

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 State Program Standing Committee for Developmental Services, and state and federal governments to ensure that programs continue to meet the changing needs of people with developmental disabilities and their families (see Attachment D: *Members of the State Program Standing Committee for Developmental Services*).

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:

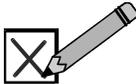
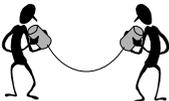
1. *Promote the principles of service stated in the DD Act and carry out all duties required by collaborating and consulting with people, their families, guardians, service providers and others.*
2. *Develop and maintain an equitable and efficiently allocated statewide system of community-based services 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 Video:*** Created two videos using actors with disabilities to help people better understand the complaint and appeal processes. Worked with providers to ensure that people and families who receive services are fully informed about these rights. 
- ❖ ***Human Rights Committee:*** Statewide committee met monthly to review positive behavioral support plans and restrictive procedures presented by service provider staff.
- ❖ ***Consumer Survey Project:*** Completed a second year of interviews with adults who receive services out of a three-year consumer survey process. 
- ❖ ***June Grad Survey:*** Coordinated with Designated Agencies to survey high schools to identify potential “June Grads” who are 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 local school districts to jointly fund children in need of services.
- ❖ ***Agency Designation Process:*** Undertook the agency designation process for five agencies (NCSS, RMHS, UVS, HCHS and UCS). 
- ❖ ***Flexible Family Funding Policy Updated:*** Took input, completed revisions and distributed new *Flexible Family Funding Guidelines*.
- ❖ ***Crisis/Clinical Services Enhanced:*** Provided training and technical assistance to increase clinical capacity in the state for evaluations and direct clinical work.
- ❖ ***Social Skills & Sexuality Education Network:*** New statewide network met to discuss statewide policy development and review available training curriculum. 
- ❖ ***Vermont Safety Awareness Training:*** Over 100 people participated in crisis prevention training that emphasized positive, proactive approaches to improve relationships through trust and attention to emotional needs.
- ❖ ***Independent Support Broker Training:*** Participated in a second multi-day training for ISBs, including an in-depth segment on funding, taxes, insurance, labor and liability issues.
- ❖ ***Supported Employment Opportunities:*** Thirty-nine percent (39%) of adults with developmental disabilities in Vermont received supported employment to work in FY 2002. 
- ❖ ***Critical Incident Report Policy Updated:*** Took input, completed revisions and distributed updates on the *Guidelines for Critical Incident Reporting*.
- ❖ ***Waiver Workgroup:*** Developed specific guidelines for use of Medicaid waiver funding.
- ❖ ***Workshop Closed:*** Closed the last sheltered workshop in Vermont when Champlain Vocational Services transitioned people into regular community supports and typical employment. 
- ❖ ***Real Choices Grant:*** Issued two requests for proposals and awarded two contracts to increase the abilities of people with developmental disabilities and their families to voice individual preferences and choices.

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:** Send out individual agency and statewide reports on the results from the Family Satisfaction Surveys. 
- ❖ **Real Choice System Change Grant:** Continue work on a 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.
- ❖ **National Core Indicators:** Continue participation in the National Core Indicators to identify and collect data on key indicators to measure common outcomes nationwide. 
- ❖ **Waiver Workgroup:** Incorporate the work completed by the Medicaid Workgroup to revise and update Medicaid Procedures.
- ❖ **Revise Policies:** Finalize revisions on *Behavior Support Guidelines*, *Health & Wellness Guidelines*, *Guidelines for Quality Services* and *Background Checks* policy. 
- ❖ **Self-Management Handbook:** Develop a guide that clearly delineates the roles responsibilities of agencies and people who self/family-manage their services incorporating the work done with interested individuals, including people with disabilities, family members, advocates and service providers.
- ❖ **Department of Justice Grant:** Continue work on the DOJ grant that will enhance and expand Vermont's system of managing sex offenders with developmental disabilities.
- ❖ **Consumer Survey:** Complete one more year of consumer interviews to provide a full statewide report including an analysis of supports over time and demographic data. 
- ❖ **Home and Community-based Waiver:** Apply for 5-year continuation of Vermont's HCBW services.
- ❖ **Statewide Clinical & Crisis Service Capacity:** Work to enhance regional and statewide clinical and crisis service capacity. Finalize standards for crisis beds. 
- ❖ **Follow-up on Legislative Report on Offenders:** Continue 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. 
- ❖ **ISA Companion Manual:** Finalize *Individual Support Agreement Manual* for use by service coordinators, individuals and families, and other members of a person's circle of support.
- ❖ **Communication Checklist:** Amend *Making Communication Happen* guide and accompanying communication checklist for use in developing communication goals and outcomes. 
- ❖ **Re-evaluate QDDP Qualifications:** Explore alternatives to QDDP Designee through a DDS endorsement of potential QDDPs who are independent of provider agencies.
- ❖ **HIPAA:** Continue collaboration with service provider groups and the Agency of Human Services to develop privacy and security policies and amend current practices in preparation of implementation of the Health Insurance Portability and Accountability Act. 

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 region²⁸. This means that a DA must provide services directly or contract with other providers or individuals to deliver supports and services consistent with available funding; the state and local System of Care Plans; outcome requirements; and state and federal regulations, policies and guidelines. There are ten Designated Agencies in Vermont. Some of the key responsibilities of a DA include the following²⁹:

- Receive and act upon referrals and applications for services and supports;
- Conduct the initial and annual Medicaid waiver eligibility assessment process;
- Inform applicants and service recipients of their rights;
- Conduct individual needs assessments and address requests for new funding;
- Assign and monitor the Authorized Funding Limit;
- Assure each recipient has an individual support plan and that it is reviewed annually;
- Respond to information on people's satisfaction, complaints and appeals;
- Maintain and review waiting lists;
- Maintain a minimal case record for people self/family-managing;
- Arrange for housing safety and accessibility checks;
- Provide regional crisis response services;
- Review and provide oversight of all critical incident reports;
- 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. As of July 2002, there are five Specialized Service Agencies who serve people with developmental disabilities.

