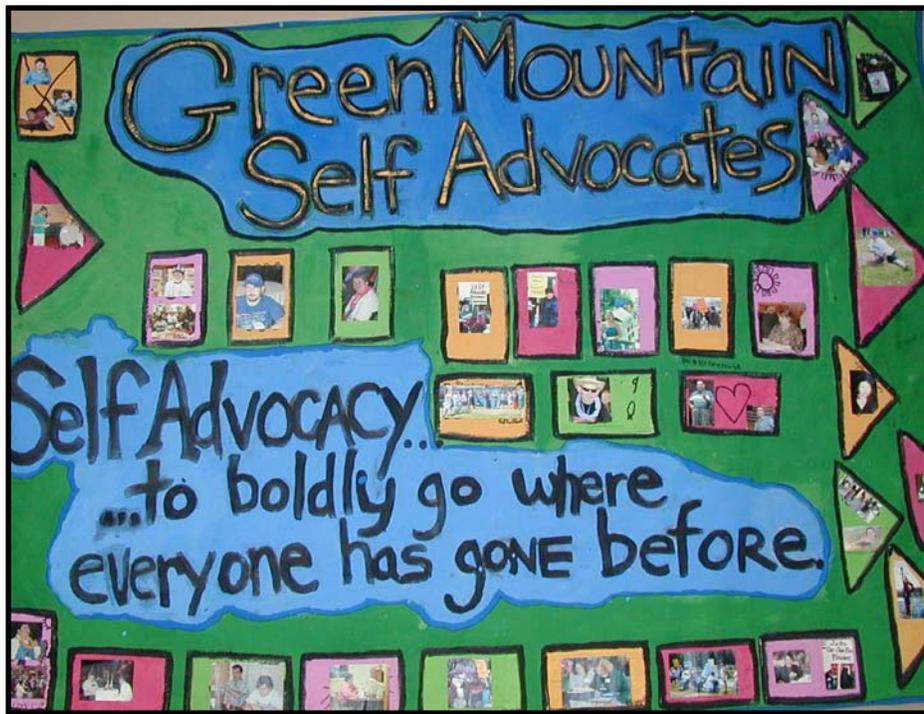


# Vermont Developmental Disability Services Annual Report 2009



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

Front cover: Poster created by self-advocates for  
Green Mountain Self Advocates.

# **Vermont Developmental Disability Services Annual Report 2009**

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



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**January 2009**



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### Notes:

- Although the Global Commitment to Health Waiver refers to all services funded by DDAS, when “waiver” funding or services are referenced in this document it refers to home and community-based services (not Flexible Family Funding, fee-for-service Medicaid, vocational grant funding, etc.).
- All data represented in this report are for FY 2008 unless otherwise stated.
- See **Attachment A** for a list of *Acronyms*.

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## **AHS Secretary's Statewide Community Award Vermont Communication Task Force**

*The Vermont Communication Task Force was recognized for the many years contributing to the support of people to communicate by being awarded the 2007 Agency of Human Services Secretary's Community Award. Secretary Cynthia D. LaWare presented the statewide award to the Task Force in recognition of providing a statewide focus on communication so that transition age youth and adults with developmental disabilities throughout Vermont can communicate more effectively to participate fully in community life, make decisions and better advocate for themselves.*

*The Vermont Communication Task Force works in partnership with the Division of Disability and Aging Services and the Vermont Assistive Technology Program to provide information, education, training and resources to people with disabilities, family members, service providers, state staff and community members.*

*This highly productive, dedicated group has accomplished many initiatives which have lead to a fundamental shift in the developmental disabilities service systems' understanding of the importance of people being able to communicate beyond the basics and familiar.*

*This group truly exemplifies Margaret Mead's well know quote:*

***"A small group of thoughtful people could change the world.  
Indeed, it's the only thing that ever has."***



Pictured left to right: Secretary LaWare, Marie Zura, Amy Roth, Abbey Carl, Jessica Benware, Sarah Hathaway, June Bascom, Mary Alice Favro, Julie Tucker, Kathy Boudreau, Jeff Nunemaker

Absent: Pascal Cheng, Jeff Coy, Harvey Lavoy, Beth Sightler, Karen Topper

## **DAIL MISSION STATEMENT**

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

### **PURPOSE**

The Division of Disability and Aging Services supports older Vermonters and Vermonters with disabilities to live as they choose, pursuing their individual goals and preferences within their chosen communities.

#### **The Division:**

Seeks to ensure their basic human and civil rights, health, well-being, and safety –  
Provides effective leadership for disability and aging policy and services in Vermont –  
Meets federal state mandates by developing and managing public resources effectively.

### **CORE VALUES/PRINCIPLES**

- Person-centered: We help people to make choices and to direct their own lives – pursuing their own choices, goals, aspirations and preferences.
- Natural Supports: We recognize the importance of family and friends in people's lives. We respect the unique needs, strengths and cultural values of each person and each family.
- Community participation: We support consumers' involvement in their communities, and recognize the importance of their contributions to their communities.
- Effectiveness: We pursue positive outcomes through effective practices, including evidence-based practices. We seek to develop and maintain a trained and competent workforce, and to use staff knowledge, skills and abilities effectively.
- Efficiency: We use public resources efficiently – avoiding unnecessary activities, costs, and negative impact on our environment.
- Creativity: We encourage progress through innovation, new ideas, and new solutions. We accept that creativity involves risk, and we learn from mistakes.
- Communication: We communicate effectively. We listen actively to the people we serve and to our partners. We are responsive.
- Respect: We promote respect, honesty, collaboration and integrity in all our relations. We empower consumers, staff and partners to achieve outcomes and goals. We provide opportunities for people to grow, both personally and professionally.
- Leadership: We strive to reach our vision and to demonstrate our values in all our work. We collaborate with consumers and other partners to achieve outcomes, goals and priorities. We are accountable.

# THE DEVELOPMENTAL DISABILITIES SERVICE SYSTEM

The Developmental Disabilities Act of 1996 requires the Department of Disabilities, Aging and Independent Living (DAIL), Division of Disability and Aging Services (DDAS), under the Agency of Human Services (AHS)<sup>1</sup>, to adopt a plan describing the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. The Division of Disability and Aging Services' *Vermont Developmental Disabilities Services Annual Report 2008*, together with the *Vermont State System of Care Plan for Developmental Services – Three Year Plan (FY 2008 – FY 2010)*, cover all requirements outlined in the developmental disabilities statute<sup>2</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> See **Attachment B: Organizational Chart – Agency of Human Services.**

<sup>2</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 the Developmental Disability Act.
  
- ✎ **Fiscal Integrity.** The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.

## Division of Disability and Aging Services

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

The Division of Disability and Aging Services contracts directly with fifteen (15) private, non-profit 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 D: Vermont Developmental Services Providers** and **Attachment E: Members of the State Program Standing Committee for Developmental Services**.

## Developmental Services Providers

### Designated Agencies

The Department of Disabilities, Aging and Independent Living (DAIL) authorizes one Designated Agency (DA) in each geographic region of the state as responsible for ensuring needed services are available through local planning, service coordination, and monitoring outcomes within their region<sup>3</sup>. There are ten DAs responsible for developmental services in Vermont. Designated Agencies must provide services directly or contract with other providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines. Some of the key responsibilities of a DA include intake and referral, assessing individual needs and assigning funding, assuring each person has a support plan, providing regional crisis response services, and providing or arranging for a comprehensive service network that assures the capacity to meet the support needs of all eligible people in the region.

### Specialized Service Agencies

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

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

## Management Options for Services

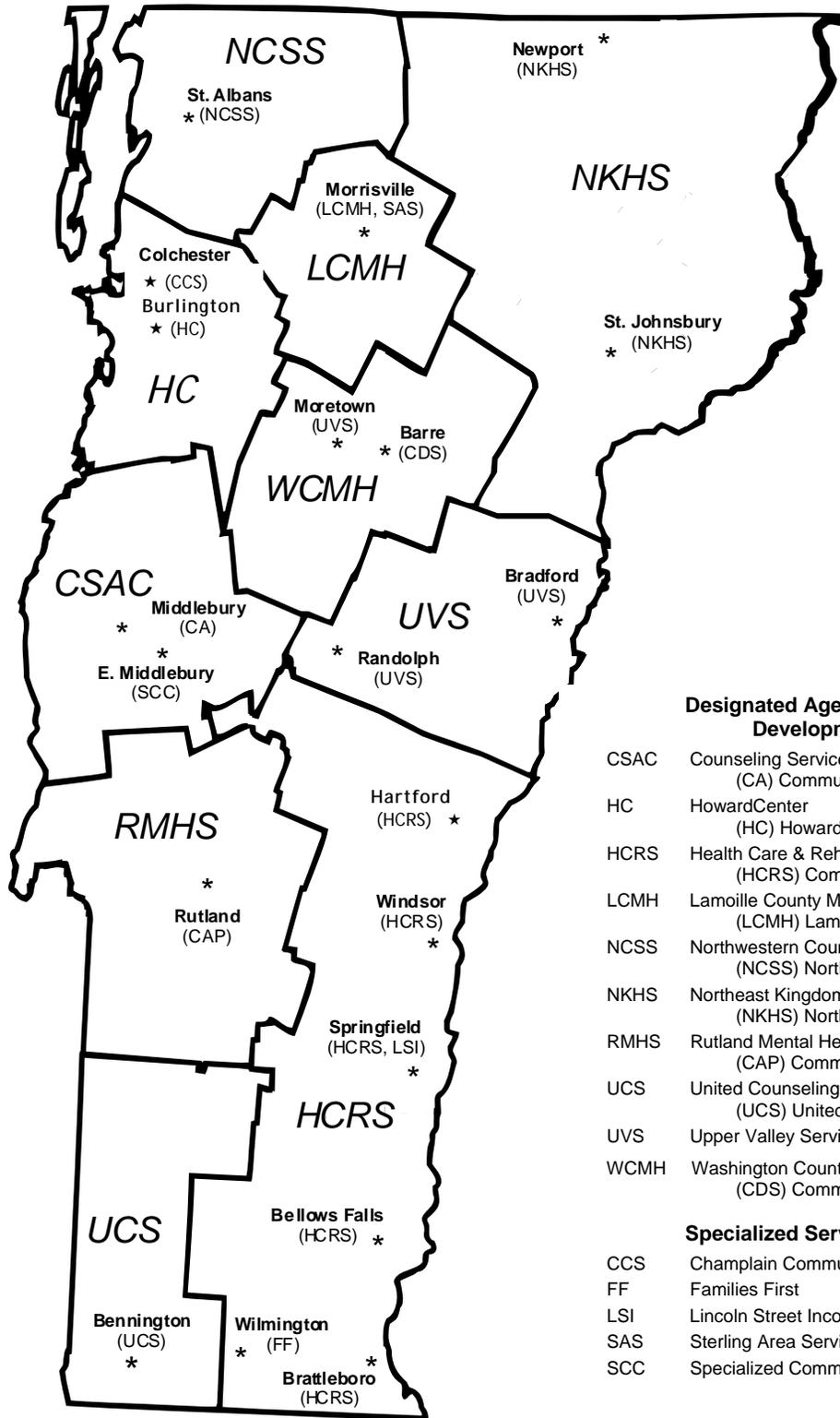
Traditionally, developmental disability services providers have managed all the services funded through DDAS on behalf of people with disabilities and their families. Today, people have a choice of four options of who will manage their services<sup>4</sup>.

- **Agency-Managed Services:** The **developmental disability service provider** manages **all** of a person's services, whether it is by the Designated Agency, Specialized Service Agency or other contracted provider. This is the most common method of how services are managed.
- **Shared-Managed Services:** The **developmental disability service provider** may manage **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. ARIS Solutions, a Fiscal Intermediary Service Organization (ISO) is available to people who share-manage to do many of the bookkeeping and reporting responsibilities of the employer.
- **Self-Managed Services:** An **individual** may choose to manage **all** of his or her developmental disability services except for 24-hour home supports. Up to 8 hours per day of paid home support for supervised/assisted living may be self-managed. This means that the person has the responsibility of hiring his or her own staff and overseeing the administrative responsibilities associated with receiving developmental disability 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. Transition-II (T-II) is a Supportive Intermediary Service Organizations (ISO) that must be used by individuals who self-manage their services. Additionally a Fiscal ISO, ARIS Solutions, must be used to help people who self-manage to do many of the bookkeeping and reporting responsibilities of the employer.
- **Family-Managed Services:** A person's **family member** may choose to manage **all** of his or her developmental disability services except for 24-hour home supports. Up to 8 hours per day of paid home support for supervised/assisted living may be family-managed. The same responsibilities and resources noted above for self-management are also associated with and required for family-managed services. Transition-II (T-II) is a Supportive Intermediary Service Organizations (ISO) that must be used by families who manage their services. Additionally a Fiscal ISO, ARIS Solutions, must be used to help families who manage services to do many of the bookkeeping and reporting responsibilities of the employer.

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<sup>4</sup> Contact the Division of Disability and Aging Services for a comprehensive guide for people who are self-/family-managing their developmental disability services funded through Medicaid.

# Vermont Developmental Services Providers



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

- CSAC Counseling Services of Addison County (CA) Community Associates
- HC HowardCenter (HC) HowardCenter Developmental 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 Services, Inc.
- UVS Upper Valley Services, Inc. (DS only)
- WCMH Washington County Mental Health Services, Inc. (CDS) Community Developmental Services

**Specialized Service Agencies (SSA)**

- CCS Champlain Community Services, Inc.
- FF Families First
- LSI Lincoln Street Incorporated
- SAS Sterling Area Services, Inc.
- SCC Specialized Community Care

## Highlights from FY 2008



**Flexible Family Funding Guidelines** – New Flexible Family Funding Guidelines were implemented that increased the maximum family allocation from \$1,122 to \$1,300 and updated the sliding scale.



**State Interagency Plan on Autism Spectrum Disorders** – A state interagency plan was developed for providing services to individuals with Autism Spectrum Disorders and their families across the lifespan in their homes, schools and communities.



**Domestic Violence Initiative** – The DAIL Domestic Violence (DV) Advisory worked in partnership with the Vermont Network Against Domestic and Sexual Violence to design and present six workshops on DV, effectively training 80% of all DAIL staff.



**High National Ranking of Vermont Services** – Vermont is ranked second (2<sup>nd</sup>) in the nation in the quality of Medicaid-funded services for people with developmental disabilities by United Cerebral Palsy<sup>5</sup>.



**Youth Transition to Employment** – Fifty three percent (53%) of graduates who exited high school in 2008 were employed at graduation. This percentage has steadily increased since 2004 when 35% were employed at graduation.



**Communication Mentoring Project** – The Mentoring Project continued in FY '08 by providing Lamoille County Mental Health and Lincoln Street Incorporated with mentoring and technical assistance from a Speech and Language Pathologist (SLP) with Augmentative and Alternative Communication (AAC) expertise. The goal is to increase local capacity within developmental disability service agencies to support people with disabilities to communicate more effectively.



**Designated Agency Sustainability Study** – DAIL participated in the second sustainability study of the designated provider system, including ongoing caseload and workforce issues.



**Employment Training for People with Autism** – The Division of Vocational Rehabilitation partnered with DDAS in sponsoring a two-day training on employment strategies for individuals with autism spectrum disorders.

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<sup>5</sup> United Cerebral Palsy, *A Case for Inclusion*, <http://www.ucp.org/medicaid/index.cfm>, December 2008.



**Vermont Communication Task Force Receives Award** – The Vermont Communication Task Force was recognized for the many years of contributing to the support of people to be able to communicate by being awarded the 2007 Agency of Human Services Secretary’s Community Award.



**Therapeutic Options Training** – Twenty-nine (29) staff became certified instructors of Therapeutic Options, a restraint and violence elimination class, resulting in skilled practitioners in each developmental disability services agency in Vermont.



**Self Employment Initiative** – A self employment initiative, developed by Champlain Community Services, involved training and technical assistance that connecting Vermont providers with knowledge and resources in micro business planning to support consumers with business ventures.



**Children’s Creative Connection** – Children’s Personal Care Services (CPCS) launched Children’s Creative Connection (C3), a pilot designed to increase access to therapeutic services and support through CPCS. The premise is that greater flexibility breaks down barriers to services and allows access to a wider array of services to assist in a child’s self-care skill development.



**Vermont Hosts National Conversion Institute** – Policy makers, state agency staff and advocates from throughout the United States came to Vermont for a premiere conference on *Closing Sheltered Workshops*. This national conference on the conversion of sheltered workshops to community-based employment for individuals with developmental disabilities was a huge success with 80 people representing 25 states participating. Vermont’s pioneering efforts to close its last sheltered workshop in 2002 and convert them into individualized supports made Vermont the ideal state to hold this event.

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## SUCCEED!

*It's 8:00 am and JT rolls over to turn off his alarm, starting another day of college life. He's tired. He stayed up late working on his sketches in the student lounge, but despite his heavy eyes he knows he has work to do. After showering and grabbing a bite to eat he immediately hits the books, studying for his afternoon classes at UVM. JT is in his second semester of college receiving support from the SUCCEED program, an innovative post-secondary education program for students with developmental disabilities.*

*In August 2008, HowardCenter opened the SUCCEED program, in collaboration with the University of Vermont, to seven students in downtown Burlington. SUCCEED was developed in response to a growing need for college options for students with Autism, Asperger's Syndrome and Developmental Disabilities. We found that individuals wanted to engage in college courses with accommodations, but also needed life skills courses to realize their hopes and dreams for independence. SUCCEED provides the support necessary for students to be successful academically, while also learning skills for independence and building connections to their community.*



*SUCCEED students have the opportunity to take both UVM courses and functional life skills classes on campus. Their academic path is individually designed to meet their needs with the support of their SUCCEED team and a UVM advisor. The SUCCEED staff help students with their homework and provide tutoring support daily. JT is interested in a career in video game design, so he's enrolled in arts classes at UVM. A dedicated student, JT often talks about the UVM art class he took in the fall. "On the first day of class my professor said she rarely gives out A's and I remember thinking it was going to be a tough class, but at the end of the semester I got an A and I was so excited!"*

*In addition to classes, students are fully engaged in campus life. Students are required to join a UVM club or ongoing activity, as well as participate in campus events such as music festivals and activity fairs. "Our goal is to have students feel more connected to*

*friends and the campus community,” says Mark Prior, the SUCCEED Program Manager. While our students want to be involved on campus, they are sometimes uncomfortable in social settings and worry that other students may judge them. We’ve developed a peer mentoring model to provide students with the social support they need to overcome this fear. Students are matched to another UVM student based on mutual interests. The UVM student functions as a campus mentor, helping SUCCEED students join clubs, attend athletic events, or just study together in the Davis Center. JT joined the Anime club and loves it. “We meet every Sunday night and it’s a chance to make friends outside of the house.”*



*SUCCEED students also work closely with a HowardCenter Project Hire Employment Consultant. Employment Consultants help students obtain a part time job, but more importantly work with students to identify a career path. Students build a comprehensive employment portfolio and complete a required internship in a field of their interest. Upon completion of the program the goal is to have students working in a career that they love.*

*SUCCEED students live in off campus housing with their peers and a residential advisor. The housing situation functions as a transitional living situation to help students build independent living skills and practice social skills in a natural setting. Students develop a roommate agreement, share household responsibilities and attend weekly house meetings. HowardCenter provides daytime staff support to help students with time management, tutoring, and independent living skills, such as cooking and taking public transportation. Once students are ready, they move to a transition apartment and assume more responsibility.*

*JT made so much progress in his first semester that he’s already transitioned to an apartment. When asked about his progress thus far in the program, he says “SUCCEED is the best thing that’s ever happened to me.”*

## Pressures on Community Services

In FY 2008, the Division of Disability and Aging Services provided supports to **3,545** people with developmental disabilities in Vermont, approximately 27% of the eligible population<sup>6</sup>. However, the population is constantly growing with an estimated **137** children born each year with developmental disabilities<sup>7</sup>. The need for developmental services is generally life-long and on average **33** people who are currently receiving services die each year<sup>8</sup>. The demand for supports continues to outpace the available resources. The following are some of the many factors influencing this.

↪ **Medicaid services limited for children** – There are gaps in the federal entitlement to Early, Periodic Screening, Diagnosis and Treatment (EPSDT) services for Medicaid-eligible children and youth with developmental disabilities. Efforts are underway to address these gaps and increase access to EPSDT services with a new allocation of funds from the Legislature.

↪ **Special education graduates need supports at home and work**<sup>9</sup> – There were an estimated **112** graduates with developmental disabilities expected to exit the educational system in FY '08. These young adults look to the developmental disability services 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 **112** who exited, **76** met eligibility for home and community-based services funding and **13** received services through supported employment grants funded by Vocational Rehabilitation.

↪ **Autism Spectrum Disorders (ASD)** – There has been a dramatic increase in the number of children diagnosed with ASD in the past decade. National data indicate that 1 in 150 children have an ASD diagnosis<sup>10</sup>. Vermont's data show similar prevalence rates. Furthermore, there has been an average annual rate increase of 16% over the past ten years of children and adults with ADS getting mental health or developmental disability services<sup>11</sup>.

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<sup>6</sup> Based on estimated census figures for 2007 obtained from the US Census Bureau, American Fact Finder website (621,254 for Vermont).

<sup>7</sup> Based on a prevalence rate of 1.5% for mental retardation, 0.6% for Pervasive Developmental Disorders and 6,514 live births (Vermont Department of Health preliminary 2007 vital statistics).

<sup>8</sup> Based on an average of the past ten years (*National Core Indicators Mortality Data*).

<sup>9</sup> Designated Agencies survey local schools each year to find out exactly how many students with developmental disabilities are expected to graduate and who are eligible for developmental disability services and need funding.

<sup>10</sup> Rice, C. (2007). Prevalence of Autism Spectrum Disorders – Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002, *Morbidity and Mortality Weekly Report*, 56 (SS01); 12 – 25.

<sup>11</sup> *Report to the Legislature to Address Services for Individuals with Autism Spectrum Disorders*. Vermont Agency of Human Services, January 2008.

 **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 disability services to meet the need. Approximately 195 offenders with developmental disabilities are supported by developmental service agencies, a number that has increased steadily in recent years. Costs for serving these offenders are increasing at a greater rate than the costs of serving other offenders; the average cost per offender with developmental disabilities is now approximately \$100,000.00 per year. 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. A statewide survey in December 2008 identified 71 offenders with unmet needs. These unmet needs included: lack of effective programs, programs that do not adequately protect public safety, people who are not able to be served without putting an unreasonable drain on other services or if community notification is required, and people currently placed out of state because of lack of any in-state program.

