

PART II
SUPPORTS & SERVICES

SYSTEM SUPPORT

Principles of Developmental Services²⁶

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.
- ❖ ***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.

²⁶ Developmental Disabilities Act of 1996, 18 V.S.A. § 8724

- ❖ ***Community Participation.*** When people with disabilities are segregated from community life, all Vermonters are diminished. Community participation is increased when people with disabilities meet their everyday needs through resources available to all members of the community.
- ❖ ***Employment.*** The goal of job support is to obtain and maintain paid employment in regular employment settings.
- ❖ ***Accessibility.*** Services must be geographically available so that people with developmental disabilities and their families are not required to move to gain access to needed services, thereby forfeiting natural community support systems.
- ❖ ***Health and Safety.*** The health and safety of people with developmental disabilities is of paramount concern.
- ❖ ***Trained Staff.*** In order to assure that the goals of this chapter are attained, all individuals who provide services to people with developmental disabilities and their families must receive training as required by section 8731 of this title.
- ❖ ***Fiscal Integrity.*** The fiscal stability of the service system is dependent upon skillful and frugal management and sufficient resources to meet the needs of Vermonters with developmental disabilities.



Division of Developmental Services²⁷

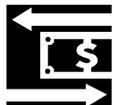
The Division of Developmental Services (DDS) plans, coordinates, administers, monitors, and evaluates state- and federally-funded services for people with developmental disabilities and their families within Vermont. The Division provides funding for services, systems planning, technical assistance, training, quality assurance, program monitoring, and standards compliance (see Attachment C: *Division of Developmental Services* for a list of DDS staff). The Division also exercises guardianship on behalf of the Commissioner for people who are under court-ordered guardianship services. The Division works with all people concerned with the delivery of services: people with disabilities, families, guardians, advocates, service providers, the Developmental Services State Standing Committee, 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: *Developmental Services State Standing Committee Members*).

Services and supports offered emphasize the development of community capacities to meet the needs of all individuals regardless of severity of disability. The Developmental Disability Act of 1996 declares that, within the limits of available resources, the Department of Developmental and Mental Health Services shall:

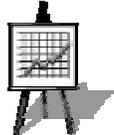
1. *Promote the principles of service stated in the DD Act and carry out all duties required by collaborating and consulting with people, their families, guardians, service providers and others.*
2. *Develop and maintain an equitable and efficiently allocated statewide system of community-based services that reflect the choices and needs of people.*
3. *Acquire and administer funding for these services and identify needed resources and legislation.*
4. *Establish a statewide procedure for applying for services.*
5. *Facilitate or provide pre-service training and technical assistance to service providers consistent with the system of care plan.*
6. *Provide quality assessment and quality improvement support for the services provided throughout the state.*
7. *Encourage the establishment and development of locally administered and controlled non-profit services based on the specific needs of individuals and their families.*
8. *Promote and facilitate participation by people and their families in activities and choices that affect their lives and in designing services that reflect their unique needs, strengths and cultural values.*
9. *Promote positive images and public awareness of people and their families.*
10. *Certify services that are paid for by the Department.*
11. *Establish a procedure for investigation and resolution of complaints regarding the availability, quality and responsiveness of services provided.*

²⁷ See Attachment B: *Division of Developmental Services: Acronyms*.

Goals Accomplished

- ❖ ***Complaint and Appeal Process Booklets:*** Provided easy-to-understand pamphlets on complaint and appeal processes and worked with providers to ensure that people and families who receive services are fully informed about these rights.
- ❖ ***Human Rights Committee:*** Established statewide committee to provide independent review of positive behavioral support plans and restrictive procedures. 
- ❖ ***Guardianship Services Statute:*** Enacted a revised Guardianship Services statute into law.
- ❖ ***Communication Task Force:*** Developed Communication Resource Guide that focuses on Augmentative and Alternative Communication (AAC).
- ❖ ***Grant Opportunities:*** Applied for and received Department of Justice grant. Applied for and awarded 3 year, \$2 million, Real Choice System Change grant in collaboration with DAD and DMH.
- ❖ ***Consumer Survey Project:*** Revamped the consumer survey process used to interview adults who receive services. Conducted analysis of multi-year data. 
- ❖ ***June Grad Survey:*** Coordinated survey identifying potential high school graduates eligible for developmental services.
- ❖ ***Interagency Communication:*** Developed interagency agreements with Adult Protective Services and PATH. Continued liaison with APS to cooperatively address complaints of abuse, neglect and exploitation. Collaborated with SRS, PATH and DOE to jointly fund children in need of services.
- ❖ ***Agency Designation Process:*** Completed agency designation process for five agencies (LCMH, HCRS, NCSS, NKHS, WCMH) and one initial designation process for a Specialized Service Agency (VSL).
- ❖ ***Sexuality Workshop:*** Conducted a two-day training on sexuality and social skills. Discussion from this statewide workshop lead to the start-up of the Social/Sexual Education Network. 
- ❖ ***Vermont Safety Awareness Training:*** Over 90 people participated in revised crisis prevention training that emphasized positive, proactive approaches to improve relationships through trust and attention to emotional needs.
- ❖ ***Vermont Self-Determination Project:*** After 5 years of groundbreaking work, the Vermont Self-Determination Project comes to a close, setting the stage for ongoing initiatives.
- ❖ ***Independent Support Broker Training:*** Participated in multi-day training for ISBs, including follow-up workshops on funding, taxes, insurance, labor and liability issues. 
- ❖ ***Supported Employment Opportunities:*** Forty-one percent (41%) of adults with developmental disabilities in Vermont received supported employment to work in FY 2001 versus only 32% of all disabled adults nationally (Harris Poll, 2000). The number of people with developmental disabilities in Vermont employed in individual jobs increased by 5% since last year.
- ❖ ***Brandon Training School Reunion:*** Approximately 60 people attended the 2nd BTS reunion.
- ❖ ***Management Information System:*** Simplified and unified service definitions and cost centers used by service providers and DDMHS, resulting in more accurate and consistent information at the provider and state level. 

Work in Progress

- ❖ **Agency Designation:** Continue to refine the re-designation process to assure responsibility of one agency in each geographic region of the state for developing a comprehensive network of services.
- ❖ **Family Satisfaction Survey:** Collate and analyze the data from satisfaction surveys mailed to all families whose family member receives developmental services. 
- ❖ **Real Choice System Change Grant:** Start work on joint grant with DAD and DMH that addresses work force issues; independent information and assistance; direct consumer funding; and continuing education and training on self-determination and self-advocacy.
- ❖ **Social/Sexual Education:** Establish Social/Sexual Education Network that focuses on the need for sexuality, relationships and socialization education for adolescents and adults. 
- ❖ **Core Indicators Project:** Continue participation in the National Core Indicators Project to identify and collect data on key indicators to measure common outcomes nationwide.
- ❖ **Revise Policies:** Finalize revisions on *Guidelines for Positive Behavior Support and Restrictive Procedures for Support Workers Paid with DDS Funds*, *Medical Guidelines*, and *Guidelines for Quality Services*.
- ❖ **Self-Management Handbook:** Develop a handbook for people and families who want to self-manage their supports and services.
- ❖ **Waiver Workgroup:** Develop specific guidelines for use of Medicaid Waiver funding; revise and update Medicaid Procedures.
- ❖ **Consumer Survey:** Resume consumer interviews after taking a year to evaluate the process. Analyze data from 2001 interviews and report results to local agencies.
- ❖ **Department of Justice Grant:** Start work on new grant that will enhance and expand Vermont's system of managing sex offenders with developmental disabilities. 
- ❖ **Training & Technical Assistance:** Provide ongoing training and technical assistance to private organizations and state agencies that offer services to people with developmental disabilities.
- ❖ **Statewide Clinical & Crisis Service Capacity:** Work to enhance regional and statewide clinical and crisis service capacity. Draft standards for crisis beds.
- ❖ **Follow-up on Legislative Report on Offenders:** Work to get proposed amendments to Act 248 passed and get support to strengthen the system's capacity to serve offenders with disabilities.
- ❖ **School-to-Adult Services Transition:** Continue collaboration with the Department of Education and Division of Vocational Rehabilitation to improve the processes of planning and support to individuals with developmental disabilities transitioning from school to adult services. 
- ❖ **Complaint & Appeal Video:** Develop two videos that help people with disabilities, families and providers better understand the complaint and appeals processes.
- ❖ **Criminal Justice System:** Collaborate with the Office of the Defender General to improve fairness and accessibility for people with developmental disabilities who are involved with the criminal justice system.
- ❖ **ISA Companion Manual:** Finalize guide to Individual Support Agreement requirements for support coordinators and the accompanying *Communication Checklist* for use in developing communication goals and outcomes. 

The Structure of the Service System

Designated Agencies

The Department of Developmental and Mental Health Services designates one Designated Agency (DA) in each geographic region of the state as responsible for ensuring needed services are available through local planning, service coordination, and monitoring outcomes within their geographic region²⁸. This means that a DA must provide 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. There are ten Designated Agencies in Vermont. Some of the key responsibilities of a DA include the following:

- Receive and act upon referrals and applications for services and supports;
- Inform applicants and service recipients of their rights;
- Assure a person-directed support plan is developed for each recipient;
- Respond to information on people's satisfaction, and complaints and grievances;
- Provide crisis response services for any eligible individual in the geographic area;
- Evaluate and address training needs of board members, staff, family members, and service recipients;
- Identify or develop a comprehensive service network, and assure the capacity to meet the service needs and desired outcomes of eligible people in the region; and
- Monitor data about regional performance and report it to DDMHS.

Specialized Service Agencies

A Specialized Service Agency (SSA) is a separate entity that is also contracted by DDMHS. It must be an organization that either; 1) provides a distinctive approach to service delivery and coordination; 2) provides services to meet distinctive individual needs; or 3) had a contract with DDMHS developed originally to meet the above requirements prior to January 1, 1998. In FY '01, there were four Specialized Service Agencies.

Certified Providers

Certified Providers (CP) are contracted through DAs and SSAs to provide supports to people in the region. Any organization that wishes to provide direct services to people with developmental disabilities funded by DDMHS must meet standards identified in the Regulations Implementing the Developmental Disabilities Act of 1996. Organizations that provide supports and services meet basic quality standards and have the organizational capacity to support people to achieve the outcomes they desire. Any organization that receives state or federal funds administered by DDS must meet these standards. In FY '01, there were two Certified Providers.

Self-Directed & Self-Managed Supports

²⁸ For developmental services, geographic regions are defined along county lines.