Contracted Providers

Contracted providers are providers who do not have a direct contract with DDMHS but are subcontracted through DAs and SSAs to provide supports to people in the region. Any

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

²⁹ This is not an exhaustive list of DA responsibilities. Some of these responsibilities apply to SSAs as well.

organization that wishes to provide direct services to people with developmental disabilities funded by DDMHS must meet the standards identified in the Regulations Implementing the Developmental Disabilities Act of 1996. Organizations that provide supports and services must meet basic quality standards and have the capacity to support people to achieve the outcomes they desire. Any organization that receives state or federal funds administered by DDS must meet these standards.

Self/Family-Management

Traditionally, developmental service providers have managed all the services funded through the Division of Developmental Services on behalf of people with disabilities and their families. Today, people have more choices as to who will manage their services. Many family members, as well as some people with developmental disabilities, have chosen a *shared-management* arrangement. This is when the service provider manages *some*, but not all, of the services for the person or family. For example, the service provider may provide service coordination and contract for the person's home supports, while the person manages the community and work supports separately.

Alternatively, some family members and people who receive services have chosen to *self/family-manage all* of their developmental services. Self/family-management of one's developmental services means that the person or his or her family member has the responsibility of hiring his or her own staff members and overseeing related administrative responsibilities associated with receiving developmental services funding.

Under both the shared-management and self/family-management scenarios, developmental services funding is passed from the Designated Agency through a fiscal intermediary called an Intermediary Service Organization, or ISO. The ISO is responsible for disbursement of home and community-based waiver funding according to the person's budget and Individual Support Agreement, under the direct authorization of the person self/family-managing. The ISO is fundamentally a payroll and tax service, but is additionally responsible for some other administrative functions, such as service data reporting and conducting background checks.

Some responsibilities of the person self/family-managing³⁰ include:

- Contracting for services;
- Fulfilling responsibilities of the employer, such as hiring, supervising, evaluating and firing staff;
- Arranging training for staff;
- Developing an Individual Support Agreement; and
- Planning and arranging for emergency respite or temporary supports.

Many of the responsibilities of the employer are done by the ISO. The person may also choose to hire or contract with someone, such as an Independent Support Broker, to assist in self/family-management responsibilities. Under all scenarios, the Designated Agency maintains system responsibilities, such as those listed on the previous page.

³⁰ This is not an exhaustive list. Some of the responsibilities listed overlap with the responsibilities of the ISO. Contact a local developmental service provider or the Division of Developmental Services for more information.

Whether a person decides to take part in some or all of the management of his or her services, or leaves those responsibilities to the service provider, the important thing is the person still has the right of control over his or her life. This means people, with help from their circle of support, will define what their life should be like; decide how they will get supports to make that happen; from whom the support will be obtained; and what those supports look like. To make informed decisions, the person and his or her circle need full information about choices, support options and requirements. The person may also need support to take part in conversations about responsibilities and decide how involved to be in his or her supports. These decisions are very important and very personal and may change over time.

Role of People with Disabilities and Families in Services – Increase in 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 be held accountable for responding effectively to the needs of people. The following aspects of the service system help make this possible.

- **People with disabilities will actively participate in *planning* their supports and arranging for services through *informed choices*.**
 - People are given a description of the application and eligibility determination process and the process for determining service need and the funding limit.
 - People are given information about their rights as an applicant, service options and their rights as a service recipient at the time of eligibility determination and reassessment, and again at the time of individual service plan development.
 - 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.
 - People have the ability to choose services from a provider other than the DA, if available.
- **People with disabilities and families will have a strong role in *system oversight, evaluation and decision-making*.**
 - DDMHS 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 and SSAs 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.
 - People and families have direct input into the designation process. The re-designation process includes public hearings, interviews with people with disabilities, families and others, and an impartial review by the State Program Standing Committee.
 - DDMHS has the ability to de-designate agencies, or place them on probationary status, if they are unresponsive to people's needs.

- **People with disabilities will register *satisfaction and dissatisfaction* with services, and file *complaints and grievances* through proper avenues.**
 - There is a strong, uniform statewide complaint and appeals process.
 - People are given information about the complaint and appeals process at the time of application, eligibility determination and reassessment; at the time of funding decisions; and again at the time of individual service plan development.
 - DDMHS 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 with disabilities and families will help train and educate providers and others.**
 - People with disabilities and family members participate as trainers in regional training provided to direct support staff.
 - People with disabilities provide training, from the perspective of the individual, to agency workers, DDS staff, families, and other self-advocates.
 - People with disabilities play important roles as members of self-advocacy groups.