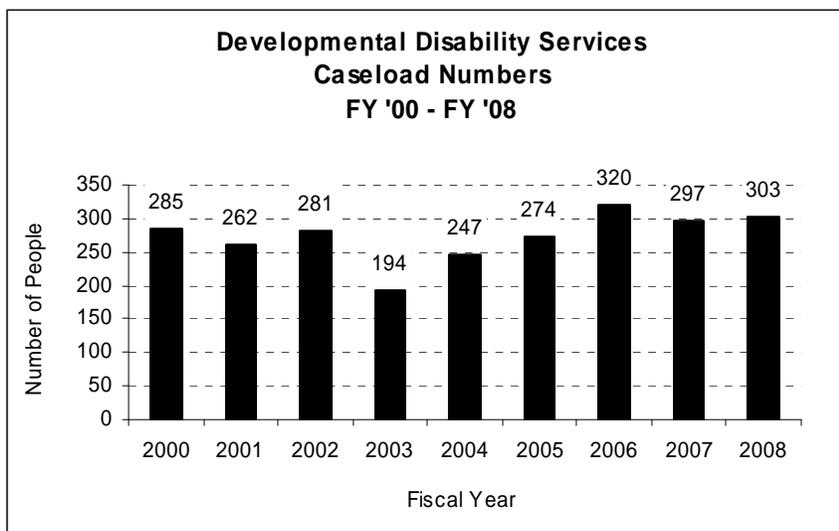
 **New caseload funding allocated to most in need** – New caseload resources were provided to **303** individuals in FY '08 who met the State System of Care Plan funding priorities for developmental disability services. The chart on the following page provides a summary of the reasons people received new caseload funding.

 **Applicant List tracks people who do not meet funding priorities** – There were **241** people on the Applicant List at the end of FY '08. This number includes people who are eligible for services based on their disability but whose needs do not meet the State System of Care Plan's funding priorities. In addition, there were **36** people on the **Waiting List** who were eligible for services – specifically Flexible Family Funding – but for whom there were insufficient funds. Most of those waiting received one-time funding in FY '08 to temporarily meet their needs and all of them received a Flexible Family Funding allocation in FY '09.

## Caseload Funding<sup>12</sup> – FY 2008

<b>Reasons for Receiving Caseload Resources<sup>13</sup> – FY 2008</b>	
Imminent risk to person’s health or safety – for adults (age 19 and over)	218
Loss of home / imminent risk of homelessness – for adults	96
Risk of abuse, neglect or exploitation – for adults	65
High school graduation and job loss prevention – for adults (age 19 and over)	61
Loss or reduced capacity of caregiver – for adults	43
Risk to public safety – for adults	30
Risk of institutional placements or diversion from institutional placement – for children and adults	25
Employment Conversion Plan / Parenting skills training for parents with DD	5
<b>Total people served from caseload resources (unduplicated)</b>	<b>303</b>

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



The nature of developmental disabilities often leads to services that support people throughout their lifespan. Of the 70 people who left home and community-based funded services in FY '08, 29 died; 16 declined or left services; 19 moved out of state; and 6 received alternative supports or funding.

<sup>12</sup> “Caseload Funding” includes all newly appropriated funding from New Caseload, Equity, High School Graduate, and Public Safety Funds. Many funding approvals meet more than one System of Care Plan funding priority and some people are approved for funding from more than one category of funding, so the list above includes 47 people who had more than one reason for receiving caseload resources and/or received funding from more than one fund. Unless stated otherwise, adult means age 18 and over.

<sup>13</sup> See **Attachment F** for a complete listing of the *State System of Care Plan Funding Priorities FY 2008*. For more details, see the *Vermont State System of Care Plan for Developmental Services Three-Year Plan FY 2008 – FY 2010 and FY 2009 UPDATE (Revised January 2009)*.

## Financial Summary

People with developmental disabilities have a greater likelihood of experiencing limitations in major life activities than those with any other major class of chronic mental, physical, or health condition. As a result, people with developmental disabilities need individualized services that are comprehensive and generally life long. To capitalize on the resources available, the Division of Disability and Aging Services emphasizes cost effective models and maximization of federal funds. See **Attachment G: Division of Disability and Aging Services FY 2008 Fiscal Resources**.



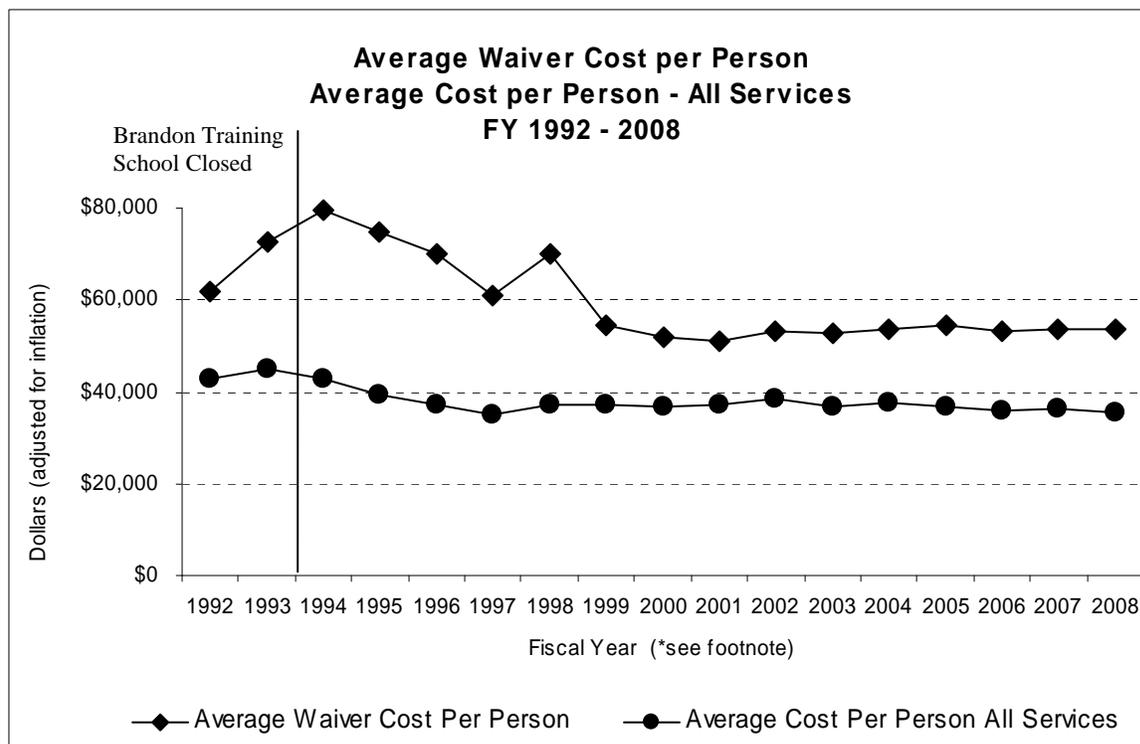
With the inception of the Global Commitment to Health 1115 Medicaid waiver, **100% of all community-based services are now matched with federal funds.**



**The average waiver cost per person was \$53,798 in FY 2008.**



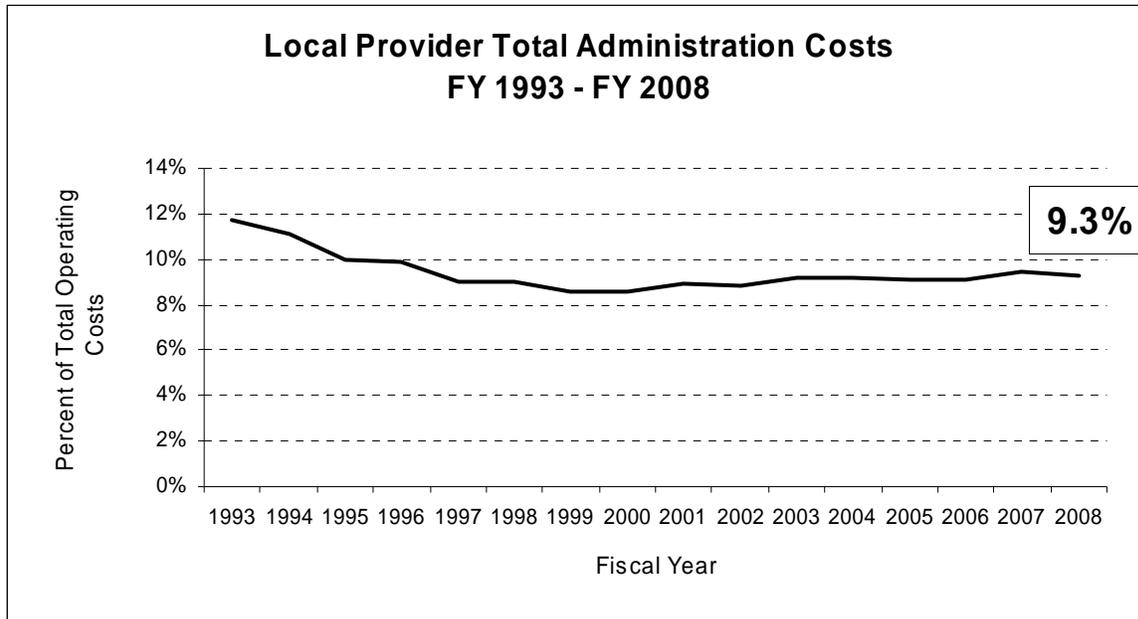
**The average cost<sup>14</sup> per person for all services was \$35,494 in FY 2008.** This average cost has remained stable. An increase over time in the number of individuals supported by less costly (non-residential) family support, like Flexible Family Funding, contributes to the stability of the average cost per person.



<sup>14</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.



Administrative expenses include those that are required to run the total local agency<sup>15</sup>. These administrative costs have **remained relatively stable** for the past ten years.<sup>16</sup>

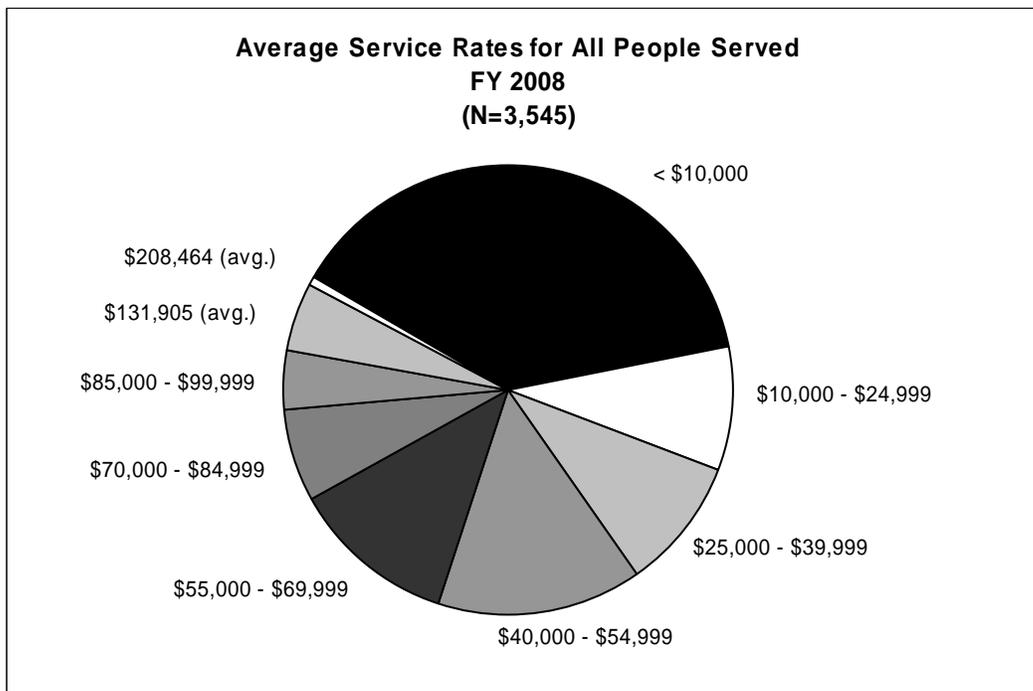


<sup>15</sup> Management expenses (e.g., developmental service director, buildings) relating to major program areas (e.g., developmental services) are considered program expenses, not administration.

<sup>16</sup> The impact of “corporate compliance” and other measures caused a .4% increase between FY ’06 and FY ’07.



**Almost one-half (45%) of all individuals served are funded for less than \$20,000 per person per year.** The average cost of all services per person in FY '08 was \$35,494. The average per person cost of supports in the most intensive community services category<sup>17</sup> is \$208,464 per year, which is 26% less than what the estimated annual per person cost would have been at Brandon Training School in today's dollars (\$283,470). Sixty percent (60%) of all families served receive support through Flexible Family Funding at the low annual rate of \$1,300<sup>18</sup>. Supporting people living with their own families continues to be the most cost effective method of support.

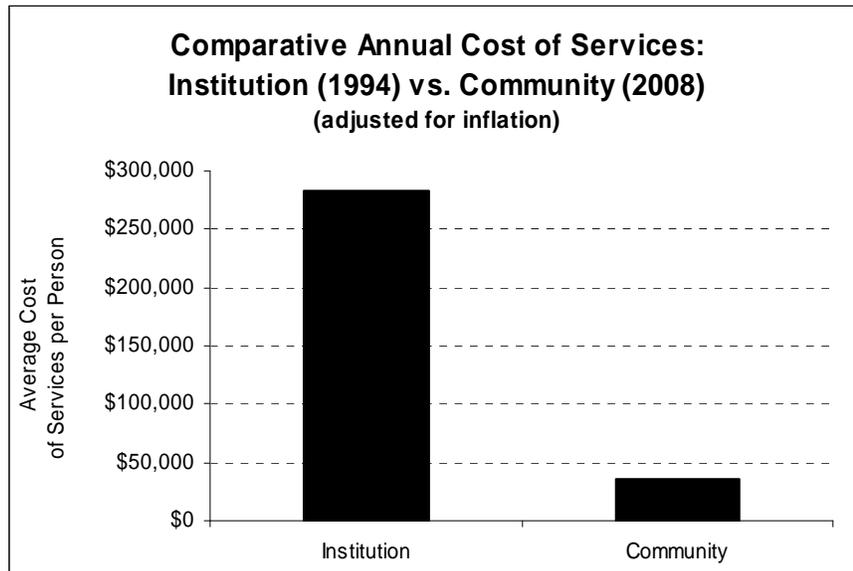


<sup>17</sup> This highest rate category includes 6 people with intensive medical needs in an Intermediate Care Facility for People with Developmental Disabilities (ICF/DD) and other people getting waiver funding at a rate equal to or higher than the ICF/DD rate.

<sup>18</sup> Flexible Family Funding is based on a sliding scale of which the maximum family allocation is \$1,300.



Since the closure of Brandon Training School (BTS) 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 **\$283,470** per year for each person served. In current dollars, **8 families** can be supported with intensive in-home support, or **219 families** can be supported with Flexible Family Funding, for the same amount of money (adjusted for inflation)<sup>19</sup>.



Flexible Family Funding is a cost-effective, family-directed support. It results in a relatively large number of people receiving services that are low cost. In addition, because **almost 100% of developmental disability services funding is from Medicaid via the Global Commitment waiver**, Vermont's developmental disability service system leverages a higher proportion of federal funds compared with other states.

<sup>19</sup> The Flexible Family Funding number was calculated using the \$1,300 maximum family allocation.

## Quality Assurance & Quality Improvement

Quality Service Reviews – 2008	
Agencies reviewed <sup>20</sup>	7
People reviewed	100
Percentage of people reviewed getting Medicaid-funded services	10%

**Assessment, assurance and improvement of service quality** are critical functions of the Division of Disability and Aging Services. Quality Management Reviewers conduct on-site reviews of all Medicaid-funded services provided by each agency. The quality review teams assess the quality of services with respect to the Division of Disability and Aging Services' Quality Service Standards 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<sup>21</sup>.

The Quality Management Reviewers do on-site reviews at half the agencies each year, covering around ten percent of the people served at those agencies; thus all agencies will be reviewed every two years. The quality reviews also inform the designation process that takes place for each developmental disability services agency every four years. In FY '08, four agencies completed the re-designation process.

As part of the agency review process, the Quality Management Reviewers incorporate information from the following DDAS quality assurance activities:

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

<sup>20</sup> The developmental disabilities services agencies reviewed in 2008 included Champlain Community Services, Families First, Inc., Health Care and Rehabilitation Services of Southeastern Vermont, Lincoln Street Incorporated, Northwestern Counseling and Support Services, Upper Valley Services, Washington County Mental Health Services, as well as Rutland Mental Health Services Community Access Program's ICF/DD.

<sup>21</sup> In July 2007, DDAS implemented a new DDAS Quality Management Plan. After implementing the Plan for one year, DDAS decided to make revisions to the Quality Services Reviews for agencies funded by DDAS. It is expected this redesign process will be completed in FY '09.

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

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

- **Training** that ensures workers gain the expertise necessary to meet the needs of people they support is arranged or provided by DDAS on several levels:
  - Ongoing training programs developed for agency staff.
  - Training for staff of each agency about the best ways to support people with developmental disabilities.
  - Support of regional and statewide training through funding and collaborating with stakeholders to tailor training to meet specific needs.
- **Training** was provided in the following areas:
 

• Grief Support	• Wills and Estate Planning
• Person Centered Approaches	• Dementia
• Person Centered Planning	• Communication
• Autism	• Assistive Technology
• Inclusion	• Health and Wellness Guidelines
• Positive Behavioral Support	• Therapeutic Options Instructor Certificates
• Individual Support Agreements	• Self-Advocacy
• Employment	• Alternatives to Guardianship
• Trauma	• Family Support
• Choices for Care	• Bio-Psycho-Social Model of Support
• Sex Offender Issues	• Peer Educator Sexuality
• Sexuality	• Boundaries and Purpose in Relationships
- **Collaboration** with the Continence Project, Planned Parenthood of Northern New England and Green Mountain Self-Advocates.
- **Technical assistance** is provided to each agency by DDAS staff in a wide variety of areas including:
 

• Intake process	• Policies and guidelines
• Funding of services	• Best practices
• Individual Support Agreements	• Organizational development
• Children and family services	• Employment services
• Training and staff development	• Health and wellness
• Data and other information reporting	
• Positive support strategies and behavior support plans	

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

The Division of Disability and Aging Services convenes a number of advisory and work groups with representation from various advocacy and service organizations, including:

- Vermont Communication Task Force
- Quality Management Committee
- Therapeutic Options Group
- Sex Offender Discussion Group
- Developmental Services State Program Standing Committee
- Social/Sexual Education Resource Network
- Supported Employment Managers Group
- Training Advisory Group
- Human Rights Committee
- Ethics Committee
- Children's Coordinators Group

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

Grant Funds were used to:

- Develop a Quality Management Plan to address the home and community-based funded programs.
- Include consumers, their families and community members as active participants in Vermont's quality management activities.
- Develop and implement quality management activities to improve supports and services to Vermont's older citizens and those with disabilities.
- Develop a guardianship review process.
- Develop an ongoing system of technical assistance to all providers of services across age and disability and provide training to service recipients and relevant staff.

This grant ended September 30, 2008.

## Highlights



### **Changes to the Division of Disability and Aging Services Quality Management Plan**

The Division of Disability and Aging Services continued to implement the DDAS Quality Management Plan in 2008. The plan is currently being revised with changes to the Quality Review Process. The plan provides a framework to assure and improve the quality of the home and community-based services delivered to people with developmental disabilities, people with traumatic brain injury, people with physical disabilities and older adults throughout Vermont. The plan was developed through broad consumer, family and service provider input as part of the Quality Assurance/Quality Improvement Real Choices System Change Grant.

The Quality Management Plan is based on a set of shared values that are captured in the DAIL Mission Statement and Core Principles (see page 2). These shared values and principles are the foundation for the desired outcomes of services. These outcomes, their associated indicators and the way information is gathered form the new DDAS Quality Service Standards and are the criteria by which quality services are measured.

### **DDAS Quality Service Standards**

1. **Respect:** Individuals are treated with dignity and respect.
2. **Self-Determination:** Individuals direct their own lives.
3. **Independent Living:** Services support independent living.
4. **Relationships:** Individuals receive support to foster and maintain relationships.
5. **Participation:** Individuals participate in their local communities.
6. **Person-Centered Practices:** Services and supports are individualized to meet people's needs and honor their strengths and preferences.
7. **Well-being:** Individuals' services and supports promote health and well-being.
8. **Communication:** Individuals communicate effectively with others.
9. **Collaboration:** Individuals receive effective, coordinated, and efficient services.
10. **Support Systems:** Individuals benefit from a trained and competent support system.



### **New Guardianship Review Process**

A new Guardianship Review Process was developed as part of the Quality Assurance/Quality Improvement Systems Change Grant. The review was implemented in 2008 and identified strengths of the Office of Public Guardian program and made recommendations for improvements within the program. The Office of the Public Guardian was the first guardianship program in the country to seek independent review in collaboration with the National Guardianship Association.



To help **maintain consistent and quality services and supports** across the state, the Division of Disability and Aging Services has the following policies:

- Critical Health Care Decisions (1996)
- Guidelines for Critical Incident Reporting (2002)
- Individual Support Agreement Guidelines (2003)
- Policy on Education and Support of Sexuality (2004)
- A Guide for People who are Self/Family Managing Medicaid-Funded Developmental Services (2004)
- Qualified Developmental Disabilities Professional (QDDP) Definitions, Qualifications and Roles / QDDP Endorsement (2004)
- Health and Wellness Standards and Guidelines (2004)
- Behavior Support Guidelines for Support Workers Paid with DDS Funds (2004)
- Background Check Policy (2006)
- Housing Safety and Accessibility Review Process (2006)
- Flexible Family Funding Guidelines (2007)
- Grievance and Appeals Processes (2007)
- Quality Management Plan (2007)

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## LORELEI'S STORY

*Lorelei takes great pride and pleasure in her new enterprise The Bagel Brigade. Launched seven months ago, Lorelei retails New York Style bagels to businesses in the White River Jct. area. She purchases her product wholesale from a local bakery.*



*Currently operating three days a week, Lorelei makes the rounds to her customers and sets up displays of freshly baked bagels. Her careful attention to creating attractive displays showcases the “Baker’s Studio” bagels with style and elegance.*

*“The Bagel Brigade” is a true collaborative success. During Lorelei’s last remaining year of high school, her support team, comprised of staff from Upper Valley Services Inc., Vocational Rehabilitation and the Hartford Regional Resource Center, established a joint effort to meet Lorelei’s vocational goal and transition needs.*

*A creative idea grew to a vision; a small business plan was developed, a VR grant provided start-up funding and local businesses were surveyed for interest. Lorelei’s enthusiasm grew. The Bagel Brigade was soon up and running delivering to three, then five area business. The need for a small space for a base of operations was met through the generosity of “The Haven” in White River.*

*“The Baker’s Studio” owner/operator Chris Calvin has been integral to the development and successful launching of “The Bagel Brigade”. His ongoing support and willingness to help anywhere he can will aide in the continued success of Lorelei’s business.*

*As Lorelei “the entrepreneur” goes about her business, she is building new relationships and gaining confidence in herself as a vibrant young business woman. It is common for all to hear Lorelei exclaim; “I’m the owner of “The Bagel Brigade” am I am a hard-working woman!”*

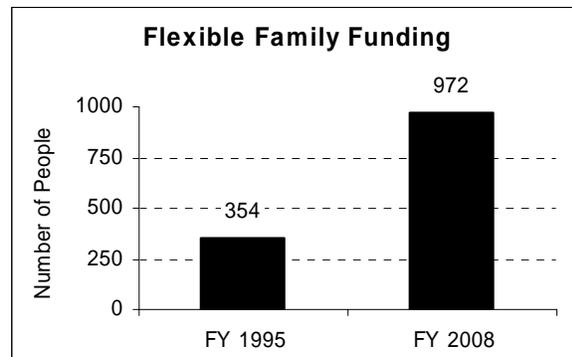
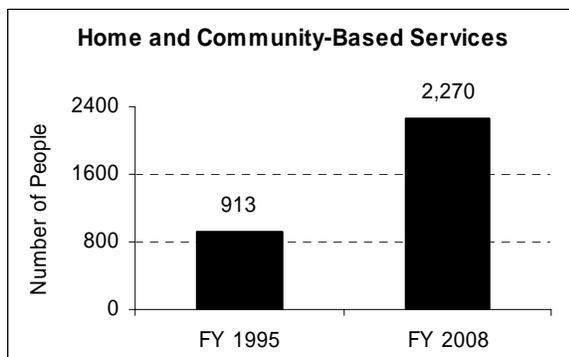
# SERVICES & FUNDING

## Funding Sources

Numbers Served – FY 2008	
Home and community-based services	2,270
Flexible Family Funding	972
Other funding	303
<b>Total people served (unduplicated)</b>	<b>3,545</b>

Since the inception of the Global Commitment to Health (GC) Medicaid waiver in FY '07, 100% of the services funded by DDAS are for people with developmental disabilities are funded under GC.

