Problem Solving
  
- ★ The *Get on Board and Make a Difference* manual was developed describing practices to include self-advocates and family members on boards and making boards more accessible. A workshop on this material was also given.
  
- ★ **Two workshops** were held for self-advocates entitled *So You Want to be a Public Speaker*. A brochure was developed and recruitment effort implemented with the goal of developing a pool of presenters who are self-advocates and available to assist in training on a variety of topics. The result is a *Speakers' Bureau* of self-advocates who can assist in statewide and regional training efforts.
  
- ★ **Four workshops on Alternatives to Guardianship** were held. An *Alternatives to Guardianship* toolkit with resources to assist self-advocates and their families is under development and will be ready in the spring of 2004.
  
- ★ **Two workshops** for families and self-advocates on *Interviewing and Hiring Your Staff* and *Promoting Decision Making Skills* were presented at the Vermont Voices and Choices conference.
  
- ★ **Two workshops** for family members on *Being on Boards* were presented.
  
- ★ A weekend **Leadership Retreat** for family members was coordinated to help support and encourage families to advocate for themselves.

Over the past year, **Direct Consumer Funding** began to become a reality for people with developmental disabilities who self/family-manage their services. The objectives of the first year of the grant has been to:

- Hire a consultant to facilitate this change grant,
- Research options related to implementing a pilot project for direct consumer funding, and
- Establish a workgroup to advise the Division of Developmental Services in the work of this grant.

## Highlights

- ★ A grant coordinator was contracted to manage the Real Choices grant and conduct completed reviews of:
  - Different types of Medicaid waivers to determine the one most conducive to direct consumer funding;
  - Intermediary Service Organizations to assess the type of structure that best supports grant objectives; and
  - Policies and procedures related to direct consumer funding, as well as best practices and lessons learned from other states implementing this type of model.
  
- ★ A workgroup was developed to provide input to DDS on their view of the best method of pursuing direct consumer funding in Vermont. The make-up of the **Direct Consumer Funding Workgroup** is such that it assures that a diversity of perspectives and voices are heard. The workgroup consists of four people with a developmental disability who are familiar with self-management, four family members of children with a developmental disability, and two directors of developmental service agencies.
  
- ★ The grant coordinator participated on an **Information and Assistance Task Force** representing DDS as part of the broader Real Choices System Change Grant. The goal of the task force is to identify measures to improve the current system through:
  - Seamless links among information and assistance systems;
  - Shifting primary responsibility for the provision of information and assistance away from service providers;
  - Identifying training needs and mutual cross training opportunities;
  - Providing information in various formats;
  - Identifying additional financial resources or shifting of resources; and
  - Uniform quality standards and continuous improvement measures.
  
- ★ The grant coordinator participated on a **Paraprofessional Staffing Task Force** representing DDS as part of the broader Real Choices System Change Grant. The goal of the task force is to establish a paraprofessional organization and implement recommendations of the Paraprofessional Staffing Report to improve the quality and stability of frontline workforce, including:
  - Expanding the pool of workers;
  - Improving wages;
  - Providing benefits;
  - Improving working conditions;
  - Providing thorough orientation and in-service training opportunities;
  - Developing career ladders; and
  - Strengthening supervision and management.

## Memories of Real Choices Grant Training



## Consumer Survey

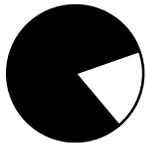
<b>Numbers Surveyed – 2003</b>	
Number of participants – Direct interview & demographics	167
– Demographics only	188
<b>Total number of adult participants</b>	<b>355</b>

**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 for all adults 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 third and final year in the survey cycle, resulting in adults served from all agencies participating in the survey process. Interviews were conducted at five agencies<sup>47</sup> during 2003. The data presented below are aggregate data representing statewide results. Just a small sampling of the data collected from the survey is included in this document. For a more complete report, contact the Division of Developmental Services.

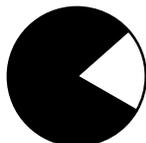
### Consumer Survey Results<sup>48</sup> – 2003

#### Highlights

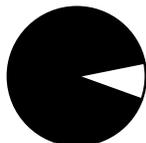
★ **Overall:** Satisfaction was high (over **85%** satisfied/positive) in categories<sup>49</sup> of residential, neighborhood, work, day activities, and health



★ **Residential:** **81%** said they were happy where they were living.



★ **Autonomy:** **80%** said they can have friends over whenever they want.

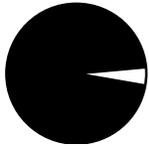


★ **Work:** **91%** said they like their jobs.

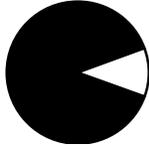
<sup>47</sup> The five agencies that took part in the Consumer Survey Project in 2003 were Community Access Program, Community Developmental Services, Howard Community Services, Lamoille County Mental Health Services and Lincoln Street Incorporated.

<sup>48</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.

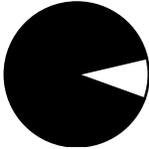
<sup>49</sup> Categories are the grouping of questions based on certain commonalities.



★ **Daytime Activity: 96%** said they like the activities that they do during the day.



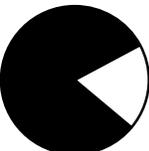
★ **Guardianship: 89%** said they are happy about their guardian.



★ **Agency: 91%** said they are happy with their service coordinator.



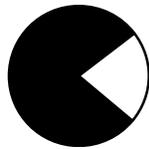
★ **Agency: 96%** said they feel listened to at their ISA meetings.



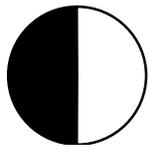
★ **Self-Determination: 81%** said they feel they have enough control over their life.

### Areas of Focus

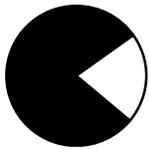
◎ **Overall:** Satisfaction was lower (**64%** satisfied/positive) in the autonomy category<sup>50</sup>.



◎ **Residential: 79%** said they did not have a say about who lives there with them.

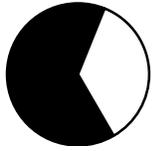


◎ **Autonomy: 50%** said they did not choose where they lived.

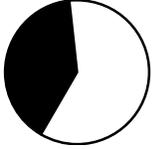


◎ **Work: 79%** of the people who do not work said they wanted a paid job.

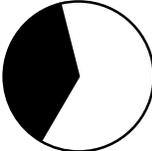
<sup>50</sup> Categories are the grouping of questions based on certain commonalities.



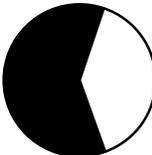
**Coming & Going: 64%** said they have to wait for someone to take them out.



