



Technology Helping Self-Advocacy



Self-Advocates Registering to Vote

PART II

SUPPORTS & SERVICES



Full House at the Annual Provider Conference



Workshop on Having Relationships



Creating with the Grace Project

SYSTEM SUPPORT

Principles of Developmental Services²⁹

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.

²⁹ 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 Services³⁰

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 staff). The Division also exercises guardianship on behalf of the Commissioner for people who are under court-ordered protective 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* for a list of members.)

Services and supports offered emphasize the development of the capacity of generic community resources 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:

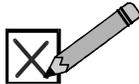
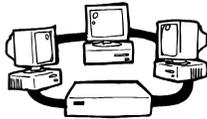
1. *Promote the principles of service stated in the DD Act and carry out all duties required by collaborating and consulting with people, their families, guardians, service providers and others.*
2. *Develop and maintain an equitable and efficiently allocated statewide system of community- based services 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.*

³⁰ For a list of *Division of Developmental Services: Acronyms*, see Attachment B.

Goals Accomplished

- ❖ ***Self-Advocacy Network Grows:*** The Green Mountain Self-Advocates opened a new office in Montpelier and hired a self-advocate to work as outreach coordinator.
- ❖ ***Self-Determination Supported:*** Provided technical assistance to 145 self-advocates from around Vermont and their circle of supports since 1998. 
- ❖ ***Increased Supports for Children with PDD:*** Obtained additional caseload dollars to address the increase in need of children with Pervasive Developmental Disorders. To date, an estimated 177 children have received home and community-based waiver funded supports. Additionally, over 80 children are served with Flexible Family Funding and/or Personal Care Services.
- ❖ ***Conducted Family Satisfaction Survey:*** Family members who receive supports were surveyed on their satisfaction with services. Over 500 families completed the survey for a 58% return rate. 
- ❖ ***Supported Employment Opportunities Increased:*** Increased the number of people with developmental disabilities employed in individual jobs by 25% over the past two years.
- ❖ ***Continence Project Successful:*** Provided technical assistance, resource information and education about continence training to 47 people since the project started and to another several hundred through outreach.
- ❖ ***Interagency Communication Improved:*** Continued liaison with Adult Protective Services to cooperatively address complaints of abuse, neglect and exploitation. Collaborated with SRS, PATH (formerly DSW) and DOE to jointly fund children in need of services. 
- ❖ ***Sex Offender Workshop:*** Conducted statewide training on principles and best practices on supporting people with developmental disabilities who are sex offenders.
- ❖ ***Intermediary Service Organization (ISO) Used:*** Financial and payroll services contracted through an ISO allowed 420 people with disabilities, their families and home providers to self-manage their services. An estimated 100 more used independent bookkeepers or other resources to manage their paid supports. 
- ❖ ***Crisis Training Successful:*** 120 people participated in crisis intervention and prevention training, including representatives from eight developmental service agencies. The training focused on positive, proactive approaches to improve relationships through trust and attention to emotional needs.
- ❖ ***Completed Legislative Report on Act 248:*** Submitted recommended revisions to “Act 248” (the law on offenders with developmental disabilities) to reflect closure of Brandon Training School and other technical amendments. 
- ❖ ***Vermont Self-Determination Project Evaluated:*** An independent evaluation of the accomplishments made by the Self-Determination Project was completed by the Center on Human Policy at Syracuse University.
- ❖ ***Employment on the Rise:*** Forty percent (40%) of adults with developmental disabilities in Vermont received supported employment to work in FY 2000 versus only 32% of all disabled adults nationally.
- ❖ ***Choice in Payroll Service Providers Offered:*** Contracted with both Alpha One and ARIS to provide a payroll and tax service for people with disabilities, families and shared living providers who hire their own workers. 

Work in Progress

- ❖ **Agency Designation:** Continue to refine the process for re-designating one agency in each geographic region of the state that will be responsible for developing a comprehensive network of services within the area.
- ❖ **Provider Certification:** Continue work on designation and certification process for service providers that will integrate with broader quality assurance processes. All organizations providing developmental services with Division funding will be certified or required to operate under a certified provider.
- ❖ **Outcomes:** Finalize the FY 2002 DS system outcomes for measuring quality of services. 
- ❖ **Core Indicators Project:** Continue participation in the National Core Indicators Project to identify and collect data on key indicators to measure common outcomes nationwide.
- ❖ **Management Information System:** Begin statewide use of new service definitions and cost centers to better track and evaluate services and supports at the provider and state level. 
- ❖ **Training Regulations:** Work with providers to understand and implement training regulations and standards for staff and contracted workers.
- ❖ **Restrictive Procedures Guidelines:** Revisit restrictive procedures and restraint policy and develop statewide Human Rights Review Committee.
- ❖ **School-to-Adult Services Transition:** Started 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. 
- ❖ **Consumer Survey Project:** Clarify the purpose of the consumer survey process and convene an advisory board to provide ongoing guidance to the project.
- ❖ **Training & Technical Assistance:** Provide ongoing training and technical assistance to private organizations and state agencies that offer services to people with developmental disabilities.
- ❖ **Sex Offender Programs:** Continue to develop guidelines and training resources for staff working with sex offenders. Continue monthly training for people who work with sex offenders around the state.
- ❖ **Statewide Clinical & Crisis Service Capacity:** Work to enhance regional and statewide clinical and crisis service capacity.
- ❖ **Criminal Justice System:** Collaborate with the Office of the Defender General to improve fairness and accessibility for people with developmental disabilities who are arrested or involved with the criminal justice system. 
- ❖ **Update DS Statutes:** Work to update the Guardianship Services statute.
- ❖ **Information on Appeal Process:** Provide easy-to-understand pamphlets on complaint and appeal processes and work with providers to ensure that people and families who receive services are fully informed about these rights. 
- ❖ **Consumer Trainers/Quality Reviewers:** Create the opportunity and successfully recruit self-advocates to join the DDS's Community Alternative Specialist teams.

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 region³¹. This means that a DA must provide directly or contract with other certified providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines. Some of the key responsibilities of a DA include 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.

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 will be certified by the Division of Developmental Services according to a uniform set of standards. This includes SSAs in their capacity as a service provider, and the service provider entity of a DA if there is one. The purpose of certification is to assure that 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 either be certified or operate under contract or subcontract with a certified provider. Any person paid with funds administered by DDS must work for a certified provider or operate under the auspice of a certified provider.

Providers may apply to be certified in one or more of the following areas:

1) Home Supports

³¹ For developmental services, geographic regions are defined along county lines.

- 2) **Community/Social Supports**
- 3) **Work Supports**
- 4) **Support Coordination**
- 5) **Family Supports**
- 6) **Crisis Support**
- 7) **Other Supports** (not specified above)

Self-Directed & Self-Managed Supports

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 pass 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 and administrative duties associated with the management of paid support staff, the person may contract with a certified provider or designated agency 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, DDMHS, Designated Agencies, Specialized Service Agencies and Certified Providers 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 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 25% are people with developmental disabilities), which is responsible for review of program performance.*
- *There is a strong, uniform statewide **grievance 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 grievance 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 grievance process.*
- *The Department routinely collects information on “**consumer satisfaction**” of DA’s and CP’s responsiveness and performance regarding outcomes. Satisfaction and responsiveness are included as key performance indicators related to the designation and certification processes.*
- *People and families have **direct input into the designation and certification processes**. 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 de-certify providers**, 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 CP associated with 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 Self-Determination Project provides information to help people/families make **informed***

choices and decisions around the services that they receive.