- Home and Community-Based Services (HCBS) – 2,270 people**  
 A wide range of home and community-based services are available under the Global Commitment. Home and community-based services account for **97%** of all DDAS appropriated funding for developmental disabilities services.
- Flexible Family Funding (FFF) – 972 people**  
 Flexible Family Funding is money, provided to eligible families with children or adult family members with disabilities living at home, used at their discretion toward services and supports that are in the person’s/family’s best interest. The maximum amount available is generally \$1,300/year<sup>22</sup>. Flexible Family Funding accounts for **1%** of all DDAS appropriated funding for developmental disabilities services and is also funded under Global Commitment.



- Other Funding** – Other funding sources include GC fee-for-service targeted case management and the Intermediate Care Facility (ICF/DD), plus vocational grants in partnership with the Division of Vocational Rehabilitation. These account for **2%** of all funding for DDAS community-based services.

<sup>22</sup> The Flexible Family Funding maximum family allocation was increased from \$1,122 to \$1,300 as of 7/1/07.

## Types of Services Provided

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

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

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

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

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

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

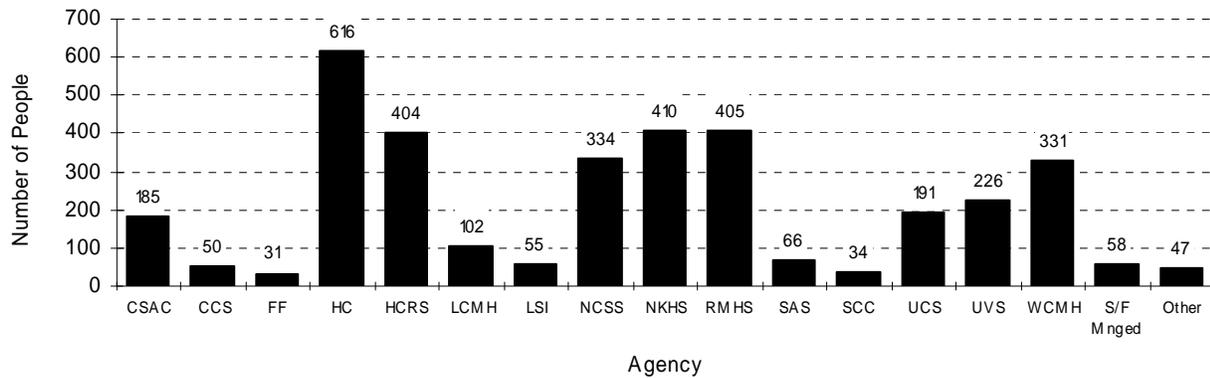
**Shared Living/Home Provider** – Individualized shared-living arrangements for one or two people offered within a contracted home provider's home.

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

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

## Total Served

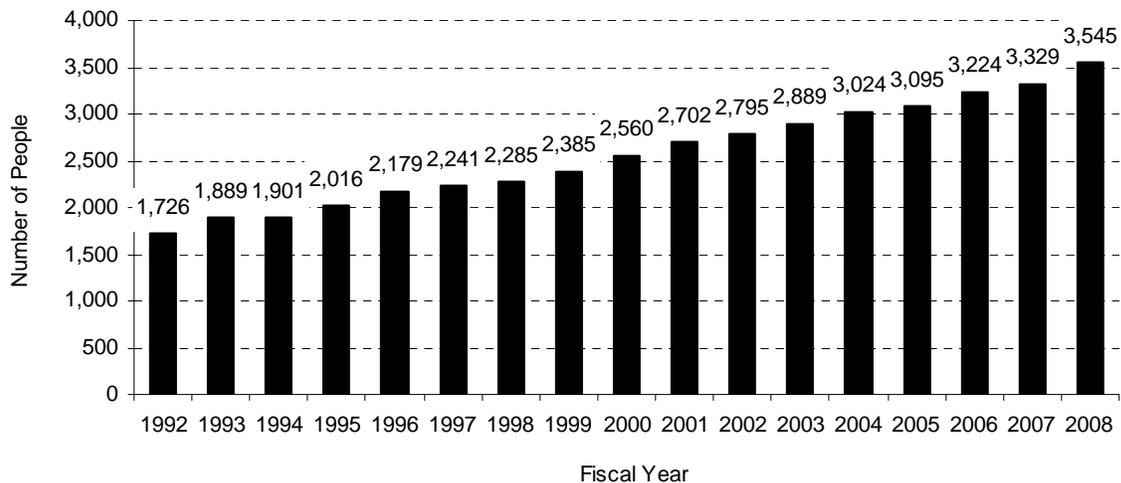
**Total Number of People Supported by Service Provider  
June 30, 2008**



### Developmental Disability Services Providers

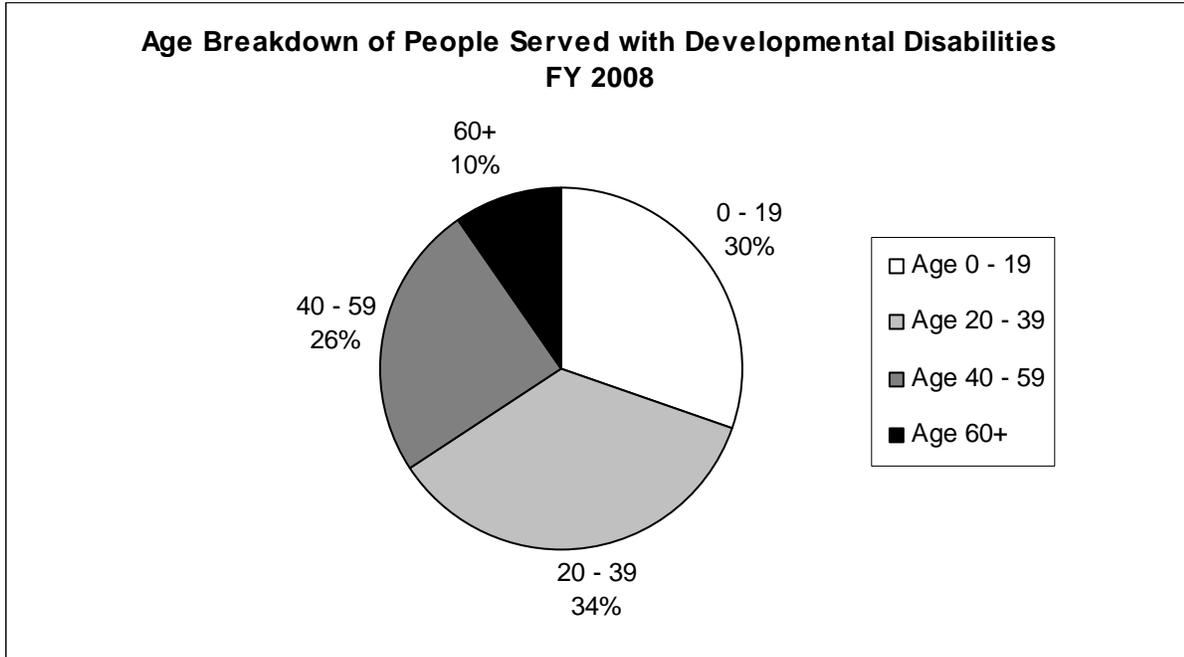
CSAC	Counseling Service of Addison County	SCC	Specialized Community Care
CCS	Champlain Community Services, Inc.	UCS	United Counseling Services, Inc.
FF	Families First	UVS	Upper Valley Services, Inc.
HC	HowardCenter	WCMH	Washington County Mental Health Services, Inc.
HCRS	Health Care and Rehabilitation Services of SE Vt.	Self- or Family-Managed	Includes all people who use the Supportive ISO (Transition II).
LCMH	Lamoille County Mental Health Services, Inc.		
LSI	Lincoln Street Incorporated		
NCSS	Northwestern Counseling and Support Svs., Inc.	Other	Includes people supported by Transition II employment services or the Office of Public Guardian and who are <u>not</u> served by any other developmental disability services provider.
NKHS	Northeast Kingdom Human Services, Inc.		
RMHS	Rutland Mental Health Services		
SAS	Sterling Area Services, Inc.		

**Total Number of People Served  
FY 1992 - FY 2008**





The relative age breakout of people with developmental disabilities receiving services has **changed very little over the past six years.**



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## AMY AND GUY'S STORY

*August 30<sup>th</sup> is a special day for Amy and Guy. Not only is it Amy's birthday and not only is it Guy's birthday, but it is also now their anniversary. On August 30, 2008, Amy and Guy were married!*

*Amy and Guy met at the food court in the mall two years ago. Guy sat down at the table next to Amy and what he saw was "one knock out lady." He didn't waste anytime. Guy asked Amy right then and there if she was going out with anybody. She wasn't....and so their relationship started.*

*They went out on dates now and then and talked on the phone every night. Eventually Guy asked Amy's father for his permission to marry his daughter. Although Amy's parents really liked Guy, her father was hesitant at first. Guy finally sold the idea when he reminded Amy's parents that they weren't losing a daughter but gaining a son-in-law. As he said later, "It was meant to be."*

*Amy and Guy had a beautiful wedding with lots of clapping and celebration. They traveled to Florida for their honeymoon and went to all the attractions. There was seldom a dull moment.*

*For Amy and Guy, life is good – excellent even. Amy works for Walmart as a Greeter and they both enjoy Special Olympics. Best of all they share their life together.*

*As Guy says, "It can't get any better than this!"*



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

## Service Planning & Coordination

<b>Numbers Served – FY 2008</b>	
Home and community-based waiver service coordination	2,270
Fee-for-service service coordination (unduplicated with waiver)	368
<b>Total people receiving service coordination</b>	<b>2,638</b>

**Service Planning and Coordination** assists individuals and their families in planning, developing, choosing, gaining access to, coordinating and monitoring the provision of needed services for a specific individual. 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 Agreements
- Periodic review/assessment of needs
- Medicaid billing
- Evaluations and assessments
- Waiting and applicant lists
- Housing Safety and Accessibility Reviews
- Overall health and safety
- Maintaining individual case records
- Positive Behavior Support Plans
- Critical Incident Reports
- Grievance and appeals
- Quality assurance/improvement

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## ANDREAS' STORY



*Andreas did his civic duty yesterday, and voted. We watched the results come in late into the night; after the acceptance speech, he took himself to bed, happy, proud, and satisfied.*

*We targeted this goal in his last Individual Support Plan – that he would know enough to choose a candidate, be able to make a clear independent choice, would register as a voter, and he would get his vote in on Election Day.*

*Andreas had lots of exposure to the candidates on TV. When Obama did his half-hour commercial, Andreas sat in his room watching his TV attentively, laughing and clapping. Jason, Andreas' companion/worker, took him last month to the town hall to register. Andreas raised his right hand and took the voter's oath, and signed his X on the line. He was then given his ballot to bring home with him and his name went on the town register.*

*I started going over the ballot with him about a week before Election Day. The day before the election, I told him that the time had come, and went to get the ballot. The return envelope and his registration documents were there, but no ballot! I went into a panic and frantically searched the house. Then I had a thought – I went into Andreas' room, and there it was. He had taken it himself. He hadn't folded it or torn it or rolled it, as he usually does with paper. He had simply put it there at his bedside.*

*We sat down to mark the ballot. He did a clear point for his presidential choice. I confirmed it...I filled in the black dot. Then we went to the Governor's race. That appeared to be all the offices where he wanted to cast a vote. When I went to vote, I hand carried his envelope and gave it to one of the election judges at the polls. Our town is small, and all the judges at the table celebrated with me that Andreas is now a full, participating citizen of our town, state, and country!*

*-- Susan, Andreas' mother*

## Home Supports

<b>Numbers Served – FY 2008</b>	
Number of homes (6/30/08)	1,234
Average number of people per residential setting	1.2
<b>Total people getting home supports (6/30/08)</b>	<b>1,479</b>

**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

- **Shared Living/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 – 1,143**

**Number of homes – 979**

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

**Number of people – 215**

**Number of homes – 209**

- **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 – 81**

**Number of homes – 18**

- **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.

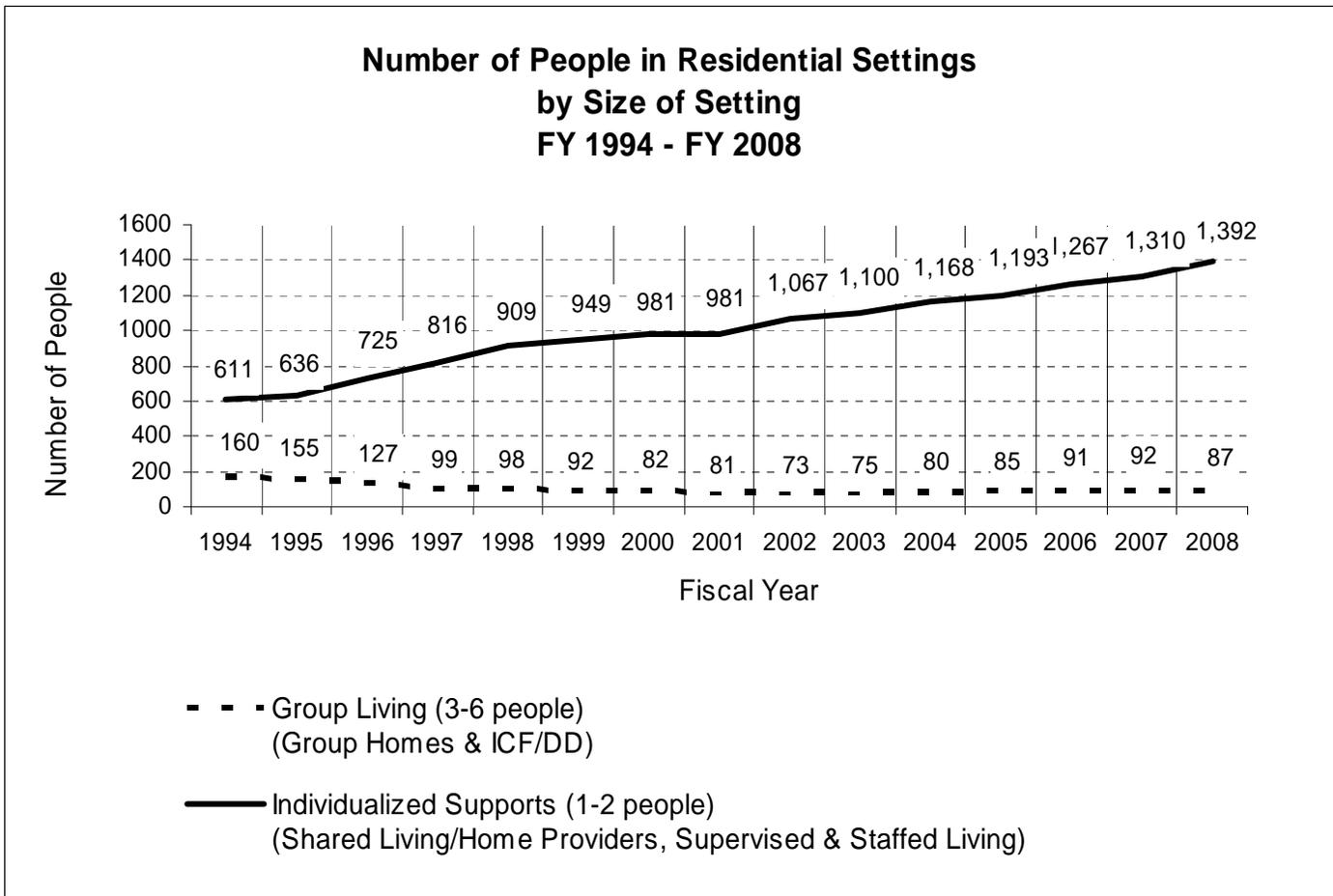
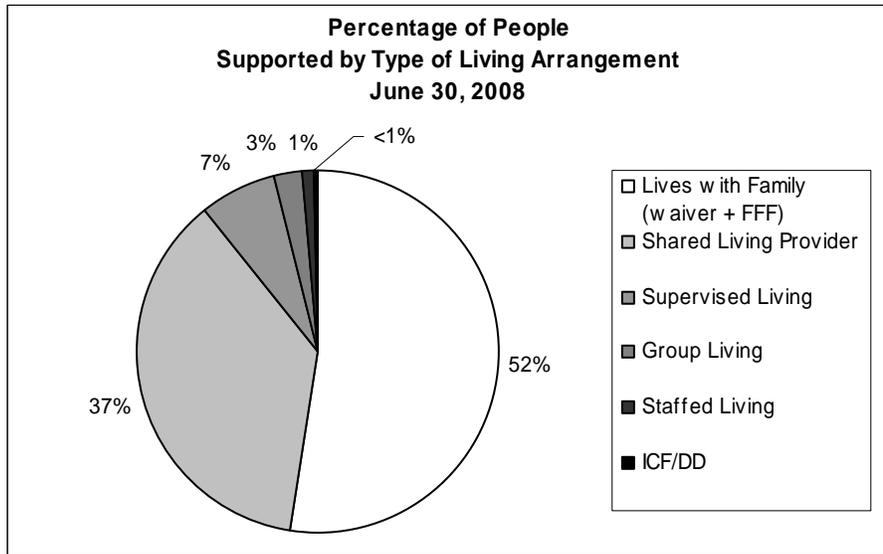
**Number of people – 34**

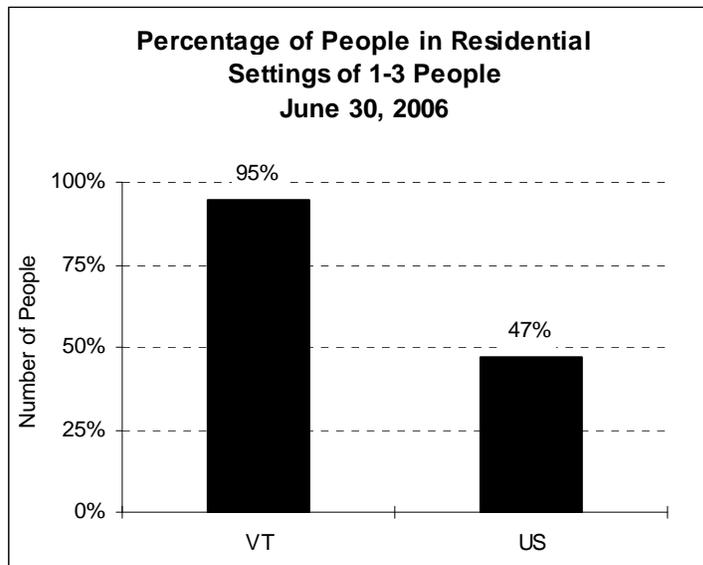
**Number of homes – 27**

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

**Number of people – 6**

**Number of homes – 1**

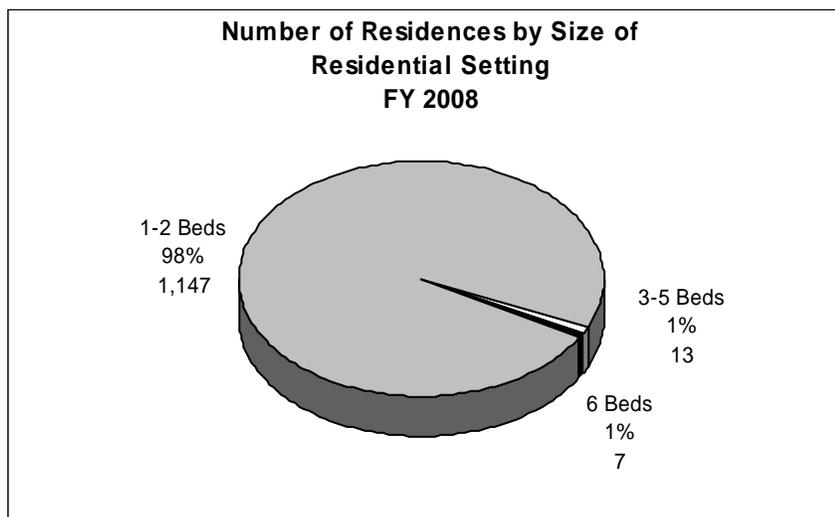




Source: Prouty, R, Albla, K. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, August 2008.



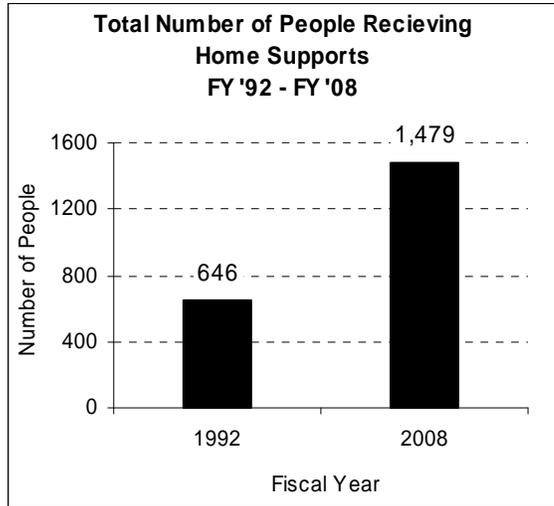
Vermont is the only state in the country that has **100% of the people** funded for home supports living in residential placements with **six or fewer** people receiving services<sup>23</sup>.