All services and supports can and should be self-directed. This means that the person, with help from the circle of support, will define what their life should be like, how they will get supports to make that happen, and from whom the support will be obtained. To make an informed decision, the person and the circle need full information about choices, support options, requirements, responsibilities, and how involved the person will be in their supports. This involvement can range from the person and the circle choosing the providers for services (self-directed services) to the person choosing to fully manage the range of supports needed, including responsibilities of being an employer (self-managed services). These decisions are personal ones, and change during a person's life.

Non-negotiables:

Whether self-directed or self-managed, the following must be in place in accordance with both state and Medicaid waiver regulations and guidelines:

- A circle of support: people chosen by the person who are the supports and trusted people in the person's life;
- All waiver funding must pass through a designated agency or fiscal intermediary for funding disbursement—it cannot go directly to the person, parents or spouse;
- An Individual Support Agreement which follows the current state guidelines;
- A contingency or backup support plan in the event of a life crisis;
- Establishment and maintenance of all required record keeping and documentation of the person's supports/services;
- Participation in reviews of service quality at all levels;
- Responsibility for program evaluations, supervision, oversight and monitoring of services;
- Housing safety reviews; and
- Training and technical assistance to the person, circle of support and staff.

Self-Directed Supports may include:

- Person participates in interviewing, hiring, and evaluating workers.
- Person contracts with agency or provider to manage supports.
- Agency is responsible for overseeing budget and provision of crisis supports.

Self-Managed Supports may include:

- Person (with circle) manages money to pay for supports.
- DA passes dollars through a fiscal intermediary.
- Fiscal intermediary responsible for disbursement of funds according to budget.

Responsibilities of employers include:

- Hiring/firing/evaluation/supervision;
- Fair labor practices and labor laws;
- Personnel records;
- Payroll maintenance;
- State and federal tax laws and record keeping;
- Insurance: workers' compensation, state and federal unemployment, personal property and professional liability; and
- Employee benefits.

Choosing to use an agency to provide this management service does not eliminate the person's involvement in these tasks. Involvement may include creating service budgets, interviewing,

hiring and evaluating staff. The person may request a monthly financial report of all monies spent.

If the person and his or her circle decide they do not want to take the responsibility for administrative duties associated with the management of paid support staff, the person may contract with a provider to be responsible for these employment-related tasks.

Role of People with Disabilities and Families in Services

- **People with disabilities will actively participate in planning their supports and arranging for services through informed choices.** Greater involvement and the making of informed decisions by people in developing their own plans of support will increase service effectiveness. Designated agencies are required to inform applicants and service recipients of *all* relevant service providers, and provide guidance and opportunities for people to self-direct their services.
- **People with disabilities and families will have a strong role in system oversight, evaluation and decision-making.** The inclusion of people receiving services and family members on provider and state boards and standing committees, and in service evaluation, will increase quality and accountability.
- **People with disabilities will register satisfaction and dissatisfaction with services, and file complaints and grievances through proper avenues.** The better understanding providers have about the quality of their services and what works, the more responsive they will be in providing effective supports.
- **People with disabilities and families will help train and educate providers and others.** People's first-hand knowledge is valuable in helping educate and train the workforce about practices that are effective and desirable by people with disabilities and their families. Self-advocates play a particularly important role in the education of others on many issues including the strengths, rights and desires of people with developmental disabilities.
- **People with disabilities and family members will be employed to deliver services.** Because of the knowledge they have through direct experience, people with disabilities and family members often make valuable staff and play important roles in peer support groups.

Increase in People's Choice and Control

The ultimate goal of the developmental service system is to ensure that services and supports are of high quality, fiscally efficient, responsive, and respectful of people and their needs. To this end, the system must all be held accountable for responding effectively to the needs of people. The following aspects of the service system help make this possible:

- *The Department has a **State Program Standing Committee**, comprised of a (disclosed) majority of people with developmental disabilities and family members, (of whom at least 25% are people with developmental disabilities), which will review statewide performance and participate in the designation process.*
- *Designated Agencies, SSAs, and CPs each have a **Local Standing Committee** of their Governance Board comprised of a (disclosed) majority of people with developmental disabilities and family members, (of whom at least 25% are people with developmental*

disabilities), which is responsible for review of program performance.

- There is a strong, uniform statewide **complaints and appeals process**.
- People have direct involvement in their annual **assessment process** and will develop their own **individual plan and budget**, including defining their own expected outcomes and strategies for support.
- Each person is directly notified at the time of application of their **rights as an applicant and service recipient** and the complaint and appeals process; and will be given a description of the application and eligibility determination process, and the process for determining service need and the funding limit.
- At the time of eligibility determination and reassessment, and again at the time of individual service plan development, each person is given **information about service options** and the complaint and appeals process.
- The Department routinely collects information on “**consumer satisfaction**” of provider’s responsiveness and performance regarding outcomes. Satisfaction and responsiveness are included as key performance indicators related to the designation process.
- People and families have **direct input into the designation process**. The re-designation process includes public hearings and an impartial review panel comprised of people with disabilities, families and others.
- The Department has the **ability to de-designate agencies**, or place them on probationary status, if they are unresponsive to people’s needs.
- People have the **ability to choose** services from a provider other than the DA, if available. The DA must honor this choice, except under unusual circumstances.
- The Division of Developmental Services provides direct **technical assistance** to people, families or agencies interested in developing **alternative service options** or **new service providers**, if determined to be a need.
- The Commissioner has the ability to develop funding agreements with Specialized Service Agencies at the state, regional or local level to **address unmet service needs**. The Commissioner makes a determination that a need is unmet based on a number of factors, including satisfaction and demand for services.



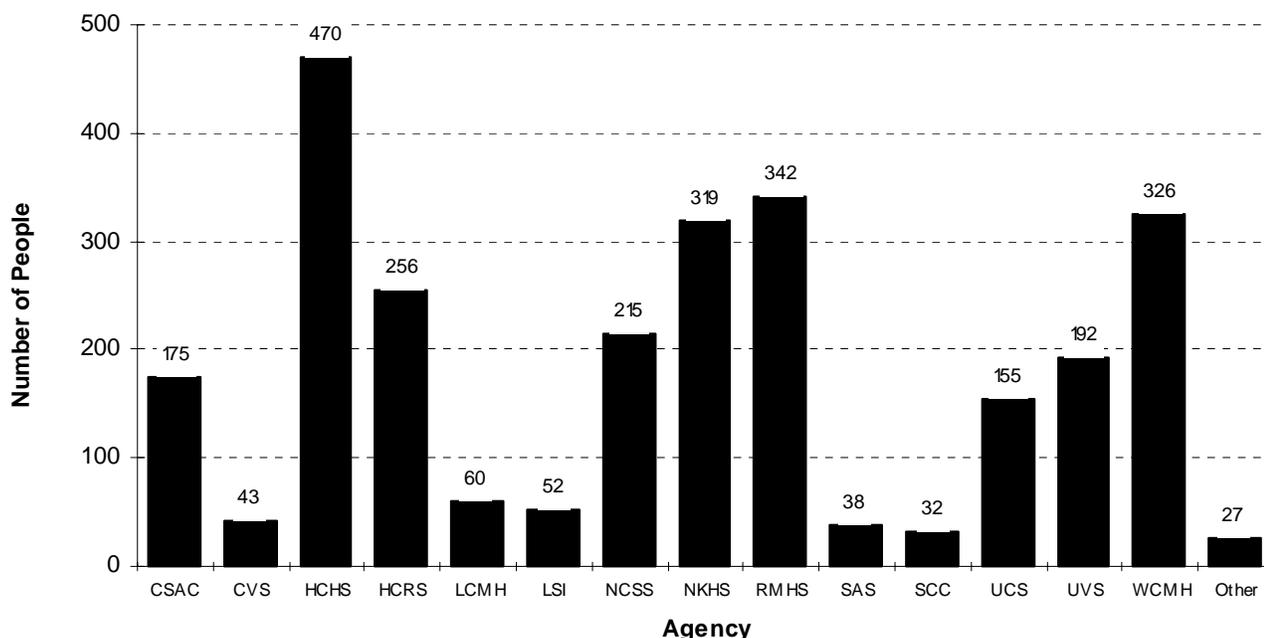
STATUS OF SERVICES

Developmental Services Providers

Following the closure of the Brandon Training School in November 1993, all DDS funded services for people with developmental disabilities are provided in local communities throughout the state (see map on next page). Services include intake and assessment, support coordination, residential supports, community supports, work supports, clinical services, crisis supports, respite, and family supports. The home and community-based waiver funded 1,810 individuals in FY '01. This funding source accounts for 94.5% of all funding for people served through the Division of Developmental Services²⁹.

The Division of Developmental Services contracts with fourteen (14) private, nonprofit developmental services providers (see chart below) who provide supports to a total of **2,702** people with disabilities and their families (see Attachment E: *Vermont Developmental Services Providers*).