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



**Friends: 37%** said they need to know more about dating.



**Friends: 61%** said someone else decides when they can have friends and family over to visit.

## National Comparison of Vermont's 2002 Consumer Survey Results<sup>51</sup>

### Highlights – Categories<sup>52</sup>



**Personal Choices:** Vermont ranked **highest (91%)**, including the proportion of people who say they:

- choose people they live with
- choose their daily schedule
- choose how to spend free time
- choose what to buy with spending money



**Community Inclusion:** Vermont ranked **highest (90%)**, including the proportion of people who say they:

- go shopping
- go out on errands or appointments
- go out for entertainment
- go out to eat
- go to religious services

<sup>51</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*.

<sup>52</sup> Data was analyzed by category (grouping of questions based on certain commonalties) and individual questions. Categorical data presented in this section (as well as individual question about mail being opened) is outcome adjusted or “risk adjusted” to control for differences in the individual characteristics of people interviewed across states.

- ★ **Supports-Related Choices:** Vermont ranked **highest (84%)**, including the proportion of people who say they:
  - choose the place where they live
  - choose staff who help them at home
  - choose the place that they work
  - choose their service coordinator

### **Highlights – Individual Questions**

- ★ **Satisfaction with their work:** Vermont ranked **1<sup>st</sup> (99%)**
- ★ **Mail opened without permission:** Vermont ranked **1<sup>st</sup> (15%)**
- ★ **Service coordinator helps them get what they need:** Vermont ranked **2<sup>nd</sup> (94%)**
- ★ **Feel safe in their neighborhood:** Vermont ranked **2<sup>nd</sup> (88%)**
- ★ **Feel safe in their home:** Vermont ranked **3<sup>rd</sup> (91%)**
- ★ **Caring relationships other than paid support staff:** Vermont ranked **4<sup>th</sup> (83%)**

### **Areas of Focus – Individual Questions**

- ◎ **Relationships:** Vermont ranked **well below the national average** in terms of the proportion of people who:
  - report having a close friend
  - are able to see their family when they want
  - are able to see their friends when they want
  - feel lonely

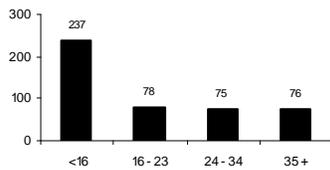
## Family Satisfaction Survey

<b>Numbers Surveyed – 2001</b>	
<b>Number of families surveyed</b>	<b>539</b>
Response rate	49%

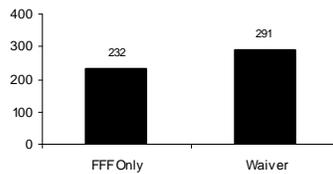
**The Family Satisfaction Survey:** A confidential statewide family satisfaction survey was mailed out in November 2001 to ask about satisfaction with DDS-funded services<sup>53</sup>. The survey was sent to over 1200 families of individuals with developmental disabilities who live at home and were receiving support, either waiver-funded services or Flexible Family Funding (FFF). The survey related to a wide range of issues, such as information and planning, choice and control, and access to and delivery of services. The survey allowed for anonymity, but space was provided for written comments and to request follow-up from staff if the respondent desired. Just a small sampling of the data collected from the survey is included in this document. For a more complete report, contact the Division of Developmental Services.

### Family Survey Demographics – 2001

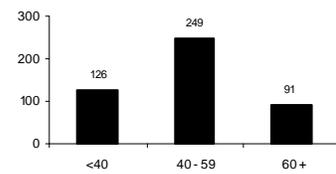
**Age of Family Member with a Disability**



**Funding Source**



**Caregiver Age**



### Family Survey Results – 2001

#### Highlights

- ★ **Family Member Happy:** 79% said overall their family member was happy.
- ★ **Staff Respect:** 85% said staff were respectful and courteous.
- ★ **Supports Make a Difference:** 72% said family supports make a positive difference in the life of their family member.
- ★ **Work & Community Supports:** 84% said work supports are worthwhile to their family member; 86% said community supports are worthwhile to their family member.

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<sup>53</sup> This survey is sent to all people who have their family member receiving services living with them. Therefore, the survey is only mailed out every few years to avoid problems associated with over-surveying.

## Areas of Focus

- ◎ **Overall Satisfaction:** 63% said they were satisfied overall with developmental services.
- ◎ **Changes in Staff:** 26% said changes in support staff is a problem.
- ◎ **Grievance Process:** 51% said they were informed of their agency's grievance process.
- ◎ **Communication:** 46% said there are enough staff available that can communicate with their family member.

## Satisfaction in Relation to Type of Funding

- 67% of families of young children (<16 yrs. old) receive FFF only.
  - 85% of families of adults (24+ years old) receive Waiver funding.
  - 22% of family caregivers are 60+ years old.
- ★ Families of people receiving waiver funding reported being significantly more satisfied than people only receiving Flexible Family Funding regarding:
    - Receiving information
    - Services help keep family member home
    - Informed of complaint/appeal process
    - Planning services
    - Access to services
    - Overall satisfaction with services
  - ★ There was no difference in satisfaction in terms of type of funding the family received regarding:
    - Knowledge and effectiveness of staff
    - Feeling that the family member is happy
    - Service coordinator

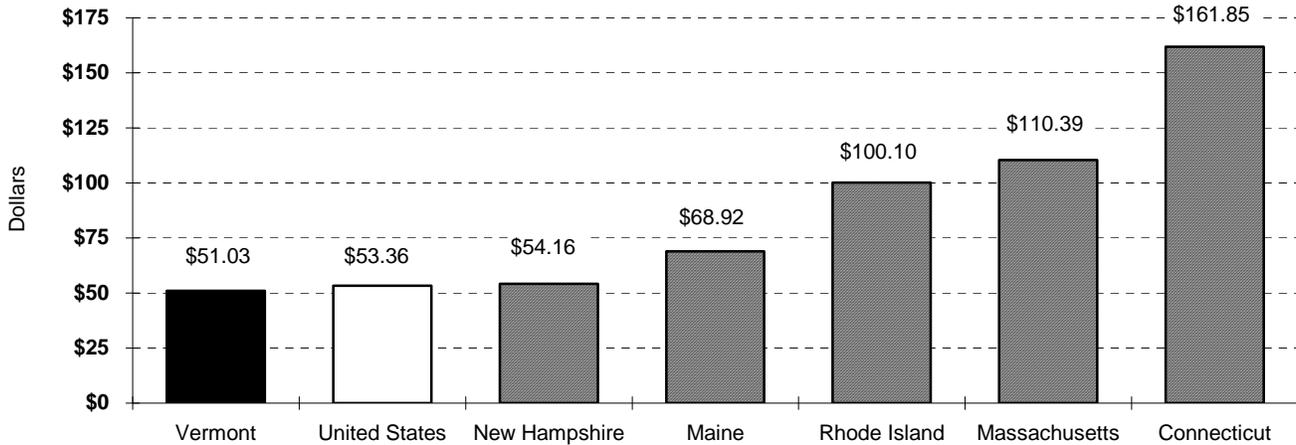
## Satisfaction in Relation to Age of Family Member

- ★ Families of young children (<16 yrs. old) report being **more satisfied** with choice of support workers and wanting more control over the hiring and management of support workers, than families of youth and adults (16+ years old).
- ★ Families of young adults (24 – 34 yrs. old) report being **more satisfied** with receiving information about services; staff helping figure out what is needed; and receiving help right away in an emergency, than all other families.
- ★ Families of adults (24+ yrs. old) report **more satisfaction** with services and supports; knowing who to contact; receiving information to help plan services; getting services that are needed when they are needed; and the service coordinator helping get what is needed, than families of children and transition age youth (<24 yrs. old).