- *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.*

Thoughts on Self-Determination & Communication

By Larry Bissonnette

Papering walls with series of letters of self-determination is working only on the level of intellectual ways of advocacy. I like techniques of wearing out the keys on my computer like reporters on the steps of the statehouse in Montpelier who are paid by newspapers to agitate public thinking.

Larry speaks really well when he's provided with the right support. You can't get your thoughts out to people if you don't have the power to express your ideas. Barriers to determination of our life aren't inadequacies of yourself but shortcomings in other people's beliefs about your abilities. Proud to be a good Vermonter should take into consideration doing a sales job on the community to support the freedom to communicate.

October 2000

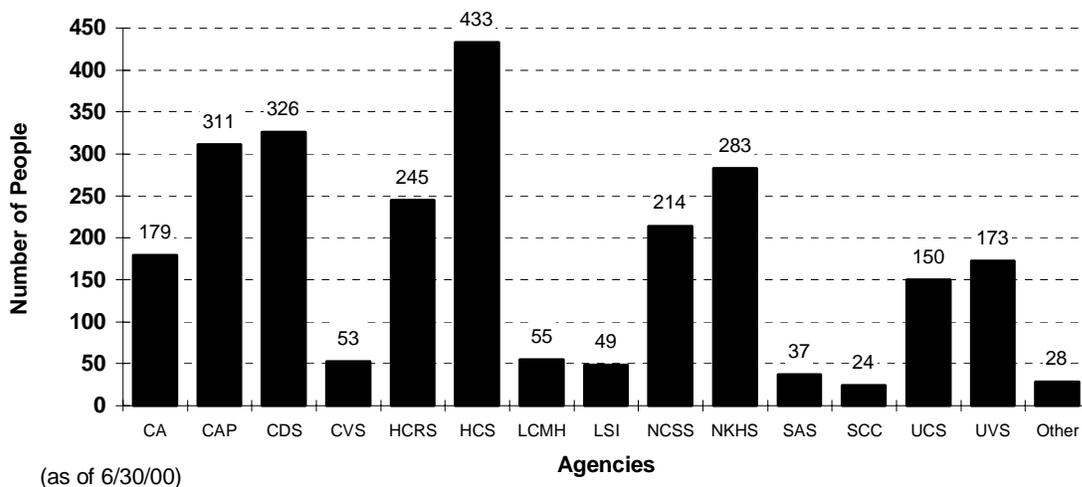


STATUS OF SERVICES

Developmental Service 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 1,719 individuals in FY'00. This funding source accounts for 94.4% of all funding for people served through the Division of Developmental Services³².

The Division of Developmental Services contracts with fourteen (14) private, nonprofit developmental service providers (see chart below) who provide supports to a total of **2,560** people with disabilities and their families. Attachment E (*Vermont Developmental Service Providers*) provides a list of these agencies.

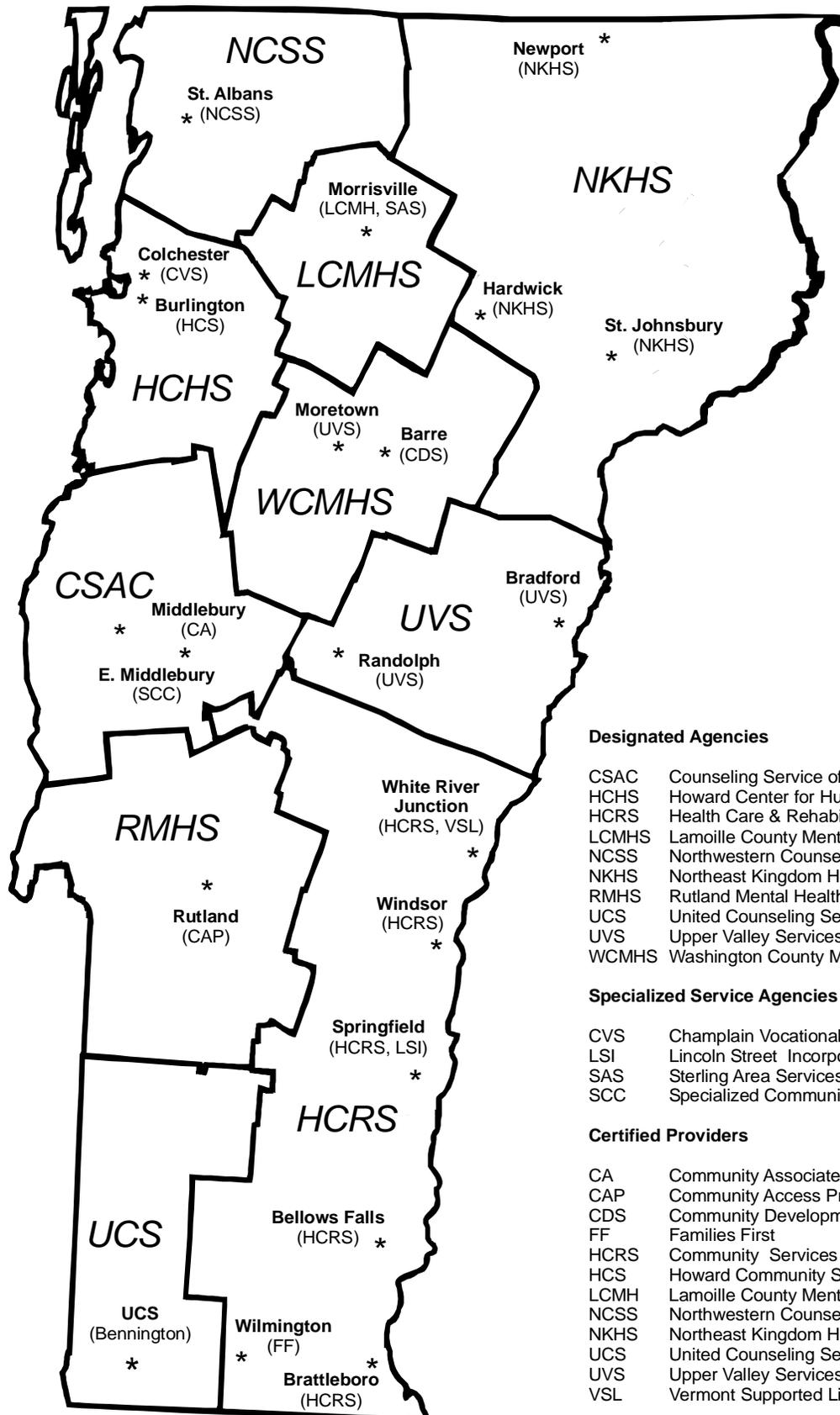


Total Number of People Supported by Agency

CA	Community Associates	NCSS	Northwestern Counseling & Support Svs., Inc.
CAP	Community Access Program of Rutland County	NKHS	Northeast Kingdom Human Services
CDS	Community Developmental Services	SAS	Sterling Area Services, Inc.
CVS	Champlain Vocational Services, Inc.	SCC	Specialized Community Care
HCRS	Health Care and Rehabilitation Services	UCS	United Counseling Services, Inc.
HCS	Howard Community Services	UVS	Upper Valley Services, Inc.
LCMH	Lamoille County Mental Health Services, Inc.	Other	Transition II Employment Services (only includes people not served through other agencies)
LSI	Lincoln Street Incorporated		

³² All Medicaid (including targeted case management, ICF/MR, rehabilitation, transportation & clinic) accounts for 98.9% of all DDS funding (including the state match). The remaining 1.1% is paid by state general funds.