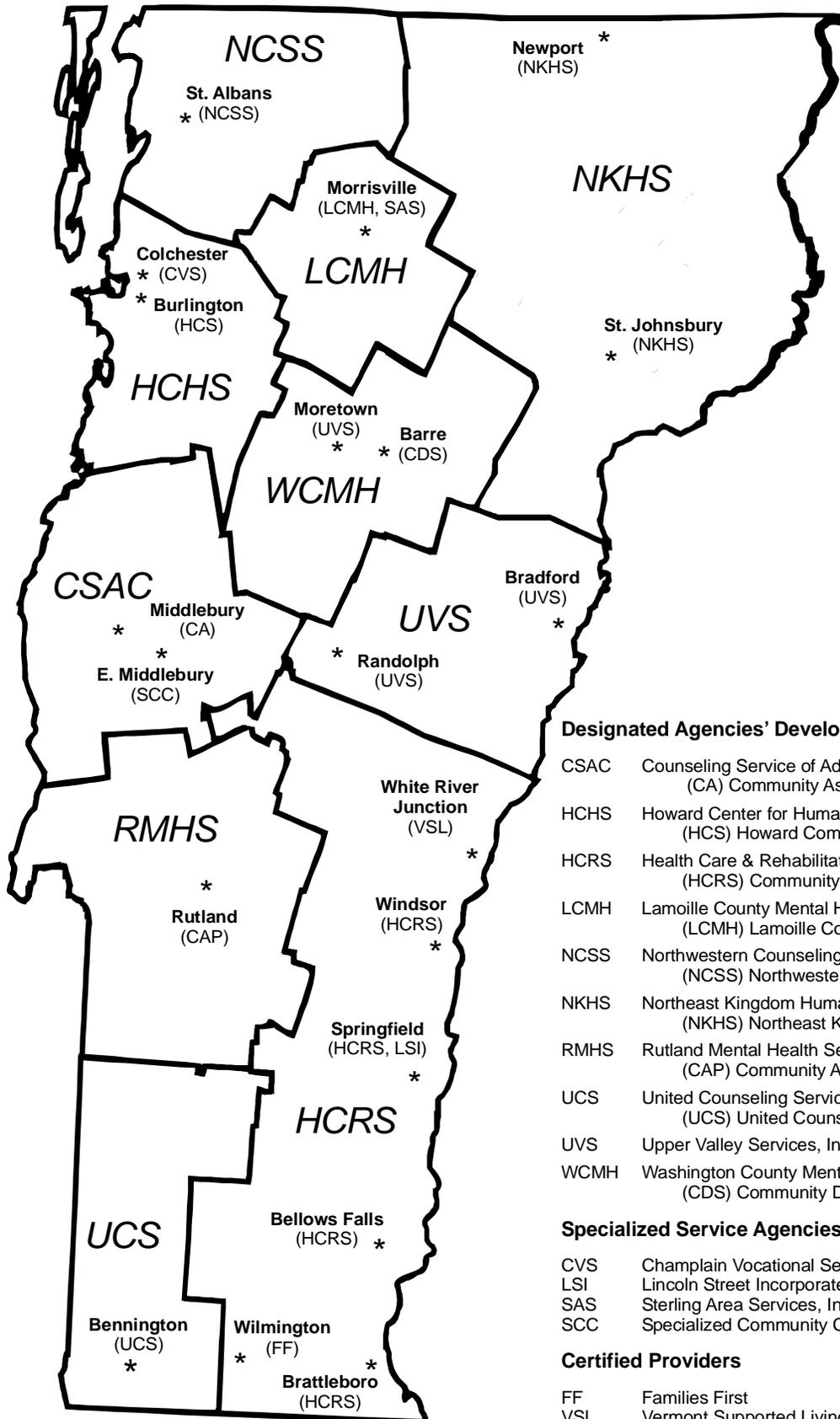
Total Number of People Supported in FY 2001 by Agency



CSAC	Counseling Service of Addison County	RMHS	Rutland Mental Health Services
CVS	Champlain Vocational Services, Inc.	SAS	Sterling Area Services, Inc.
HCHS	Howard Center for Human Services	SCC	Specialized Community Care
HCRS	Health Care and Rehabilitation Services of SE Vt.	UCS	United Counseling Services, Inc.
LCMH	Lamoille County Mental Health Services, Inc.	UVS	Upper Valley Services, Inc.
LSI	Lincoln Street Incorporated	WCMH	Washington County Mental Health Services, Inc.
NCSS	Northwestern Counseling & Support Svs., Inc.	Other	Includes people supported by Transition II Employment Services or Guardianship Services Specialists who are not served by any other DS agency.
NKHS	Northeast Kingdom Human Services, Inc.		

²⁹ All Medicaid (including targeted case management, rehabilitation, transportation, clinic and ICF/MR) accounts for 98.7% of all DDS funding (including the state match). The remaining 1.3% is paid by state general funds.

Vermont Developmental Services Providers



Designated Agencies' Developmental Services Programs

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

Specialized Service Agencies

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

Certified Providers

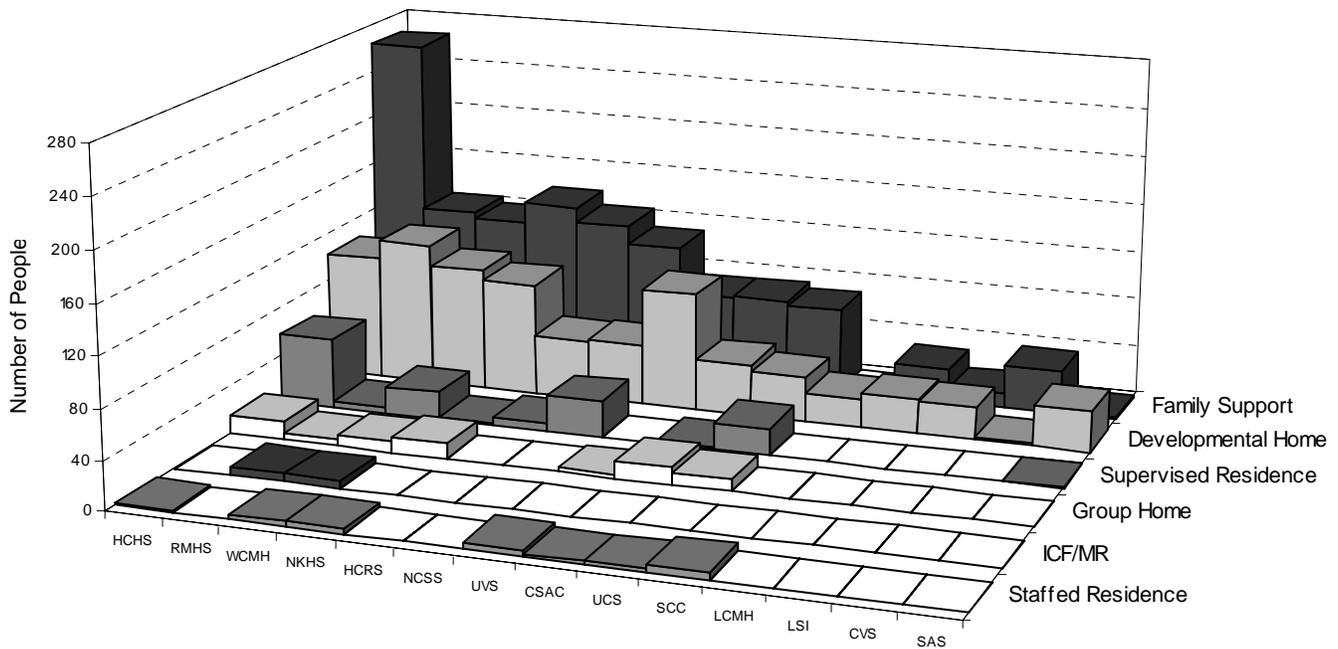
FF	Families First
VSL	Vermont Supported Living

Supported Living

Provider agencies 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:

- Residential Supports
- Community/Social Supports
- Employment Services
- Family Support
- Support Coordination
- Medical/Psychiatric/Nursing
- Emotional & Behavioral Support
- Transportation
- Clinical & Crisis Support
- Support for Independent Living & Decision Making
- Special Needs Support, such as:
 - Communication & Literacy
 - Social/Sexual Education
 - Adaptive Equipment, Accessibility & Home Modification
 - Parents with Disabilities
 - Sex Offenders
 - Aging & End-of-life Care

People Supported by Type of Living Arrangement



(as of 6/30/01)

Residential Supports

There were a total of **1,062** adults and children receiving residential supports on June 30, 2001. Supports were provided in 878 homes, averaging **1.2** people per residential setting.

- **Developmental Home:** Shared living with individualized home supports offered within a “family” setting for one or two people. Home providers are contracted workers and are not considered agency staff in their role as provider.

Number of People – 811

Number of Homes – 704

- **Supervised Residence:** Residential setting for one or two people who do not need the structure of a “staffed” living situation, but who are not ready for totally independent living. Generally the home is owned or rented by the person with the disability.

Number of People – 145

Number of Homes – 139

- **Group Home:** Residential setting for three to six people offering full-time supervision (though there may be exceptions of less than full-time supervision for some individuals).

Number of People – 69

Number of Homes – 15

- **Staffed Residence:** Residential setting for one or two people providing intensive, individualized support with full-time, live-in staff (e.g., staffed apartment). Generally the home is owned or rented by the provider agency.

Number of People – 25

Number of Homes – 18

- **ICF/MR:** Medicaid-funded residential setting for six people which provides intensive medical and therapeutic services.

Number of People – 12

Number of Homes – 2



Other Home and Related Supports (as of June 30, 2001)

- **Rent/Own Home:** An estimated 236 people live in a home that they own (22) or rent (214). This is about 22% of the people receiving residential services (compared to 20% nationwide³⁰).
- **Independent Living:** An estimated 134 adults live independently without paid home supports, but who receive services in other areas of their life (e.g., work supports).
- **Supervised Care:** Nine people receive modest assistance for their residential supports through Supervised Care funding (state general funds).
- **Residential Care Homes:** Service providers support 34 people who live in Residential Care Homes (residential settings licensed and monitored by the Department of Aging and Disabilities) with non-residential supports, such as service coordination or community supports.



- **Service Coordination:** Virtually all people on the Medicaid waiver receive service coordination. In addition, Medicaid targeted case management services were provided to an additional 163 people (count unduplicated with waiver). Of these, 58 were children under 22 and 105 were adults.
- **Home Safety:** One hundred eighty-nine (189) home safety reviews were conducted in FY 2001, including 24 accessibility reviews. A housing specialist contracted by DDS conducted these reviews. Compliance and follow-up to safety reviews by agencies has dramatically improved over the past few years. Forty-eight percent (48%) of the homes responded to the review recommendations within 30 days. The fiscal year ended with 100% of the homes meeting compliance within the maximum 90-day grace period. Two agencies, United Counseling Services and Northeast Kingdom Human Services, perform their own safety reviews.
- **Special Services Fund:** Sixty-six (66) people received assistance to purchase goods and services through the Special Services Fund (e.g., non-Medicaid funded dental services, communication devices, audiological and other adaptive equipment, etc.). In addition, 45 people received funding assistance to go on vacation. Both funds are maintained with state general funds.



³⁰ Based on FY 2000 numbers (Source: Prouty, R. Smith, G., Lakin, C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Institute on Community Integration/UAP, University of Minnesota, June 2001).

Family Supports

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, family trips, appliances, etc. The maximum amount available to a family of an adult or child is generally \$1,122/year. Depending on need, enhanced FFF, up to \$3,000/year, may also be available.

Home and Community-Based Waiver Funding (HCBW): Varying degrees and types of more intensive family supports intended to help maintain family stability, enhance positive family interaction and keep the family intact. Services may include providing support to the child, family-directed respite, service coordination, behavioral consultation, skills training, and other supports (such as employment and community supports) that, consequently, helps the individual to continue living at home with their family.