## National Comparisons<sup>54</sup>

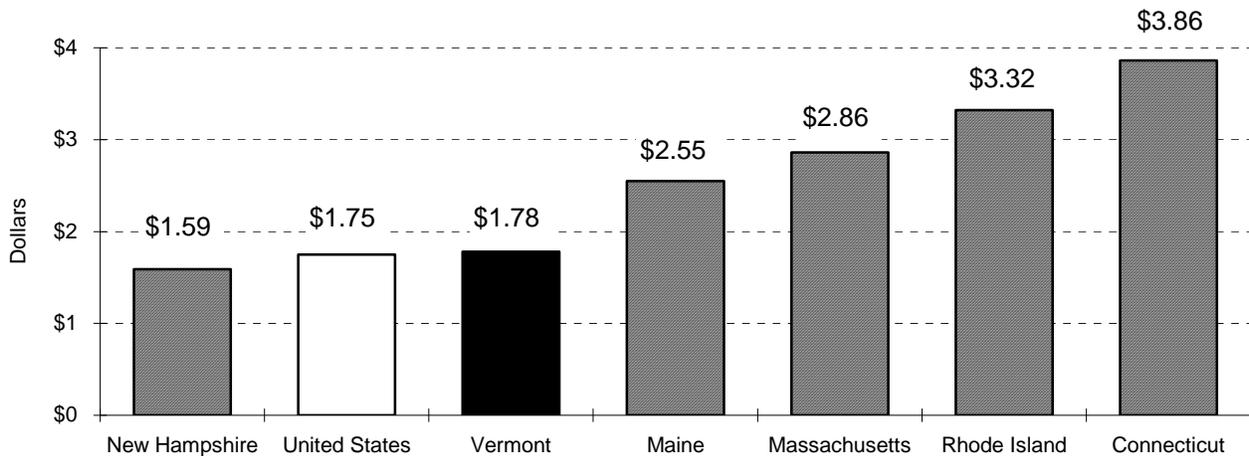
- ★ Vermont spends **fewer state dollars** (including Medicaid match) per state resident for mental retardation/developmental disability (MR/DD) services than any other New England state and **less** than the national average.

**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.

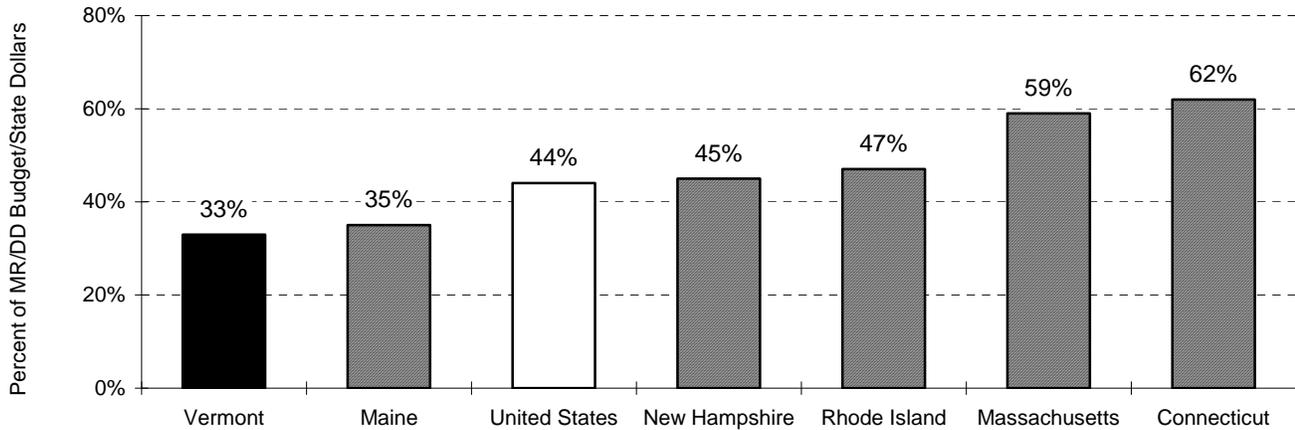
**State Fiscal Effort  
Total MR/DD Spending per \$1,000 in Personal Income  
FY 2002**



<sup>54</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.

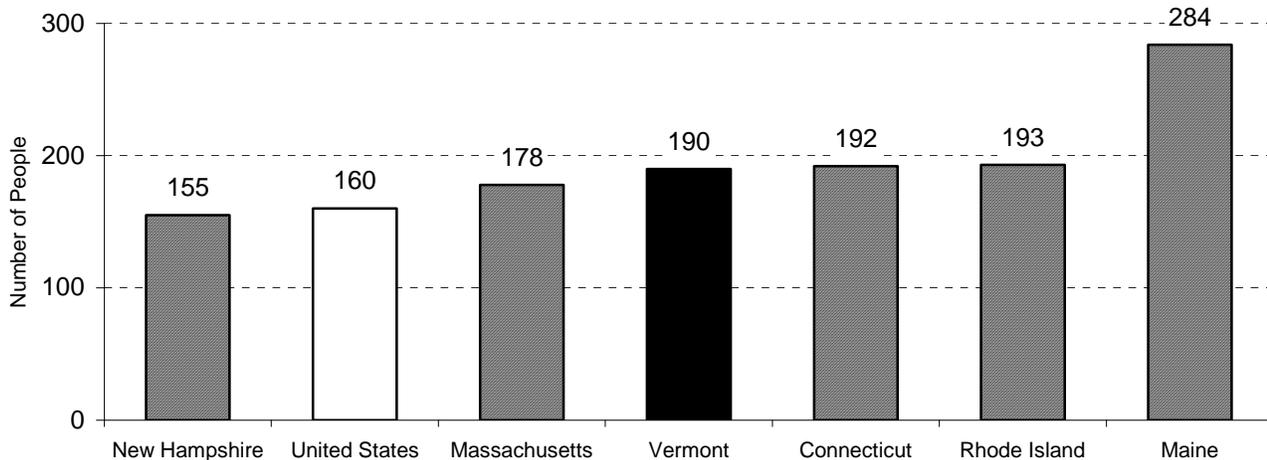
★ State funds (including state funds used for Medicaid match) account for a **smaller proportion** of the budget from mental retardation/developmental disability (MR/DD) services in Vermont than in any other New England State. Vermont accesses a **higher** proportion of federal dollars than any other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