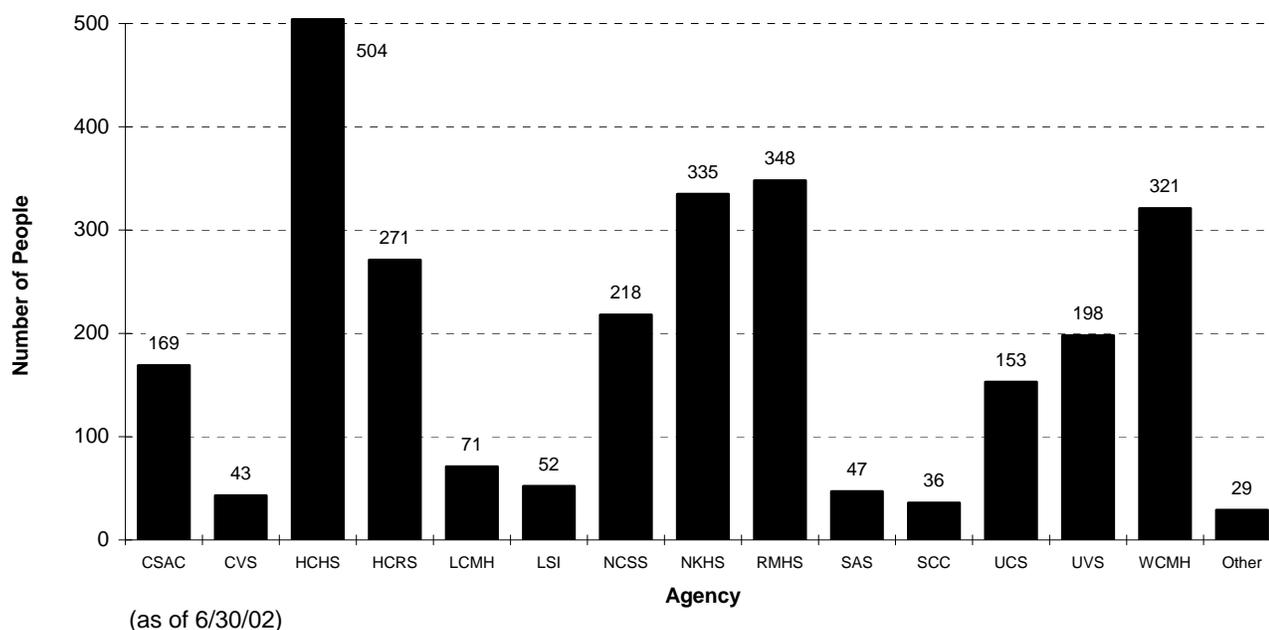
STATUS OF SERVICES

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, service coordination, home supports, community supports, work supports, clinical services, crisis supports, respite, and family supports. The home and community-based waiver funded 1,885 individuals in FY '02. This funding source accounts for 94.6% of all funding for people served through the Division of Developmental Services³¹.

The Division of Developmental Services contracts with fourteen (14) private, nonprofit developmental services providers (see chart below) who provide supports to a total of **2,795** people with disabilities and their families (see Attachment E: *Vermont Developmental Services Providers*).

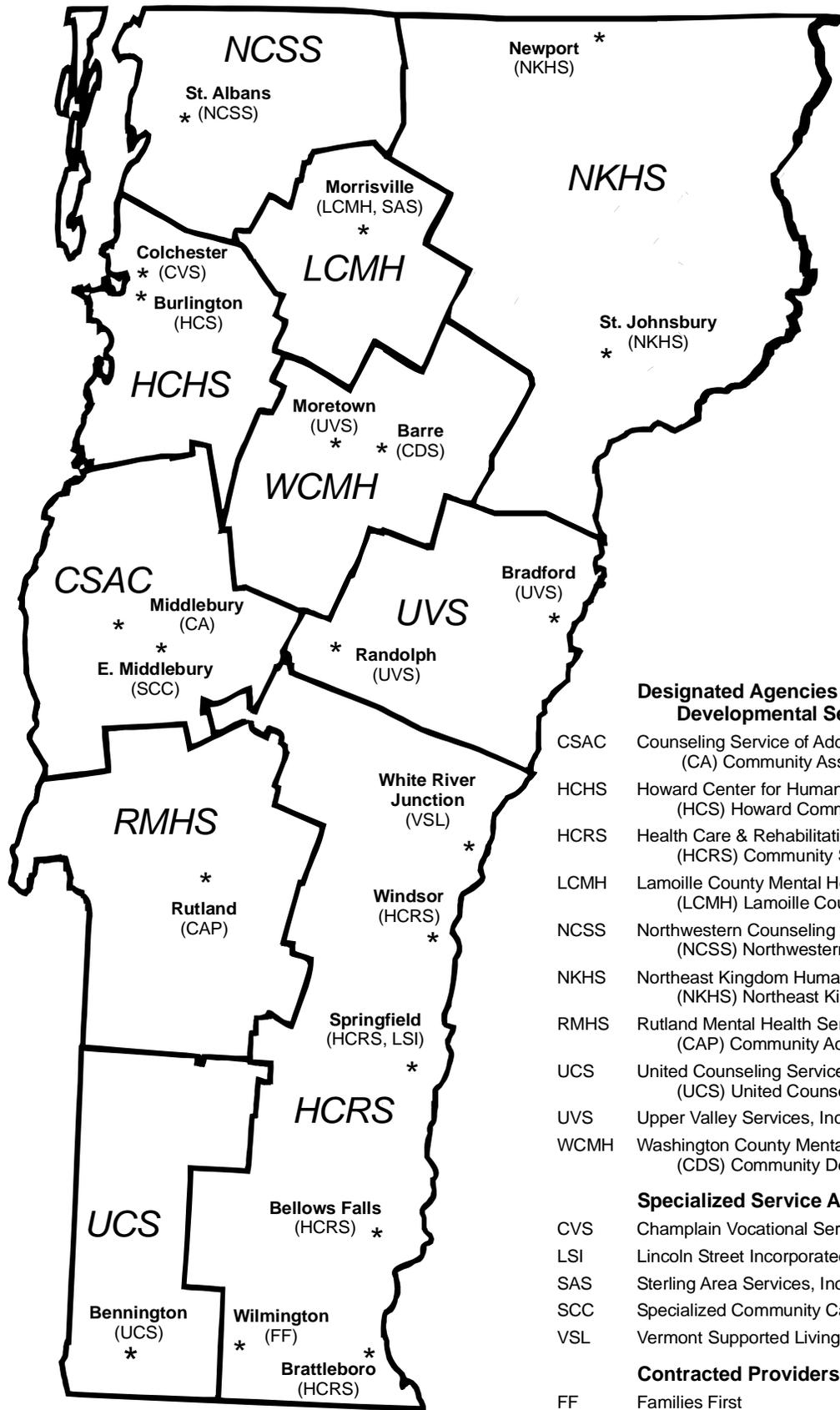
Total Number of People Supported in FY 2002 by Agency