Total Number People Receiving Family Support FY 2001

Funding/Support	Adults (22 & over)	Children (under 22)	Total
Flexible Family Funding	141	527	668
Home & Community-Based Waiver:	340	299	639
Respite/In-home Supports	197	268	465
Other Supports (Employment & Community Supports)	297	104	401
(minus duplications between FFF & HCBW)	(78)	(67)	(145)
Total – Unduplicated	403	759	1,162

GOALS ACCOMPLISHED

- More Families Served:** A total of 1,162 people received family supports that lived with their families in FY '01. This represents almost 43% of *all* people served.
- Respite Homes:** The Division funded four respite homes around the state to provide planned out-of-home respite support to eligible individuals. Forty-five (45) people (of whom 30 were children) received out-of-home respite in FY '01 for a total of 526 days.
- Outreach to Families:** An average of 1.9 people per 1,000 population received family support throughout the state in FY '01.
- Flexible Funding Increase:** An additional allocation for Flexible Family Funding was made for FY 2001 by the legislature in response to family advocacy efforts.

WORK IN PROGRESS

- Continue ongoing effort to help more families receive information about family support services that are available to them.
- Explore the development of a “family support” waiver.



Supports for Children

GOALS ACCOMPLISHED

- More Children Served:** There was a 17% increase in children supported in the past year.
- Family Support in Vermont:** Vermont devoted a higher percentage of its budget for developmental services to families than any other New England state.
- SRS Collaboration:** The Division continued its cooperative agreement with SRS for accessing developmental services for children in SRS custody who were placed out-of-home. There were 32 children on the DS Medicaid waiver in SRS custody in FY '01. Five of these children were returned home to Vermont from out-of-state institutions.
- PATH Collaboration:** Assisted PATH in the development of family-directed personal care service options for children.
- DOE Collaboration:** Worked with the Department of Education and local schools to bring one child home to Vermont from a residential school as well as diverting six children from residential school placements.



Total Number of Children Supported FY 2001

Funding/Support	Age	Birth – 6	7 – 18	19 – 21	Total
Flexible Family Funding		111	359	57	527
Home & Community-Based Waiver:		22	286	111	419
	Lives with family	21	226	52	299
	Does not live with family	1	60	59	120 (32 w/SRS)
Other (Medicaid, vocational grant, self/private pay)		5	31	28	64
	(minus duplications between FFF & Waiver)	(6)	(50)	(11)	(67)
Total – Unduplicated		132	626	185	943

WORK IN PROGRESS

- Work with SRS to revise the transition policy for youth aging out of SRS into adult services.
- Continue efforts to enhance clinical and crisis services to children with co-occurring developmental disabilities and emotional/psychiatric issues.
- Collaborate with PATH, Children with Special Health Needs and the Agency of Human Services to enhance services available to children with high tech medical needs.
- Work with PATH to explore alternative management of funding for Personal Care Services for DS eligible children.



Peer Support

Green Mountain Self-Advocates (GMSA) is a network of 17 peer support groups from throughout Vermont (see Attachment F: *Green Mountain Self-Advocates*). We come together to listen to each other, make new friends, learn about our rights and tell politicians and others why we are important. Our board includes representatives from local groups. We help self-advocates by letting them speak up for themselves for what they believe in. We are building a movement for self-advocacy through public education and awareness, peer mentoring, support, advocacy and direct action.

WHAT WE DO

- ❖ Four times a year we hold our monthly board meetings on interactive television.
- ❖ We give out loans and grants to people who used to live at Brandon Training School.
- ❖ Self-advocates teach free workshops on *How To Stay Safe, Empowerment and Dreams, Legislative Advocacy, How To Start and Run a Self-Advocacy Group* and *What Allies Can Do To Support the Self-Advocacy Movement*.
- ❖ Start new self-advocacy groups and support those already going.
- ❖ In the spirit of “*Nothing about us without us!*” we support our members to serve on local and statewide advisory boards and committees.
- ❖ We are active members of the national organization Self-Advocates Becoming Empowered.



GOALS ACCOMPLISHED



- ☑ ***Invisible Victims of Crime Project:*** Vermont Protection and Advocacy provided funding to GMSA for the Invisible Victims of Crime Project. We developed and provided abuse prevention training for people with developmental disabilities, family members, developmental services providers, and advocates. Two trainers were women with developmental disabilities. Another key element included teaching self-advocates to be co-trainers of the abuse prevention workshops. Thirty-one (31) interactive workshops were conducted in 2001 throughout Vermont. We also sponsored four all-day workshops with Dave Hingsburger about relationships, rights and self-protection.

- ☑ ***Nationally Speaking:*** The President of our Board served as a board member for the national organization, Self-Advocates Becoming Empowered. This opportunity broadened GMSA's contacts with Vermont's Congressional Representatives and various federal agency administrators.

- ☑ ***Two Leadership Retreats:*** In May and October we held retreats for our board members and other peer leaders to work together to understand what leadership is, what leaders do, what makes it hard to exercise leadership, and what skills are helpful for leadership.

- ☑ ***Solidarity Agreement:*** In July, GMSA signed a statement of solidarity with Vermont Center for Independent Living (VCIL), Vermont Psychiatric Survivors (VPS), and Green Mountain ADAPT to recognize the need for and the power of organizations that are composed of and run by people with disabilities. As consumer run organizations we pledged solidarity and commitment to common goals. We believe that the promise of equal rights will be fulfilled when individuals with disabilities in Vermont have their civil rights respected.





- ADA March on Montpelier:** In July, we co-sponsored a march and rally at the State House with VCIL and VPS to celebrate the 11th anniversary of the signing of the Americans with Disabilities Act.
- Voices and Choices Conference:** We worked with VCIL, VPS and the Self-Determination Project to organize our fourth annual conference. Over 250 self-advocates and their allies participated in eleven workshops including, Tips About Housing, Keeping Your Benefits While You Get a Job, Transportation, Can You Get There From Here, How Computers Can Help You in Your Daily Life, and Self-Advocacy.

Self-advocates Serving on Boards and Advisory Committees: GMSA has supported self-advocates to participate on the advisory boards for the Developmental Services State Standing Committee, Vermont Protection and Advocacy, State Rehabilitation Council, Developmental Disabilities Council, and Self-Advocates Becoming Empowered. We continued working with the Defender General's office to end the silence about people with disabilities being victims of crimes.



Disability Awareness Workshops: We work with self-advocates from local groups to present Disability Awareness workshops to elementary students to help kids understand that people with disabilities are the same as them. We just want respect like anyone else who does not have a disability.



Drafted a Bill of Rights: Self-Advocates from all over the state worked with Dave Hingsburger to learn about our rights and responsibilities. Together we drafted a Bill of Rights for Green Mountain Self-Advocates (see Attachment G: *GMSA Bill of Rights*).

DREAMS FOR 2002

Collaborate with the ARC of Vermont, VCIL, VPS and the Division of Developmental Services to implement the Real Choices System Change Grant. Our role will be to provide training to people with developmental disabilities, family members, service providers, and advocates on self-advocacy and self-determination.



- Complete a booklet of stories about the volunteer contributions that people with disabilities make to their communities.
- Finalize our Bill of Rights and produce a video by and for people with disabilities about our rights.



Self-Determination

Six Years of System Change

THE HISTORY

In March of 1995, a group of interested people gathered together to discuss the concept of self-determination and what it means for people with developmental disabilities in Vermont. Around the same time, the developmental service system was culminating an extensive restructuring effort. Six years later, these initiatives have contributed to significant changes in the landscape of services in Vermont and how people with disabilities are perceived by others and themselves.

Applying the principles of self-determination has been a multi-dimensional endeavor. There has been a need to incorporate self-determination from a system's perspective while gaining support from program administrators. Technical barriers (financial, legal, administrative, monitoring, and liability issues) needed to be explored and addressed. Perhaps most of all, self-determination needed to be nurtured at the individual level, taking the philosophy and values and working to apply them in real life. Individual teams worked on the practical while challenging convention and shifting perspectives. Strong individual and systemic self-advocacy became crucial. Much was learned and accomplished, and much more is still yet to be done.

GOALS ACCOMPLISHED



Information

- People are more knowledgeable about the developmental service system and better informed about what supports are available.
- Better understanding about consumer rights, budget and support plans and other aspects of services.
- Information is made more accessible and easier to understand.

Supports

- Service providers focus energy and resources on supporting people to take part in self-advocacy activities and to speak out for themselves.
- More people are really listened to and helped to find creative ways to express themselves.
- Heightened awareness of self-determination and flexibility within the system with an increasing willingness to support different options.

System

- Creation of an Intermediary Service Organization (fiscal intermediary/payroll service) offers people and their families and home providers a way to manage services themselves.
- Technical considerations when hiring and contracting for support workers, such as legal, tax, insurance and liability issues, have been explored and continue to be clarified.
- People are asked what they think about their services and the control they have in their lives through independent surveys and during Division of Developmental Services' quality service reviews.
- The concept of self-determination is starting to be explored by other departments within the Agency of Human Services.

Influence

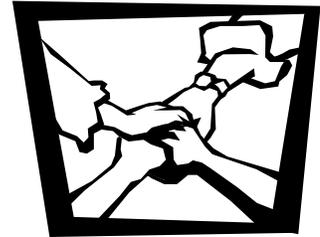
- ☑ People are seen as capable and supported to make important day-to-day decisions central to their lives.
- ☑ People are valued members of boards and committees, and are supported in leadership roles and as decision-makers.
- ☑ People and their families are seen as experienced and valuable trainers. Training and workshops are presented by and for self-advocates, locally and nationally, including organization of the annual self-advocacy *Voices & Choices* conference.
- ☑ Leadership development among self-advocates.
- ☑ People share their stories through political advocacy.
- ☑ Collaboration with state and national disability advocacy organizations.



A COLLABORATIVE EFFORT

Many individuals and organizations played a role in facilitating and supporting the principles of self-determination in Vermont, including:

- ☆ People who receive services and their families
- ☆ Service providers and their staff and contracted workers
- ☆ Division of Developmental Services’ staff
- ☆ ARC of Vermont, DD Council, UVM, VCIL and ARIS
- ☆ Other human service organizations
- ☆ Advocates, legislators, community members, friends and neighbors...