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



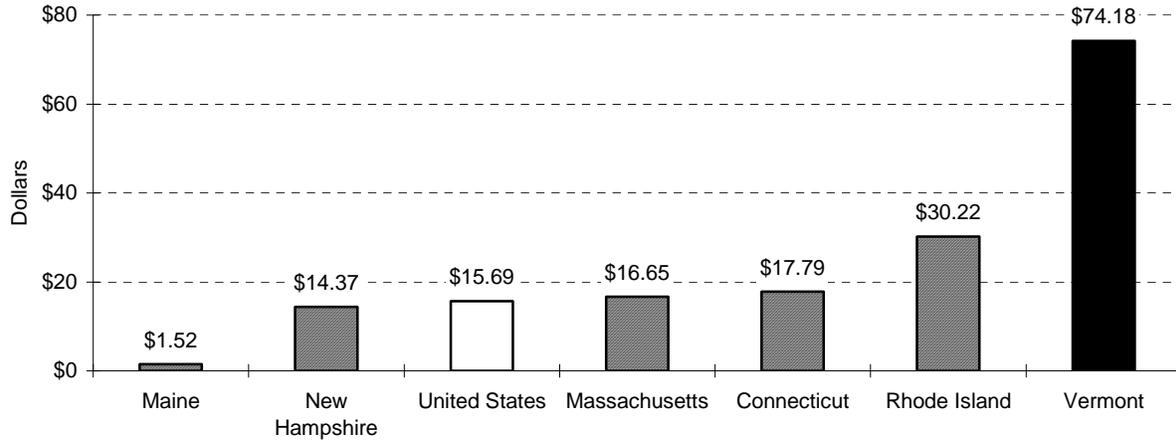
★ The number of people receiving residential services in the mental retardation/developmental disability (MR/DD) service system (with the addition of people living in nursing facilities) per 100,000 of the state population is **above** the national average but **on par** with the majority of New England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

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



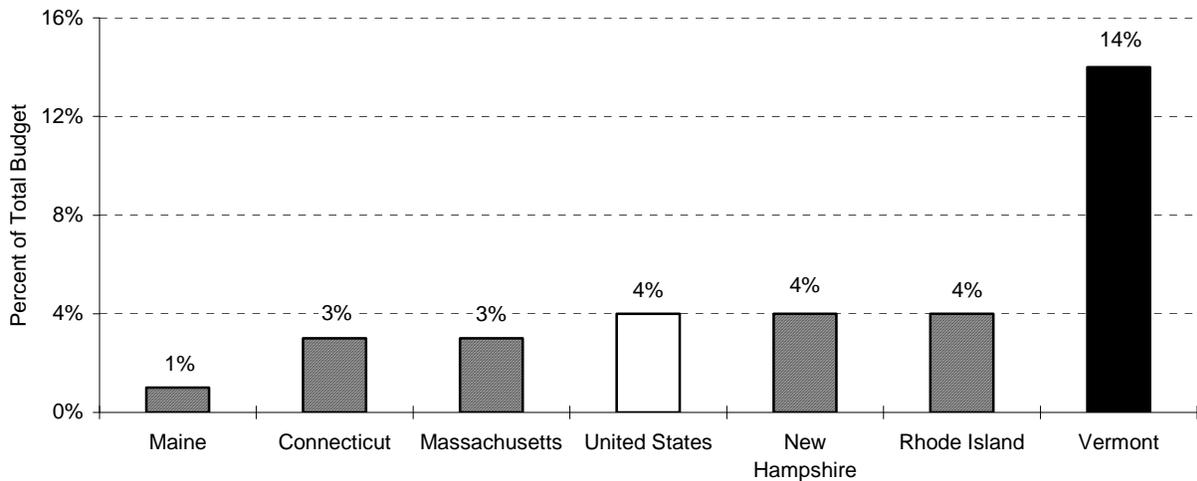
★ Vermont is ranked **1<sup>st</sup>** in New England and **3<sup>rd</sup>** in the nation in total family support spending per \$100,000 personal income. Greater support of families' results in lower costs overall.

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



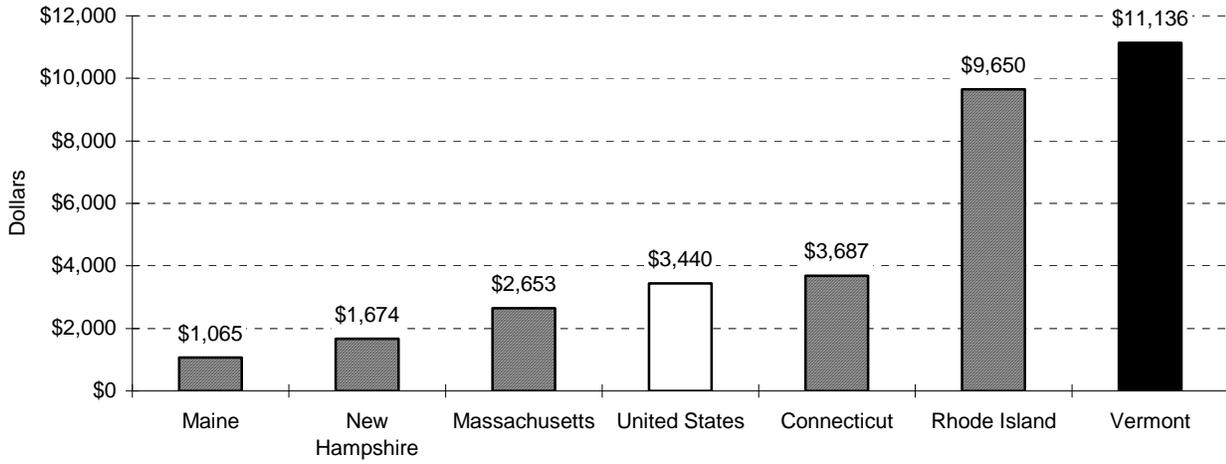
★ Vermont's family supports are ranked **1<sup>st</sup>** in New England and **4<sup>th</sup>** in the nation in spending of total MR/DD budget.

**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

Developmental Services Acronyms.....	Attachment A
Division of Developmental Services Staff:	
Waterbury Office Staff	
Community Alternative Specialists: Red & Blue Teams	
Guardianship Services Specialists	
Guardianship Services Offices (map)	
Community Alternative Specialists: Blue & Red Team Structure	
Blue & Red Teams (map).....	Attachment B
Vermont Developmental Services Providers.....	Attachment C
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Developmental Services .....	Attachment D
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Division of Developmental Services FY 2003 Budget Summary .....	Attachment H



**DEVELOPMENTAL SERVICES 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 & 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 & Community Inclusion (formerly UAP)
<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 & 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
<b>DBT</b>	Dialectical Behavioral Therapy
<b>DD</b>	Developmental Disability or Developmentally Disabled
<b>DD ACT</b>	Developmental Disability Act of 1996
<b>DDC</b>	Developmental Disabilities Council
<b>DDLDP</b>	Developmental Disabilities Law Project – Obsolete, see DLP
<b>DDMHS</b>	Department of Developmental and Mental Health Services
<b>DDS</b>	Division of Developmental Services
<b>DH</b>	Developmental Homes – see also SLP
<b>DLP</b>	Disability Law Project – formerly DDLDP
<b>DME</b>	Durable Medical Equipment
<b>DMH</b>	Division of Mental Health
<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>DSW</b>	Department of Social Welfare – Obsolete, see PATH