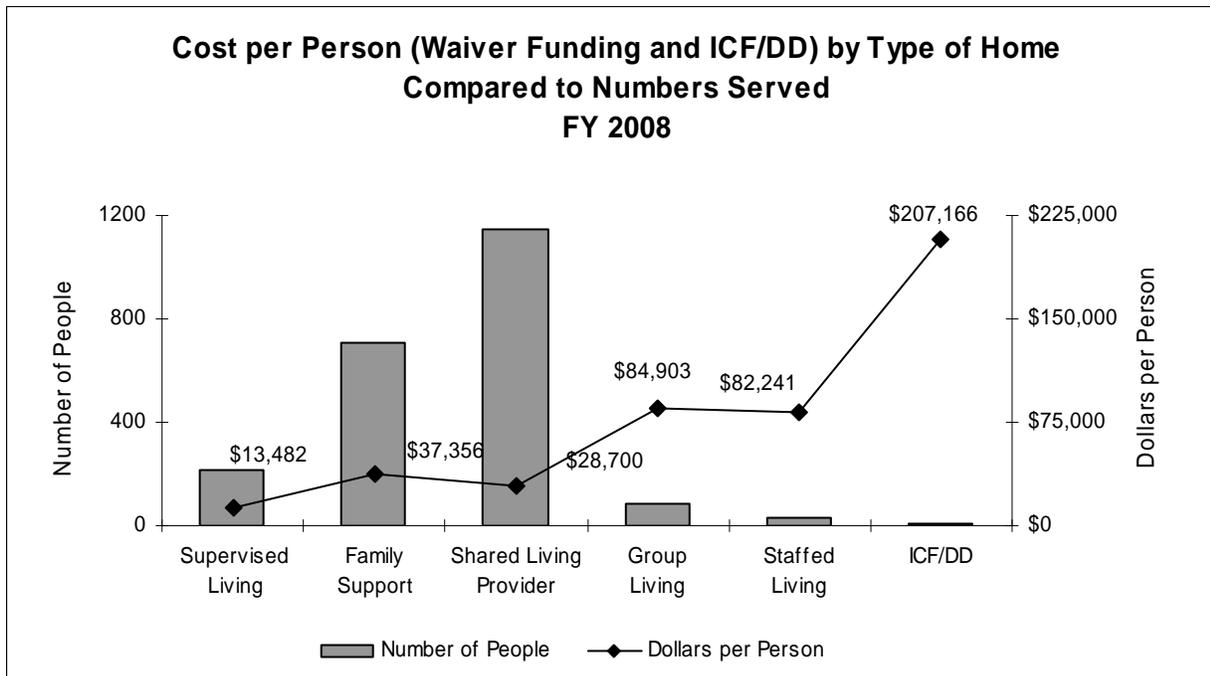
<sup>23</sup> Source: Prouty, R, Alba, K. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, August 2008.



Home supports has steadily increased, yet Vermont has maintained an average of **1.2 people supported per residential setting**; still the lowest rate in the country compared with the national average of 2.7<sup>24</sup>



**Home safety reviews were conducted on 289 homes and accessibility reviews were done on three homes in FY '08.** Of those inspected homes, 92% were in compliance or became in compliance. There were a remaining 16 homes that had not yet met compliance at the end of 2008.



Note: The Family Support dollar figure is the person's full waiver amount including Community and Work Supports. ICF/DD dollars also include all 24 hour supports.

<sup>24</sup> Source: Prouty, R, Alba, K. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, August 2008.

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## SHERRY'S STORY

*Sherry is a 44-year old woman who adores any kind of animal – especially dogs, horses and camels. She has Prader-Willi Syndrome (PWS) which causes chronic hunger and slow metabolism. Many people with PWS are not able to live in a family setting due to food restrictions, rapid weight gain and behavioral issues, resulting in people living in group homes.*

*However, Sherry was fortunate to find Rose, a shared living provider who was willing to give Sherry a chance. The beginning few years were very rocky and filled with crisis. There were many hard days but neither Sherry nor Rose gave up.*

*It is now seven years later. The bond between these two women is special and can be described as mother and daughter. Sherry has lost a significant amount of weight and her subsequent medical issues are under control.*

*Rose's dedication has given Sherry a second chance for things she never had....a chance for love and family.*

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### THREE YOUNG MEN

*This is a success story of three young men with developmental disabilities. Once they got out of High School, they all wanted to work, live independently, get a driver's license, save money for a car and become members of their community.*

*Each of these young men is unique. They each have different work skills, different outlooks on how to live independently and different social skills, but all wished to be productive members of their community.*

*I met these men over the course of six years, working with them to find gainful employment. Though I was their Employment Training Specialist, it is important for an individual to be socially integrated in the community and have their wants, needs and desires fulfilled to be successful with employment.*



*Pictured from left to right: Ben, Jordan and Andrew*

*I first met Jordan when he graduated in 2000. I found him several different jobs during a three year span. He finally settled down with a job he excelled at working for Dartmouth College Dining Services. He got his drivers license and bought a car with the money he saved. But, he was still living at home with his parents and was not completely satisfied as he was not living independently.*

*I met Andrew in 2004. He was already working, but not happy with his job. He was also still living with his parents. He felt he was too old to live at home and they lived too far from where he worked and he had no real friends. He already had his driver's license and a car.*

*Ben, the third young man, graduated in 2006. He had many skills that prepared him for work. He had attended a private High School in Massachusetts and so had lived away from home. He did not want to live with his parents, did not drive and needed a job. I found him a job as a prep cook and maintenance man at a local restaurant. Still he did not want to live at home with his parents.*

*In the summer of 2006 all these young men's dreams were about to come true and yet they did not even know each other. I spoke to my Director about the idea of finding these three young men a house that they could share and to live independently. I spoke to all their parents about this before I proceeded and they all thought this was a great idea. I introduced the young men to each other during lunch outings and meetings at my office. They all got along and they were excited about the idea. Fortunately, a four bedroom house used by the agency became vacant. I took the young men with their parents to look at the home. They were all pleased. The process began for them to move in.*

*They all had different skills to share and were eager to teach each other. Each gained new independent living skills and new social skills. They all became friends and, through each others friends, a new network of socialization and support in the community began. They helped each other with rides to work when needed, went shopping together for household items and they worked together as a team cleaning the house. As they all now lived close to their jobs, this made things easier.*

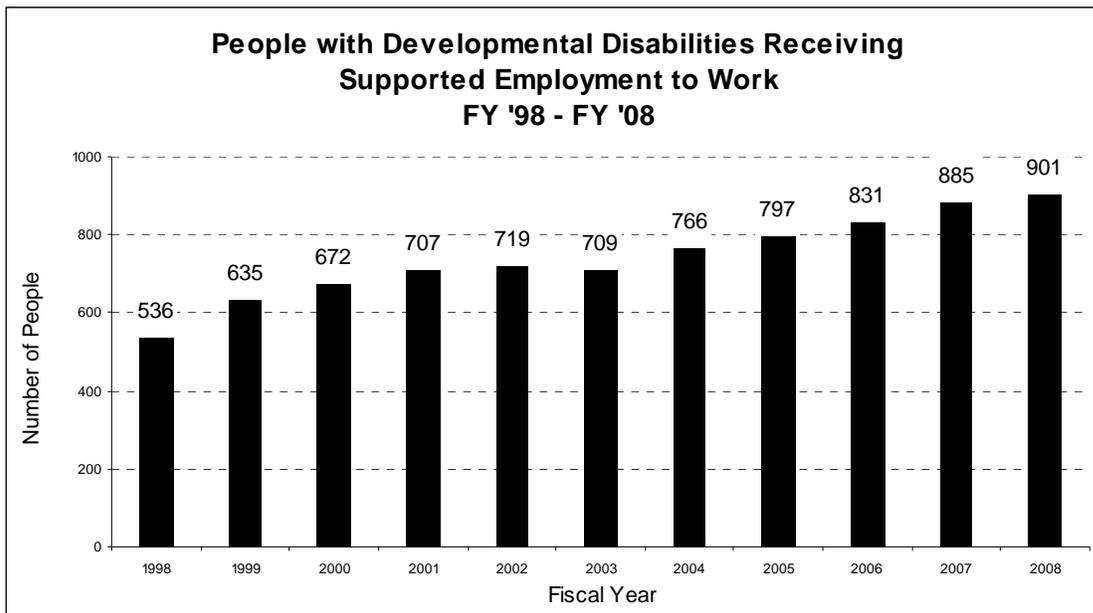
*It has been almost two years since they rented this home together. They all have had some bumps in the road, but as a team they worked through the tough times and found ways to overcome obstacles in their way to continue to live their dream.*

-- Robert Burdette, Team Leader II  
HCRS – DS Division, Employment Services

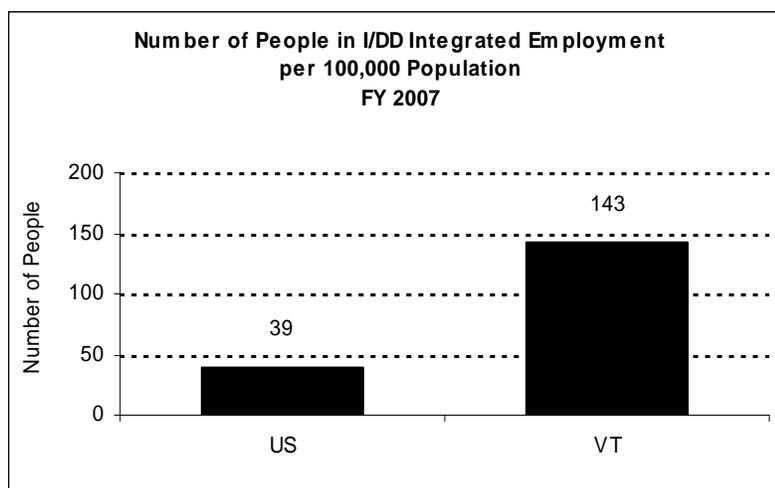
## Employment Services

<b>Numbers Served – FY 2008</b>	
Average hourly wage	\$8.34
Average hours worked per week	10 hrs./week
Estimated public benefits (SSI) saved	\$1,582,429
<b>Total people employed</b>	<b>901</b>

**Employment Services** assist individuals to achieve career and work goals; and include employment assessment, employer and job development, job training and ongoing support to maintain employment. Workforce inclusion generates a lasting positive impact to the person and to the public by way of an increased presence of people with disabilities in the social fabric of Vermont. Supported Employment is funded through a collaborative effort between the Division of Disability and Aging Services and Division of Vocational Rehabilitation (VR) by using home and community-based waiver and VR Supported Employment grant funds.



**38% of working age adults receiving developmental services are supported to work.**



Source: Butterworth, J., Smith, F., Hall, A., Migliore, A., Winsor, J. *StateData: The National Report on Employment Services and Outcomes*. Institute on Community Inclusion/UCEDD, University of Massachusetts Boston, Fall 2008.

↪ The average wage for people receiving employment services (\$8.34) is **9% higher than minimum wage** in Vermont in 2008 (\$7.68).

↪ A new self-employment initiative started several years ago has assisted more individuals to become self-employed in a micro business. **Thirteen (13) individuals are currently self-employed** working 2 to 24 hours per week.

**Self-employed wage earners tend to earn a higher rate –  
making between \$12.50 and \$16.96 per hour.**

↪ Vermont is **ranked #1** in the nation (FY '06) in the number of people with developmental disabilities **who receive supported employment to work** per 100,000 of the state population<sup>25</sup>.

↪ Vermont is **ranked 4<sup>th</sup>** nationally (FY '06) in people in supported employment as a proportion of **total people getting community supports and/or work supports**<sup>26</sup>; 48% in Vermont compared with the national average of 22%.

↪ Of those adults with developmental disabilities interviewed in Vermont who are unemployed, **59% said they want a paid job**<sup>27</sup>. Of those interviewed who have jobs, **52% said they want to work more hours**.

<sup>25</sup> *The State of the States in Developmental Disabilities*: Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Revised Report, 2008.

<sup>26</sup> Ibid.

<sup>27</sup> Data is based on results from *Survey of Adults Receiving Developmental Services in Vermont – Spring 2008*, Consumer Survey Project, Division of Disability and Aging Services, State of Vermont.

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## HAROLD'S STORY

*Harold will be celebrating his 13th year anniversary this May working for Black River Produce of North Springfield. He understands that work gives him a sense of security, accomplishment and self-worth. He long ago learned to handle his own money and the value of having his own income, yet would be the first to admit that his paycheck is not the most important benefit from his job. Harold truly loves his job and the people with whom he works. That feeling is returned by his many co-workers who appreciate his dedication, work ethic, and gentle nature.*

*Harold is a tall soft-spoken gentleman, whose quiet and polite demeanor conceals a subtle sense of humor and inquisitive mind. He is an avid reader of history and Hardy Boys books, and greatly looks forward to Friday, his day for banking and the library.*



Business owners Steve and Mark with Harold



*Harold has been served by Health Care and Rehabilitation Services Employment Services Program for over 20 years. In the past, Harold had been described as someone who seemed uninterested in things and dependent on others. Family members now say that his work experiences helped him grow and mature to the point where he became much more outgoing, independent, and interested in life in general.*

*Harold expressed some anxiety about starting work many years ago, and has said he had some jobs he did not like. But all contributed to his growth and increasing sense of independence and self worth. His length of service at Black River Produce is truly admirable. He rarely misses a day of work and as the Operations Manager has said on more than one occasion, "I wish all our employees were like Harold."*

*Harold is a great example of the dignity and power of work to make positive changes in a person's life.*

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## SCOTT'S STORY

*Scott's accomplishments are the quiet ones; the kinds that often get overlooked but are really the basis of United Counseling Service's success. His work history goes back to 1999 when he began his career as a kitchen/utility worker at Southwestern Vermont Medical Center. He has continued in that role since 2004 at Bennington College. With the support of Jules from Employment Connections, United Counseling Services' supported employment program, Scott has honed and widen his skills over the past nine years so that he works independently and manages his own transportation.*



*His supervisor says, "Scott has come a long way.... He comes in whenever we need him. He is a highly valued employee; we can count on him whenever we call. He loves to be with people in the work environment."*

*Scott says, "I like going to work; the best thing is running the dish line – putting them in (the dishwasher)." Scott works 5 days a week. He is proud of his abilities and enriched by the people he has gotten to know. He contributes to his employer, to the community and to his family.*

*What greater success can there be?*

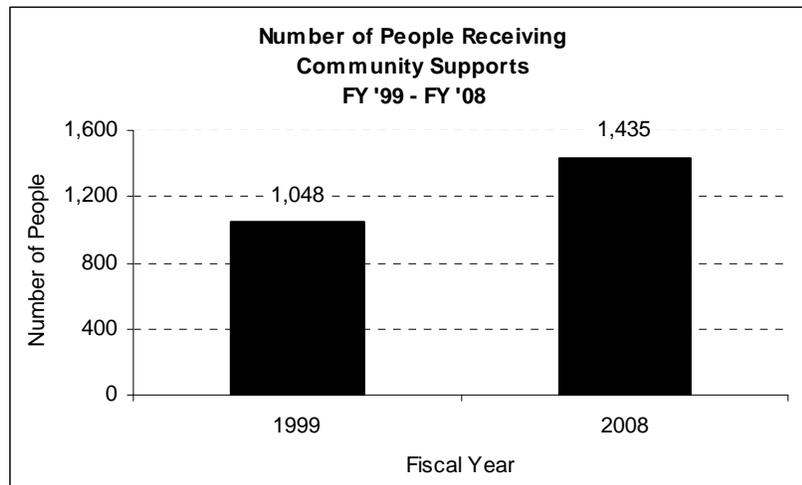
## Community Supports

<b>Numbers Served – FY 2008</b>	
Total annual cost of community supports	\$22,675,609
<b>Total people receiving community supports</b>	<b>1,435</b>

**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.



Adults getting developmental disability services in Vermont continue to express their desire to **have more community activities** (45%) and to **get help to do or learn new things** (55%)<sup>28</sup>.



<sup>28</sup> Data is based on results from the *Survey of Adults Receiving Developmental Services in Vermont – Spring 2008*, Consumer Survey Project, Division of Disability and Aging Services, State of Vermont.

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## Julie's Story

*Julie keeps track of everyone's birthdays, and takes it upon herself to call the local radio station regularly so their Birthday Show is up to date. So when she heard about Disability Mentoring Day, she told us her dream; to go to the radio station and go on the air and do birthday announcements.*

*The local Disability Mentoring Day coordinator arranged a special meeting between Julie and the radio station's General Manager. When she got there the office recognized her from her voice! It was as though she had become an instant celebrity.*

*The General Manager gave her a full tour, including the recording studio where she recorded her own lead-in for the station's Birthday Program; the fulfillment of her greatest wish. The next morning it was played not once – but 4 times!*



## Family Supports

<b>Numbers Served – FY 2008</b>			
<b>Funding/Supports for Families</b>	<b>Adults (22 and over)</b>	<b>Children (under 22)</b>	<b>Total</b>
Flexible Family Funding recipients	117	855	<b>972</b>
Home and community-based service recipients	497	214	<b>711</b>
Respite/In-home supports	387	192	579
Other Supports (Employment/Community Supports)	424	71	495
(Duplications between FFF and HCBS recipients)	(29)	(23)	(52)
<b>Total family supports (unduplicated)</b>	<b>585</b>	<b>1,046</b>	<b>1,631</b>

**Family Supports** include Flexible Family Funding or home and community-based supports funded under GC (e.g., respite, family support, employment services, community supports) to people living with their biological 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 \$1,300 per year<sup>29</sup>.
  
- **Home and Community-Based Services Funding (HCBS):** 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.



Almost **one third (31%)** of people who receive home and community-based services **live with their family**.

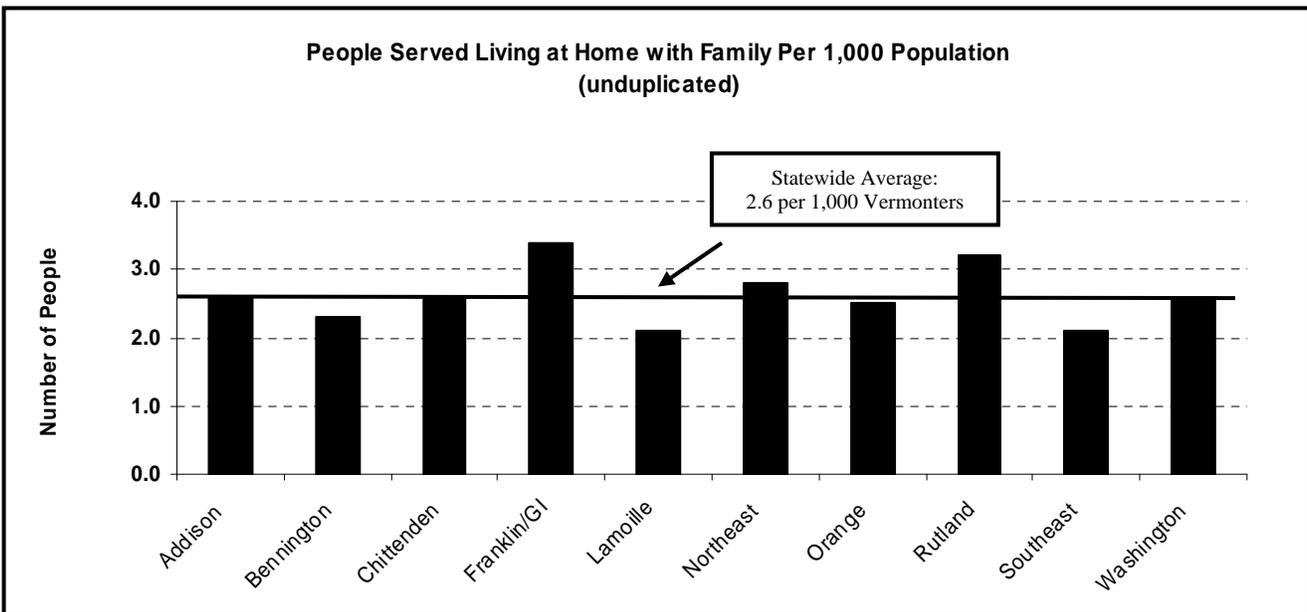
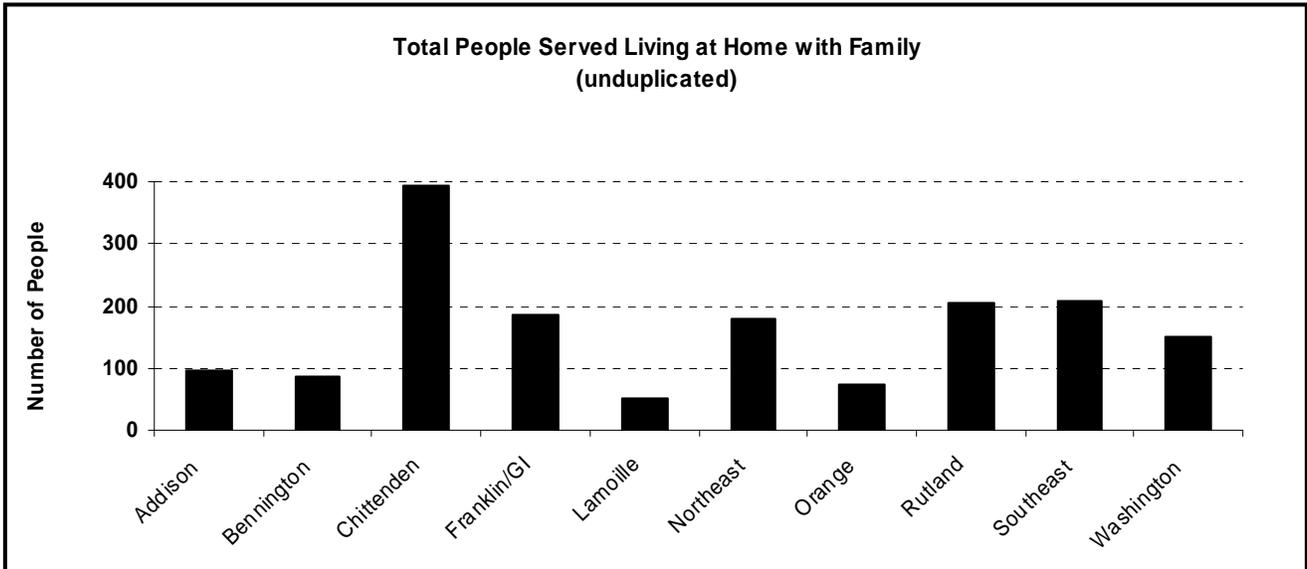


**58 people self- or family-managed** all of their own services in FY 2008.

People receiving family support represents **46%** of all people served with DD funding.