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.		

³¹ 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 (DA)
Developmental Services Programs**

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

Specialized Service Agencies (SSA)

- CVS Champlain Vocational Services, Inc.
- LSI Lincoln Street Incorporated
- SAS Sterling Area Services, Inc.
- SCC Specialized Community Care
- VSL Vermont Supported Living

Contracted Providers

- FF Families First

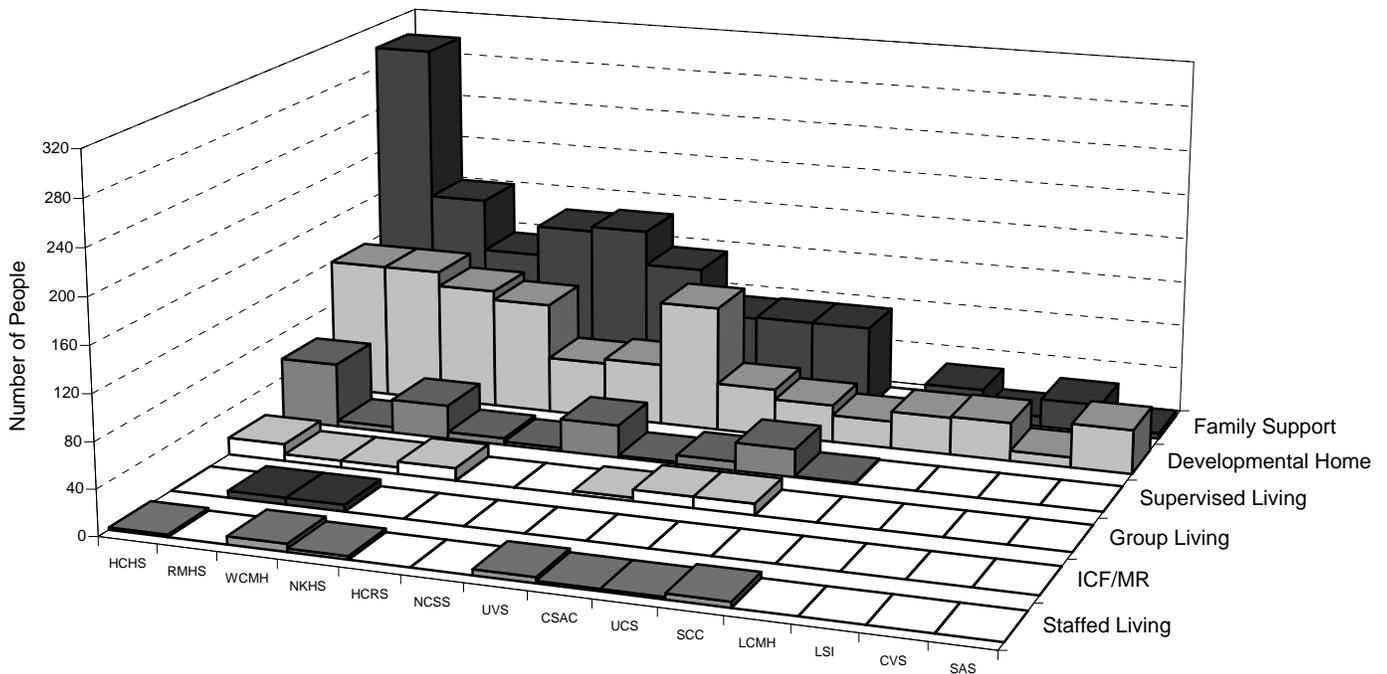
(as of 7/1/02)

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 Skills & Sexuality 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 6/30/02)

Home Supports

There were a total of **1,140** adults and children receiving home supports on June 30, 2002. Supports were provided in 945 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 – 875

Number of Homes – 758

- **Supervised Living:** 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 – 166

Number of Homes – 153

- **Group Living:** 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 – 61

Number of Homes – 13

- **Staffed Living:** 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 – 26

Number of Homes – 19

- **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, 2002)

- **Rent/Own Home:** An estimated 211 people live in a home that they own (22) or rent (189). This is about 19% of the people receiving residential services (compared to 21% nationwide³²).
- **Independent Living:** An estimated 123 adults live independently without paid home supports, but who receive services in other areas of their life (e.g., work or community supports).
- **Supervised Care:** Thirteen (13) people receive modest assistance for their residential supports through Supervised Care funding (state general funds).
- **Residential Care Homes:** Service providers support 30 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, 106 were children under 22 and 57 were adults.
- **Home Safety:** One hundred fifty-six (156) home safety reviews were conducted in FY '02, including 22 accessibility reviews. A housing specialist contracted by DDS conducted these reviews. Compliance and follow-up to safety reviews by agencies has continued to improve over the past few years. Fifty-nine percent (59%) of the homes responded to the review recommendations within 30 days. The fiscal year ended with only eight homes (6%) not in compliance within the maximum 90-day grace period. Two agencies, United Counseling Services and Northeast Kingdom Human Services, performed their own safety reviews in FY '02.
- **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 and protective and adaptive equipment and modifications). In addition, 47 people received funding assistance to go on vacation. Both funds are maintained with state general funds, though the vacation fund was discontinued as of June 2002.