<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>F/GIMHS</b>	Franklin/Grand Isle Mental Health Services – Obsolete see NCSS
<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
<b>GSS</b>	Guardianship Services Specialist
<b>HCBS</b>	Home and Community-based Services
<b>HCBW</b>	Home and Community-based Waiver
<b>HCFA</b>	Health Care Financing Administration
<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>HRD</b>	Human Resources Data
<b>ICF/MR</b>	Intermediate Care Facility for people with Mental Retardation.
<b>IEP</b>	Individualized Education Program
<b>IPP</b>	Individual Program Plan – Obsolete, see ISA
<b>ISA</b>	Individual Support Agreement
<b>ISO</b>	Intermediary Service Organization
<b>LCMH</b>	Lamoille County Mental Health
<b>LIT</b>	Local Interagency Team
<b>LSI</b>	Lincoln Street, Inc.
<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 (formerly F/GIMHS)
<b>NKHS</b>	Northeast Kingdom Human Services (formerly NEKMHS)
<b>NEKMHS</b>	Northeast Kingdom Mental Health Services – Obsolete, see NKHS
<b>OT</b>	Occupational Therapy or Occupational Therapist
<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
<b>PDD</b>	Pervasive Developmental Disorder
<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
<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>SAP</b>	Supervised Apartment Program
<b>SAS</b>	Sterling Area Services
<b>SCC</b>	Specialized Community Care
<b>SD</b>	Self-determination
<b>SIT</b>	State Interagency Team
<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 Insurance
<b>SSI</b>	Supplemental Security Insurance
<b>TASH</b>	The Association for Persons with Severe Handicaps
<b>TBI</b>	Traumatic Brain Injury
<b>TCM</b>	Targeted Case Management (Medicaid)
<b>T-II</b>	Transition II
<b>TXIX</b>	Title XIX of the Social Security Act (Medicaid)
<b>UAP</b>	University Affiliated Program – Obsolete, see CDCI
<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>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 2004

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**

Staff Name	Title	Phone (802)	E-mail Address
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Falk, Gail	Director of Guardianship Services	241-2616	gfalk@ddmhs.state.vt.us
Garabedian, Jennifer	Administrative Assistant	241-2663	jgarabedian@ddmhs.state.vt.us
Morse, Muriel	Administrative Assistant	241-2648	mmorse@ddmhs.state.vt.us
Rogers, Jackie	Clinical Director and Children's Policy	241-3955	jrogers@ddmhs.state.vt.us
Topper, Karen	Consumer Development Coordinator	241-3175	ktopper@ddmhs.state.vt.us
Wood, Theresa	Director	241-2648	twood@ddmhs.state.vt.us

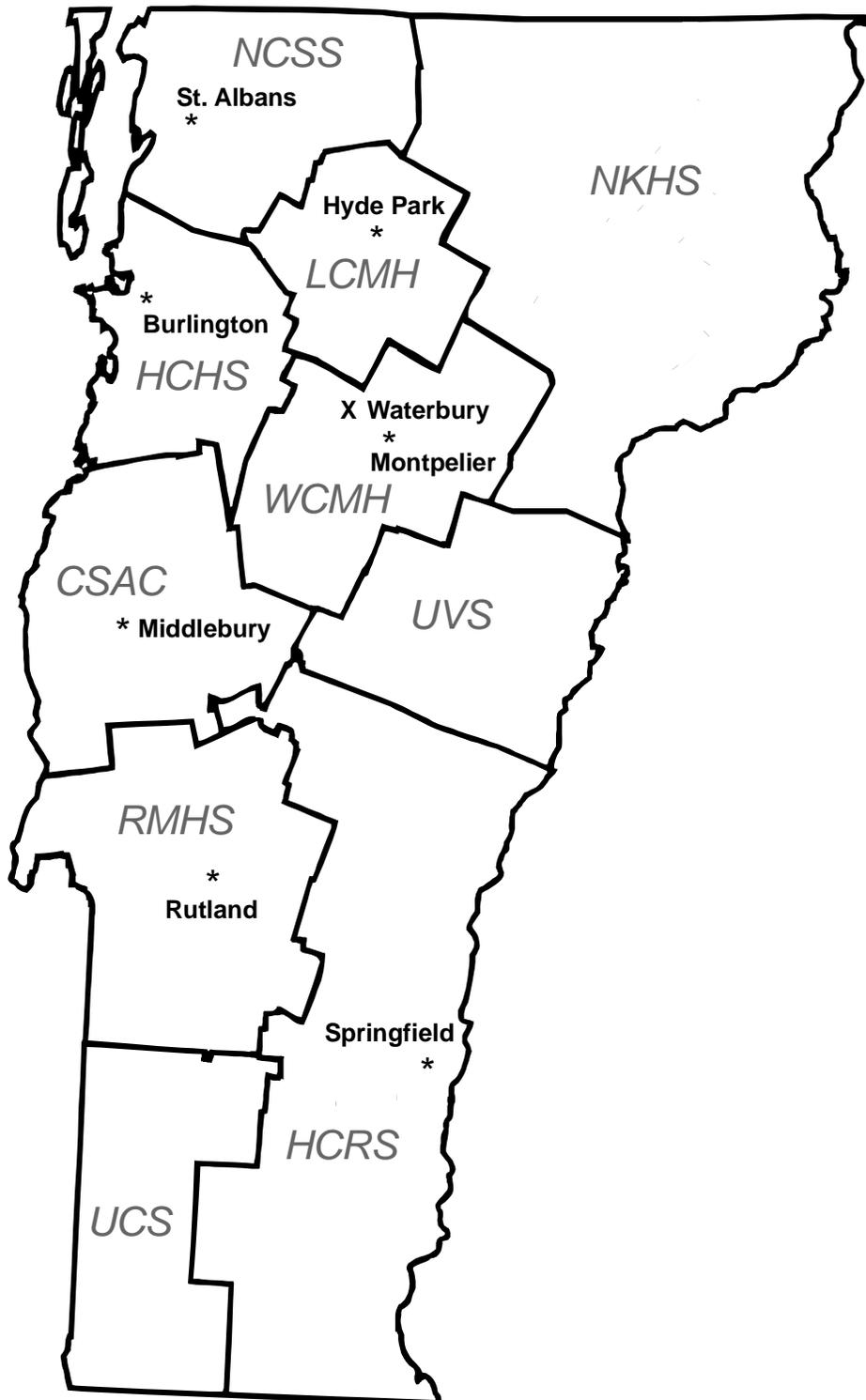
**Community Alternative Specialists  
 Red & Blue Teams**