<sup>29</sup> The Flexible Family Funding maximum family allocation was increased from \$1,122 to \$1,300 as of 7/1/07. The sliding scale used to determine the amount of Flexible Family Funding a family is eligible for was also adjusted as of 7/1/07.

### Family Support to People Living at Home (Flexible Family Funding and Home and Community-Based Services) FY 2008



-  The Division of Disability and Aging Services funded **four respite homes** around the state in FY '08 to provide planned out-of-home respite support to **36 eligible individuals for a total of 466 days**.
  
-  Vermont **ranks 4<sup>th</sup>** in the country in terms of **total family support spending** per \$100,000 personal income<sup>30</sup>, and **ranks 6<sup>th</sup>** in terms of **total intellectual/developmental disability (I/DD) budget**.
  
-  The number of families getting **Flexible Family Funding doubled** in the past ten (10) years.
  
-  **Ninety percent (90%)** of Flexible Family Funding is used for **Goods**, with the remaining **10% used for Respite**.

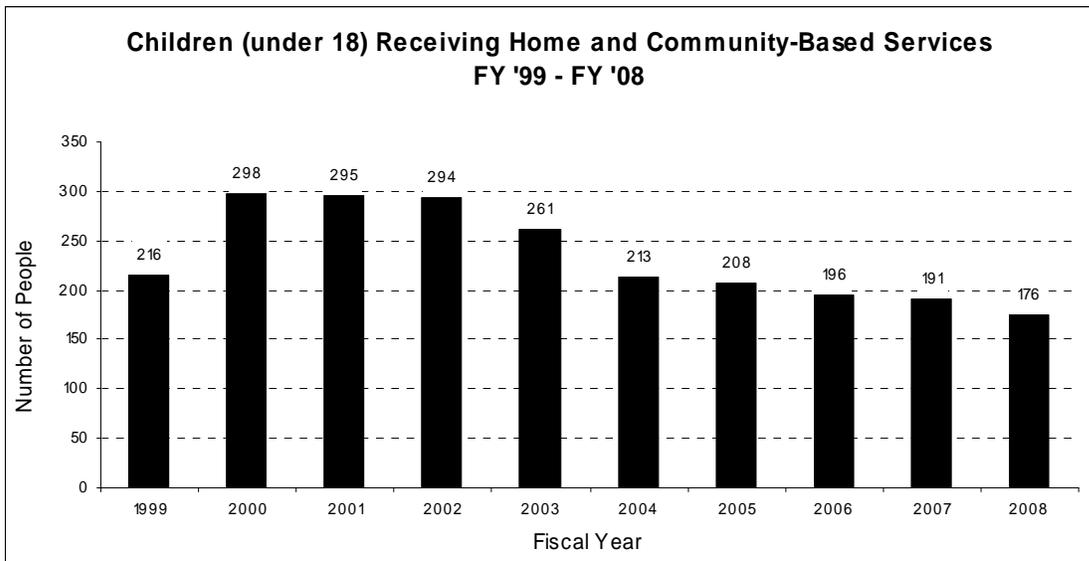
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<sup>30</sup> *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Revised Report, 2008.

## Children’s Services

<b>Numbers Served – FY 2008</b>				
<b>Funding/Support for Children</b>	<b>Birth – 6</b>	<b>7 – 17</b>	<b>18 – 21</b>	<b>Total</b>
Flexible Family Funding recipients	182	522	151	<b>855</b>
Home and community-based service recipients	3	173	163	<b>339</b>
Lives with family	1	121	92	214
Does not live with family <sup>31</sup>	2	52	71	125 (50 w/DCF)
Other: Targeted Case Management or vocational grant only	10	35	31	<b>76</b>
(Duplications between FFF and HCBS recipients)	(0)	(11)	(18)	<b>(29)</b>
<b>Total children services (unduplicated)</b>	<b>195</b>	<b>719</b>	<b>327</b>	<b>1,241</b>

**Children’s Services** are provided to children and youth with developmental disabilities who live with their biological or adoptive families and children who live with other individuals (e.g., foster family, other relatives). 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 other supports.



<sup>31</sup> The two children under age 7 who are listed as “not living with family” live in a shared parenting situation and therefore live with family on a part time basis. Fifty (50) of the 52 children ages 7 – 17 who do not live with family are in state custody and/or have their services paid for through the Department for Children and Families (DCF) and received a range of supports from developmental disability services providers. These numbers include people who terminated services during the year.

## Medicaid Entitlement Services

<b>Numbers Served – FY 2008</b>	
Children’s Personal Care Services recipients	<b>1,752</b>
High Technology Home Care recipients	<b>109</b>
(Duplications between CPCS & HTHC recipients)	<b>(57)</b>
<b>Total people served</b> (unduplicated)	<b>1,804</b>

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

**Demographics of CPCS enrollment – FY ’08:**

- **1,880** Total number of people who were approved for CPCS funding
- **93%** Percentage of people who used some or all of their allocated CPCS funding
- **6%** Increase in people receiving CPCS funding from last year
- **12** Average age of children who received CPCS
- **22** Average hours authorized per week for CPCS
- **65%** Percentage of hours used out of total hours allocated
- **44%** Percentage of people getting CPCS who also receive developmental disability home and community-based funding and/or Flexible Family Funding
- **95%** Percentage of CPCS that are family-managed
- **5%** Percentage of CPCS that are provided by an agency

**High Technology Home Care (HTHC)** is an array of intensive home care services for both adults and children; though the majority (75%) of the 109 recipients were children under age 21. The program provides skilled nursing care and high technology aides, and coordinates treatments, medical supplies and sophisticated medical equipment for technology-dependent Medicaid beneficiaries. The goal is to support the transition from the hospital or other institutional care, to the home, or prevent institutional placement.

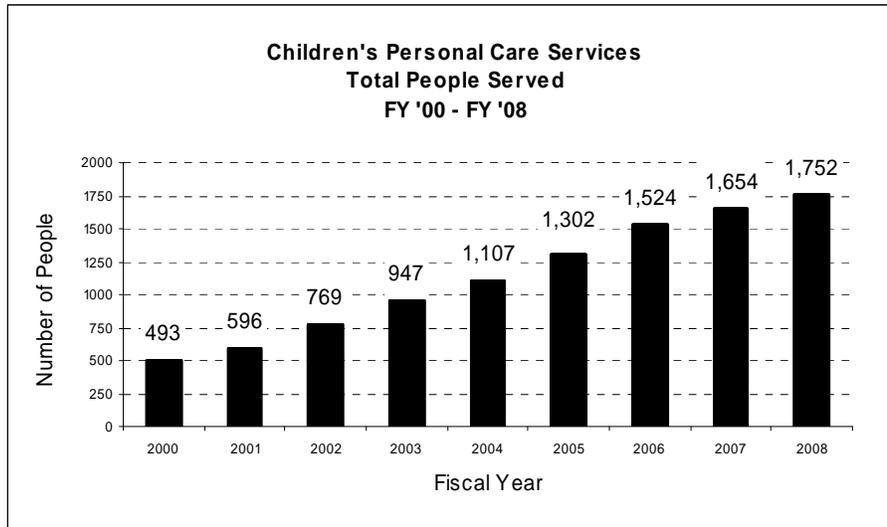
**Cross-over of funding for people who get CPCS<sup>32</sup>:**

- **601 children** also get Flexible Family Funding
- **180 children** also get home and community-based funding
- **57 children** also get High Technology Home Care

**Cross-over of funding for people who get HTHC:**

- **25 people** also get Flexible Family Funding
- **14 people** also get home and community-based funding

<sup>32</sup> The eligibility definition for CPCS and HTHC is broader than the Vermont definition used for developmental disability services.



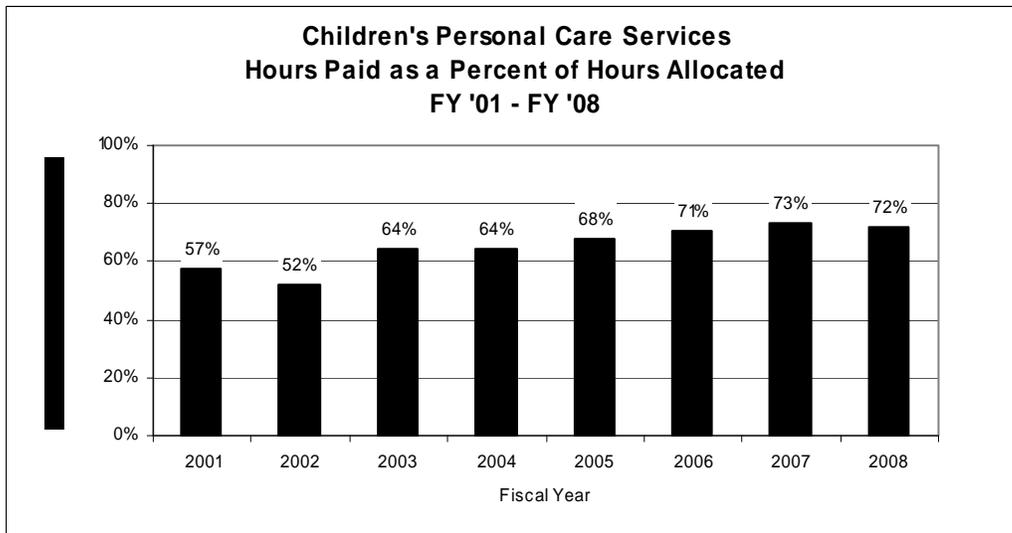
Unified Services Plans continue to be an option for addressing intensive and/or unmet medical and/or behavioral needs. In FY '08, **16 additional individuals had services unified.**



Children's Personal Care Services launched "**Children's Creative Connection**" (C3), a pilot designed to increase access to therapeutic services and goods through CPCS. The premise of this pilot is that greater flexibility breaks down barriers to services and allows access to a wider array of services to assist in a child's self-care skill development.



The **High Technology Home Care** program worked closely with Children's Personal Care Services in **reviewing eligibility and diagnoses.** A specific population that was identified as sometimes requiring on-going nursing supports is toddlers diagnosed with uncontrolled juvenile diabetes. A plan to include this population in eligibility for HTHC services was implemented.



## Clinical and Crisis Services

<b>Vermont Crisis Intervention Network Numbers Served – FY 2008</b>	
Level II – Technical assistance Number of people supported (est.)	111
Level III – Crisis beds	
Number of stays	31
Number of total days	566
Avg. length of stay (range 2-63 days)	18 days

**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):** 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.



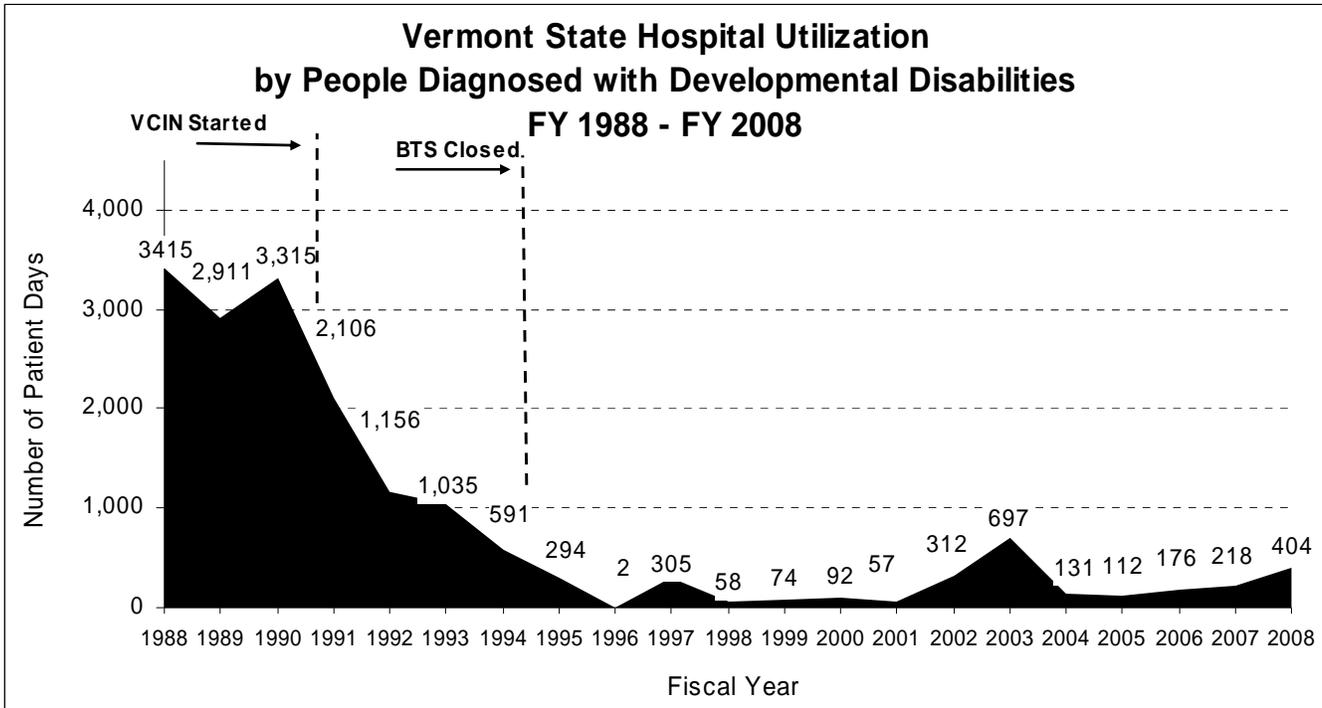
The availability of the statewide Human Rights Committee to **review restraint procedures and the provision of training in the development of positive behavior support plans** have assisted agencies to provide safer and more effective supports to people with the most challenging needs.



Human Rights Committee reviewed **11 Behavior Support Plans** in FY '08.



The **Vermont Crisis Intervention Network** continues to help maintain **low usage of the Vermont State Hospital** by people diagnosed with developmental disabilities<sup>33</sup>.



<sup>33</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 disability services. It does include people served by developmental disabilities services but paid in full by mental health or who were grandfathered into services by having received services on 7/1/96, but who are not diagnosed with Intellectual or Developmental Disabilities (I/DD). As of FY '97, these numbers include people diagnosed with Pervasive Developmental Disorders (PDD). The spikes in 2003 and 2008 were due to one person's stay lasting the full year (365 days).

## Nursing Facilities

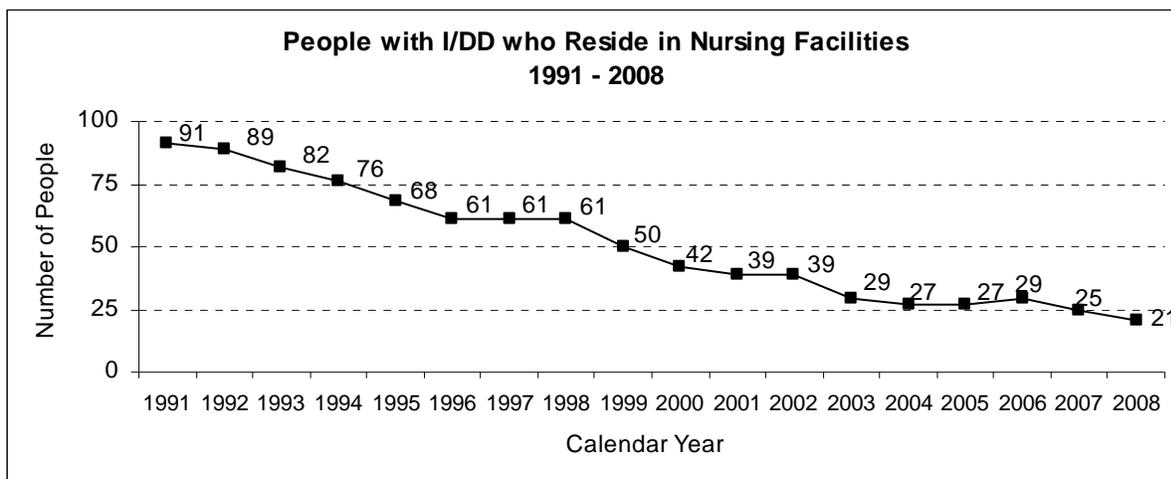
<b>Numbers Served – December 31, 2008</b>	
People receiving specialized services	11
PASARR screenings	12
Diversions to keep people out of nursing facilities	6
Community placements of people from nursing facilities	4
<b>Total people living in nursing facilities<sup>34</sup></b>	<b>21</b>

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

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



In 2008, there was an **all-time low of 21 people with I/DD in nursing facilities**. This decrease in residents with I/DD in nursing facilities was accomplished, in part, through a combination of diversions through pre-admission screening and placements to more individualized community settings<sup>35</sup>. Additionally, as would be expected from this older population, a number of deaths also contributed to the decrease.

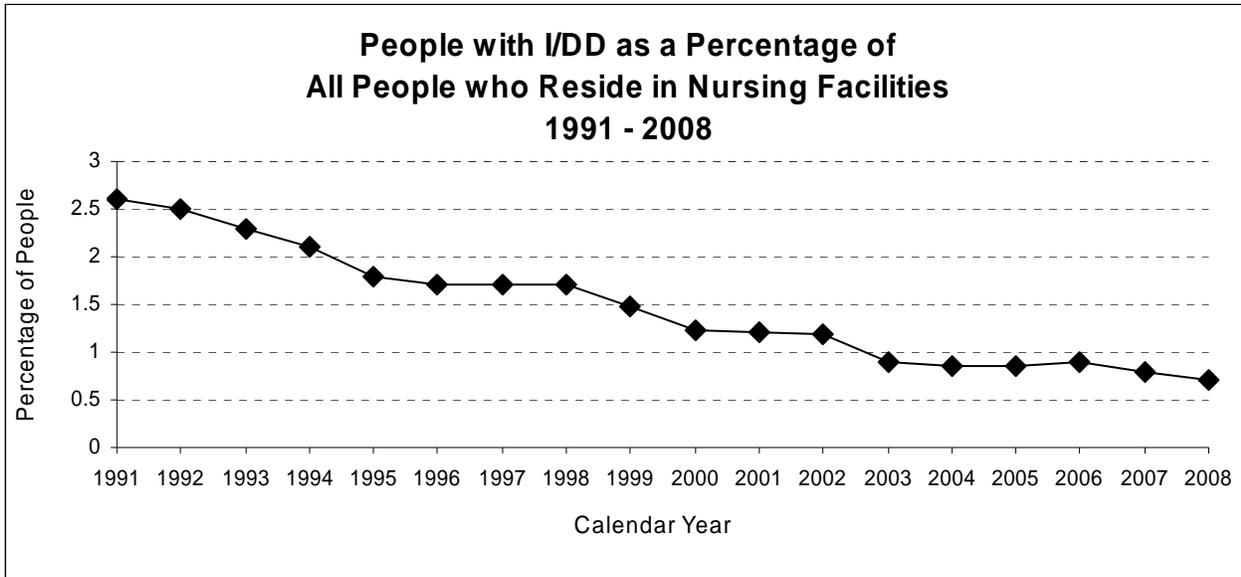


<sup>34</sup> PASARR uses the federal definition of “mental retardation or related conditions.” The terminology used in this report is “intellectual/developmental disabilities” (I/DD)

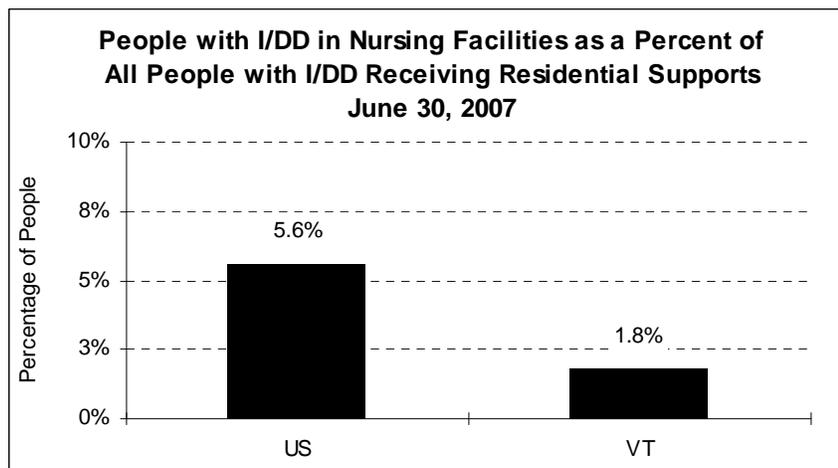
<sup>35</sup> Based on the initial 1988 screening that found 125 people with I/DD living in nursing facilities.



The national utilization rate of people with Intellectual/Developmental Disabilities (I/DD) living in nursing facilities was 10 per 100,000 of the state's general population<sup>36</sup>. **The Vermont rate for people with I/DD living in nursing facilities was 5, well below the national average.**



The number of people in Vermont with I/DD in nursing facilities compared to all residential services for people with developmental disabilities in Vermont was **1.8%** in 2007, considerably **lower than the national average.**<sup>37</sup>



<sup>36</sup> *The State of the States in Developmental Disabilities: 2008*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Preliminary Report, 2008.

<sup>37</sup> Residential supports in this context include home and community based waiver, ICF/DD and nursing facilities. Source: Prouty, R, Alba, K. and Lakin C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2007*. Research & Training Center on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, August 2008.

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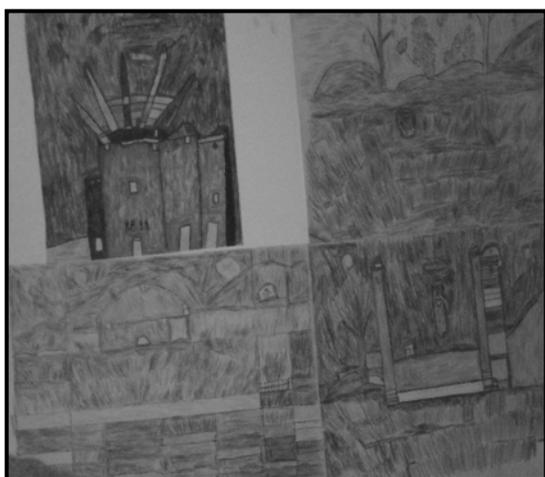
## RODNEY'S STORY

*Rodney is a movie aficionado and loves science-fiction movies and all the Star Wars films. He can recite them almost verbatim. He is also an incredible artist and draws elaborate pictures, each with a story to tell. His passion is his art work.*

*This year, with the help of his shared living provider and a college student, he created his own children's comic book. It was a compilation of his many pictures and the story that ran along with them. It is the story of the "Blob."*



*Once the book was completed, he and his assistant had two public readings of his book; one at the St. Albans Library for story hour with children and the other at a local café for the general public. Because of his new connections, both events were very well attended. His mother and his sister came to St. Albans to attend the festivities, too, making the events even more special for him. This was a long time dream come true.*



*Rodney wishes someday to have his story published. As a start, he has created a calendar based on illustrations from his book. His many loyal fans hope soon to have their own copy of the calendar.*

## Self-Advocacy

**Green Mountain Self-Advocates (GMSA)** is a statewide self-advocacy network in which people who have a developmental disability, in partnership with allies, families and friends, speak-up, become leaders, work together, and make a difference on issues that are important to them. People with developmental disabilities are supported to direct network educational and mentoring activities. In 2008 there were 18 local self-advocacy groups supported by GMSA. See **Attachment I: Green Mountain Self-Advocates Local Chapters and Map**.