³² 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). Note: The Vermont number may include some people who do not receive any home supports.

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, household items, etc. The maximum amount available to a family of an adult or child is generally \$1,122/year.



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

Total Number People Receiving Family Support FY 2002

Funding/Support	Adults (22 & over)	Children (under 22)	Total
Flexible Family Funding	139	586	725
Home & Community-Based Waiver:	351	325	676
Respite/In-home Supports	205	298	503
Other Supports (Employment & Community Supports)	304	115	418
(minus duplications between FFF & HCBW)	(75)	(57)	(132)
Total – Unduplicated	415	854	1,269

GOALS ACCOMPLISHED

- More Families Served:** A total of 1,269 people received family supports that lived with their families in FY '02. This represents 45% 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-nine (49) people (of whom 24 were children) received out-of-home respite in FY '02 for a total of 536 days.
- Outreach to Families:** An average of 2.1 people per 1,000 population received family support throughout the state in FY '02.
- Flexible Funding Increase:** An additional allocation for Flexible Family Funding was made for FY '02 by the legislature in response to family advocacy efforts.
- Flexible Family Funding Policy Updated:** Completed revisions on the Flexible Family Funding Guidelines.



WORK IN PROGRESS



- Continue to participate in the AHS Respite and Personal Care Policy Cluster and collaborate with other AHS departments in supporting specific families.
- Explore the development of a “family support” waiver.

Supports for Children

GOALS ACCOMPLISHED

- More Children Served:** There was a 9% increase in children supported between FY '01 and FY '02.
- Family Support in Vermont:** Vermont devoted a higher percentage of its budget for developmental services to families than any other New England state (FY '00).
- 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 33 children on the DS home and community-based waiver in SRS custody in FY '02.



- Family Satisfaction Survey:** Disseminated individual agency and statewide reports on the results from the 2002 Family Satisfaction Surveys.

Total Number of Children Supported FY 2002

Funding/Support	Age	Birth – 6	7 – 18	19 – 21	Total
Flexible Family Funding		132	394	58	584
Home & Community-Based Waiver:		24	309	112	445
	Lives with family	22	246	57	325
	Does not live with family	2	63	55	120 (33 w/SRS)
Other (Medicaid, vocational grant, self/private pay)		3	27	22	52
	(minus duplications between FFF & Waiver)	(7)	(38)	(12)	(57)
Total – Unduplicated		152	692	180	1024

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.



Self-Advocacy

Green Mountain Self-Advocates (GMSA) is a statewide self-advocacy network run and operated by people with developmental disabilities. Our board includes representatives from local self-advocacy groups (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. 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, Legislative Advocacy, How to Start and Run a Self-Advocacy Group* and *What Allies Can Do to Support Self-Advocacy*.
- ❖ 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 Region 8 of the national organization Self-Advocates Becoming Empowered.



GOALS ACCOMPLISHED

☑ **Real Choices Project:** GMSA is receiving funds from the Real Choices Grant to promote self-advocacy. We are providing practical “how to” tools necessary for anyone who is interested in being a self-advocate and leader in making choices and decisions about how they live their lives. The four goals of this 3-year project are:

1. **Self-Advocacy workshops** (a series of six 2-hour seminars) were developed and are being taught by people with disabilities for people with disabilities:

Knowing Yourself – What you are good at and what you need help with, goals and priorities, and what to tell others about yourself.

Communication – Learn to be assertive instead of shy or aggressive. Learn effective use of body language, listening and other communication skills.

Problem Solving – Learn ways to solve problems; how to identify your emotions and positive ways to work through them; and how to act to achieve the outcomes you want.

Rights and Responsibilities – Learn the difference between basic, everyday rights and responsibilities and specific laws about the rights of people with disabilities.

How to Be a Strong Self-Advocate – Encourage people to make personal choices and advocate for themselves.

Being Part of the Community – How to get involved in community activities and make your voice heard.



2. **Leadership workshops** for people with developmental disabilities on *Using the 7 Habits of Highly Effective People*.

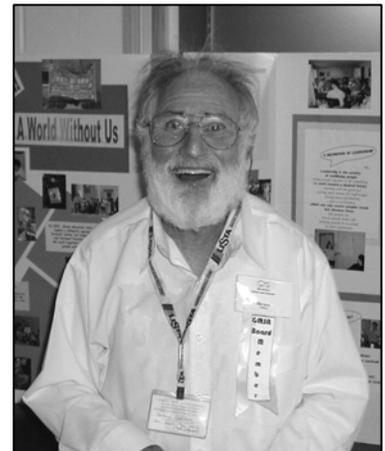
- 3. **Board Training** for people with developmental disabilities to be board members and best practices for including people with disabilities.
- 4. **Training for parents, providers and DDS staff** on how to support people with developmental disabilities to be all that *they* want to be.



☑ **Shifting the Power:** GMSA was one of 10 states chosen to participate in a Project of National Significance funded through the U.S. Administration on Developmental Disabilities. Last May, a 4-person training team of people with and without disabilities from North Carolina came to Vermont to provide a 4-day training. The four days involved teaching the “*Pathways to Community Leadership*” curriculum in a train-the-trainer model. GMSA choose 15 self-advocates to be the official “core group” that was trained to be trainers for Vermont.