Staff Name	Title	Phone (802)	E-mail Address
Coy, Jeff	Red Team Training Specialist	241-2727	jcoy@ddmhs.state.vt.us
Freund, Avi	Blue Team Training Specialist	241-2723	afreund@ddmhs.state.vt.us
Goslant, Marie	Program Services Clerk	241-2678	mgoslant@ddmhs.state.vt.us
Masterson, Jennie	Red Team Employment Specialist	786-2571	jmasterson@ddmhs.state.vt.us
Malone, Ellen	Red Team Leader	786-5047	emalone@ddmhs.state.vt.us
McFadden, Clare	Blue Team Children's Specialist	241-2863	cmcfadden@ddmhs.state.vt.us
Morse, Martin	Blue Team Generalist	241-4494	mamorose@ddmhs.state.vt.us
O'Neill, Chris	Blue Team Employment Specialist	786-8831	coneill@ddmhs.state.vt.us
Parker-Moulton, Janine	Red Team Children's Specialist	786-5081	jpmoulton@ddmhs.state.vt.us
Rappeno, Maureen	Blue Team Nursing Specialist	786-5052	mrappeno@ddmhs.state.vt.us
Roth, Amy	Red Team Generalist	241-2675	aroth@ddmhs.state.vt.us
Spencer, Kate	Red Team Nursing Specialist	786-5054	kspencer@ddmhs.state.vt.us
Turchin, Bob	Blue Team Leader	786-5048	bturchin@ddmhs.state.vt.us

**Guardianship Services Specialists**  
**1-800-642-3100**

<p><b>Burlington Office</b>  108 Cherry Street  Box 205, Suite 205  Burlington, VT 05401  Fax: 951-4036</p>	<p>John Homiller – GSS  Ed Wells – GSS</p>	<p>865-7720  865-7721</p>	<p>jhomiller@ddmhs.state.vt.us  ewells@ddmhs.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 – GSS</p>	<p>888-2525</p>	<p>sulrich@ddmhs.state.vt.us</p>
<p><b>Middlebury Office</b>  700 Exchange Street, #204  Middlebury VT 05753  Fax: 388-4694</p>	<p>Lisa Lamoureux – GSS  Dale Severy – GSS  Joan Stephens – Senior GSS  Linda Vondle – GSS</p>	<p>388-4691  388-4692  388-4693  388-5761</p>	<p>lamoureux@ddmhs.state.vt.us  dsevery@ddmhs.state.vt.us  jstephens@ddmhs.state.vt.us  lvondle@ddmhs.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 – GSS  Becky Guyett – Senior GSS  Leslie Pinkham – GSS  Lisa Sipsey – GSS</p>	<p>828-3623  828-3622  828-3620  828-3621</p>	<p>nzucca@ddmhs.state.vt.us  bguyett@ddmhs.state.vt.us  lpinkham@ddmhs.state.vt.us  lsipsey@ddmhs.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 – GSS  Rodger Goodrich – GSS  Timothy Haley – GSS  Karen Hawley – Senior GSS  Cassandra Torrey – Prog. Svs. Clerk  Jan Sherman – Senior GSS  Vicki Wetmore – Community  Financial Specialist</p>	<p>786-5042  786-5049  786-5040  786-5043  786-5840  786-5041  786-5045</p>	<p>mfisher@ddmhs.state.vt.us  rgoodrich@ddmhs.state.vt.us  thaley@ddmhs.state.vt.us  khawley@ddmhs.state.vt.us  ctorrey@ddmhs.state.vt.us  jsherman@ddmhs.state.vt.us  vwetmore@ddmhs.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 – GSS  Diane Morris – GSS</p>	<p>524-7991  524-7992</p>	<p>mblakeney@ddmhs.state.vt.us  dmorris@ddmhs.state.vt.us</p>
<p><b>Springfield Office</b>  100 Mineral Street  Suite 306  Springfield VT 05156  Fax: 885-6471</p>	<p>Jay Derderian – GSS  Jon McGovern – GSS</p>	<p>885-4980  885-8893</p>	<p>jderderian@ddmhs.state.vt.us  jmcgovern@ddmhs.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  Jennifer Garabedian – Administrative  Assistant</p>	<p>241-2616  241-2663</p>	<p>gfalk@ddmhs.state.vt.us  jgarabedian@ddmhs.state.vt.us</p>