The core activities of GMSA are:

- Self-advocates teach workshops for youth and adults with developmental disabilities; lead workshops and provide technical assistance to providers and family members; and present to the public at large. Topics include:
  - Introductory Self-Advocacy
  - Sexuality
  - Voting
  - Personal Safety
  - Peer Leadership
  - Independent Living
  - Disability Awareness
  - How to Start and Run a Self-Advocacy Group
  - Supporting a Person to Direct their own Services
  - How to be an Active Member of a Board/Committee
  - How to Include People with Disabilities on Boards and Committees
  - ADA Accommodations for People with Intellectual Disabilities
  - Myth-busters: Debunking Stereotypes about People with Developmental Disabilities
  - Know your Legal Rights
  - Legislative Advocacy
  - Supportive Decision-Making
  - Self-Determination
  - Reaching My Own Greatness
  - 7 Habits of Highly Effective Teens
  - Orientation Training for Agency Staff
- GMSA facilitates the establishment of new self-advocacy groups and supports those already meeting.
- Self-advocates are supported to 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).

**Why Self-Advocacy?:** Self-advocacy is the civil rights movement for people with intellectual and developmental disabilities. In Vermont it refers to people receiving developmental services taking control of their own lives, including being in charge of their own services (to the maximum extent possible). Vermonters with intellectual disabilities are extremely vulnerable to abuse due to their social and physical isolation. Difficulties with reading and communicating, combined with other challenges, are barriers for people with intellectual disabilities. The self-advocacy movement seeks to reduce the isolation of people with developmental disabilities and increase their abilities and opportunities to speak up and take greater control over their own lives.

## Highlights



**Agency Staff Training Curriculum:** GMSA developed a curriculum for self-advocates to train employees of developmental service agencies to maximize a person's ability to make his/her own decisions and to hire, train and evaluate support staff. The curriculum includes over 8 hours of activities proven effective at recognizing and challenging everyday misconceptions about disability. It incorporates best practices to support self-advocacy and empower people with disabilities to speak up for themselves and to change the way society views them. A 2-day training of trainers was conducted for 12 local agency teams consisting of 58 trainers with and without developmental disabilities.



Collaborated with Planned Parenthood of Northern New England to provide a second **Peer Sexuality Educators Training** for 17 adults with developmental disabilities and 12 agency staff. The 3-day training and follow-up technical assistance taught self-advocates to provide non-biased, accurate information about sexuality and relationships; understand the qualities of a sexually healthy adult; and master skills to be a good peer educator. This training includes an introduction to using a curriculum co-authored by GMSA for peer educators to use when teaching sexuality to people with developmental disabilities.



Twenty-one (21) youth and adults with developmental disabilities were supported to present seven workshops at a **national self-advocacy conference**. The workshops described effective practices used in Vermont to support people with developmental disabilities.



GMSA developed the **Get the Life You Want Toolkit** for youth with developmental disabilities transitioning out of high school and into adult services. This resource includes stories written by adults with developmental disabilities on 25 different issues high school students struggle with as they transition out of special education services into living in the "real world".



GMSA worked with Planned Parenthood of Northern New England, and DDAS staff to present **Celebrating Sexuality**, the second Vermont conference on issues of sexuality and relationships in the lives of adults with developmental disabilities. The same one-day conference was held in both Burlington and Killington with over 220 people in attendance.



GMSA taught two 2-day leadership retreats to high school students with developmental disabilities and their teachers. The **7 Habits of Highly Effective Teens** curriculum, adapted by GMSA, provided steps for becoming assertive, achieving goals, resisting peer pressure, participating in decision-making about life choices and practicing communication and listening skills.



GMSA completed the second year of piloting three **Hire Up!** employment support groups facilitated by people with developmental disabilities to encourage those reluctant to work to seek employment and people underemployed to look for a job better matched to their interests. The peer facilitators were supported to develop a 16 session facilitator's guide including 15 stories written by workers with developmental disabilities.



**Produced two newsletters** with stories and pictures about people with developmental disabilities working and living in their communities and actively involved in self-advocacy.



Collaborated with the Vermont Center for Independent Living and Vermont Network Against Domestic and Sexual Violence to make **programs for survivors of abuse more accessible** to women with disabilities.

### Areas of Focus



Increase **public awareness** about self-advocacy and continue collaborating with Vermont Center on Independent Living to **increase accessibility** for all people with disabilities.



Increase the capacity of self-advocates, and their providers and families to **support people with developmental disabilities to express their sexuality**.



Support people with developmental disabilities to be actively involved in the political process by **voting and communicating with their elected officials**.

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## TODD'S STORY



*I am Todd Washburne and I am autistic and cannot communicate in the usual ways, nor could I for 39 years. I think it was a Godsend that I was allowed to learn fc [facilitated communication] in my early thirties and deeply regret that it took me so long to realize that I could use it for my own benefit. I am starting to talk but I will have to work hard for a long time to get to a point where it is useful. I am starting to be able to learn new phrases but it is not a natural thing for me. I have the ability to start things but I cannot keep it going long enough.*

*I think it is short sighted to even think about speech when I can do so well with fc. Yet I believe speech is somewhere in my future. I think I am having to be a big man about life and just do the best I can. In the meantime I need to have good facilitators so I can make my life goals better and keep moving forward.*

*I think the reason I have done so well with fc is that my mom has pushed me and challenged me consistently and we do lots of typing all the time. I am less complimentary about the agency's support of the facilitators and making good people available to me. I do think I am making progress in having better people from the agency if the individuals stick with me now.*

*I am working hard on many goals at once towards making myself a better adult like a real high school diploma and college. I am hoping to be a professional writer some day. I think I have a long way to go at this point but I am determined to succeed. My home is my biggest help in my journey including advocating for more things that a responsible adult does. I recently testified at Legislature about budget cuts. I don't think my mom knew all these years she was raising an activist. How the world changes is indeed fascinating.*

## Office of Public Guardian

<b>Caseload – June 30, 2008</b>	
Guardianship services (developmental disability specialty)	581
Guardianship services (aging specialty)	51
Case management (developmental disability specialty)	7
Guardianship services – pending (developmental disability specialty)	10
Guardianship services – pending (aging specialty)	3
Commitment order – Act 248 (developmental disability specialty)	31
Commitment order – pending (developmental disability specialty)	3
<b>Total people in Office of Public Guardian program (unduplicated)</b>	<b>675</b>
<b>Total representative payee services</b>	<b>309</b>

**The Office of Public Guardian** provides guardianship and other court-ordered supervision when a person is unable to make basic life decisions and there are no friends or family to serve as guardian. Under Vermont law, the Office of Public Guardian is authorized to provide guardianship to:

- **Adults who have developmental disabilities, or**
- **Individuals who are age 60 or older.**

The program has a staff of 25 public guardians, a public safety specialist, a director and an administrative assistant<sup>38</sup>. The two-person representative payee staff was reduced by one employee in January 2009 because of budget cuts.

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

The Office of Public Guardianship provides:

- **Guardianship** to adults with developmental disabilities and adults age 60 and over.
- **Representative payee services** for governmental benefits for more than 300 people. This service is provided to people under guardianship as well as an alternative to guardianship.
- **Case management supports** where this service can provide a less restrictive alternative to guardianship.
- **Supervision of offenders with developmental disabilities** placed on Act 248 commitment after being found not competent to stand trial.
- **Court-ordered evaluations** for Probate and Family Court guardianship cases.
- **Public education** on guardianship and alternatives to guardianship.
- **Recruitment and support for private guardians.**

<sup>38</sup> See Attachment C: *Division of Disability and Aging Services Staff*.



Hired a public safety specialist to coordinate community notification policy and oversee safety and treatment for offenders.



Participated in a Legislative Task Force on Guardianship monitoring.



Participated in a coalition to reform the Vermont law on adult guardianships resulting in passage of a new guardianship law.



Worked with Probate Judges to obtain their support for use of a model evaluation tool for guardianship evaluations for people who are aging.

## Offenders with Developmental Disabilities

The Division of Disability and Aging Services is proud of its public safety record of supporting and treating offenders in non-institutional settings. When individuals with developmental disabilities commit crimes, the courts and correctional system may not be able to respond to their special needs for supervision and treatment, and the public looks to the developmental disabilities service system to meet the need. In FY 2008, the developmental disabilities services system supported approximately 195 individuals who committed serious offenses which were against the law in Vermont. Approximately 130 of these offenders committed a sexual offense and the remainder committed other offenses, such as arson and assault.

Developmental services agencies experience stresses and dilemmas when expected to serve a public safety function in the context of a system designed to promote self-determination and community participation. The Division sponsors a monthly training and support program and provides specialized consultation for staff who are supervising offenders with developmental disabilities in community settings. Through a contract with Northeast Kingdom Human Services, DDAS funds a specialized crisis and respite program for sex offenders with developmental disabilities.

Funds designated for offenders are managed through the Public Safety Fund. The fund is supervised by the Public Safety Funding committee, which meets monthly to review proposals. Criteria for access to the fund are included in the *Vermont System of Care Plan*. Twenty-one (21) people received Public Safety funding in FY 2008. Eight of these individuals were new to the developmental disability services system and 13 were people already getting services with increased costs related to public safety concerns.

The Division of Disability and Aging Services continues to collect data regarding all sex offenders served through the developmental disabilities services system in order to track the efficacy and cost of treatment, training needs and support of offenders. Information on demographics, offense characteristics and Treatment Progress Scale scores collected and analyzed on an annual basis contributes to our understanding about best practices in serving this group. We are currently in the midst of conducting the survey for 2008 but do not yet have the data.



A Public Safety Specialist was hired whose primary duties include, but are not limited to: oversight and coordination of supports and services, and victim and community notifications for offenders with developmental disabilities who pose a risk to public safety with the goal of improving victim and community safety.



The Policy on Community Notification Procedures for Sex Offenders with Developmental Disabilities went into effect and the Community Notification Review Committee began reviewing referrals.

## Communication

The Division of Disability and Aging Services continues to focus attention on the communication goal:

*Increase opportunities and supports for individuals to improve their communication and increase awareness of the need for people to communicate beyond the basics and familiar.*

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

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

**The Vermont Communication Task Force** was established in the spring of 2000 so that adults with developmental disabilities who live in Vermont can communicate more effectively to participate fully in community life, make decisions and better advocate for themselves. Ongoing efforts provide information, education, training and resources to people with disabilities, family members, service providers and community members. The Vermont Communication Task Force works in partnership with DDAS, service providers, Green Mountain Self-Advocates, Vermont Assistive Technology Program, Speech and Language Pathologists and others who are knowledgeable about Augmentative and Alternative Communication (AAC) to help realize the goals of the statewide communication initiative.



In FY '08, the Task Force presented two **full-day workshops**, focusing on AAC and partner skills and communication problem solving, to local communication resource people from all the developmental disability service agencies. Since 2004, an average of 23 local communication resource people attended 10 workshops.



The Task Force held **Making Communication Happen III**, the third bi-annual statewide communication conference with 45 presenters and vendors. There were 17 breakout sessions attended by 275 participants.



The **Mentor Project** continued in FY '08 with Lamoille County Mental Health Services and Lincoln Street Incorporation receiving mentoring and technical assistance from a Speech and Language Pathologist (SLP) with AAC expertise. The overall goal is to increase local capacity within developmental disability service agencies to support people with disabilities to communicate more effectively.

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## WANDA'S STORY

*Wanda is nonverbal. In the past, her needs and emotions were a guessing game even on the most basic of levels. Over the last four years, with the assistance of the communications facilitator and the unflagging efforts of her extraordinary Community Supports staff, Wanda is making enormous strides using alternative means of communication.*

*Wanda's communication to the outside world is by writing with hand-over-hand support from her staff and a Link Plus voice output keyboard. Wanda's growing ability to express her opinions and needs and to provide proof of her understanding and insight regarding complex situations has helped her to significantly reduce stress and behaviors based on frustration, fear or anger.*

*Wanda surprises and delights us all repeatedly with demonstrations of sophisticated vocabulary, compassionate insight, comprehension of complex issues and sly humor. These abilities and attributes were not apparent until she was given a "voice".*

*Wanda is now able to have influence on her environment and how she is treated. Her peers read her film critiques and often quote her. Recently she was able to communicate directly to her doctor about a concern. When she was asked how it went, she responded, "It was good." And when asked what was good, she wrote, "He gave me respect."*

*For the first time in her 37 years Wanda is able to share some of her inner world with the rest of us.*

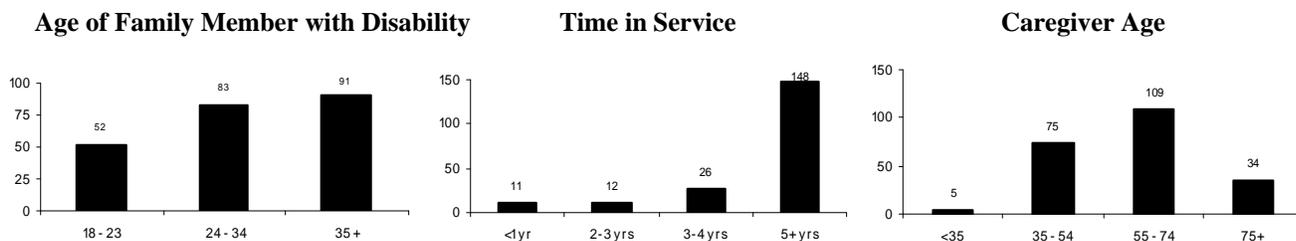


## Family Survey

<b>Numbers Surveyed – 2006</b>	
<b>Number of families surveyed</b>	<b>226</b>
Response rate	49%

**The Family Satisfaction Survey:** A confidential statewide family satisfaction survey was mailed out in September 2006 to ask about satisfaction with DDS-funded services. The survey was sent to 476 families of adults (age 18 and over) with developmental disabilities who live at home and were receiving waiver-funded services<sup>39</sup>. 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, though 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 Disability and Aging Services.

### Family Survey Demographics – 2006



### Family Survey Results – 2006

#### Highlights

- Access to Health Services:** 93% said they have access to health services for their family member.
- Staff Respect:** 85% said staff were respectful and courteous.
- Contact for Information:** 84% said they know who to contact for information.
- Family Member Happy:** 83% said overall their family member was happy.
- Services Make a Difference:** 82% said services make a difference in helping keep their family member at home.

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<sup>39</sup> This is a change from previous years when the survey also included families of children with developmental disabilities and those who received funding other than waiver (i.e., Flexible family Funding, Targeted Case Management).

## Areas of Focus



**Overall Satisfaction: 73%** said they were satisfied overall with developmental services.



**Changes in Staff: 26%** said changes in support staff is a problem.



**Help provided in a Crisis: 66%** said that if they ever asked for supports in an emergency or crisis, help was provided right away.



**Access to Community Activities: 62%** said their family member has access to community activities.



**Choice of Support Workers: 56%** said they choose the support workers who work with their family.



**Information about Services: 50%** said they receive information about services and supports that are available to their family.

## Satisfaction in Relation to Age of Family Member



Families of **adults** (24+ yrs. old) report **more satisfaction** than families of **children and transition age youth** (<24 yrs. old) with services and supports:

- Getting enough information to help in planning services
- Being able to reach/talk to agency staff
- Getting help from the services coordinators
- Getting services/support the family needs
- Employment/community support settings are healthy and safe
- Employment/community support providers involve the family in decisions
- Staff help the family connect to supports in the community
- Family member participates in community activities
- Services have made a positive difference in the life of the family

## Satisfaction in Relation to Caregiver Age Groups



Families where the caregiver was **age 55 and over** report **greater satisfaction** than families where the caregiver was **younger than age 55**:

- Getting enough information to help in planning services
- Being able to reach/talk to agency staff
- Getting help from the service coordinator
- Frequent changes in support staff are not a problem
- Staff help the family connect to supports in the community
- Services have made a positive difference in the life of the family

## Consumer Survey

<b>Numbers Surveyed – 2008</b>	
Number of participants –	
Consumers interviewed and demographic survey	181
Demographic survey only	210
<b>Total number of adult participants</b>	<b>391</b>

**Consumer Survey Project:** The Division of Disability and Aging Services contracts with an independent group to conduct interviews on a statewide basis of adults who receive services. In addition to the personal interview, basic demographic information is collected from service coordinators for all adults selected whether or not they are able to individually participate in the interview. 2008 was the first year in the three-year survey cycle during which surveys and interviews were conducted at five agencies<sup>40</sup>. We did not conduct the survey the previous year (2007) as we changed the timing of the interviews from summer to spring and made some other adjustments in the survey process and tool.

The data presented below are aggregate data representing statewide results. This is just a small sampling of the data collected from the survey. For the complete report, contact the Division of Disability and Aging Services.

### Consumer Survey Results<sup>41</sup> – 2008

#### Highlights

-  **Residential: 87%** said they like where they live.
-  **Work: 93%** said they like their job.
-  **Community Supports: 95%** said they like their individual community activities.
-  **Guardianship: 86%** said they feel happy about their guardian.
-  **Friends: 86%** said they have opportunities to meet new people.

<sup>40</sup> The five agencies that took part in the Consumer Survey Project in 2008 were Champlain Community Services, HowardCenter, Northwestern Counseling and Support Services, Sterling Area Services and Transition II (people who were self-/family-managing services).

<sup>41</sup> Not all consumers answered all the questions in their interviews. Percentages are based on the total number of consumers who responded to the questions. Consumer survey data needs to be taken in the same context as any study of satisfaction, as a general reflection of a person's perspective of life. Results from the surveys are anonymous and confidential.

 **Agency: 82%** said they feel happy with their service coordinator.

 **Agency: 92%** said they feel listened to at their ISA meetings.

 **Transportation: 86%** said they almost always had a way to get there when they wanted to go somewhere.

### **Areas of Focus**

 **Residential: 61%** said they did not choose who they live with.

 **Residential: 45%** said they did not choose the place where they live.

 **Work: 59%** of the people who do not work said they wanted a paid job.

 **Community Supports: 45%** said they would like more community activities.

 **Service Agency: 55%** said they would like (more) help to do or learn new things.

 **Friends: 43%** said they wish they had more friends.

 **Dating: 40%** said they need to know more about dating.

 **Rules: 44%** said someone else decides when friends and family can come visit.

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

 **Self-Advocacy: 43%** said they had not been to a self-advocacy meeting, conference or event.

## Demographic Summary<sup>42</sup> – 2008

### Basic Information

<b>Gender</b>		<b>Guardian Status</b>		<b>Representative Payee</b>	
Males	58%	Private	51%	Yes	76%
Females	42%	None	29%	No	19%
		Public	19%	Unknown	5%
		Unknown	1%		
<b>Marital Status</b>		<b>Court Ordered Restrictions</b>		<b>Family Involved in Person's Life</b>	
Never married	93%	No	98%	Yes	88%
Married/Civil Union	4%	Yes	<2%	No	12%
Single/Married in past	3%	Unknown	<1%		

### Residential Summary

<b>Residential Type</b>		<b>Household Composition</b>		<b>Paid Residential Support</b>	
Home provider	43%	Non relatives	48%	24-hour	48%
Lives with family	30%	Parents	28%	Daily	14%
Person's own home	22%	Lives alone	10%	Less than daily	7%
Group living	2%	Other relatives	8%	As needed	6%
Residential Care Home/ Nursing Home/Other	3%	Spouse/children	4%	None/Family	24%
		Unknown/Other	2%	Unknown	1%

<b>Who Own/Leases the Home</b>		<b>Residential Location</b>		<b>How Long Living in Home</b>	
Family member	34%	Rural/Physically remote	47%	Over 5 years	58%
Paid home provider	42%	Walking distance to town/city	32%	3 – 5 years	16%
Provider agency	3%	Centrally located in town/city	19%	1 – 2 years	14%
Person rents home	17%	Unknown	2%	Less than 1 year	10%
Person owns home	2%			Unknown	2%
Unknown/Other	2%				

### Health Concerns Summary

<b>Is weight a concern?</b>		<b>Does person smoke/chew tobacco?</b>		<b>How physically active is person?</b>	
No	57%	No	91%	Moderately	64%
Yes, overweight	37%	Yes	7%	Inactive	21%
Yes, underweight	4%	Unknown	2%	Very	13%
Unknown	2%			Unknown	2%

<sup>42</sup> Data is based on results from the *Survey of Adults Receiving Developmental Services in Vermont – Spring 2008* report and includes all participants (those interviewed and those not interviewed who only had the demographic survey done).

## Comparison of Vermont’s 2004 – 2006 and 2008 Consumer Survey Results

The method for collecting the consumer survey data since 2001 has been done by interviewing a random selection of consumers each year from a sampling of agencies based on agency size and regional representation. Starting in 2008, the order of visiting agencies was revised to better reflect the demographic composition of the consumer base in Vermont. Therefore, the following comparison overtime is based on statewide responses from all of the 2004 – 2006 surveys as there is not one equivalent year from the previous cycle.