...and a *special acknowledgement* to all the individuals who contributed their hard work and dedication as staff or contracted workers of the Vermont Self-Determination Project:

- | | | | |
|--------------------|--------------------|--------------------|-------------------|
| ☆ Sue Aichroth | ☆ Kye-Sun Forbes | ☆ Rosemary Morse | ☆ Cindy Smith |
| ☆ Sydnee Boyd | ☆ Ken Gagne | ☆ Amie Murray | ☆ Denise Smith |
| ☆ Jeremy Carpenter | ☆ Carmen Gioia | ☆ Susan O’Malley | ☆ Phil Smith |
| ☆ Calvin Cheney | ☆ Nanaymie Godfrey | ☆ Laura Phillips | ☆ Andrea Stefani |
| ☆ Susan Ciappara | ☆ Patty Grassette | ☆ Josh Quenneville | ☆ Michelle Sures |
| ☆ Kim Daniels | ☆ Heather Hendrick | ☆ Joanne Rice | ☆ Heather Tienken |
| ☆ Nola Denslow | ☆ Darlene Kelly | ☆ Robert Rivard | ☆ Karen Topper |
| ☆ Pam Dow | ☆ Judy LaVanway | ☆ Gaye Schaufus | ☆ Carol Warner |
| ☆ Lyle Downing | ☆ Crystal Leno | ☆ Jessica Sears | |

Supported Employment

Supported employment offers people with disabilities access and ongoing support to maintain jobs in their communities. Participation in the work force results in a lasting positive impact to the person and to the public by way of an increased presence of people with disabilities making up the social fabric of Vermont. Supported employment has traditionally been funded through a collaborative effort between the Division of Developmental Services and Division of Vocational Rehabilitation (VR) by using home and community-based waiver and VR grant funds.

Supported Employment FY 2001

	Total
Number of People Employed	704
Average Hourly Wage	\$6.58
Average Hours Worked/Week	13 hr./wk.

GOALS ACCOMPLISHED

- Employment on the Rise:** Overall increase of 32 people with developmental disabilities employed since last year, resulting in 41% of working age adults receiving services being supported to work.
- Vermont ranked #1:** Vermont is top in the nation in the number of people with developmental disabilities who receive supported employment to work per 100,000 of the state population.
- June Grad Survey:** Completed a survey identifying potential high school graduates eligible for developmental services.
- Enhanced Supported Employment Services:** Worked with employment programs at two agencies (CAP & Transition II) to boost employment services and outcomes. Created new supported employment programs at two agencies (SAS & LCMH).
- Sponsorship of Leadership Training Curriculum:** Continued development of new training to be offered to all employment staff at agencies.

WORK IN PROGRESS

- Continue technical assistance to agencies to support people with developmental disabilities to locate and maintain employment and to increase earning power and access benefits.
- Expand and provide enhanced career development and personal planning services to people in an ongoing process to assure access to upward mobility in people's careers.
- Continue conversion of the one remaining sheltered workshop in Vermont with a goal of typical employment for all participants.
- Expand the new comprehensive statewide database which tracks all employment outcomes and services achieved with state funding.
- Continue to promote and support the Regional Core Transition Teams and their work with students, families, service providers and schools.





Tammara Geary, APSE Executive Director, Kathy Hamilton and Michelle Burnham, UCS, Pat Rogan, APSE Board President

UCS AWARDED FOR BEST PRACTICES

The United Counseling Service (UCS) of Bennington County received the Best Practice Award at the 2000 national APSE (The Association for Persons in Supported Employment) conference. Employment Connections, the UCS supported employment program, was recognized for their innovative, imaginative and exemplary performance as an organization. Six years ago, UCS received a grant to convert their sheltered workshop to community-based supported

employment. In less than three years, all the individuals were assisted to find competitive jobs. The UCS team strove to be sensitive to the concerns of family members and worked closely with program participants to ensure their wishes and needs were addressed. Employment Connections of UCS is passionate about their commitment to improve the quality of life of those they support. Through hard work and dedication, Employment Connections has become an exemplary supported employment program in Vermont.

LONG TERM EMPLOYMENT YIELDS RETIREMENT BENEFITS

Sandra Manning has been employed by the dining services of Middlebury College for fourteen (14) years. As a full time employee, Sandra's benefits include paid time off, medical and dental insurance, and a retirement contribution package that will provide income and stability upon Sandra's retirement. Sandra is the first person receiving supported employment that was given a full benefit package upon retirement. Supervisor, Russell Holtz, states that Sandra is one of his best, most loyal employees, willing to go the extra mile to get the job done.

Sandra lives with her husband, Winfield, in Ripton, VT. When not at work, Sandra enjoys spending time with her family and friends. Sandra has taken a trip to Disney World in Florida with savings from her employment. She also enjoys time off to go to the Great Escape amusement park in Lake George, NY.



Sandra Manning at work at Middlebury College

Guardianship Services

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

The 2001 Legislature revised the Guardianship Services law for the first time since 1977. The new amendments:

- ❖ Remove the term “mental retardation” and substitute “developmental disability”,
- ❖ Rename the program Guardianship Services (instead of Protective Services),
- ❖ Authorize probate courts to make temporary appointment of a public guardian for a person with a developmental disability,
- ❖ Clarify confidentiality of court proceedings and evaluations,
- ❖ Make small changes in the court procedures and timelines, and
- ❖ Clarify the guardian’s authority to consent to medical and dental treatment.

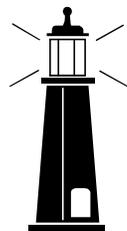


Total Number of People on Guardianship Services FY 2001

Guardianship Services	523
Case Management	22
Guardianship Services Pending	15
Commitment Order (Act 248)	20
Commitment Order Pending	0
Total (unduplicated)	576

In addition to guardianship, Guardianship Services Specialists provide:

- Case management services as a means of preventing public guardianship or assisting a person to transition out of guardianship.
- Oversight and service coordination to people who have been committed to the custody of the Commissioner of DDMHS after being found incompetent to stand trial for a criminal offense (Act 248).
- Support and assistance to private guardians.
- Family reunification for people with developmental disabilities who have been separated from relatives for years.
- Representative payee services for 316 people in FY ‘01. The program’s representative payee assures that people’s income from Social Security, SSI and earnings are invested responsibly and accounted for, and that bills are paid on time.



Training

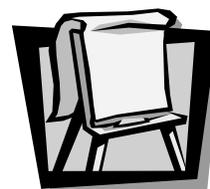
Training and technical assistance are provided by the Division of Developmental Services to the developmental services system to facilitate workers having the expertise necessary to meet the needs of people they support. More than 1500 people received training supported by DDS in 2001.

- **Introductory Training** is a five-day basic course for developmental services staff that provides a foundation for all individuals working or living with people with developmental disabilities. The training promotes the Principles of Developmental Services from the DD Act. Each 5-day session includes a panel of people with disabilities and a panel of family members sharing their perspectives on the role of services in their life. The training is co-facilitated by a person with developmental disabilities. Two sessions of Introductory Training were provided in 2001.
- **Division Supported and Sponsored Training** brings information about best practices to people who provide and receive services, family members and others. Specialized training supports local training efforts by making funds available and giving groups the flexibility to tailor training to their own needs. In 2001, Division training resources supported:

<input checked="" type="checkbox"/> <i>Leadership Training for Self-Advocates</i>	<input checked="" type="checkbox"/> <i>Training Series for Families</i>
<input checked="" type="checkbox"/> <i>Augmentative Communication Training</i>	<input checked="" type="checkbox"/> <i>Training for Intake Coordinators</i>
<input checked="" type="checkbox"/> <i>Housing Safety & Accessibility Training</i>	<input checked="" type="checkbox"/> <i>Emotional Self-Regulation Training</i>
<input checked="" type="checkbox"/> <i>Leadership Series for Supported Employment Staff</i>	<input checked="" type="checkbox"/> <i>Sexuality & Social Skills Education</i>
<input checked="" type="checkbox"/> <i>Workshop Series for Self-Advocates about Developing Personal Relationships</i>	
- **Crisis Intervention and Prevention Training** was revised to include current best practices and an Emotional Self Regulation component focusing on positive, proactive approaches to improve relationships through trust and attention to emotional needs. This resulted in a new *Vermont Safety Awareness Training*, including a presentation by a person who receives services.

GOALS ACCOMPLISHED

- Technical Assistance** provided to agency staff on developing Individual Support Agreements and the use of person centered planning processes.
- Supervisory Training** was provided for the sixth consecutive year for supervisors in the developmental and mental health systems.
- Training Advisory Group** developed to review the objectives and direction of training initiatives.



WORK IN PROGRESS

- Develop a statewide training plan that coordinates with local training needs.
- Develop and support training in the areas of communication, relationships, Dialectical Behavior Therapy, and positive behavior supports.
- Build a network of skilled facilitators to promote sexuality and social skills education.
- Develop and provide training for future trainers of *Supervisory Training*.
- Enhance the distribution of training information to ensure availability to all stakeholders.
- Ensure consistency and quality in presentations of *Vermont Safety Awareness Training* through development of a Trainers Manual and continued certification of new trainers.

Clinical & Crisis Support

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

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

Vermont Crisis Intervention Network FY 2001

Level II – Technical Assistance	
Number of people supported (est.)	51
Level III – Crisis Bed	
Number of stays	14
Number of total days	273
Avg. length of stay (range 3-43 days)	20 days
Institutional Diversions (est.)	12



GOALS ACCOMPLISHED

- Increase in Technical Assistance:** FY 2001 saw a continued high use of on-site consultations, providing more opportunities for crisis prevention.
- Positive Behavior Support Plans:** Provided training to agencies regarding the process of developing positive behavior support plans, including how to conduct a functional analysis of challenging behavior and integration of psychiatric/pharmacological interventions.
- Crisis Bed Universally Accessed:** Most Designated Agencies have used the crisis bed at least once in the past two years.
- Dialectical Behavior Therapy:** Continued to promote development of a network of clinicians skilled in Dialectical Behavior Therapy for people who have developmental disabilities.
- Human Rights Committee Established:** The statewide committee provides an independent review of positive behavior support plans and restrictive procedures.

WORK IN PROGRESS

- Create an additional statewide crisis bed and increase regional clinical and crisis capacity statewide.
- Implement standards for crisis intervention programs for people with developmental disabilities to help ensure that a person’s health, safety and emotional needs are recognized and addressed when they go to a crisis bed.
- Re-establish regular statewide Clinical Network meetings with agency clinical providers.

Quality Assurance

Assessment and assurance of service quality is a critical function of DDS. Annually, Community Alternative Specialists (CAS) conduct on-site reviews of all Medicaid funded services provided by each agency. The CAS teams assess the quality of services with respect to the Division of Developmental Services' quality goals and outcomes to assure compliance with state and federal Medicaid standards and individuals' desires for their supports. The quality of individuals' services is evaluated as well as systems and organizational issues. In addition to the agency review process, the Vermont developmental services system has numerous quality assurance components in place (see Attachment H: *Sources of Quality Assurance and Protection*).