Vermont Developmental Service Providers



Designated Agencies

- CSAC Counseling Service of Addison County
- HCHS Howard Center for Human Services
- HCRS Health Care & Rehabilitation Services of Southeastern Vt.
- LCMHS Lamoille County Mental Health Services, Inc.
- NCSS Northwestern Counseling & Support Services, Inc.
- NKHS Northeast Kingdom Human Services, Inc.
- RMHS Rutland Mental Health Services
- UCS United Counseling Services, Inc
- UVS Upper Valley Services, Inc.
- WCMHS Washington County Mental Health Services, Inc.

Specialized Service Agencies

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

Certified Providers

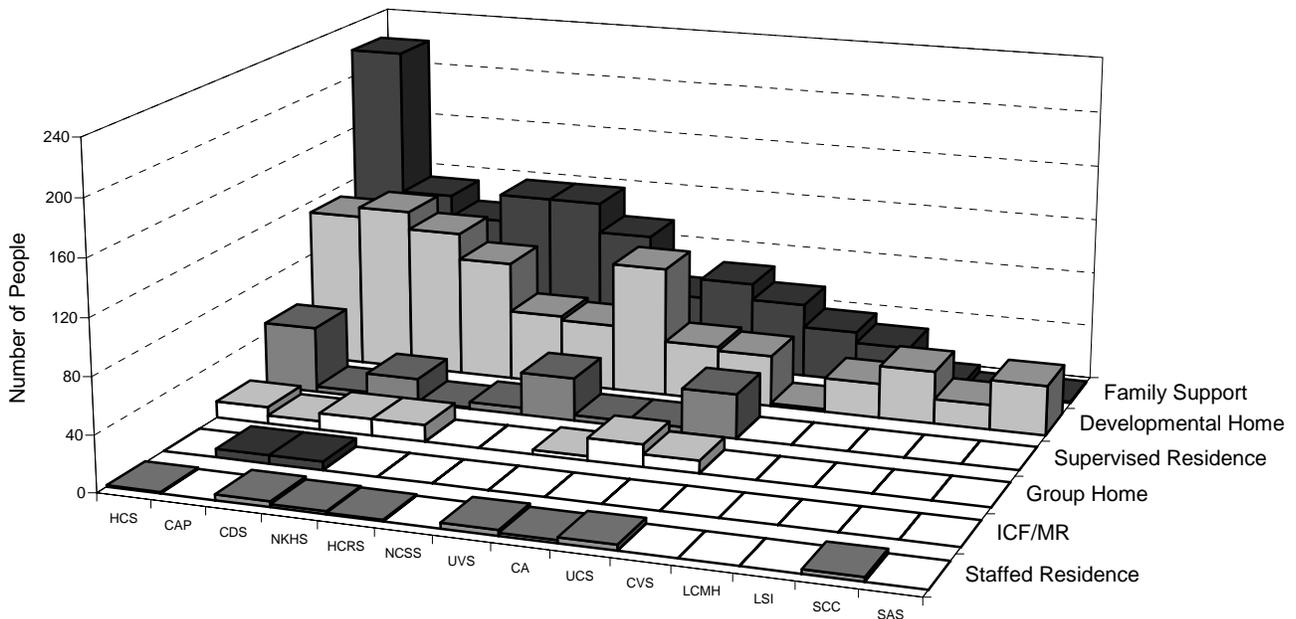
- CA Community Associates
- CAP Community Access Program of Rutland County
- CDS Community Developmental Services
- FF Families First
- HCRS Community Services Division of HCRS
- HCS Howard Community Services
- LCMH Lamoille County Mental Health Services, Inc.
- NCSS Northwestern Counseling & Support Services/DS
- NKHS Northeast Kingdom Human Services, Inc.
- UCS United Counseling Service, Inc.
- UVS Upper Valley Services, Inc.
- 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
 - Adaptive Equipment, Accessibility & Home Modification
 - Parents with Disabilities
 - Literacy
 - Sex Offenders
 - Aging & End-of-life Care

People Supported by Type of Living Arrangement



(as of 6/30/00)

Residential Supports

There were a total of **1,063** adults and children receiving residential supports on June 30, 2000. Supports were provided in 890 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 – 813

Number of Homes – 721

- **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 (e.g., supervised apartment). Generally the home is not owned or rented by the provider agency.

Number of People – 147

Number of Homes – 138

- **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 – 70

Number of Homes – 14

- **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 – 21

Number of Homes – 15

- **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, 2000)

- **Rent/Own Home:** An estimated 218 people live in a home that they own (16) or rent (202). This is about 21% of the people receiving residential services compared to 18% nationwide.
- **Independent Living:** An estimated 140 adults live independently without paid home supports, but who receive services in other areas of their life (e.g., work supports).
- **Supervised Care:** Twelve (12) people receive modest assistance for their residential supports through Supervised Care funding (state general funds).
- **Residential Care Homes:** Service providers support 37 people who live in Residential Care Homes (residential settings licensed and monitored by the Division of Aging and Disabilities) with non-residential supports, such as service coordination or day supports.



- **Case Management:** Virtually all people on the Medicaid waiver receive case management supports. In addition, targeted case management services were provided to an additional 153 people (count unduplicated with waiver). Of these, 46 were children under 22 and 107 were adults.
- **Home Safety:** One hundred seventy (170) homes received housing safety reviews in FY 2000, including 18 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. Sixty-nine percent (69%) 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:** Forty-two (42) 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, 42 people received funding assistance to go on vacation. Both funds are maintained with state general funds.



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. 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 2000

Funding/Support	Adults (22 & over)	Children (under 22)	Total
Flexible Family Funding	105	448	553
Home & Community-Based Waiver:	301	256	557
Respite/In-home Supports	165	230	395
Other Supports (Employment & Community Supports)	271	90	361
(minus duplications between FFF & HCBW)	(45)	(62)	(107)
Total – Unduplicated	361	642	1,003

GOALS ACCOMPLISHED

- More Families Served:** A total of 1,003 people received family supports that lived with their families in FY '00. This represents almost 40% 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. Fifty-five (55) people (of whom 37 were children) received out-of-home respite in FY'00 for a total of 492 days.
- Outreach to Families:** An average of 1.7 people per 1,000 population received family support throughout the state in FY '00.
- 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

- Establish an additional state-funded respite home for a total of five homes located throughout the state.
- Continue ongoing effort to help more families receive information about family support services that are available to them.



Supports for Children

GOALS ACCOMPLISHED

More Children Served: There was a 31% increase in children supported between FY '98 and FY '00.

Family Support in Vermont: Vermont devoted a higher percentage of its budget for developmental services to families than any other New England state (other than New Hampshire with whom Vermont tied).



SRS Collaboration: The Division expanded its cooperative agreement with SRS for accessing developmental services for children in SRS custody who were placed out-of-home. There are currently 29 children on the DS Medicaid waiver in SRS custody.

PATH Collaboration: Assisted PATH (formerly DSW) in the development of family-directed personal care service options for children.

**Total Number of Children Supported
FY 2000**

Funding/Support	Age	Birth – 6	7 – 18	19 – 22	Total
Flexible Family Funding		84	306	58	448
Home & Community-Based Waiver:		37	263	103	403
	Lives with family	32	185	39	256
	Does not live with family	5	78	64	147 (29 w/SRS)
Medicaid Targeted Case Management		8	29	9	46
(minus duplications between FFF, Waiver & TCM)		(14)	(63)	(17)	(94)
Total – Unduplicated		115	535	153	803

WORK IN PROGRESS

Collaborate with the Departments of Education and SRS toward bringing children home to Vermont from out-of-state institutions and diverting children from these placements.