# Division of Developmental Services Guardianship Services Offices

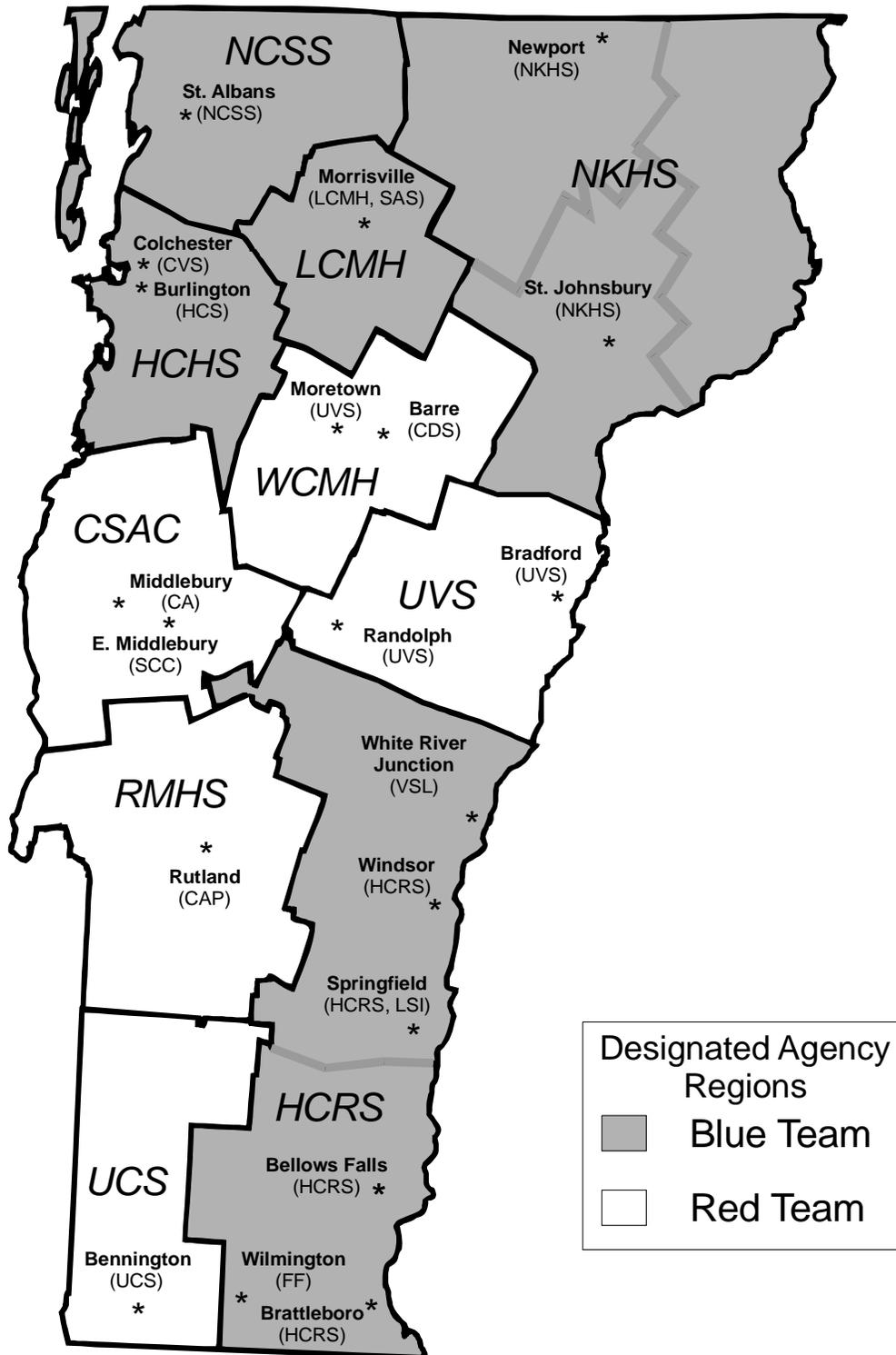


**Community Alternative Specialists  
Blue and Red Team Structure**

<b>Blue Team</b>		
<b>Role</b>	<b>Staff Name</b>	<b>Provider Contact</b>
DS Team Leader	Bob Turchin	SCC
Generalist	Martin Morse	HCRS, NEK, FF
Children Specialist	Clare McFadden	HCS
Employment Specialist	Chris O'Neill	CVS, LCMH
Nursing Specialist	Maureen Rappeno	---
Training Specialist	Avi Freund	NCSS
Program Services Clerk	Marie Goslant	---

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

# Division of Developmental Services Red & Blue Teams





**VERMONT DEVELOPMENTAL SERVICES PROVIDERS**  
**January 2004**

**(CVS) CHAMPLAIN VOCATIONAL SERVICES, INC.**

77 Hegeman Ave., Fort Ethan Allen  
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

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

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

Director: Josh Compton  
Counties: Windsor & Windham

Regional Offices:

230 Main Street, 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

**(FF) FAMILIES FIRST**

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

Director: Julie Cunningham  
Counties: Windham & Bennington

**(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  
Springfield, VT 05156  
Phone: 885-9533 FAX: 885-9575

Executive Director: Cheryl Thrall  
County: Windsor

**(NCSS) NORTHWESTERN COUNSELING & SUPPORT SERVICES, INC.**

107 Fisher Pond Road  
St. Albans, VT 05478  
Phone 524-6561 FAX: 527-8161

Director: Jean Gilmond  
Counties: Franklin & 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: Eric Grims  
Counties: Caledonia, Orleans & 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 & Rutland

**(SAS) STERLING AREA SERVICES, INC.**

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

Executive Director: Kevin O'Riordan  
County: Lamoille & 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 & 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

**(VSL) VERMONT SUPPORTED LIVING**

2456 Christian St., White River Jct. VT 05001  
Phone: 295-9100 FAX: 295-9107

Director: Robert Vaillencourt  
County: Windsor

**MEMBERS OF THE STATE PROGRAM  
STANDING COMMITTEE FOR DEVELOPMENTAL SERVICES  
January 2004**

<b>Name</b>	<b>Address, Phone &amp; 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	2004
<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	2004
<b>Cheney, Karen</b>	170 Centerview Terrace St. Johnsbury, VT 05819 Phone: 695-3373 (w) 748-1447 (h) e-mail: karehank@together.net	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: danielsm@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	2004
<b>Grassette, Patty</b>	PO Box 867 Morrisville, VT 05661 Phone: 241-2617 (w) 888-8407 (h)	People with Developmental Disabilities	2004

Name	Address, Phone & 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>	2391 Music Mountain Road Stockbridge, VT 05772 Phone: 234-9177 (h) 272-3144 (cell) e-mail: roadrnrner_3@hotmail.com	Professionals/Advocate	2005
<b>Neron, Steven</b>	PO Box 8 Bethel, VT 05032 Phone: 234-5594	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	2004



State Standing Committee Members left to right: Dawn Arsenault, Anne Bakeman, Connie Woodberry, Sarah Hathaway, Karen Cheney, Gerald Bernard, Patty Grassetto, Edwin Place, Janeen Jarvis-Morse and Steven Neron. Missing from photo: Nancy Breiden, Joshua Compton, Martin Daniels, Jean Gilmond, and Suzanne Leavitt.

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

January 2004

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 Developmental and Mental Health Services:

- A. **Designation Process.** The Department of Developmental and Mental Health Services (DDMHS) 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. **Guardianship Services Specialists.** Twenty (20) staff provide guardianship services as specified by law to about 580 adults with developmental disabilities. Guardianship Services Specialists 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. Guardianship Services Specialists are expected to have face-to-face contact with people for whom they are guardian at least once a month.
- D. **Safety and Accessibility Checks.** All residences (except those licensed through the Department of Aging and Disabilities 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 & 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 Guardianship Services Specialist or other Division of 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 Disabilities licenses residences where three or more unrelated people with disabilities live.
- B. **Abuse Complaints.** The Department of Social and Rehabilitation Services and the Department of Aging and Disabilities 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 conducts 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.
- E. **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, Department of Aging & Disabilities (DAD). 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.
- F. **Medicaid Fraud Unit.** This Unit investigates allegations of criminal activity, including abuse, neglect or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports. The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General.

### III. Within Developmental Services Agencies:

- A. **The Individual's Circle of Support.** Each person applying for or receiving services is encouraged to develop a circle of support. If they do not already have a circle, the service provider can help them form one. The circle is a group of people who helps the individual identify his/her dreams, takes responsibility to help the person create his/her plans and budgets, and determine the quality of his/her life. The primary focus of the circle is on the individual and what that person wants and needs. A circle of support is the ultimate safety net for that person.
- B. **Local 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 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. The committee submits a report to DDMHS annually.
- 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 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. **Developmental Services State Standing Committee.** The Developmental Services State Standing Committee 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 disabilities, family members, advocates, and people with professional expertise in the field of developmental disabilities. It 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 15 local chapters in various stages of development around the state.
- F. **Brandon Training School Association.** An association of parents and other people concerned with the well being of former residents of Brandon Training School.
- G. **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.
- H. **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.
- I. **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.
- J. **The Federal Government.** Through Medicaid audits and look-behind surveys, the federal government provides a back-up system of quality assurance.
- K. **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 & legislative communication.
- L. **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.