Quality Service Reviews 2001

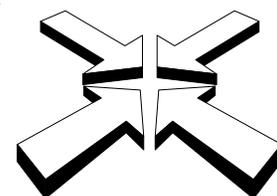
Agencies Reviewed	16
People Reviewed	405
Priority Areas for Improvement – Most Frequently Noted	
<ul style="list-style-type: none"> ❖ Person-centered individual support plans ❖ Health & safety/medical documentation ❖ Training & personal development of staff ❖ Supervise & monitor staff 	<ul style="list-style-type: none"> ❖ Community supports/resource development ❖ Employment supports ❖ Development & documentation of support plans ❖ Organizational development & practices

GOALS ACCOMPLISHED

- Agency Reviews:** All fourteen (14) developmental services agencies and two certified providers participated in DDS quality service reviews in 2001. Reviews were done for approximately 20% of people getting Medicaid-funded services.
- Training & Technical Assistance:** The CASs provided a variety of technical assistance and training on an agency-by-agency basis. They also provided local and regional training on ISA development, community resource development, futures planning, eligibility, medical guidelines and employment services.
- Designation Process:** In 2001, five agencies went through the designation process. In addition, one agency went through an initial designation process to become a Specialized Service Agency. Collection of information for designation is gathered during the quality review process.
- Home Safety Reviews:** One hundred-eighty nine (189) home safety reviews and 24 accessibility reviews were conducted. In addition, two training sessions were held to update agency staff on current housing safety and accessibility practices.

WORK IN PROGRESS

- Update the *Guidelines for Quality Services* to reflect current practices and the DD Act. Revisions in medical guidelines, guidelines for positive and behavior support, and restrictive procedures and incident reporting policies will be included.
- Work to clarify guidelines for self-directed and self-managed services.
- Work with other units of DDMHS to refine and streamline the designation process.
- Develop companion manual for case managers and others to help them better understand the requirements of the Individual Support Agreement.



AN EVOLUTION TO POSITIVE APPROACHES LYN'S STORY

Once a year, the Division of Developmental Services reviews services for individuals whose waiver allotments are among the highest in Vermont. One of the questions asked during these reviews is, "Are the services dazzling?" This past year, a "high end" quality review involved a team from the Community Access Program (CAP) in Rutland. Below are excerpts of submissions from team members that tell the story of Lyn (a pseudonym), a woman who spent much of the first forty-five years of her life in crisis, and whose team, after nearly four years of utter frustration, moved to a positive approach. The quality review team found her services "dazzling".



The woman I met in September 1992 is not the same woman I know today.

- Marcia Gadway, Case Manager for Lyn

Working on this team was one of the most memorable and professionally satisfying experiences I had.

- Darlene Kelly, Former Managing Director for Lyn's team

All I know is that I was a small part of helping a group of caring, dedicated individuals to challenge traditional behavioral science and look within their hearts and minds to find the proper way to help someone in distress.

- Pat Frawley, PhD, Director of the Vermont Crisis Intervention Network (VCIN)



Lyn was born on February 5, 1950 in Hanover, New Hampshire. She was placed in a foster home in 1955. On July 18, 1957, Lyn was admitted to the Vermont State Hospital (VSH). Lyn was transferred from VSH to Brandon Training School (BTS) on September 2, 1982. In February of 1992 Lyn moved into an apartment program in Rutland with CAP. Lyn's history at VSH and BTS included periods of intense self-injurious behavior (SIB) manifested as slaps to both sides of her face and/or hits to her chin with her fist. It has at times been so intense that her face has been marred with open cuts and bruises. She has slapped herself so hard that she has worn the hair off her head. Lyn has been followed by a number of psychiatrists and psychologists from her admission to VSH to the present. The medications and the various behavioral interventions that have been tried would fill hundreds of pages. She would often require a 1:1 staff person around the clock in an attempt to block the blows she was inflicting on herself.

- Jan Sherman, Guardianship Service Specialist, 1996

When I first saw Lyn, my initial impression of her was, "My God, she looks like a battered woman." She spent most of her time withdrawn and isolated in her bedroom, tightly wrapped up in her sheets and a blanket. It was heart wrenching. In spite of the efforts of her entire support team, Lyn seemed to be existing in life from a distance, and was stuck in survival mode. She was so fragile looking, so disconnected and alone. - Marie, Lyn's Home Provider

Lyn's early life, her story of self-injury and abandonment, institutionalization at the age of 7, her lack of a childhood, broke our hearts. - Marcia

The team has spent an incredible amount of time trying to figure out what we can do to ease Lyn's relentless drive to harm herself. Many, many different kinds of medications have been tried and, again, a variety of different behavioral interventions. - Jan

1995 was a particularly difficult year for Lyn. All the typical methods (behavioral protocols, med changes, double staffing, etc.) were not having an impact. - Marcia

I had just taken over as managing director for this team and Lyn was in the throes of extreme self-abuse. Lyn was in crisis and her team was in crisis. - Darlene

In September, Lyn's team met and basically admitted defeat...it was time to ask for outside help and a call was placed to VCIN. We began meeting with Pat Frawley in November and Lyn spent a week at VCIN's site in Moretown. - Jan

Lyn was a woman who was obviously in distress, obviously depressed. We began to take a look at the behavioral plan. The staff had been instructed whenever Lyn hit herself, to make her stand and then begin blocking her attempts. The staff spent all of their time just blocking these hits. Lyn had a painful knee at the time. The behavioral intervention seemed harsh. It had a real punitive feel to it. When I asked the staff what they thought of this intervention every one of them said it felt like the exact wrong thing to do. They felt like they were not helping her. - Pat

We started by taking an entire day to work together as a team on forming a new protocol, which amounted to totally changing our approaches and attitudes toward Lyn. - Darlene

This is where the magic began. We called a team meeting at Darlene's house. Darlene had lit a fire in her fireplace. It was snowing lightly, a slow leisurely snowfall. Marcia handed out one page of the current behavior plan to each person and, one by one, we placed the pages in the fire. - Pat

We made a promise to each other that that was the last of our dealing in the past. - Darlene

Putting aside the old behavioral methods and that philosophy was difficult, but was helped by throwing the protocol into the fire. We constructed a new support plan from the ashes. - Marcia

Darlene and Marcia began to lead us. What is Lyn all about? What is going for her now? What does she need? We described how we would want to be treated if it were one of us. - Pat

Our hearts and gut instinct said to take Lyn back to where acceptance is unconditional, calm and quiet. First, we needed to teach Lyn that you could receive touch in a positive way. - Marcia

They decided they wanted to hold her, like in a hug. At this same time, Lyn had gone to stay at VCIN and the staff there found their way to holding her as well. They would sit with her when she was self-injurious and simply hold her arms, with one arm around the back. They could slowly loosen the grip and it became very warm, cozy, really. - Pat

We began to realize that the interventions that had been used were depriving Lyn of emotional security. The plan that developed focused on reducing expectations during high abuse periods. But the most important addition was unconditional nurturing. Staff would spend a great deal of time sitting with her, holding her hands, hugging, talking and just giving her the extra attention she craved. In the past, whenever Lyn had engaged in SIB, staff would use a hands-off approach, except for blocking. Now, whether she was engaged in SIB or not, the nurturing would be accessible to her. - Jan

One of the major concepts within our new plan was that we were not going to worry about reinforcing her SIB by holding her and being nice. We even practiced what we would say to people who told us we were going to reinforce the SIB. - Pat

Lyn was diagnosed with a treatment resistant depression. Her medical team worked together and developed a treatment plan of medications in an effort to ward off the symptoms of depression. With this new plan in place, the team was ready to welcome Lyn back to her home. - Jan

When she came home from VCIN we celebrated. We were all there to assure her that she was all right; we were going to work together to get through this. We began healing relationships. - Darlene

The new plan went into effect and it took a while, but was fantastically effective. The new antidepressant helped. We made sure that she received this nice attention often and not only when she was hitting. I remember I went back to see Lyn after I hadn't seen her for a month or two. I will never forget the look on her face as she came down the stairs. The transformation defies description. All I had to do was look at her face to know things were fantastic. She looked like a different person. - Pat

Lyn was able to reach the point where she seeks out cuddling and be totally relaxed and at ease with it. She would also signal friends when she did not want to continue. - Marie

Lyn slowly began to access life in the community. She has already been out to more places in the past three months than in the three years before that. Her communication skills have improved dramatically. Instead of hitting, she uses her increasing vocabulary to ask for what she needs. - Jan

The first time I heard Lyn say the word no, the no was barely a little whisper. Now, Lyn can, and will, say "NO", with much clarity and self-confidence - Marie

Slowly her self-abuse decreased. As time went on, more words started to come. She began to reach out. The day that she hit her favorite staff person we all secretly celebrated that her anger was at least coming outward. - Darlene

Lyn has been able to slowly open herself up, feeling safer and safer. - Marie

Eventually, a new community support person was hired to work with Lyn. She and her new staff were off and running. Lyn began to go places she had never been before. Each day she was at the door waiting for her staff to arrive so she could go into the community. I have seen great changes in her self-esteem. For most of her life, Lyn walked around with her hand over her eyes. Now she walks with head erect and makes direct eye contact. She is accepted and loved unconditionally and this has made all the difference. - Jan

Fast forward to early 2002 and the difference is amazing. The stories of Lyn's success are voluminous. Lyn's comfort with herself and others around her is evident in all her interactions. - Marcia

There has been incredible progress in Lyn's communication. Very rarely does she resort to SIB to communicate. Her improved self-esteem is wonderful. She has grown to value herself and recognizes that others value her, too. - Marie

The turning point came from team members listening to what the heart was saying. Seeing Lyn is a reminder of the need to reach out. I am honored to be a part of her life. - Marcia

Direct service staff know when they are doing the right thing and when they are not. They know the answer and my job is only to help them realize that and put it into a plan. We owe a great deal to Lyn. She taught us well. All we had to do was listen. - Pat

Lyn has been a wonderful teacher and truly an inspiration to many who have known her. She is a wonderful person in ways too numerous to say. - Marie

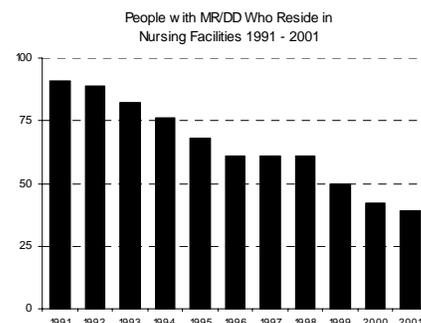


Nursing Home Reform

Pre-Admission Screening and Resident Review (PASARR): The Omnibus Budget Reconciliation Act of 1987 established PASARR which mandates the screening of all nursing home residents and new referrals to determine the presence of mental retardation and related conditions and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services³¹.