Work with SRS to revise the transition policy for youth aging out of SRS into adult services.

Establish enhanced clinical and crisis services to children with co-existing 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.



Peer Support

Green Mountain Self-Advocates (GMSA), formerly Vermont Peer Support Network, is a network of 17 peer support groups from throughout Vermont³³. 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.
- ❖ Self-advocates teach free workshops, such as *How to Stay Safe*, *Legislative Advocacy*, *How to Start and Run a Self-Advocacy Group*, and *What Allies Can Do to Support Self-Advocacy*.
- ❖ We help start new self-advocacy groups and support those already going.
- ❖ We give out loans and grants to people who used to live at Brandon Training School.
- ❖ We support our members to serve on local and statewide advisory boards and committees.
- ❖ We are active regional members of the national organization Self-Advocates Becoming Empowered.

GOALS ACCOMPLISHED

- ☑ **Name Change:** We changed our name from Vermont Peer Support Network (VPSN) to Green Mountain Self-Advocates (GMSA).
- ☑ **The Great Computer Give-away:** We rebuilt old computers and gave them away to self-advocates.
- ☑ **New Office:** We opened a new office in Montpelier and hired a self-advocate to work as outreach coordinator.
- ☑ **Invisible Victims of Crime Project:** Three self-advocate trainers worked with the Awareness Theater Company to present 14 workshops on *How to Stay Safe*. It is estimated that around 80% of people with disabilities experience abuse sometime in their lives. Project staff teach people how to avoid abusive situations and how to get help if needed.



How to Stay Safe: Invisible Victims of Crime Project

Self-advocates from the Randolph group gathered to learn how to stay safe. They watched a play produced by self-advocates, made "monster boxes" to hold their fears and volunteered to perform. Edwin and Lisa, peer trainers from the local group, played the part of high school students outside of a corner store. Carol, a trainer from the Project, played the part of a self-advocate with a lot of friends. As Carol walks by, Edwin and Lisa try to get her to buy beer for them, but she is torn because she really wants to hang out with these teenagers. Carol turns to the audience, "What should I do?" A number of self-advocates call out suggestions. Much to her surprise, Edith, a somewhat shy self-advocate, approached Carol, grabs her hand and pulls her into the store. Edwin and Lisa. Everyone clapped and cheered!

- ☑ **Voices and Choices Conference:** We worked with the Self-Determination Project to organize our third annual conference. Over 300 self-advocates

³³ See Attachment F (*Green Mountain Self-Advocates*) for a list of local chapters and contact people.

and their allies participated in 20 workshops, including *Having Relationships* and *How to Hire your Own Support Staff*.

- Nationally Speaking:** Self-advocates presented at the International Conference on Self-Determination, and the TASH and Self-Advocates Becoming Empowered national conferences.
- March on Montpelier:** Fired-up self-advocates from all around the state gathered in Montpelier on March 14, 2000 to rally support for people with disabilities. Several hundred self-advocates, parents, support workers and disability-rights activists took part.

Ride the Wave 2000

The Division of Developmental Services and service providers paid tribute to self-advocates for their strong voice in advocating for change by supporting them to attend Ride the Wave, a national self-advocacy conference in Rhode Island. This 4-day event was jam-packed with self-advocate presenters and participants from around the United States. Vermonters played an important part in helping other self-advocates organize this extraordinary event.

“I think the conference as a whole was great because it gave self-advocates the confidence to speak up for themselves and say what’s on their mind,” commented Dawn Arsenault of GMSA. “I got to work with Minnesota [self-advocacy] organizers...to do six different workshops about self-advocacy. I also think it is helpful for support staff to be at the conference so they can understand where people with disabilities are coming from and where they want to go.”

Edwin Place from Randolph was one of hundreds who helped build a giant story wall by sharing the story of his life. His heart-felt words described his struggles while living in Brandon Training School, which contrast sharply with the valued roles he now has working for the Town of Randolph and serving as president of his local self-advocacy group.

WORK IN PROGRESS

- Finalize the non-profit status of Green Mountain Self-Advocates.
- Offer new workshops by self-advocates, including *Shaking Off Stereotypes; My Choice, Your Decision;* and *Disability Culture and Identity*.
- Present *Disability Awareness* workshops by self-advocates for local schools.
- Teach *Partners and Policymaking* classes to self-advocates and their allies.
- Continue work with the Defender General’s office to end the silence about people with disabilities being victims of crimes. Support the training of cognitive facilitators working in the criminal justice system.
- Organize a leadership retreat for members of the Green Mountain Self-Advocates Board.



Self-Determination Project

The Vermont Self-Determination Project began in the fall of 1997. Originally funded by a three-year grant from the Robert Wood Johnson Foundation to the Division of Developmental Services, the Project has more recently received one-time funding from the Vermont legislature. The Project works to develop the capacity in Vermont so that people with developmental disabilities – self-advocates – and their families will be empowered to have real choice and control over their supports.

One Self-Determination Project Staff Member Talks About Her Work:



“As a self-advocate, I look out for other people with disabilities. My job is to help them look at reality. Reality means how things really are – the truth. How things really are is that we all have very special gifts. Everybody does, but everybody doesn’t know it. That’s the truth. I know I have special gifts. My job is to help people see their very special gifts.

Sometimes it’s hard to speak up. I know how it feels. It takes me a while to think of what I want to say. If people put their mind to something, they can achieve their goal. If you want something done, you have to do it yourself. I did. They can.

We all need to speak up for what we believe in. I believe everyone should speak up. I speak up for people who haven’t been able to speak up for themselves.”

Sue Aichroth

In the spring of 2000, DDS undertook a collaborative planning process to explore ways of making sure that the principles of self-determination would become an essential part of the foundation of our system of supports. A planning committee of diverse stakeholders was gathered. Led by an outside facilitator, they gathered information about how the Self-Determination Project might change to better reflect the needs of the developmental services system. They agreed on a set of goals for the project:

- ❖ Providing independent and accurate information;
- ❖ Training independent service brokers;
- ❖ Working collaboratively with Green Mountain Self-Advocates; and
- ❖ Providing grants to local agencies to help them make changes in their practices.



They also designed a three-team structure for the Self-Determination Project:

- ❖ **Local Team** – to provide technical assistance and information to referrals and others;
- ❖ **Grant Technical Assistance Team** – to provide support and technical assistance to two agencies who receive small grants through an RFP process; and
- ❖ **Information Team** – to develop information tools and materials; network with various stakeholders; and provide training and support for the Project and others.

GOALS ACCOMPLISHED

- ☑ **Training Provided:** Training was provided to self-advocates, families, providers and community members on a variety of topics, including guardianship, grievance and appeals processes, legislative processes, funding, alternative support options, person-centered planning, and a host of other areas.



- ☑ **Technical Assistance Provided:** The Self-Determination Project has provided technical assistance to 145 self-advocates and their circles of support since 1998.



- ☑ **Information Shared:** Project staff conducted workshops and outreach meetings regarding self-directed and self-managed support options with people with disabilities, families, providers, community members, and DDS staff.

- ☑ **Self-Advocacy Conference Coordinated:** In collaboration with Green Mountain Self-Advocates, the third annual “Voices and Choices” conference was held on October 19, 2000 in Northfield. A keynote address was delivered by a self-advocate from Ohio. Breakout sessions, co-facilitated by self-advocates, ranged from how to start your own business, person-centered planning, art, how to write your own Individual Support Agreement, hiring staff, African-inspired dance and drumming, and information about legislative processes. Over 300 self-advocates and their allies attended the conference.