☑ **Share the Spirit – Shuffle off to Buffalo:** Thanks to financial support from DDS, the Developmental Disabilities Council and many provider agencies, 55 Vermonters attended the 2002 National Self-Advocacy Conference. One support person commented, "My favorite part of the conference was that self-advocates ran all of the 64 workshops." GMSA presented a popular workshop called *The Dating Game* based on the classic television game show.

☑ **The 5th Voices and Choices Conference:** We collaborated with the ARC to organize our fifth annual self-advocacy conference. Over 275 self-advocates and their allies participated in 16 workshops including: *How to Buy a House; Self-Advocacy and Theater; Writing a Country Song; Caring About the Environment; How to Pick the Right Career; Making and Keeping Relationships; and African Dance.*



☑ **Self-advocates Serving on Boards and Committees:** GMSA has supported self-advocates to be part of a variety of advisory boards, including: DS State Standing Committee, Vermont Protection and Advocacy, Center on Disability and Community Inclusion, Barrier Free Justice, Vermont Transportation Equity Network, State Rehabilitation Council, Real Choices Grant, Developmental Disabilities Council and Self-Advocates Becoming Empowered.



☑ **Creating Acceptance:** GMSA worked with Self-Advocates Becoming Empowered of Rutland to present disability awareness workshops in Rutland schools to help students understand that people with disabilities are the same as them. Often, people with disabilities are made fun of and kids just don't understand that this hurts us. We just want respect like anyone else.

Real Choices Grant Vermont's Real Choice Systems Change

A COLLABORATION BETWEEN DDMHS AND THE DEPARTMENT OF AGING AND DISABILITIES

Vermont was awarded a three-year systems change grant in the amount of \$2,000,000 to increase community integration, real choice and control for elders, younger adults with physical disabilities, people with developmental disabilities and their families, and adults with severe mental illness. The Division of Developmental Services' share of the overall grant is \$620,599.

During the grant development process a Consumer Task Force was created representing all of the groups noted above. The Consumer Task Force, together with the State partners and a Provider Task Force, identified the following issues that affect choice and control for consumers over their own services:

- ❖ Lack of access to independent, consistent, accurate, cross-systems information about long term care options and assistance to navigate the service delivery system;
- ❖ Lack of statewide access to training and on-going support for self-advocacy, self-determination and recovery education for consumers, families and providers;
- ❖ Shortage of appropriately trained, adequately compensated and valued frontline workers;
- ❖ Lack of access to home and community-based services for elders and younger people with severe physical disabilities that is equal to the access enjoyed by others who receive home and community-based care, and;
- ❖ Lack of options for direct consumer funding of developmental services and supports.

The goals of the Real Choice Systems Change Project are to effect enduring systems that:

- Promote continued progress toward community integration of services, and;
- Provide real choice about how, where and by whom, services and supports are delivered.

To address the identified problems, the Project will undertake activities to:

- Create an accessible cross-age and disability system to provide information and assistance;
- Provide self-advocacy skills to consumers and families, and training for providers to promote facilitation of consumer self-advocacy;
- Create a stable, valued, appropriately trained and compensated workforce through development of a paraprofessional association and implementation of other strategies;
- Create access to home and community-based care for elders and younger adults with physical disabilities that is equal to nursing home access through the development of a new 1115 waiver, and;
- Create a pilot that can be replicated statewide for direct consumer funding for developmental services.

In May 2002, grants were awarded to the Green Mountain Self-advocates and the Vermont ARC to carry out the Division's objectives to provide training in self-advocacy skills for people with developmental disabilities, their families, Division staff and provider staff. Through this process, a group of consumer and family trainers will be identified to carry on the work of the grant after its completion.

Work Supports

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 2002

	Total
Number of People Employed	719
Average Hourly Wage	\$6.78
Average Hours Worked per Week	13 hr./wk.
Estimated Taxes Paid by People Employed	\$428,936
Estimated Public Benefits Saved	\$1,063,146

GOALS ACCOMPLISHED

Employment on the Rise: 39% of working age adults receiving services are being supported to work.



Increased Resources: Expanded supported employment program resources at LSI, SAS, CVS and CAP through joint funding process between DDS and DVR.

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 annual survey of schools 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 program at LSI.

Last Workshop Closed: Completed the conversion of the last remaining sheltered workshop in Vermont to typical employment and other activities for all participants.

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.

Expand the new comprehensive statewide database that 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.

Continue to facilitate quarterly employment manager network and training meetings available to all Supported Employment Program Coordinators.



CVS COMPLETES FINAL CONVERSION FROM WORK CENTER TO FULL COMMUNITY-BASED SERVICES

Jeff Lawrence is a long-time CVS Work Center employee. He had enjoyed the familiarity and routine of the work center program for fourteen (14) years and the friendships he'd formed. Jeff is legally blind, has hearing difficulties and struggles with transitions of any kind. The work center conversion was a major change for him. By the time the program ended in June 2002, Jeff had not yet found employment, but he did spend time volunteering at a couple of sites in Burlington. Through careful job development activities, the long-term outlook for Jeff's employment remained positive. He explored a variety of community-based activities, and in early January, got a call from *Sweet Energy* in South Burlington. Their holiday season rush was over, and the connections made in the fall came to fruition. Jeff was interviewed and offered a position.