GOALS ACCOMPLISHED

- ✓ **Successful Placements Continue:** One community placement for a person living in a nursing facility was developed in 2001.
- ✓ **Diversions Keep People Out of Nursing Homes:** Nine people who had community placements developed were diverted from ever entering a nursing facility at all.
- ✓ **Specialized Services Improve Quality of Life:** Thirty-one (31) individuals received specialized services in 2001 while living in a nursing facility.
- ✓ **Numbers Decline & Quality of Life Improves:** The number of people with MR/DD living in nursing facilities (39 people in 2001) has declined 66% since 1988³², and the quality of life for people placed out of nursing facilities has improved dramatically.
- ✓ **Percentages Below National Average:** The number of people in Vermont with MR/DD in nursing facilities compared to all DD residential services (2.4%) is well below the national average (7.3%)³³.
- ✓ **PASARR Screenings:** The Division of Developmental Services screened twenty-five (25) potential nursing facility admissions in FY 2001, a significant increase over past years.



Community Offers a New Life – A Personal Story

Donald is a 68 year-old man who moved in with a home provider after spending more than 50 years in various institutional settings. Donald lived at the Brandon Training School and when he got older moved to a nursing home. Donald's team began planning a move from the nursing home well over a year ago. There were many concerns about meeting Donald's needs due to the number of years that he had spent in institutionalized settings. Plans were made, details worked out and Donald and his team were ready to give it a try.

Last spring, Donald moved in with a family in the Brattleboro area. Life has changed dramatically for Donald. Living with a family has provided Donald with many opportunities he did not have while living in the nursing home. He receives the support necessary to take part in all his community has to offer. He even took a vacation last summer to the Poconos where he visited a water park and went tubing. Donald's life has been greatly enriched by his team's commitment to him and to community living. According to Donald's home provider, the move has brought out the best in him. Donald is very happy with his new life and his new home.

³¹ Changes in federal law in 1996 eliminated the requirement for an annual resident review.

³² Based on the initial 1988 screening that found 125 people with MR/DD living in nursing facilities.

³³ Source: Prouty, R., Smith G. and Lakin, C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2000*. Institute on Community Integration/UAP, University of Minnesota, June 2001.

Consumer Survey

Consumer Survey Project: The Division of Developmental Services contracts with the University of Vermont to conduct interviews of adults who receive services on a statewide basis. In addition to the personal interview, basic demographic information is collected for all adults whether or not they are able to participate in the interview. Over the course of three years, an estimated 65% of adults who receive services will participate in the survey.

Last year was spent re-evaluating the consumer survey process to clarify the purpose of the survey, update the survey to reflect current issues and concerns, and come up with a better reporting methodology. In addition, a new process was developed for conducting the surveys. It involves doing all the interviews at four or five agencies each year, resulting in a full report for each agency³⁴. This also allows for a valid statewide sample each year. During the fourth year, the complete statewide data will be analyzed and reported, and the survey updated as needed for the next round of interviews.

The following guidelines were drafted to steer future surveying efforts. They incorporate ideas and concerns that were expressed by service providers, consumers and others with the goal of having an effective surveying process that results in meaningful and useful information.



Assumptions:

- Independent, confidential surveying of consumers is an effective way to reflect consumer voice.
- Continue use of the University of Vermont as the independent source for surveying consumers. Continue use of a standardized tool.

Purpose:

- Use statewide data to get a sense of what is important to people who receive services and what types of services most promote positive consumer outcomes.
- Use local agency data for internal use to learn more about the opinions of people they support so as to improve services locally.
- Use some of the data in the DDS quality review process, but not publish reports comparing one agency to another at this time.
- Provide people who receive services a common experience, and information to support self-advocacy efforts.

Details:

- Surveying of consumers at any given agency will be completed within 1-2 years.
- Agency data will be analyzed only after all consumers who can respond to the survey have been interviewed. The data will be compiled and provided to the agency in a timely manner.
- Data collected will be varied and cover a broad scope of information (e.g., demographic data, personal perspective of life circumstances, satisfaction with services, third party information).

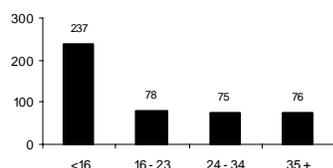
³⁴ Consumers at five agencies were interviewed in the fall 2001. Results will be available in spring 2002.

Family Survey

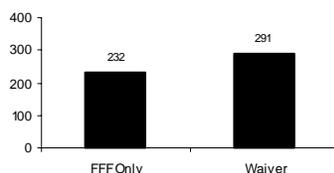
The Family Satisfaction Survey: An updated family satisfaction survey was mailed out in November 2001³⁵. The last confidential statewide family survey was conducted in the fall of 1999. A multi-page survey was sent to families of individuals with developmental disabilities who live at home and were receiving support to ask how they feel about DDS-funded services. The surveys contained 37 questions relating to a wide range of issues, such as, access to services, choice and planning, and receiving help from staff. The surveys allowed for anonymity, but space was provided for written comments and to request follow-up from staff, if the respondent desired. There were 523 surveys completed and returned by families for a high response rate of 58%. An initial report was published in the fall of 1999. Further review of the data was conducted and a follow-up report was released³⁶.

FAMILY SURVEY RESULTS - 1999

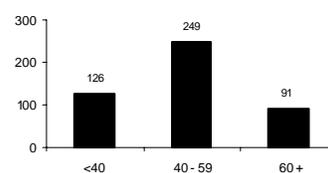
Age of Family Member with a Disability



Funding Source



Caregiver Age



Satisfaction in Relation to Type of Funding

✓ Families of people receiving **Waiver funding** reported being **significantly more satisfied** than people receiving **Flexible Family Funding only** regarding:

- Knowing what supports are available through the agency.
- Receiving enough information to help participate in the planning process.
- Services help keep the family member at home.
- Overall satisfaction with services.



✓ There was **no difference in satisfaction** in terms of type of funding the family received regarding:

- Control over the hiring and management of support workers.
- Staff respect of families' choices and opinions.
- Help, when requested, being provided right away in an emergency.
- Supports being available when the family needs them.

Satisfaction in Relation to Age of Family Member

- 70% of families of young children (<16 years old) receive Flexible Family Funding only.
- 62% of families of adults (22+ years old) receive Waiver funding.



- ✓ Families of young children (<16 years old) report both wanting and having more control over the hiring and management of support workers.
- ✓ Families of young adults (24 – 34 years old) report being more informed about services than families of young children and transition age youth (<24 years old).
- ✓ Families of adults (24+ years old) report services offered most often meet their needs and are more available when needed than families of young children and transition age youth (<24 years old).
- ✓ Families of older adults (35+ years old) report they more often get what they need when they ask for assistance than families of children, youth and young adults (<35 years old).

³⁵ Data from this survey was not available for this report. Results will be available in the spring 2002.

³⁶ Family Satisfaction Survey Detail Analysis: Sample Representation, Funding Source & Age of Family Member – Statewide Results 1999 Survey.

CURRENT PRESSURES ON COMMUNITY SERVICES

Caseload Pressures

The Division of Developmental Services provides supports to 2,702 people with developmental disabilities in Vermont, approximately 25% of the eligible population. This is accomplished through contracts with fourteen (14) developmental services providers located regionally around the state. System restructuring efforts implemented over the past four years have shifted the control of funding from the state level to local agencies. Generally, this has been a successful transition. Funding decisions are made “closer” to individuals and families, giving providers a greater degree of flexibility in making sure the limited funds go to people with the greatest needs.

However, the population is constantly growing and advances in technology have increased the rate of survival of many infants who would not have survived in the past. The demand for supports continues to outpace the available resources. There are many factors influencing this. The diagram on the next page depicts the extent of these pressures. Some of the more predominant and costly pressures on the developmental service system in Vermont include:

- **About 115 children are born each year with developmental disabilities³⁷.** The need for supports is generally life long, and only an average of 28 people who are currently receiving services die each year.


- **There is a continuing rise in the number of children being diagnosed with Pervasive Developmental Disorders.** Current predictions far exceed previous estimates (see page 61³⁸).
- **Special Education graduates need ongoing supports to keep them employed and living at home³⁹.** Large numbers of graduates from Special Education programs (90 in FY '02) are exiting the educational system and looking to the adult service system to provide necessary support services to enable them to continue to learn new skills and live in their own homes. Of those 90, only 38 people are expected to be eligible for home and community-based waiver funding⁴⁰ and 21 for Transition services. Thirty-one (31) graduates, therefore, are not expected to meet any funding priorities.


- **More families are waiting for Flexible Family Funding.** As of January 2002, 71 families have requested this modest but highly valued assistance and are currently on waiting lists.
- **People aging need additional supports.** People who receive services often need additional supports as they get older. Aging parents who have never asked for help before are seeking support before they die.