- ☑ **Brandon Reunion Organized:** In partnership with Green Mountain Self-Advocates, a reunion of residents from the former Brandon Training School was held in February, 2000. The event gave participants an opportunity to tell stories that celebrated their lives in the natural communities, as well as a time to socialize and visit with old friends.



- ☑ **Legislative Access Provided:** In an effort to help self-advocates and their families learn more about the legislative process and its impact on their lives, a series of hands-on activities were supported. These opportunities gave self-advocates, family members, and their allies the opportunity to visit and communicate with their legislators at the State House.

- ☑ **Project Evaluation Performed:** The Self-Determination Project contracted with the Center on Human Policy at Syracuse University in New York, to perform an independent evaluation of the first three years of its work. Attachment G (*Contributions of the Vermont Self-Determination Project*) outlines the highlights of their evaluation.



- ☑ **Article Written:** Project staff wrote an article based on their experiences of self-advocates and their allies in Vermont, entitled “Creating A New System of Supports: The Vermont Self-Determination Project.” The article has been accepted for publication in a nationally recognized peer-review journal, the *Rural Special Education Quarterly*.

Supported Employment

Supported Employment offers people with disabilities support to obtain and maintain employer-paid competitive jobs in their communities. Services have traditionally been funded with grant funds available through a collaborative effort between the Division of Developmental Services and Division of Vocational Rehabilitation (VR). Increasing numbers of people have been accessing supported employment services via Home and Community-Based Waiver funding.

Supported Employment FY 2000

	Total
Number of People Employed	672
Average Hourly Wage	\$6.45
Average Hours Worked/Week	13 hr./wk.

GOALS ACCOMPLISHED

- Job Assessments Provided:** All referrals seeking employment are provided comprehensive vocational assessments and personal planning to yield the best job match.
- Enhanced Supported Employment Programs:** The Division of Developmental Services worked with employment programs at three agencies (Community Associates, Howard Community Services and Sterling Area Services) to increase employment services
- Employment on the Rise:** There was an overall increase of 37 people with developmental disabilities employed since last year, resulting in 40% of adults receiving services being supported to work.
- Developed & Implemented Leadership Training Curriculum:** About 30 provider staff have received leadership training, with an estimated 50 more to be trained in FY 2001.

WORK IN PROGRESS

- Provide training and technical assistance to agencies to support people with developmental disabilities find and maintain employment in integrated settings and earn increased wages.
- Work to assure that people with even the most substantial disabilities have opportunities for employment by expanding knowledge and use of waiver funding for vocational services.
- Promote the unification and consolidation of all employment services within designated agencies and enhance the quality and quantity of employment opportunities through technical assistance provided by DDS, VR and UVM.
- Expand consumer-directed vocational services through increased personal planning methods.
- Complete and implement a comprehensive statewide database that will track all employment outcomes and services achieved with state funding.
- Continue support of the Regional Core Transition Teams and their work with students, families, service providers and schools.
- Expand awareness and support for career exploration and development for people with developmental disabilities.



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 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 2000

Level II – Technical Assistance Number of people supported (est.)	62
Level III – Crisis Bed	
Number of stays	15
Number of total days	272
Avg. length of stay (range 8-42 days)	18 days
Institutional Diversions (est.)	11

GOALS ACCOMPLISHED

- Increase in Technical Assistance:** FY 2000 saw a continued high use of on-site consultations, providing more opportunities for crisis prevention.
- Crisis Bed Universally Accessed:** All Designated Agencies have used the crisis bed at least once in the past two years. The average length of stay for those who used the crisis bed in FY '00 was reduced from the past two years.



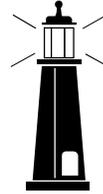
WORK IN PROGRESS

- Create an additional statewide crisis bed and increase regional clinical and crisis capacity.
- Establish a human rights committee to review behavior support plans and practices.
- Promote the development of a network of clinicians skilled in Dialectical Behavior Therapy for people who have developmental disabilities.
- Develop 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.

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. In addition, Guardianship Service Specialists (GSS) 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. For example, one gentleman was reunified with two of his siblings, while another was reconnected with an old friend from Brandon Training School.
- Representative payee services for 309 people. 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.
- Last year, the Guardianship Services program completed an agreement with the Probate Courts. A Probate Court judge may now appoint a Guardianship Services Specialist for an adult who does not have a suitable private guardian.



Total Number of People on Guardianship Services FY 2000

Protective Services	541
Case Management	19
Protective Services Pending	7
Commitment Order (Act 248)	15
Commitment Order Pending	1
Total (unduplicated)	579

WORK IN PROGRESS

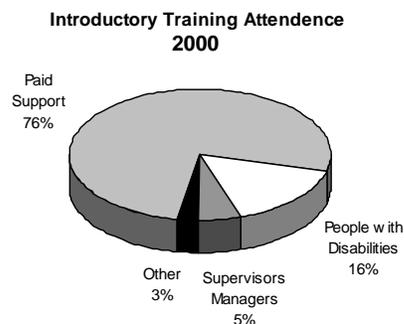
- Revise the Protective Services law, which was enacted in 1977. Revisions will reflect updated terms and concepts.
- Develop a manual for guidance of private guardians and new GSS staff.



Training

Training and technical assistance are provided by the Division of Developmental Services to the service delivery system to facilitate workers having the expertise necessary to meet the needs of people they support.

➤ **Introductory Training** is a five-day basic course for community support 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 of 1996. 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 self-advocate. Introductory Training was provided to 40 people throughout Vermont in 2000.



- **Division 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. Additionally, support for several statewide conferences resulted in over 1,500 people receiving information on a variety of topics.
- **Crisis Intervention and Prevention Training** was provided to 120 people including representatives from eight developmental service providers. The training focused on positive, proactive approaches to improve relationships through trust and attention to emotional needs.

GOALS ACCOMPLISHED

- Technical Assistance** focused on implementing DS regulations and development of a training plan for each developmental service provider. Over 100 self-advocates shared training priorities for their support workers, which was printed and disseminated as *In Our Words...*
- Supervisory Training** was provided for the fifth consecutive year for supervisors in the developmental and mental health systems. Part of the focus this year was to train trainers to continue this training in the future.
- In-service Training Package** completed for use by developmental service providers.
- DS Training Calendar** continues to be printed quarterly and is posted on the DDMHS web site.

WORK IN PROGRESS

- Assist agencies in implementing local training plans and develop and implement a statewide training plan.
- Increase the availability of training whose content supports the Principles of Developmental Services in the DD Act of 1996.
- Develop a Training Advisory Committee to assist in the review of the objectives and direction of training initiatives.
- Tailor training opportunities to self-advocates and families.

Quality Assurance

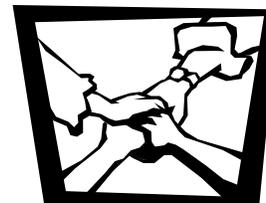
Assessment and assurance of service quality is a critical function of DDS. All programs and services funded by the state must be in compliance with state and federal regulations. In addition, services must address the needs of individuals and families in a manner that is consistent with their goals for support. People need to be satisfied with the services they receive and feel they have direct and valued input into decisions that concern their lives.