Jeff continues his volunteer interests through a local library and enjoys recreational pursuits. He is earning more money as a part-time employee than he did spending many more hours in the Work Center program. He still maintains those old friendships and is looking forward to making new ones through his employment. Jeff's mother endorsed the work center conversion, despite her personal fears for her son's well being. "It was a real worry, you know. Jeff likes to be busy and feel like he's doing something worthwhile. I'm so glad he's found something.... He came home and said he really liked it."



Alan Bushey had been an employee at the CVS Work Center for twenty-seven (27) years at the time the program ended. For several months last spring, Alan expressed how anxious he was about the change, and his concern that he may not be able to find a new job. Alan uses a wheelchair to get around and didn't consider himself very 'marketable' in a tough economy, despite great support and encouragement from his support team. CVS' Supported Employment Coordinator, Carol Leggett, spent many hours getting to really know Alan's strengths as an employee, his needs and his interests. That time paid off; Alan was offered a position at *Zachary's Pizza* on Williston Road. "I love my job", says Alan, "I never thought I'd get a job outside the work center, but I did."

Shawn Farrell, a partner of the franchise sees the value in having Alan as an employee. "He comes in on time, gets his job done, and done well", says Sean. "I really notice the days that Alan's not here; the place isn't nearly as organized." Shawn and Alan also shoot some pool from time to time on their nights off. It's a great match.

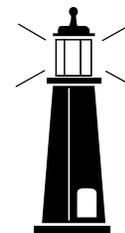
Guardianship Services

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 program’s 20 Guardianship Services Specialists (GSS) work out of eight offices throughout Vermont. They make regular home visits to the people they serve and take part in planning and monitoring. They make sure people have the supports they need to be safe, and work to protect them from abuse and exploitation. They help people to make their wishes and needs known, to become more independent, and to make connections with friends and family. As medical guardians, GSS staff provide active medical advocacy and coordination and make decisions about medical treatment. GSS staff are available for emergencies 24 hours a day through the program’s toll-free phone number.

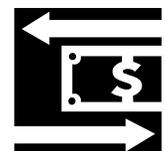
Total Number of People on Guardianship Services FY 2002

Guardianship Services	524
Case Management	24
Guardianship Services Pending	23
Commitment Order (Act 248)	20
Commitment Order Pending	0
Total (unduplicated)	584



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 312 people in FY ‘02. 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

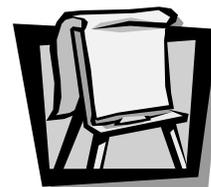
Training and Technical Assistance are provided by the Division of Developmental Services to the developmental services system to ensure workers gain the expertise necessary to meet the needs of people they support. Over 1500 people received training supported by DDS in 2002.

Training Supported and Sponsored by the Division brings information about best practices to people who provide and receive services, family members and others. The Division supports local training efforts by making funds available and giving groups the flexibility to tailor training to their own needs. In 2002, Division training resources supported:

- | | |
|--|---|
| <input checked="" type="checkbox"/> <i>A Dialectical Behavior Therapy Conference</i> | <input checked="" type="checkbox"/> <i>An Offender Conference</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>An Alzheimer's/Dual Diagnosis Workshop</i> | <input checked="" type="checkbox"/> <i>Professional Boundaries Training</i> |
| <input checked="" type="checkbox"/> <i>The APSE Conference</i> | |

GOALS ACCOMPLISHED

- Technical Assistance:** Assistance was provided to agencies, included developing Individual Support Agreements, behavior support plans, inclusion and person centered planning processes.
- Supervisory Training:** A training-of-trainers was provided to ensure the ongoing ability to offer Supervisory Training to agency staff.
- Vermont Safety Awareness Training:** This in-depth training was provided to more than 100 direct support workers.
- Sexuality & Social Skills Education:** Planned Parenthood presented a training-of-trainers to agency staff.
- Introductory Training:** This basic training continues to be provided to agencies, as requested.



ONGOING WORK

- Continue to develop facilitators to promote sexuality and social skills education.
- Develop and maintain a statewide training plan that coordinates with local training needs.
- Continue to enhance the distribution of training information to all stakeholders.

WORK IN PROGRESS



- Planning a communication conference, *Making Communication Happen*, for May 2003.
- Developing a curriculum for independent support brokers and new service coordinators.
- Developing a *Vermont Safety Awareness Training* Trainer's Manual and continuing certification of new trainers.
- Developing a speaker's bureau of consumers and families who are interested in participating in training.
- Developing a guidebook to available training.
- Updating the Pre-service, In-service and Introductory training materials.

Clinical & Crisis Supports

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 two crisis homes or through a mobile emergency team (clinical diagnosis, evaluation, treatment, direct staffing).

Vermont Crisis Intervention Network FY 2002

Level II – Technical Assistance	
Number of people supported (est.)	61
Level III – Crisis Beds	
Number of stays	22
Number of total days	359
Avg. length of stay (range 3-43 days)	18 days
Institutional Diversions (est.)	19



GOALS ACCOMPLISHED

- Technical Assistance:** Continued high use of on-site consultations and crisis prevention.
- Crisis Bed Created:** Created a second statewide crisis bed in southeastern Vermont and increased regional clinical and crisis capacity.
- Positive Behavior Support Plans:** Provided training to agencies regarding the process of developing positive behavior support plans.
- 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:** Provided an independent review of positive behavior support plans and restrictive procedures through a statewide committee.

WORK IN PROGRESS

- Implement standards for crisis intervention programs 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.
- Organize training for psychologist and psychiatrists re: differential diagnosis and PDD.
- Examine increased use of VSH during FY '02 and develop strategies to reverse trend.

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 G: *Sources of Quality Assurance and Protection*).