	2004 – 2006	2008
<b>Residential</b>		
• They like where they live	91%	87%
• They had a say in where they live	43%	55%
• They cannot think of a better place to live	67%	71%
• They feel safe at home	93%	90%
• They can invite friends over when they want	87%	79%
<b>Neighborhood</b>		
• They like their neighborhood	78%	84%
• They feel safe in their neighborhood	93%	91%
<b>Work</b>		
• They like their job	95%	93%
• They chose their job	89%	92%
• They chose who helped them at work	61%	48%
• They work enough hours	61%	48%
• There is nothing else they’d rather do during the day	65%	78%
<b>Community Supports (Individual)</b>		
• They like their community activities	97%	95%
• They have enough community activities	52%	55%
• They like the people they spend time with	83%	85%
<b>Activities</b>		
• They shop as much as they want	56%	55%
• They exercise as much as they want	56%	55%
• They go to church/synagogue as much as they want	62%	68%
<b>Friends</b>		
• They have enough friends	59%	57%
• They can see their family when they want	79%	68%
<b>Service Agency</b>		
• They chose their service coordinator	45%	34%
• They get to learn new things	77%	74%
<b>Self-Determination</b>		
• They make all the choices they want	62%	59%
• They have enough control over their life	81%	75%

## National Comparison of Vermont's 2008 Consumer Survey Results<sup>43</sup>

### Highlights – Categories<sup>44</sup>



**Everyday Choices:** Vermont ranked **highest**; with the highest average proportion of people who say they:

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



**Life Decisions:** Vermont ranked **2<sup>nd</sup> Highest**; with the highest average proportion of people who say they:

- Choose their work and/or community support activities
- Choose where they live
- Choose the staff who help them at home



**Community Inclusion:** Vermont ranked **highest**; with the highest average proportion of people who say they:

- Go out to eat
- Go shopping
- Go to community activities
- Go out for entertainment (2<sup>nd</sup> highest)
- Exercise or play sports (2<sup>nd</sup> highest)



Vermont ranked **high**; with a positive result in the average proportion of people who say they:

- Have their mail opened without permission (lowest)
- Report satisfaction with their work/community supports (2<sup>nd</sup> highest)
- Attend activities of self-advocacy groups (2<sup>nd</sup> highest)

### Areas of Focus



Vermont ranked **low**; with a negative result in the average proportion of people who say they:

- Have friends and caring relationships with people other than staff or family
- Are able to see family when they want to
- Are able to see friends when they want to
- Receive help to do or learn new things
- Have weight (underweight or overweight) as a concern
- Had a physical exam in the past year

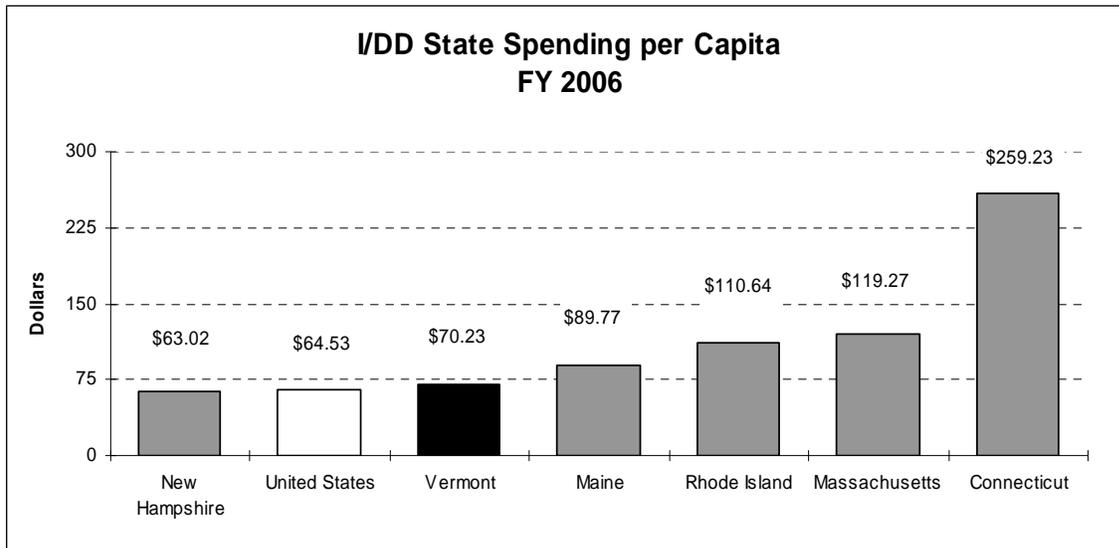
<sup>43</sup> Data is based on results from twenty-four states that participated in the 2007 consumer surveys as part of the National Core Indicators. Results are published in *Consumer Outcomes – Phase IX Report Fiscal Year 2007-2008 Data*, National Core Indicators, Preliminary Report, December 2008.

<sup>44</sup> Data was analyzed by category (grouping of questions based on certain commonalities) and individual questions. Categorical data presented in this section is outcome or “risk” adjusted to control for differences in the individual characteristics of people interviewed across states.

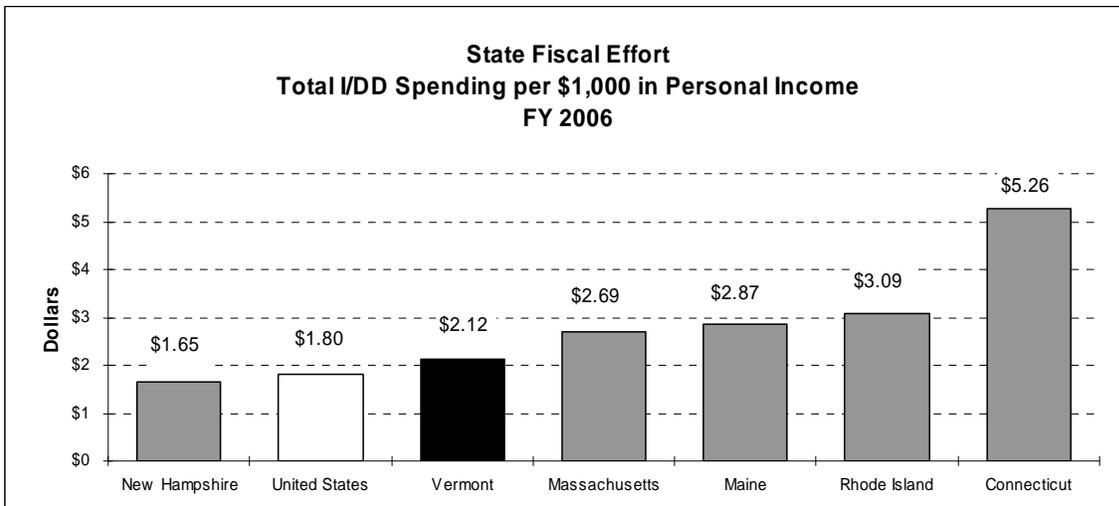
## National Comparisons<sup>45</sup>



Vermont ranks second to New Hampshire in spending fewer **state dollars** (including Medicaid match) per state resident for intellectual/developmental disability (I/DD) services than any other New England state and slightly higher than the national average.



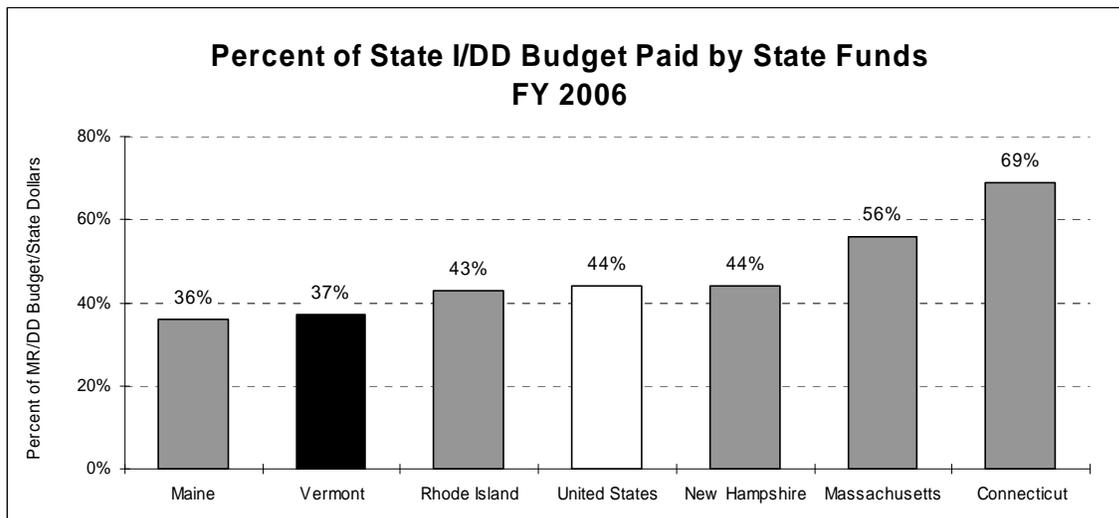
The **fiscal effort** in Vermont, as measured by total state spending for people with intellectual/developmental disability (I/DD) services per \$1,000 in personal income, indicates that Vermont ranks 2<sup>nd</sup> to New Hampshire as the lowest of all New England states and is slightly higher than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



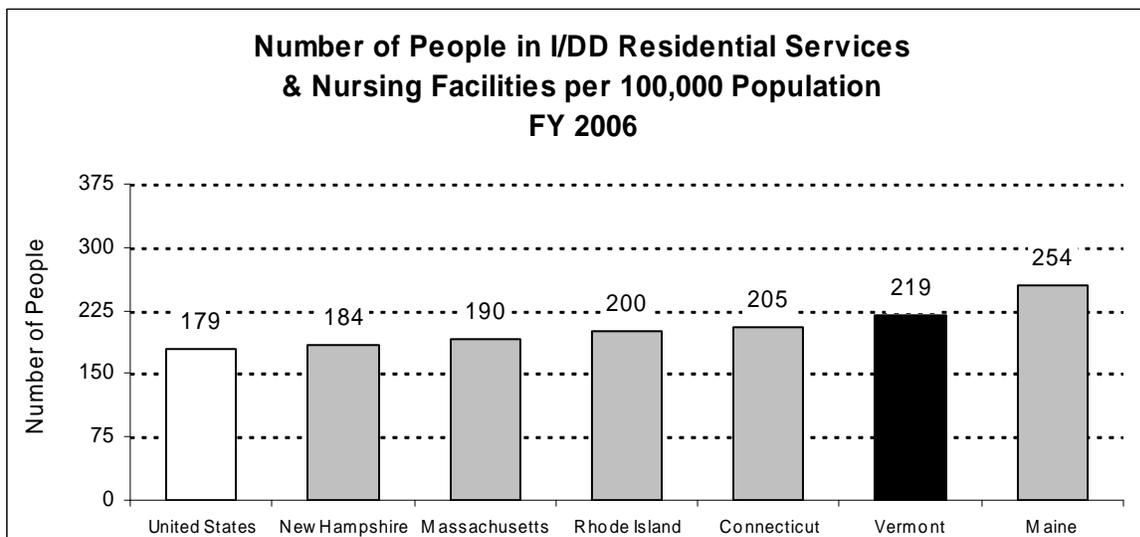
<sup>45</sup> *The State of the States in Developmental Disabilities: 2006*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Preliminary Report, 2007.



**State funds** (including state funds used for Medicaid match) account for a smaller proportion of the budget from intellectual/developmental disability (I/DD) services in Vermont than in any other New England State except for Maine. Vermont continues to access higher than the national average proportion of federal dollars.



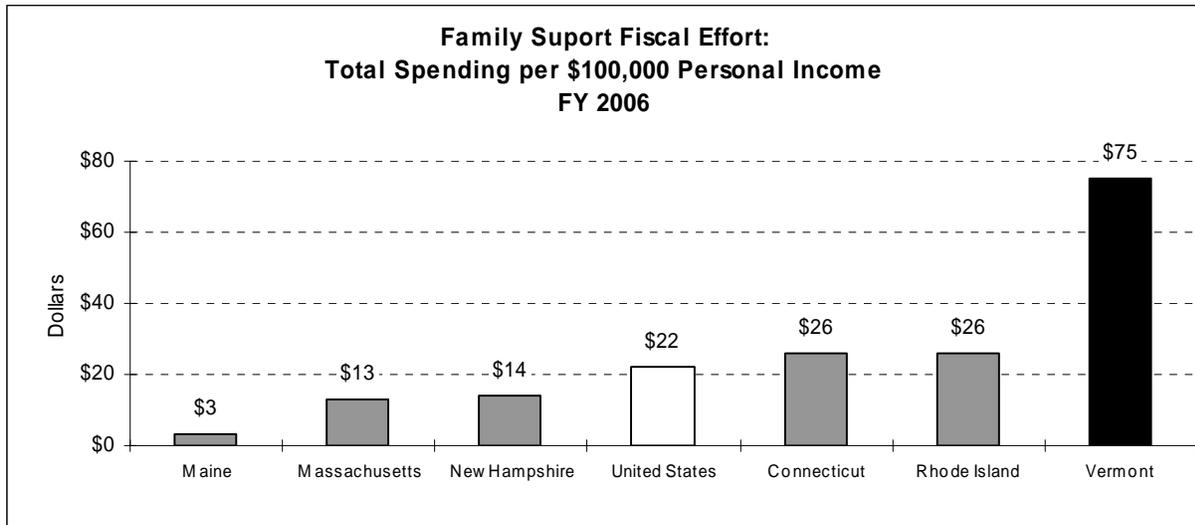
The number of people receiving **residential services** in the intellectual/developmental disability (I/DD) service system (with the addition of people living in nursing facilities) per 100,000 of the state population is above the national average and slightly higher than the majority of New England states.



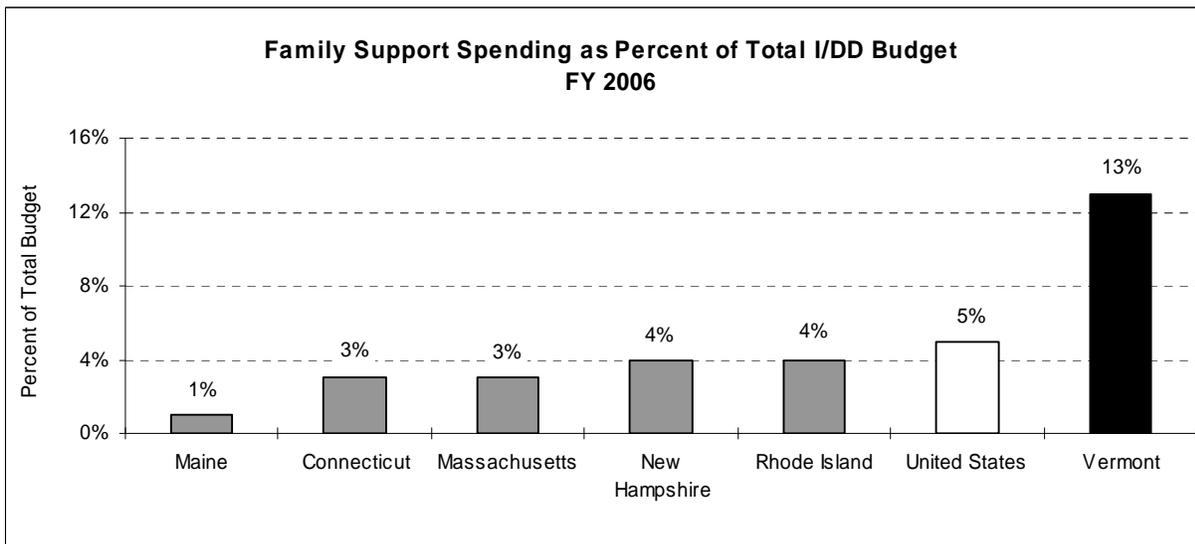
Source: *The State of the States in Developmental Disabilities*, Department of Psychiatry and Coleman Institute for Cognitive Disabilities, University of Colorado, Revised Report, 2008.



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

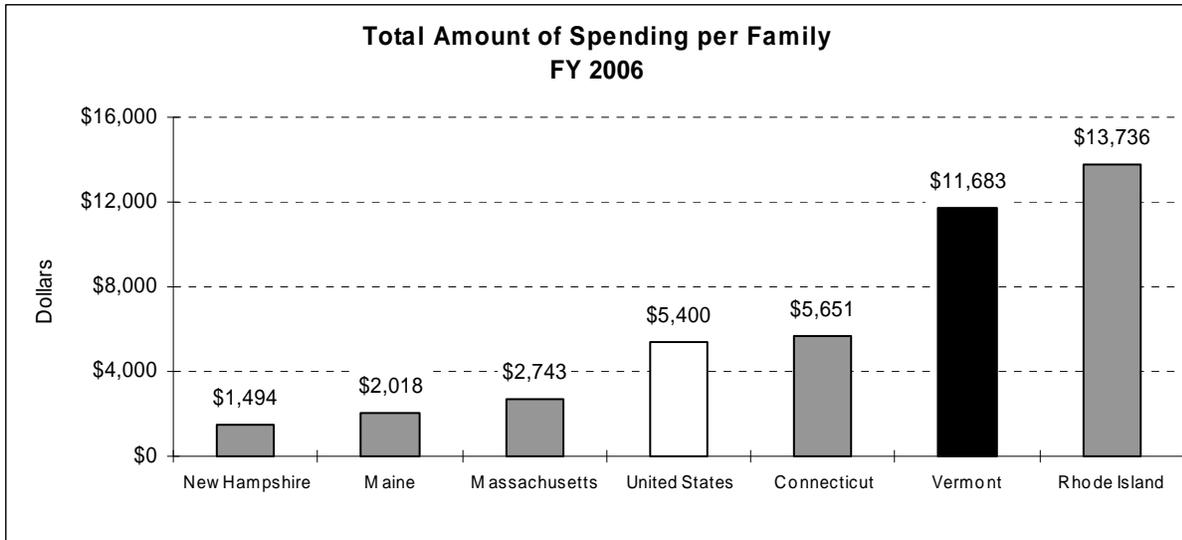


Vermont's **family support spending** is ranked 1<sup>st</sup> in New England and 6<sup>th</sup> in the nation in terms of total I/DD budget.





Vermont is ranked 2<sup>nd</sup> in New England and 8<sup>th</sup> in the nation in the amount of **spending per family** for family support.



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

Acronyms.....	Attachment A
Organizational Chart – Agency of Human Services.....	Attachment B
Division of Disability and Aging Services Staff .....	Attachment C
Vermont Developmental Services Providers.....	Attachment D
Members of the State Program Standing Committee for Developmental Services .....	Attachment E
Vermont State System of Care Plan Funding Priorities FY 2008 .....	Attachment F
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## ACRONYMS

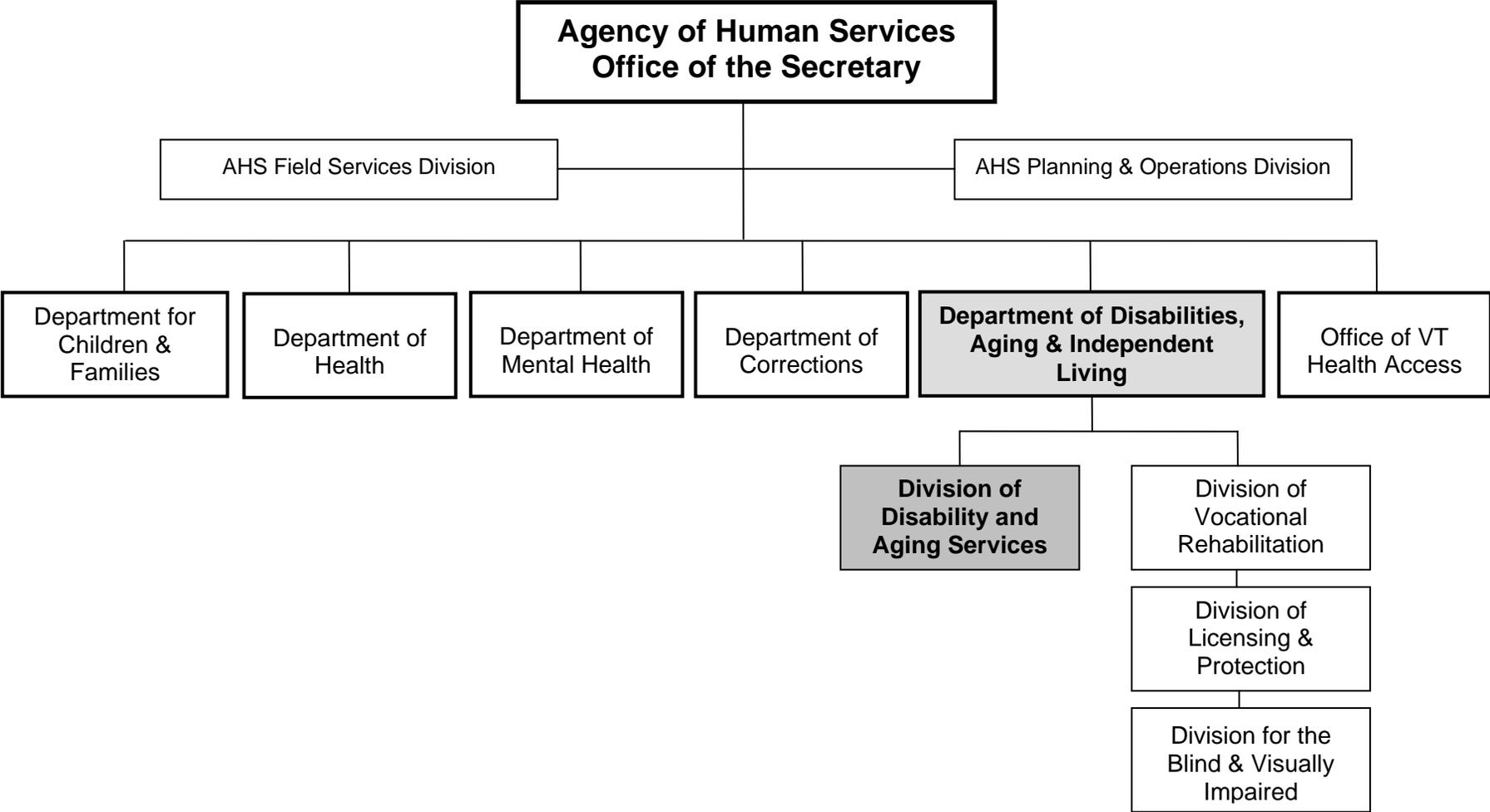
<b>AAC</b>	Augmentative and Alternative Communication
<b>AAIDD</b>	American Association on Intellectual and Developmental Disabilities
<b>ACT 248</b>	Supervision of incompetent individuals with developmental disabilities that have been charged with crimes
<b>ADD</b>	Attention Deficit Disorder
<b>ADRC</b>	Aging and Disability Resource Connections
<b>AFL</b>	Authorized Funding Limit
<b>AHS</b>	Agency of Human Services
<b>ANCOR</b>	American Network of Community Options and Resources
<b>APS</b>	Adult Protective Services
<b>APSE</b>	The Network on Employment (formerly known as: Association for Persons in Supported Employment)
<b>ARC</b>	Advocacy, Resources and Community
<b>ARIS</b>	Area Resources for Individualized Services
<b>ASD</b>	Autism Spectrum Disorders
<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>CAS</b>	Community Alternatives Specialist
<b>CCS</b>	Champlain Community Services
<b>CDCI</b>	Center on Disability and Community Inclusion
<b>CDS</b>	Community Developmental Services (DS program of WCMHS)
<b>CDU</b>	Community Development Unit
<b>CIR</b>	Critical Incident Report
<b>CMS</b>	Centers for Medicare and Medicaid Services
<b>CP</b>	Cerebral palsy
<b>CPS</b>	Child Protective Services
<b>CSAC</b>	Counseling Service of Addison County
<b>CSHN</b>	Children with Special Health Needs
<b>CVARC</b>	Central Vermont ARC
<b>DA</b>	Designated Agency
<b>DAIL</b>	Department of Disabilities, Aging and Independent Living
<b>DBT</b>	Dialectical Behavioral Therapy
<b>DBVI</b>	Division for the Blind and Visually Impaired
<b>DCF</b>	Department for Children and Families
<b>DD</b>	Developmental Disability or Developmentally Disabled
<b>DD ACT</b>	Developmental Disability Act of 1996
<b>DDC</b>	Developmental Disabilities Council
<b>DH</b>	Developmental Homes – see also SLP or HP
<b>DLP</b>	Disability Law Project
<b>DLP</b>	Division of Licensing and Protection
<b>DME</b>	Durable Medical Equipment
<b>DMH</b>	Department of Mental Health
<b>DOC</b>	Department of Corrections
<b>DOE</b>	Department of Education
<b>DOJ</b>	Department of Justice