Quality Service Reviews 2000

Agencies Reviewed	16
People Reviewed	432
Priority Areas for Improvement	
❖ Employment supports	❖ Service coordination and supervision
❖ Person-centered individual support plans	❖ Organizational structure/development
❖ Recruitment, training and supervision to staff	❖ Medical documentation/guidelines
❖ Self-advocacy and self-determination	❖ Community supports/resource development

GOALS ACCOMPLISHED

- All Agencies Reviewed:** All fourteen (14) developmental service agencies and two contracted service providers participated in DDS quality service reviews. Reviews were done for 23% of people getting Medicaid-funded services in the year 2000.
- Training & Technical Assistance Provided:** System restructuring and new regulations drove the need for technical assistance in a number of areas, including the Individual Support Agreement, requirements of Special Care Procedures, and revised eligibility criteria. There was a continued need to train agency personnel in the requirements of the medical and quality guidelines. One agency required more in-depth support by Division staff to assure the continuity of service and supports to consumers.
- Designation Process Implemented:** Division staff worked with others in DDMHS to develop a process for agency designation consistent with the Administrative Rules on Agency Designation. Information collection was incorporated into the Quality Service Reviews.
- Home Safety Reviews Conducted:** One hundred-seventy (170) home safety and 18 accessibility reviews were conducted.



WORK IN PROGRESS

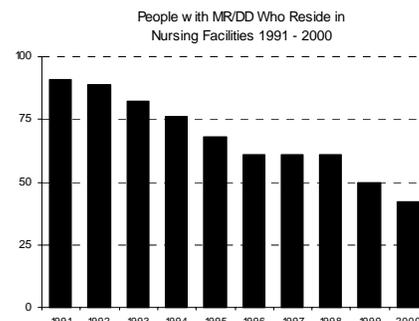
- Integrate the current quality assurance process into the process of certification of providers and incorporate other quality review and improvement activities (see Attachment H: *Sources of Quality Assurance and Protection*). Include self-advocates as reviewers in the quality review/certification process.
- Amend the quality goals and outcomes to reflect the Principles of Service in the Developmental Disability Act of 1996. Continue technical assistance to assure that Individual Support Agreements are person centered and meet Division requirements.
- Work on clarifying guidelines for self-directed and self-managed services.

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 services³⁴.

GOALS ACCOMPLISHED

- ✓ **Successful Placements Continue:** Two community placements for people in nursing facilities were developed in 2000.
- ✓ **Diversions Keep People Out of Nursing Homes:** Eight people who had community placements developed were diverted from ever entering a nursing facility at all.
- ✓ **Specialized Services Improve Quality of Life:** Twenty-nine (29) individuals received specialized services in 2000 while living in a nursing facility.
- ✓ **Numbers Decline & Quality of Life Improves:** The number of people with MR/DD living in nursing facilities has declined 66% since 1988³⁵, 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 residential services (3.5%) is well below the national average (6.3%)³⁶.
- ✓ **PASARR Screenings:** The Division of Developmental Services screened twenty-four (24) potential nursing facility admissions in FY 2000, a significant increase over past years.



Community Support Works – A Personal Story

Martha lived with family for most of her life. When her parents got older, she moved to a developmental home. Over time, she began to experience early signs of Alzheimer's. This fall, she had a rapid decline in her ability to care for herself. She began to have seizures and difficulty walking and gripping things. All the things she used to do independently, she now had difficulty doing. It got to the point that her home provider could no longer care for her. Her needs were too intense. She was admitted to a nursing facility.

After a short stay, the medical staff were able to stabilize her medical issues. She became able to care for herself somewhat, but still needed a significant level of support. She could not return to her previous home because her needs were such that her former home provider could not take care of her. It was also clear that a nursing facility was not the best place for Martha.

Staff from the developmental service agency who supported her were able to develop an alternative to the nursing home that made sense for Martha. They found a place for her to live in a group home in her local community where she would receive the level of support she needed. She now lives in her new home with a couple of other folks and is doing very well. She is active in her community and close to her family. She receives all the support she needs to live in her community. Martha is very happy in her new home.

³⁴ Changes in federal law in 1996 eliminated the requirement for an annual resident review.

³⁵ Based on the initial 1988 screening that found 125 people with MR/DD living in nursing facilities.

³⁶ Source: Prouty, R., and Lakin, C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1999*. Institute on Community Integration/UAP, University of Minnesota, Report 54, May 2000.

Consumer Survey

Consumer Satisfaction with Services: The Division of Developmental Services has contracted with an independent group for four years to conduct consumer satisfaction interviews on a statewide basis. Over the course of those four years, 877 adults with developmental disabilities, or 69% of adults who receive services, participated in the survey.

The Division of Developmental Services, in collaboration with the Consumer Survey Project at the University of Vermont, developmental service providers, family members and people who receive services, is using this year to re-evaluate the consumer survey process. The goal is to clarify the purpose of the survey and have it reflect changes in how services and supports are viewed by both the people who receive, and provide, those services.

The following (abridged) guidelines have been drafted to steer future surveying efforts of people receiving services. They incorporate a variety of ideas and concerns that have been expressed with the intent that the developmental services system will have an effective surveying process resulting in meaningful and useful information.



Assumptions:

- Independent, confidential surveying of consumers is an effective way to reflect consumer voice.
- Continue to use UVM as the independent source for surveying consumers.
- Continue to use 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.
- 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).
- A complete cycle of statewide surveying of all consumers who can respond to the survey will be done every 3-4 years. A full statewide analysis will be done at the completion of each multi-year cycle.

Consumer Survey Advisory Group:

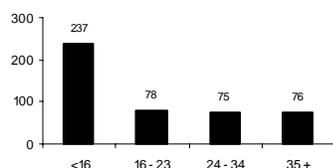
A multi-stakeholder advisory group will convene to provide ongoing oversight and advise on the consumer survey process. The group will work on many of the details that need exploration, consideration and decision (e.g., addition/deletion/refinement of specific questions/data collection, how survey results are reported, what data/reports will be made public).

Family Satisfaction Survey

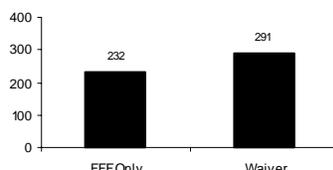
Families' Surveyed About Supports: 1999 was the second year the Division of Developmental Services conducted a confidential statewide family survey. A multi-page survey was sent to families of individuals with developmental disabilities who live at home and were receiving support to ask how they feel 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 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 this past year and a follow-up report was released³⁷. There are plans to conduct future family satisfaction surveys periodically to measure satisfaction over time.

FAMILY SURVEY RESULTS - 1999

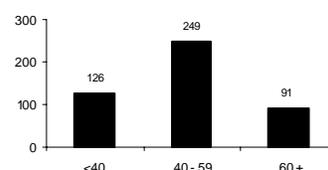
Age Group of Family Members



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).

³⁷ 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 2,560 people with developmental disabilities in Vermont, approximately 25% of the eligible population. This is accomplished through contracts with fourteen (14) developmental service providers located regionally around the state. System restructuring efforts implemented over the past three 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 is outpacing 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 disabilities³⁸.** The need for supports is generally life long, and only about 26 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 60³⁹).
- **Special Education graduates need ongoing supports to keep them employed and living at home⁴⁰.** Large numbers of graduates from Special Education programs (70 in FY '99) 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 70, only 16 were eligible for Waiver funding and 19 received Transition services.


- **More families are waiting for Flexible Family Funding.** As of January 2001, 70 families have requested this modest but highly valued assistance and are currently on waiting lists.
- **The number of offenders with developmental disabilities continues to climb.** An estimated 125 adults who pose a risk to others who might otherwise be incarcerated are supported through the developmental disability system. The safety of the community is paramount in the provision of supports to these offenders, especially to those under Act 248 commitment (see page 62).
- **People aging need additional supports.** Aging parents who have never asked for help before are seeking support before they die. People who receive services often need additional supports as they get older.