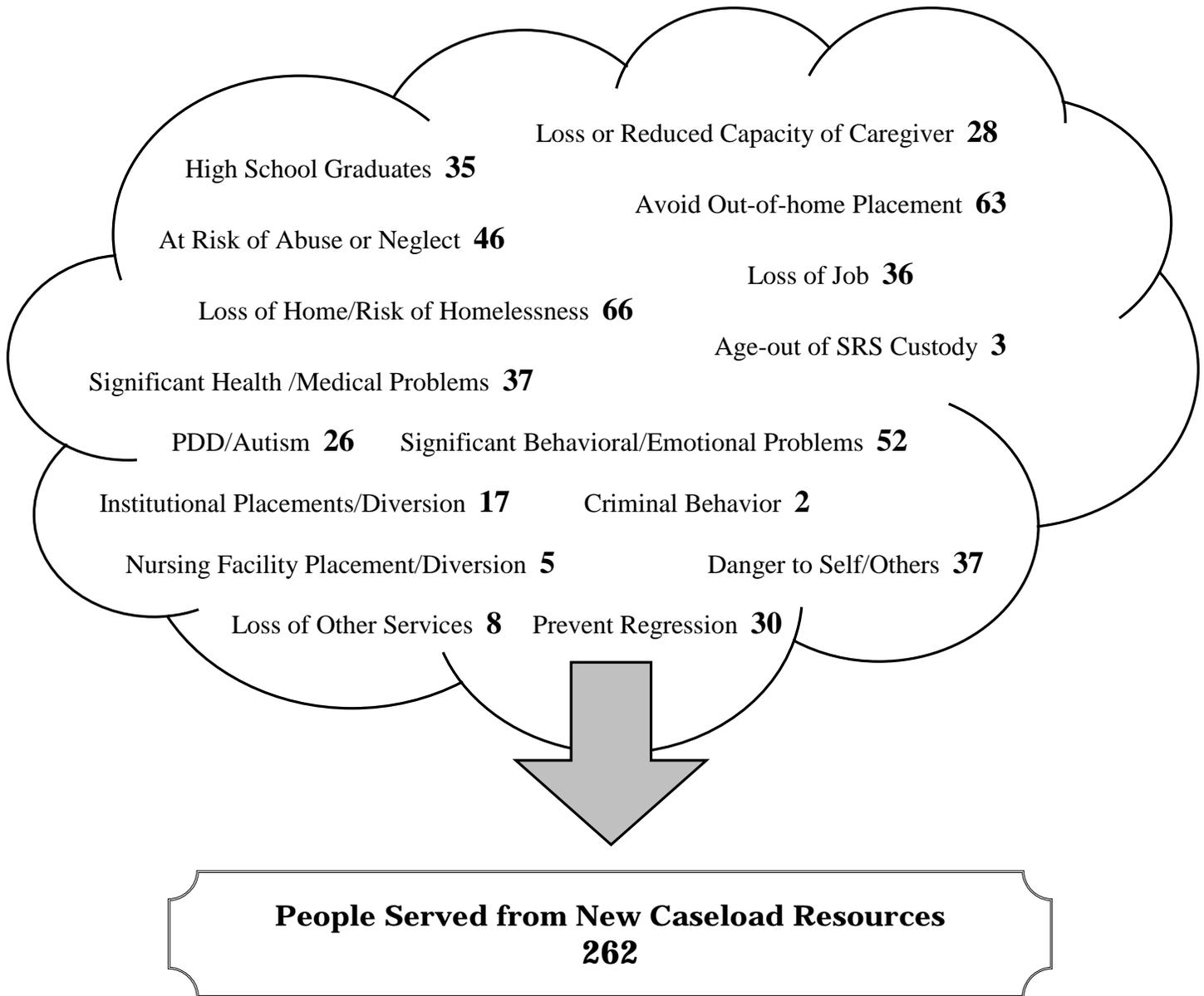
³⁷ Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6560 live births – State of Vermont 1999 Vital Statistics.

³⁸ Eligibility for developmental services was expanded in FY '97 to include people with Pervasive Developmental Disorders (PDD).

³⁹ Designated Agencies survey local schools each year to find out exactly how many students with developmental disabilities are expected to graduate who are eligible for developmental services and need funding.

⁴⁰ Based on the updated DS *State System of Care Plan* funding priorities effective December 1, 2001. Prior to the change in funding priorities, an estimated 56 graduates would have been eligible for waiver funding.

New Caseload Funding⁴¹ – FY 2001



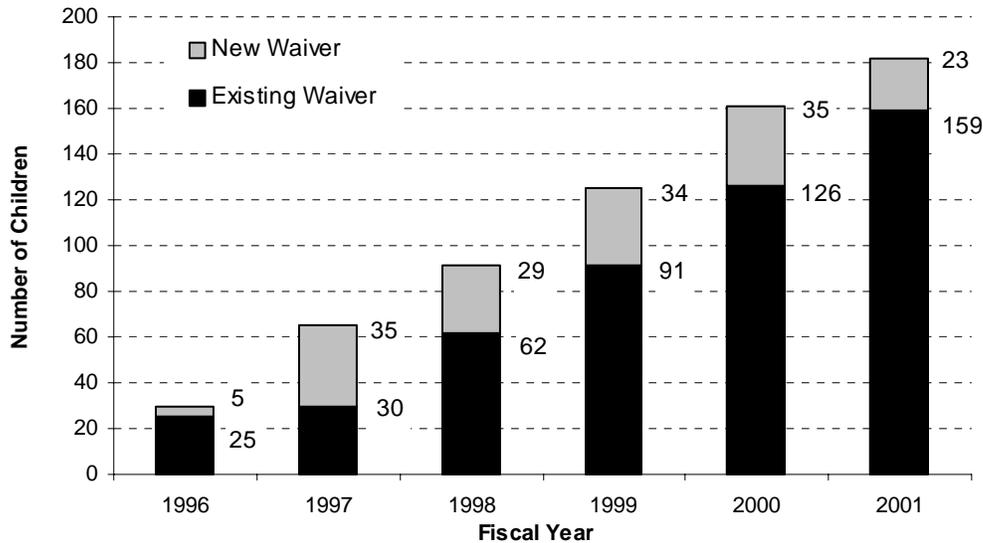
Developmental services resources are being successfully managed:

- New caseload funding goes to those most in need;
- Of the 262 getting new funding, 56% meet the definition of “new consumer;”
- Existing consumers who have a change in needs generally have their needs met through existing funding;
- A number of people leave services every year (e.g., move out of state, die).

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

⁴¹ Based on Designated Agencies’ intake information. Individuals may be counted in more than one category.

Children with Pervasive Developmental Disorders FY 1996 – FY 2001



Children with PDD Funded with New Waivers

Fiscal Year	New Waivers
1996	5
1997	35
1998	29
1999	34
2000	35
2001	23
2002 (as of 12/01)	13

- There was no specifically appropriated funding for children with PDD in FY 2001. New waivers for children with PDD were funded through regular new caseload dollars. Funding decisions for these allocations were made centrally by DDS.
- FY 2002 begins the transition process to move to local decision-making for funding for children with PDD by using the Equity Committee for one year.
- There were 13 children with PDD who received new waivers during the first six months of FY 2002 at an average annual rate of \$12,894.
- Not all children with this diagnosis will require intensive supports from a home and community-based waiver. An estimated 60 children with PDD received Flexible Family Funding from developmental services providers. Medicaid-funded personal care services through PATH may also be available to children with PDD.
- As of December 1, 2001, changes to the DS *State System of Care Plan* funding priorities were suspended (except for FFF) affecting service for all children with developmental disabilities.

Offenders with Developmental Disabilities

The developmental services system serves approximately 125 adults who have been identified as posing a public safety risk. Some are under commitment, and some are under the supervision of the Department of Corrections. Some are awaiting trial, and others are known to be dangerous but are not under court supervision.

- In January 2001, The Division of Developmental Services submitted a *Report to the Legislature on Offenders with Developmental Disabilities: Legislative and Programmatic Recommendations*. The report recommended amendments to Vermont's civil commitment law for people with mental retardation, commonly called Act 248. The proposed amendments are pending in the Legislature as S. 125. The report also recommended strengthening the system's capacity to serve offenders with disabilities through development of an emergency bed, advanced training and clinical supervision, earmarked funds for high-risk offenders, and enhanced respite.
- The Division of Developmental Services continued to sponsor a monthly training and discussion group for clinicians and case managers who work with sex offenders with developmental disabilities.
- The Division of Developmental Services applied for and received a two-year grant in the amount of \$189,594 from the United States Department of Justice for an Implementation/Enhancement Grant to document, enhance, and expand Vermont's system of managing sex offenders with developmental disabilities. The grant provides funding for a multi-agency Collaborative Team to develop a data collection system, clarify common values and goals among services agencies, educate legal system and law enforcement officers, develop a "best practices" manual, and develop a treatment needs and progress scale.
- Case managers and clinicians from Vermont met jointly with clinicians and case managers from New Hampshire who work with sex offenders with developmental disabilities to compare the ways we do our work and learn from one another.

FUTURE DIRECTIONS

The future directions of Vermont's system reflect the need to strengthen and extend the capacity of Vermont's communities to support people who have developmental disabilities. The emphasis will always be on the establishment of options for individual supports that are flexible, responsive, comprehensive and effective. Specific ideas and initiatives that require system-wide planning and development to further enhance the developmental services system include⁴²:

- **Family Services:** Define the goal of children's supports for developmental services and evaluate any changes to the scope of children services. Explore the development of a Medicaid "family support" waiver that could capitalize on match funding, yet retain the "flexibility" of Flexible Family Funding.
- **State Respite Homes:** Develop a plan for the ongoing use of respite homes considering unmet and under-met needs and criteria for use. Create a new respite home in southeastern Vermont.
- **Personal Care Services:** Develop a unified budgeting process for children with Personal Care Services and waiver supports. Work with PATH to explore an interagency agreement to have DS manage Personal Care Services funding for DS eligible children.
- **Supported Employment:** Change funding priorities to increase employment opportunities. Work to create equitable access to supported employment services across Vermont.
- **Transition Supports:** Develop support and identify resources to provide services to all "June graduates," regardless of employment or residential status. Work with schools to prioritize community work opportunities. Assure reassessment of graduates who have received services as children to insure comparability with other adults receiving services.
- **Service Coordination:** Develop infrastructure to support service coordination functions for both independent service coordinators and those that work within provider agencies. Explore ways to simplify scope of service coordinator responsibilities.
- **Community Supports:** Reprioritize the use of resources for community supports toward educational and social opportunities, as well as shifting funding from community supports to work supports. Limit the use of "institutional settings" such as nursing facilities, as community support locations. Explore creative transportation alternatives outside of DDMHS.
- **Home Supports:** Develop alternative residential options. Explore creative, safe ways to reduce 24-hour care. Develop experience and expertise that promotes home ownership.
- **Crisis/Clinical Services:** Continue training and increase local human resources to enable positive approaches. Increase clinical capacity in the state for evaluations and direct clinical work. Identify resources necessary to address mental health needs of children with developmental disabilities. Assure medical consultations and coordination via nursing is available locally. Expand local crisis response capacity and fund second statewide crisis bed.

⁴² For a more detailed description, see the *State System of Care Plan for Developmental Disabilities 3-Year Plan – FY 2002 – FY 2004*.

- **Communication Supports:** Ensure systemic and local means for supporting and enhancing communication skills, technology and training.
- **Self-determination:** Support ongoing development of self-advocacy activities, including resources for self-advocates to be paid trainers. Develop *Self-Management Handbook*.
- **Offenders with Developmental Disabilities:** Secure resources to develop emergency/short-term stay crisis bed; develop alternative placements to increase security; fund supports for high risk offenders; provide advanced training, clinical supervision and therapy options; and provide reliable enhanced respite. Amend Act 248.
- **System Issues:** Develop a mechanism for annual cost of living increases to support community services. Improve understanding of the rights of applicants and service recipients. Develop accurate and meaningful “waiting list” documentation. Evaluate “systems change” initiatives to identify processes that support, or inhibit supports, for individuals and families.