<b>DS</b>	Developmental Services
<b>DSM</b>	Diagnostic and Statistical Manual of Mental Disorders (most current edition)
<b>DV</b>	Domestic Violence
<b>DVR</b>	Division of Vocational Services – see also VR
<b>EDS</b>	Electronic Data Systems
<b>FARC</b>	Franklin ARC
<b>FIN</b>	Financial Report
<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>FY</b>	Fiscal Year
<b>GC</b>	Global Commitment for Health 115 Waiver
<b>GF</b>	General Fund
<b>GH</b>	Group Home
<b>GMSA</b>	Green Mountain Self Advocates
<b>GS</b>	Guardianship Services – also see OPG
<b>HC</b>	HowardCenter or HowardCenter – Developmental Services
<b>HCBS</b>	Home and Community-Based Services
<b>HCHS</b>	Howard Center for Human Services – Obsolete, see HC
<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) – Obsolete, see HC
<b>HHS</b>	Health and Human Services
<b>HIPAA</b>	Health Insurance Portability and Accountability Act
<b>HP</b>	Home provider
<b>HRD</b>	Human Resources Data
<b>ICF/DD</b>	Intermediate Care Facility for people with Developmental Disabilities
<b>I/DD</b>	Intellectual/Developmental Disabilities
<b>IDU</b>	Information and Data Unit
<b>IEP</b>	Individualized Education Program
<b>ISA</b>	Individual Support Agreement
<b>ISO</b>	Intermediary Service Organization
<b>ISU</b>	Individual Supports Unit
<b>LCMH</b>	Lamoille County Mental Health
<b>LSI</b>	Lincoln Street Incorporated
<b>MCIS</b>	Managed Care Information System
<b>MI</b>	Mentally Impaired/Ill
<b>MR</b>	Mental Retardation – Obsolete, see DD or I/DD
<b>MSR</b>	Monthly Service Report
<b>NASDDDS</b>	National Association of State Directors of Developmental Disabilities Services
<b>NCI</b>	National Core Indicators
<b>NCSS</b>	Northwestern Counseling and Support Services
<b>NKHS</b>	Northeast Kingdom Human Services
<b>OPG</b>	Office of Public Guardian
<b>OVHA</b>	Office of Vermont Health Access
<b>P2P</b>	Parent-to-Parent – Obsolete, see VFN
<b>P&amp;A</b>	Protection and Advocacy – see VP&A
<b>PASARR</b>	Pre-admission Screening and Resident Review
<b>PDD</b>	Pervasive Developmental Disorder

<b>PG</b>	Public Guardian
<b>QA</b>	Quality Assurance
<b>QDDP</b>	Qualified Developmental Disabilities Professional (formerly QMRP)
<b>QI</b>	Quality Improvement
<b>QMU</b>	Quality Management Unit
<b>RARC</b>	Rutland ARC
<b>RMHS</b>	Rutland Mental Health Services
<b>RWJ</b>	Robert Wood Johnson Foundation
<b>SAS</b>	Sterling Area Services
<b>SCC</b>	Specialized Community Care
<b>SLP</b>	Shared living provider
<b>SLP</b>	Speech language pathologist
<b>SSA</b>	Social Security Administration
<b>SSA</b>	Specialized Service Agency
<b>SSDI</b>	Social Security Disability Income
<b>SSI</b>	Supplemental Security Income
<b>TASH</b>	The Association for Persons with Severe Handicaps
<b>TBI</b>	Traumatic Brain Injury
<b>TCM</b>	Targeted Case Management (state plan Medicaid)
<b>T-II</b>	Transition II
<b>TXIX</b>	Title XIX of the Social Security Act (Medicaid)
<b>UC</b>	University of Colorado
<b>UCS</b>	United Counseling Service of Bennington County
<b>UVS</b>	Upper Valley Services
<b>VCDMHS</b>	Vermont Council of Developmental & Mental Health Services – formerly VCCMHS
<b>VCDR</b>	Vermont Coalition for Disability Rights
<b>VCIL</b>	Vermont Center for Independent Living
<b>VCIN</b>	Vermont Crisis Intervention Network
<b>VDH</b>	Vermont Department of Health
<b>VFN</b>	Vermont Family Network
<b>VP&amp;A</b>	Vermont Protection and Advocacy
<b>VPIC</b>	Vermont Parent Information Center – Obsolete, see VFN
<b>VR</b>	Vocational Rehabilitation – see also DVR
<b>VSH</b>	Vermont State Hospital
<b>UVM</b>	University of Vermont
<b>WCMH</b>	Washington County Mental Health



# ORGANIZATIONAL CHART AGENCY OF HUMAN SERVICES





**DIVISION OF DISABILITY AND AGING SERVICES STAFF  
January 2009**

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Phone: (802) 241-2648  
FAX: (802) 241-4224**

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Long Term Care**

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<p style="text-align: center;"><b>Burlington Office</b> 312 Hurricane Lane Suite 201 Williston, VT 05495 Fax: 879-5620</p>	Paula Brown Sara Lane Toni Morgan	879-5904	paula.brown@ahs.state.vt.us sara.lane@ahs.state.vt.us toni.morgan@ahs.state.vt.us
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Tighe, Deb	Systems Developer	241-2419	deb.tighe@ahs.state.vt.us

**Office of Public Guardian**  
**802-241-2663**  
**Emergency Toll-Free Number: 1-800-642-3100**

<b>Staff Name</b>	<b>Title</b>	<b>Phone (802)</b>	<b>E-mail Address</b>
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LaPerle, Michele	Administrative Assistant	241-2663	michele.laperle@ahs.state.vt.us

**Public Guardians – Aging Specialty**

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<b>Hyde Park Office</b> PO Box 128 Hyde Park, VT 05655 Fax: 888-5869	Keith Ulrich – Public Guardian	888-3370	keith.ulrich@ahs.state.vt.us
<b>North Ferrisburg Office</b> PO Box 122 North Ferrisburg, VT 05473 Fax: 877-6792	Laurie Gutowski – Public Guardian	877-6779	laurie.gutowski@ahs.state.vt.us
<b>Townshend Office</b> PO Box 87 Townshend, VT 05353 Fax: 365-7935	Mike Attley – Senior Public Guardian	365-4478	mike.attley@ahs.state.vt.us
<b>West Brattleboro Office</b> PO Box 2386 West Brattleboro, VT 05303 Fax: 251-2144	Beth Spicer – Public Guardian	251-2145	beth.spicer@ahs.state.vt.us



## VERMONT DEVELOPMENTAL SERVICES PROVIDERS

January 2009

**(CCS) CHAMPLAIN COMMUNITY SERVICES, INC.**

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

Exec. Director: Kelley Homiller  
County: Chittenden

**(CAP) COMMUNITY ACCESS PROGRAM OF RUTLAND COUNTY**

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

Director: Gerald Bernard  
County: Rutland

**(CA) COMMUNITY ASSOCIATES**

109 Catamount Park  
Middlebury, VT 05753  
Phone: 388-4021 FAX: 388-1868

Director: Greg Mairs  
County: Addison

**(CDS) COMMUNITY DEVELOPMENTAL SERVICES**

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

Director: Juliet Martin  
County: Washington

**(FF) FAMILIES FIRST**

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

Director: Julie Cunningham  
Counties: Windham and Bennington

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

49 School Street, PO Box 709  
Hartford, VT 05047-0709  
Phone: 295-3032 FAX: 295-0820

Director: Josh Compton  
Counties: Windsor and Windham

Regional Offices:

51 Fairview Street, Brattleboro, VT 05301  
Phone: 257-5537 FAX: 257-5769

390 River Street, Springfield, VT 05156  
Phone: 886-4567 FAX: 886-4580

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

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

**(HC) HOWARDCENTER, INC**

102 South Winooski Ave.  
Burlington, VT 05401-3832  
Phone: 488-6500 FAX: 860-2360

Director: Marie Zura  
County: Chittenden

**(LCMH) LAMOILLE COUNTY MENTAL HEALTH SERVICES, INC.**

275 Brooklyn Street  
Morrisville, VT 05661  
Phone: 888-6627 FAX: 888-6393

Director: Jackie Rogers  
County: Lamoille

**(LSI) LINCOLN STREET INCORPORATED**

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

Executive Director: Cheryl Thrall  
County: Windsor

**(NKHS) NORTHEAST KINGDOM HUMAN SERVICES, INC.**

PO Box 724, 154 Duchess Street  
Newport, VT 05855-0724  
Phone: 334-7310 FAX: 334-7455

Director: Dixie McFarland  
Counties: Caledonia, Orleans and Essex

Regional Office:

PO Box 368, 2225 Portland Street  
St. Johnsbury, VT 05819  
Phone: 748-3181 FAX: 748-0704

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

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

Director: Jean Danis  
Counties: Franklin and Grand Isle

375 Lake Road, St. Albans, VT 05478  
Phone: 524-0574 FAX: 524-0578

**(SCC) SPECIALIZED COMMUNITY CARE**

PO Box 578  
East Middlebury, VT 05740

Executive Director: Ray Hathaway  
Counties: Addison and Rutland

3627 Route 7 South  
Middlebury, VT 05753  
Phone: 388-6388 FAX: 388-6704

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

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

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

**(T-II) TRANSITION II, INC.**

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

Executive Director: Kara Artus  
County: Statewide

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

PO Box 588, 100 Ledge Hill Drive  
Bennington, VT 05201  
Phone: 442-5491 FAX: 442-1707

Director: Kathy Hamilton  
County: Bennington

**(UVS) UPPER VALLEY SERVICES, INC.**

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

Executive Director: William Ashe  
Counties: Orange and Washington

Regional Offices:

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

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January 2009**

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<b>Hindmarsh, Dale</b>	456 Browns Road Lincoln, VT 05443 Phone: 453-4102 e-mail: dale.hindmarsh@gmavt.net	Professional	2011
<b>McFarland, Dixie</b>	1516 Pudding Hill Road Lyndonville, VT 05851 Phone: 334-7310 ext. 5110 (w) 748-6350 ext. 1110 (w – alt) 626-9550 (h) Fax: 748-0704 e-mail: dmcfarland@nkhs.net	Professional	2011
<b>Neron, Steven</b>	PO Box 225 Bethel, VT 05032 Phone: 234-6591	Recipient	2011

<b>Name</b>	<b>Address, Phone and Fax</b>	<b>Represents</b>	<b>Term Expires (March 31)</b>
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<b>Sanville, Jessica</b>	PO Box 245 Lyndonville, VT 05851 Phone: 748-4304 (w) 748-1746 (h) 535-9867 workinggirl27@hotmail.com	Recipient	2009
<b>Thresher, Tracy</b>	Washington County Mental Health 50 Granview Drive Barre, VT 05641 Phone: 479-2502 (W) e-mail: rightsrus@wcmhs.org	Advocate	2009
<b>Weiss, Alicia</b>	P.O. Box 435 Plainfield, VT 05667 Phone 233-1385 (h) e-mail: nothing_about_us_without_us@yahoo.com	Advocate	2009
<b>Woodberry, Connie</b>	103 Partridge Road East Dummerston, VT 05346 Phone: 257-0300 (h) 380-0809 (c) Fax: 254-8611 e-mail: conniewo@sover.net	Recipient	2010
<b>Vacancy</b>		Professional	2011
<b>Vacancy</b>		Professional	2010



**State Program Standing Committee Members:**

Left to right: Connie Woodbury, Tracy Thresher, Jean D. Danis, Dixie McFarland, Dawn Arsenault, Eric Bakeman, Bethany Drum and Edwin Place.

Missing from photo – Joe Greenwald, Dale Hindmarsh, Steven Neron, Jessica Sanville and Alicia Weiss.

## VERMONT STATE SYSTEM OF CARE PLAN FUNDING PRIORITIES – FY 2008

	Age	Priority	Approval	Comments
A.	Children and Youth under age 21	Support needed by families to assist them with personal care tasks as defined in the Personal Care Program	Eligibility and support level determined via Personal Care Program process	Entitled Medicaid state plan service for eligible children and youth
B.	Children and Adults	Support for respite and items through Flexible Family Funding that will help the biological or adopted family or legal guardian support the person at home	Determined by the designated agency; does not need to go through local funding committee	Sliding service scale in <i>Flexible Family Funding Guidelines</i> ; maximum \$1,300/person
/C.	Children and Adults	Support needed to end or prevent imminent institutionalization in inpatient public or private psychiatric hospitals or nursing facilities or end institutionalization in Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD)	Reviewed by local funding committee and forwarded to Equity Funding Committee	
D.	Adults 18 and over	Support needed to prevent or respond to an adult being abused, neglected or exploited	Reviewed by local funding committee and forwarded to Equity Funding Committee	
E.	Adults 19 and over	Support needed by an adult to prevent an imminent risk to the person's health or safety	Reviewed by local funding committee and forwarded to Equity Funding Committee	
F.	Adults 18 and over	Support needed for parents with developmental disabilities to provide training in parenting skills to help keep a child under 18 at home	Reviewed by local funding committee and forwarded to Equity Funding Committee	Services may not substitute for regular role and expenses of parenting; maximum amount of \$7,800/ year (including admin.)
G.	Adults 18 and over	Support needed to respond to an adult who is homeless or at imminent risk of being homeless	Reviewed by local funding committee and forwarded to Equity Funding Committee	Does not apply to individuals who already receive funding for Home Supports
H.	Adults 18 and over	Support needed by an adult who is experiencing the death or other loss of an unpaid or minimally paid (e.g., family member, residential care home) caregiver	Reviewed by local funding committee and forwarded to Equity Funding Committee	
I.	Adults 18 and over	Support needed for specialized services in a nursing facility	PASARR fund manager	Limited to 5 hours per week; legally mandated
J.	Adults 19 and over	Support needed for a high school graduate to <u>maintain</u> an employer paid job.	Reviewed by local funding committee and forwarded to Equity Funding Committee	See Funding Limitations number 26
K.	Adults 18 and over	Support needed by an adult who has been committed to the custody of the Department of Disabilities, Aging and Independent Living pursuant to Act 248 (see additional requirements under Public Safety Fund)	Reviewed by local funding committee and forwarded to Public Safety Funding Committee	Services may be legally mandated
L.	Adults 18 and over	Support needed to prevent an adult who poses a risk to public safety from endangering others (see additional requirements under Public Safety Fund)	Reviewed by local funding committee and forwarded to Public Safety Funding Committee	Does not substitute for or replace DOC supervision



## DIVISION OF DISABILITY AND AGING SERVICES FY 2008 FISCAL RESOURCES

The Division is obligated to meet the needs of individuals eligible for services, *within the appropriated funding* received from the Legislature. No services may be authorized that exceed the FY '08 funding levels unless appropriate prior approval is received. It is, therefore, important that meeting personal and public safety needs are prioritized with all developmental disability services funding.

Fiscal year 2008 marked the third and final year of the negotiated 7.5% increase in funding for the designated provider system for developmental disability, mental health and substance abuse services. Of these increases, providers received an inflationary increase of 3.75% in FY '06, which was followed by a 2% reduction to meet caseload needs, leaving an actual increase of 1.75%. Providers received inflationary increases of 4% in FY '07 and FY '08. It is relevant to note that funding for developmental disability services has actually risen about 10%–11% per year.

Of the total increase in FY '08, a **4% cost of living** increase is provided for the community system. This is intended to cover the increased costs of any salary or contracted worker increases, transportation costs, insurance and fuel expenses, etc. In addition to the cost of living increase, resources to address caseload issues are also allocated. When combined with existing resources for community services, a total of **\$127,545,146<sup>46</sup>** is available for supporting people with developmental disabilities in Vermont. Given past utilization trends, it is expected that this amount will support roughly 3,325 individuals in FY '08. A summary of the available new funding follows:

### FY 2008 NEW FUNDING AVAILABLE

<b><u>Provider Inflation</u></b>	\$4,610,315
<b><u>Caseload</u></b>	
Flexible Family Funding	36,689
– 30 individuals @ \$1,122 x 9% administration	
Emergency Caseload	5,689,000
– 200 individuals @ \$28,445	
Minus Equity Fund Available	(2,092,091)
– 3 Year Equity Fund Average	
High School Graduates	1,848,925
– 65 individuals @ \$28,445	
Public Safety/Act 248	<u>1,119,987</u>
– 27 individuals @ \$41,481	
<b>TOTAL NEW FUNDING AVAILABLE</b>	<b><u>\$11,212,825<sup>47</sup></u></b>

<sup>46</sup> Does not include funding in the OVHA appropriation for Children's Personal Care Services and High Technology Home Care services.

<sup>47</sup> State match requirement for FY '08 is 40.99%; no changes in services are required because of this change; it is actually reduced from the FY '07 rate of 41.18%.



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

**January 2009**

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

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

- A. **Designation Process.** The Department of Aging and Independent Living (DAIL) designated one agency in each region of the state to ensure needed services are available through local planning, service coordination, and monitoring outcomes within their geographic region. The Designated Agency must either provide directly or contract with providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines.
- B. **Agency Reviews.** Eleven (11) full-time staff, including two registered nurses, conduct on-site reviews to assess the quality of services provided. The Quality Management Reviewers assess all Medicaid funded services to assure compliance with state and federal Medicaid standards and the outcomes detailed in the *Quality Management Plan*. Site visits are conducted every two years with follow-up as appropriate.
- C. **Office of Public Guardian.** Twenty-five (25) staff provide guardianship services as specified by law to about 665 adults with developmental disabilities and/or who are aging. Public Guardians play distinct quality assurance functions, including on-going monitoring of people's welfare, assessment of quality of life and functional accessibility, participation in individual support plans, and advocacy for appropriate services. Public Guardians are expected to have face-to-face contact with people for whom they are guardian at least once a month, and are available for emergencies 24 hours a day.
- D. **Safety and Accessibility Checks.** All residences of people with developmental disabilities (except those licensed through the Division of Licensing and Protection/DAIL or a public housing entity, such as Section 8) funded by the Division of Disability and Aging Services are inspected for compliance with safety and accessibility standards.
- E. **Consumer and Family Surveys.** The Division of Disability and Aging Services contracts for independent statewide consumer interviews to take place on a regular basis to measure the satisfaction of people receiving services. A confidential family satisfaction mail-in survey is also conducted periodically to assess how families feel about services that they receive to support their family members who live at home.

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

## II. Elsewhere in State Government:

- A. **Abuse Complaints.** The Department for Children and Families and the Department of Disabilities, Aging and Independent Living handle complaints of abuse and neglect for children and adults, respectively. Any human service worker, including Division of Disability and Aging Services staff, is legally mandated to file an immediate report of any suspected abuse, neglect or exploitation of a vulnerable adult. For adults with disabilities, Adult Protective Services staff conduct independent investigations of each complaint and pursue legal or other recourse as indicated by the needs of the individual.

- B. **Fire Safety Regulation.** Staff of the Department of Labor and Industry must approve all Level III Residential Care Homes and ICF/DD facilities. Facilities must meet appropriate standards of the National Fire Safety Code.
- C. **Medicaid Fraud Unit.** This Unit investigates allegations of criminal activity, including abuse, neglect or exploitation, in any Medicaid-funded facility or involving a person receiving Medicaid-funded supports. The Medicaid Fraud Unit is a specially staffed unit within the Office of the Attorney General.

### III. Within Developmental Services Agencies:

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

### IV. External to the Service System:

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

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

## GREEN MOUNTAIN SELF-ADVOCATES

January 2009

### Green Mountain Self-Advocates (GMSA)

73 Main Street, Suite 401

Montpelier, VT 05602

gmsa@sover.net

802-229-2600

Contact: Max Barrows and Karen Topper

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

### LOCAL CHAPTERS:

#### Advocates For Action

12 Church St,  
Bellows Falls, VT 05101  
254-7500 x1334 – Felicia Rumrill  
Board Rep: Wendy Boright

#### Bennington Peer Support

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

#### B-SAC – Burlington Self-Advocacy Club

HowardCenter  
102 South Winooski Ave.  
Burlington, VT 05401  
488-6500 – Julia Kimbell  
Board Rep: Bob Kay

#### Bully-Proof – Spaulding High School

155 Ayers Street  
Barre, VT 056412  
476-4811 – Sylvia Sweet

#### CCAA – Capital City Advocacy Association

254 Elm Street, Apt. 1  
Montpelier, VT 05602  
262-1236 – Karen Noone  
Board Rep: Stirling Peebles

#### Champlain Voices

Champlain Community Services, Inc.  
512 Troy Ave., Suite 1  
Colchester, VT 05446  
655-0511 – Dora Clay  
Board Rep: Paul Nichols

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

PO Box 678  
Springfield, VT 05156  
886-1833 – Charlotte Rishkin  
Board Rep: Helen George

#### Friends Helping Friends

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

#### Getting Acquainted

275 Brooklyn Street  
Lamoille County Mental Health  
Morrisville, VT 05661  
888-6627 – Patti Mack  
Board Rep: Lori Jones

#### Next Step of St. Albans

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

#### Our Drop In Center

153 Main Street  
Newport, VT 05855  
334-8378 Francine Heywood  
Board Reps: Roland Maurais/  
Gail Rowe

#### RAPS – Randolph Area Peer Support

Upper Valley Services, Inc.  
12 Prince Street, Suite #2  
Randolph, VT 05060  
728-4476 – Joan Carmen  
Board Rep: Edwin Place/Bethany Drum

#### Rutland High School Self-Advocates

22 Stratton Rd  
Rutland, 05701  
770-1012 – Carol Ravena

#### Self-Advocates Becoming Empowered of Rutland

Rutland ARC  
128 Merchants Row  
Rutland, VT 05701  
775-1370 – Lisa Lynch  
Board Reps: Patty Czarnecki

#### SAMS - Self Advocates Meeting of Springfield

PO Box 678  
Springfield, VT 05156  
886-1833 – Kerry Banks  
Board Rep: George Tanner

#### SAVY – Strong Advocate Voices & You

Sterling Area Services  
109 Professional Drive  
Morrisville, VT 05661  
888-7602 – Gina Brown  
Board Rep: Laura Benton

#### Speak Up Addison County

109 Catamount Park  
Middlebury, VT 05753  
388-3381 – Lindsey Hescoek  
Board Rep: Randy Lizotte

#### Vermont Choices

Northeast Kingdom Human Svcs., Inc.  
PO Box 368  
St. Johnsbury, VT 05819  
748-3181 – Scott Youngst  
Board Rep: Amanda Daniels

# GREEN MOUNTAIN SELF-ADVOCATES LOCAL SELF-ADVOCACY CHAPTERS