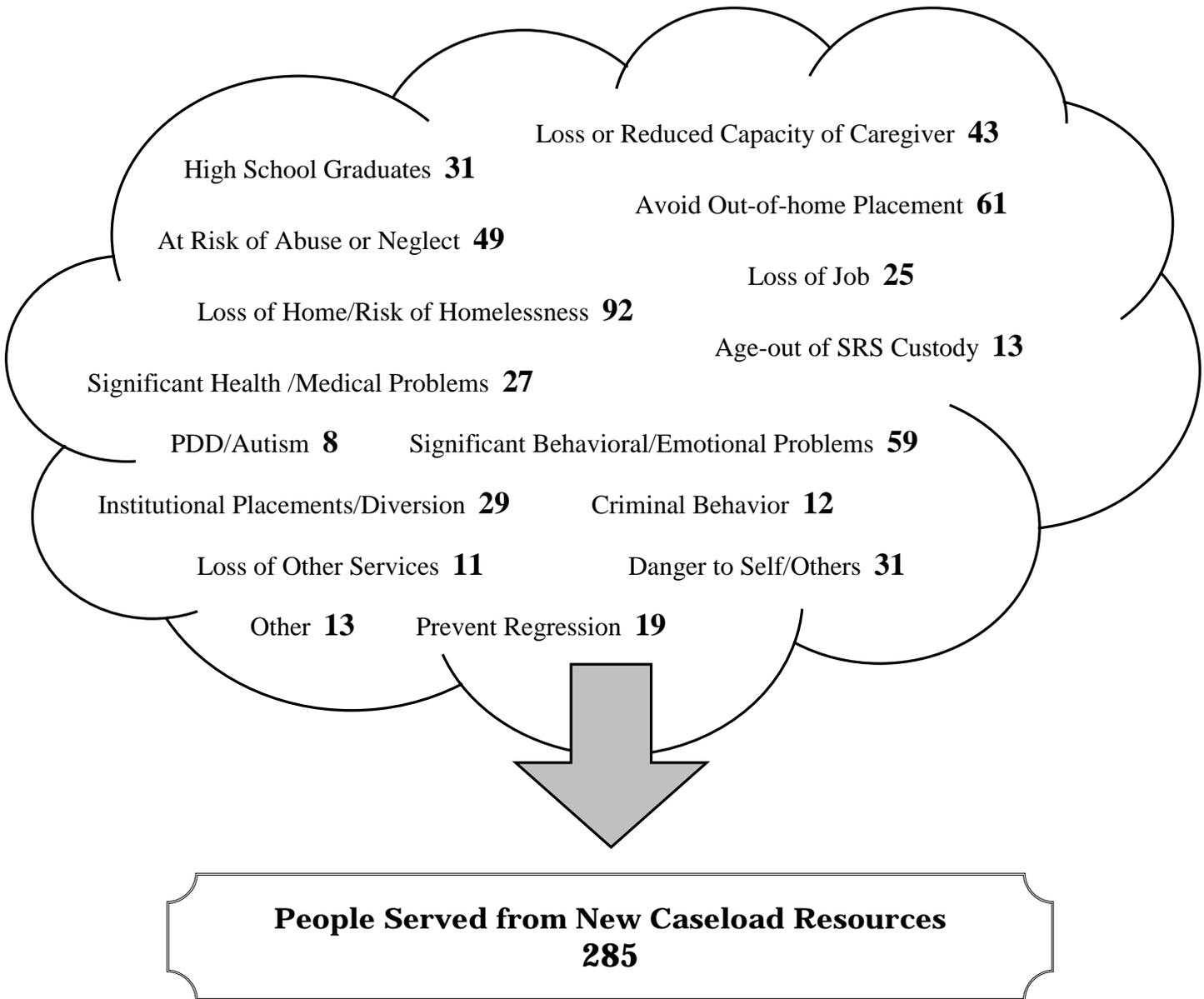


³⁸ Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6560 live births – State of Vermont 1999 Vital Statistics.

³⁹ Eligibility for developmental services was expanded in FY '97 to include people with Pervasive Developmental Disorders (PDD). There is currently a special fund to serve children with PDD in FY 2001.

⁴⁰ Designated Agencies are in the process of surveying local schools to find out exactly how many students with developmental disabilities are expected to graduate this year and will need developmental services.

New Caseload Funding⁴¹ – FY 2000



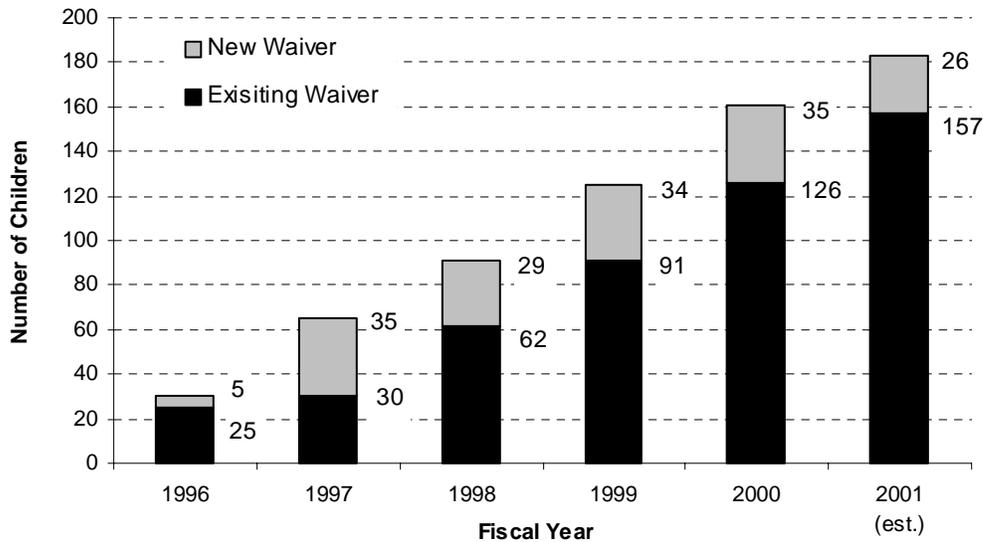
Developmental services resources are being successfully managed:

- New caseload funding goes to those most in need;
- Of the 285 getting new funding, 71% 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 25% of the eligible population, many more people with developmental disabilities are born each year, creating *new* demand for services *yearly*.

⁴¹ 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	36
2001	26 (est.)

- There were 13 children with PDD who received new waivers during the first six months of FY 2001 at an average annual rate of \$17,750. It is anticipated there will be a total of 26 by the end of the year. Several children have terminated waiver services or have turned 22 and so are no longer considered children.
- Additionally, at least 55 children with PDD receive Flexible Family Funding.
- Fiscal Year 2001 represents the last year that new caseload dollars were granted specifically for children with PDD. The amount earmarked was about half the amount available for each of the past three years.
- Not all children with this diagnosis will require intensive supports from a Home and Community-Based Waiver. Medicaid-funded personal care services are also available and have been allocated to 187 children with PDD.

Offenders with Developmental Disabilities

Legislative Report on Offenders with Developmental Disabilities⁴²

During the 2000 Legislative session, the cases of two offenders with developmental disabilities attracted widespread media attention and public concern. In response, the Legislature asked DDMHS to study current laws and programs for offenders with developmental disabilities.