**GREEN MOUNTAIN SELF-ADVOCATES**  
**January 2004**

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

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

**LOCAL CHAPTERS:**

**Bennington Peer Support**

United Counseling Services, Inc.  
PO Box 588  
Bennington, VT 05201  
(802) 442-5491 – Melanie Brunina  
Board Rep: Holly Colvin

**Burlington Peer Support**

Howard Community Services  
102 South Winooski Ave.  
Burlington, VT 05401  
(802) 658-1914 – Terry Zigmund &  
Tracy Drake

**Champlain Voices**

Champlain Vocational Services, Inc.  
77 Hedgeman Ave., Fort Ethan Allen  
Colchester, VT 05446  
(802) 655-0571 – Richard Graham  
Board Rep: Paul Nichols

**COPS – Connections of Peer  
Support of White River Jct.**

PO Box 678,  
Springfield, VT 05156  
(802) 885-9533 – Karen Daley-Regan  
Board Rep: Helen George

**Friends Helping Friends**

Community Developmental Services  
50 Grandview Drive  
Barre, VT 05641  
(802) 479-2502 – Wendy Faery  
Board Rep: Margaret Pearlstein

**HCRS Springfield Peer Support**

118 Park Street  
Springfield, VT 0515  
(802) 885-5171 – Marilyn Comstock

**Next Step of St. Albans**

Northwestern Counseling & Support  
Services, Inc.  
156 North Main Street  
St. Albans, VT 05478  
(802) 524-6561 – Connie Farrington  
Board Rep: Pamela Putnam

**Our Drop In Center**

153 Main Street  
Newport, VT 05855  
(802) 344-8378  
Board Rep: Donna Corkins &  
Scott Geoffrey

**Randolph Area Peer Support**

Upper Valley Services, Inc.  
12 Prince Street, Suite #2  
Randolph, VT 05060  
(802) 728-4476 – Janeen Morse  
Board Rep: Edwin Place

**Self-Advocates Becoming  
Empowered of Rutland**

Rutland ARC  
128 Merchants Row  
Rutland, VT 05701  
(802) 775-1370 – Lisa Lynch  
Board Rep: Patty Derouchie &  
Herman Goldberg

**Self Advocates Meeting of  
Springfield**

PO Box 678  
Springfield, VT 05156  
(802) 885-9533 – Lori Jean Lintner  
Board Rep: Mel Hill

**Speak Up Addison County**

61 Court Street  
Middlebury, VT 05753  
(802) 388-0302 – Lindsey Hescocock  
Board Rep: Randy Lizotte

**Vermont Choices**

Northeast Kingdom Human Svs., Inc.  
PO Box 368  
St. Johnsbury, VT 05819  
(802) 748-3181 – Robin Burnash  
Board Rep: Lori Gervais

**Wildcats**

PO Box 867  
Morrisville, VT 05661  
(802) 888-8407 – Patty Grassette



**SYSTEM OF CARE PLAN FUNDING PRIORITY CHANGES**  
**State System of Care Plan for Developmental Disabilities 3-Year Plan – FY 2002 – FY 2004**  
**New Caseload Funding Priority Changes as of July 1, 2003**

**Health & Safety**

- ☞ *Support needed to prevent an adult from being abused, neglected or exploited, or otherwise having his or her health and safety jeopardized.*
- ☞ *Support needed to prevent an adult or child from regressing mentally or physically<sup>55</sup>* 12/01/01

**Security**

- ☞ *Support needed to keep a child under 18 with his or her natural or adoptive family. Services may not replace the regular role and expenses of parenting (e.g., childcare, transportation, household bills, etc.).<sup>56</sup>* 12/01/01<sup>57</sup>
- ☞ *Support needed for parents with developmental disabilities to provide training in parenting skills to help keep a child under 18 at home. Services may not substitute for the parent and may not replace the regular role and expenses of parenting (e.g., childcare transportation household bills, etc.) and are limited to \$5,000/year since December 01, 2001.* 01/01/03
- ☞ *Support needed to prevent an adult from becoming homeless.*
- ☞ *Support needed by an adult who is experiencing the death or loss of a caregiver<sup>58</sup>.*
- ☞ *Support needed to prevent or end institutionalization (i.e., VSH, psychiatric hospitals, ICF/MRs, nursing homes) or residential school placements.*

12/01/01 SUSPEND NURSING HOMES FOR MEDICALLY ELIGIBLE & RESIDENTIAL SCHOOLS

**Independence**

- ☞ *Support needed to keep a person who graduated from high school during the 02-03 and 03-04 school years from losing his/her current job.*
- ☞ *Support needed to keep a person from losing a job (except as noted above).* 12/01/01 SUSPENDED
- ☞ *Support needed to assist an adult to be independent from DDS-funded services, or to move to “minimal services,” within 2 years.* 12/01/01 SUSPENDED

**Legally Mandated Services & Community Safety**

- ☞ *Support needed by an adult who has been committed to the custody of the Commissioner of DDMHS pursuant to Act 248.*
- ☞ *Support needed to prevent an adult who poses a risk of public safety from endangering others<sup>59</sup>.*
- ☞ *Support needed by a person in a nursing home for community placement under the requirements of federal law or specialized services (limited to 5 hours/week since January 2003; funded from PASARR fund, see page 39) for new referrals.*

<sup>55</sup> This includes equipment and modifications that may be needed to prevent an adult or child from regressing. This is not intended to substitute for other responsible public services (e.g., public education, child welfare, health insurance, etc.)

<sup>56</sup> Services can cover extraordinary costs as a result of the child’s developmental disability.

<sup>57</sup> Families are eligible for Flexible Family Funding in accordance with the *Flexible Family Funding Program Guidelines*.

<sup>58</sup> Caregiver means an unpaid or minimally paid (e.g., a residential care home) caregiver.

<sup>59</sup> Based upon past known behavior (e.g., arrested for serious offense, substantiated sexual abuse, under restraining order because of dangerous conduct, etc.). Not intended to substitute for or replace Corrections supervision for people who have committed and been convicted of a crime.



**DIVISION OF DEVELOPMENTAL SERVICES  
FY 2003 BUDGET SUMMARY**

For FY 2004, the Division of Developmental Services has an appropriated budget of combined state general funds and federal Medicaid funds of **\$90,739,955** including funds appropriated to the Department of Prevention, Assistance, Transition and Health Access (PATH) in support of people with developmental disabilities. This is allocated as follows:

Existing Community Services (includes \$1,302,423 for annualization of FY 03 consumers)	\$81,063,801
Flexible Family Funding (restores benefit level to \$1,122/person; no new consumers)	90,000
1.5% Workforce Compensation Increase (\$605,221 GF)	1,185,781
1.5% DA/SSA Operating Expense Increase (\$75,750 GF)	148,470
FY 04 Funding for Consumer Needs – new and changes to existing (\$1,071,568 GF)	2,791,269 <sup>60</sup>
New “June Graduates” (\$340,677 GF)	887,411
Public Safety (\$408,842 GF; includes funds for 17 people & system improvements)	1,064,970
Division of Rate Setting	17,855
Salaries and Expenses for Guardianship Services, Quality Assurance and Division Administration	<u>3,490,398</u>
<b>TOTAL</b>	<b><u>\$90,739,955</u></b>

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<sup>60</sup> Includes \$1,835,509 (\$704,652 GF) estimated Equity Fund resources already in base funding.