Over the summer and fall of this year, DDS worked with two different committees to gather information and analyze current laws. One committee, comprised primarily of attorneys, looked at the language of Vermont's civil commitment laws for people with developmental disabilities, and made recommendations about amendments to the law. The other committee consisted of developmental services program directors and staff from throughout Vermont who implement programs for offenders with developmental disabilities. This committee worked with DDS staff to assemble data about the number of offenders with developmental disabilities served by state-funded services and the legal status of those served. It also assessed the adequacy of current program resources. The report is entitled *Report to the Legislature on Offenders with Developmental Disabilities: Legislative and Programmatic Recommendations*.

The report concludes that Vermont's civil commitment law for people with mental retardation, commonly called Act 248, has generally been effective in its primary purpose of protecting public safety. However, amendments to the law are recommended with respect to competency evaluations, the purpose of civil commitment, standards for commitment, procedures for commitment hearings, confidentiality, noncompliance, and annual review and notice of discharge. The report contains the language of suggested amendments.

The report further concludes that growing responsibility for public safety has significantly strained the developmental services system's resources and energies, and recommends infrastructure strengthening in the form of an emergency bed, more secure individualized placements, earmarked funds for high risk offenders, advanced training and clinical supervision, and enhanced respite.

Developmental Services for People Who Pose a Risk to Public Safety

In FY 2000, DDS surveyed developmental service providers to determine how many people were being served who might be termed "dangerous." A total of 125 adults were identified as posing a public safety risk. This number was considerably higher than had been expected. In addition, over 62% of the people who had committed known dangerous acts were not under any court or correctional supervision, but only being supervised by the developmental services system.

⁴² See Appendix I for the *Executive Summary of the Report to the Legislature on Offenders with Developmental Disabilities* and Appendix J for *Programmatic Needs of Offenders with Developmental Disabilities in FY 2002*.

The developmental services system is involved with protecting public safety for people with widely varying legal status. For adults considered to pose a risk to public safety, the status of those served by the developmental services system (as of June 30, 2000) was as follows⁴³:

Act 248 or other civil commitment	16
Probation/parole	12
Awaiting trial	10
Case dismissed with plan for services	10
Maxed out of criminal sentence	7
Restraining order	4
SRS or APS substantiation	38
Known offense but no adjudication	40

Act 248: Commitment Law for People with Mental Retardation

Act 248 is the name of Vermont's commitment law for people with mental retardation who have been found to be a danger to the community. The law authorizes the District Court to commit people who are incompetent to stand trial on the basis of mental retardation to the custody of the Commissioner of Developmental and Mental Health Services. Commitment is for an indefinite period, with annual reviews by the court.

Most people are committed under Act 248 for seriously dangerous behaviors. Major charges which have led to people being committed under Act 248 (as of August 2000) include:

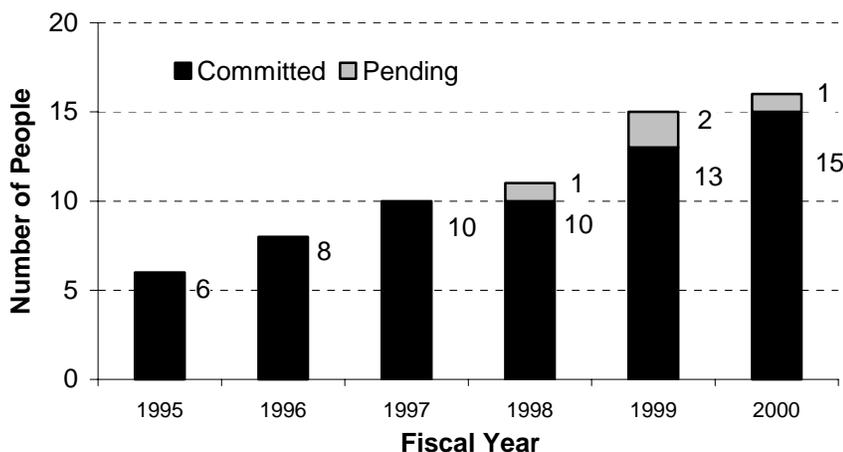
Sexual Assault on minor female	7
Lewd & lascivious with child	4
Arson	4
Domestic & simple assault	2
Sexual assault on adult female	2
Burglary & aggravated assault	1
Operating car without consent	1

When a person is committed under Act 248, the primary goal becomes protection of community safety. All services are provided within a framework that puts community safety first.

Services under Act 248 are provided in individualized, community-based settings throughout Vermont. A typical program involves 24-hour supervision, including "arms-length" or "eyes-on" supervision when the person is outside his or her home. The individual participates in therapy and receives employment and educational support. Staff are carefully trained to recognize danger signs and to support the person to gain control of his or her behavior. The goal for people committed under Act 248 is for them to gain control of their behavior so that restrictions can gradually be lessened, with the ultimate goal of restoring the person to liberty, when possible.

⁴³ Some individuals were in more than one legal status. For more information on the survey, see the *Report to the Legislature on Offenders with Developmental Disabilities: Legislative and Programmatic Recommendations*.

**People on Act 248
FY 1995 - FY 2000**



**Act 248 – Number Committed and Discharged
1990 – 2000 (thru 8/00)**

Calendar Year	Newly Committed	Discharged
1990	1	0
1991	2	0
1992	2	0
1993	0	1
1994	1	0
1995	4	2
1996	4	1
1997	0	0
1998	2	0
1999	2	2
2000 (thru 8/00)	3	0
Total	21	6

- To date, the year-by-year total of people committed under Act 248 has been stable, ranging from 0–4 commitments a year.
- The total number of people in custody increases every year. This increase is expected to continue because the number of people newly committed will most probably continue to exceed the number of people discharged from custody.
- The majority of people committed under Act 248 (12 out of 21) were receiving no state funded developmental services at the time of commitment. Many were living independently in the community.
- Of those discharged from custody, half (3 out of 6) chose to leave developmental services when they were no longer court-ordered to receive them.

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 areas that require system-wide focus around supports and services are⁴⁴:

- *Assistance with planning for future support of individuals currently living with aging parents.* Providing reassurance to aging parents that there will be help for their son or daughter.
- *Incorporate the principles and values of self-determination into the fabric of the service system.* Securing ongoing funding to help the system be more responsive to individuals making decisions about their own lives and support needs.
- *Review of current resources and supports for individuals with mental retardation who pose a danger to other individuals or property.* Continue efforts to update Act 248, secure specific appropriation, and develop additional service options.
- *Develop intensive support system and crisis response for children with significant needs.* Develop crisis and clinical resources that help children with multiple challenges to remain with their families and in their communities.
- *Enhance communication skills, technology and training for people with disabilities and those who support them.* Increased emphasis is being placed on this extremely important issue through the development of a communication task force to evaluate and improve the supports provided in the developmental services system that help people to communicate their own needs.
- *Assure necessary ongoing supports after school ends for high school graduates.* Secure resources to serve young adults leaving an entitlement service (public school) and entering a no entitlement system (adult developmental services).
- *Comparable employment services regardless of the source of funding or support.* Greater emphasis needs to be placed on evaluating the current use of "day service" funding as compared to supported employment services. Spending on supported employment is less than one-third of the resources spent on "day services". There needs to be greater balance in the proportion of current funding spent between these two areas.
- *Continue training, technical assistance and outreach from DDS and DAs on access to the system, including consumer rights and knowledge about funding.* Increased efforts to provide more information about consumer rights and knowledge about how the system works.



⁴⁴ For a more detailed description, see the *State System of Care Plan for Developmental Disabilities—FY 2001 Update*.