Quality Service Reviews 2002

Agencies Reviewed	16
People Reviewed	420
Priority Areas for Improvement – Most Frequently Noted	
❖ Person-centered individual support plans	❖ Effective communication
❖ Health & safety/medical support documentation	❖ Employment supports
❖ Training & supervision of staff	❖ Behavior support plans
❖ Quality assurance activities	❖ Residential living options

GOALS ACCOMPLISHED

Agency Reviews: Reviews were done for approximately 21% of people getting Medicaid-funded services.



Technical Assistance: Technical assistance to agencies was provided for issues such as critical incidents, crisis intervention, funding, eligibility, service options, housing issues, ISAs and support plans, health concerns, employment services and self-management of services. CAS also responded to consumer and family complaints and investigated appeals.

Training: Training was provided on ISA development, supported employment, skill building and teaching strategies, behavior support, personal futures planning and community inclusion.

Designation Process: In 2002, four agencies went through the designation process. Collection of information for designation is gathered during the quality review process.

Home Safety Reviews: One hundred fifty-six (156) home safety reviews and 22 home accessibility reviews were conducted.

Policies: Revisions of the *Guidelines for Critical Incident Reporting* were completed.

WORK IN PROGRESS

Update and revise the *Guidelines for Quality Services, Health & Wellness Guidelines, Behavior Support Guidelines, Individual Support Agreement Manual* and *Background Check* policy.

Work to clarify guidelines for self/family-managed services.

Work with other units of DDMHS to refine and streamline the designation process.

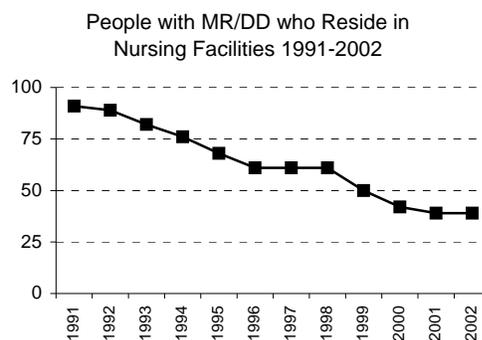


Nursing Facility Reform

Pre-Admission Screening and Resident Review (PASARR): The Omnibus Budget Reconciliation Act of 1987 established PASARR which mandates the screening of all nursing facility residents and new referrals to determine the presence of mental retardation and related conditions and the need for specialized services. Services include pre-admission screening and development of community placements and specialized services³³.

GOALS ACCOMPLISHED

- ✓ **Successful Placements:** Two community placements for people living in nursing facilities were developed in 2002.
- ✓ **Diversions from Nursing Facilities:** Sixteen (16) people who had community placements developed were diverted from entering nursing facilities³⁴.
- ✓ **Specialized Services Improve Quality of Life:** Twenty-nine (29) individuals received specialized services in 2002 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 2002) 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 DD residential services (2.7%) is well below the national average (7.4%)³⁶.
- ✓ **PASARR Screenings:** DDS screened forty-three (43) potential nursing facility admissions in 2002 (including 10 reassessments); a 72% increase over last year.



Specialized Services – Building Community Membership

The Division of Developmental Services provides support to individuals with developmental disabilities who live in nursing homes. These services are referred to as Specialized Services. In addition to the nursing care individuals receive, the intent of specialized services is to provide support to individuals to address their social and recreational needs as well as their overall well-being.

Gloria lives in a nursing facility due to her medical condition. She receives 15 hours per week of Specialized Services. Through these supports Gloria is able to go out into the community to go shopping, meet with friends, and attend social gatherings. Over this past fall Gloria visited the Berlin mall, a flower shop in South Royalton and the various shops in the West Lebanon area. She is a regular at the Vermont Technical College library where she explores books on animals, her favorite subject. She faithfully attends and is a VIP in the local women's group. The support she receives has allowed her to have an active social life and engage her interests at her leisure. She has clearly become an active member of her community.

³³ Changes in federal law in 1996 eliminated the requirement for an annual resident review.

³⁴ Six of these people were placed in nursing facilities for short-term rehabilitation before returning to the community.

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

³⁶ Source: Prouty, R., Smith, G. and Lakin, C. *Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2001*. Research & Training Center on Institute on Community Living, Institute on Community Integration/UCEDD, University of Minnesota, June 2002.

Consumer Survey

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

Interviews were conducted at six agencies during 2001, with five more agencies participating in 2002. This coming year (2003) will be the third and final year in the survey cycle. This survey methodology enables a full report to be created for each participating agency, as well as having a valid statewide sample each year. There were 410 survey participants in 2001, all of whom provided demographic information, of which 253 took part in the interviews. The data presented below are the aggregate data, by survey question, collected from CVS, CA, HCS, NKHS, SCC and UCS.

CONSUMER SURVEY RESULTS³⁷ - 2001

- Overall:* Satisfaction was high (over 85% satisfied/positive) in categories³⁸ of residential, work, day activities and health.
- Residential:* 82% were happy where they were living. 65% felt they had no say about with whom they lived. 28% would like to have more chores to do at home.
- Autonomy:* 51% report not having a choice where they live. 82% were allowed to invite friends over when they want. 74% had privacy during visits. 66% have a key to their home. 43% have to ask someone for their money. 15% report people enter their bedroom without asking.
- Neighbors:* 6% said their neighbors were not friendly. 84% felt safe in their neighborhoods.
- Work/Day/Volunteer:* 95% report having a good place to work. 89% were happy with their jobs. 36% want to work more hours. 87% report people at work treat them with respect. 95% were happy with their daytime activities. 91% liked their volunteer activities.
- Friends/Social Support:* 24% reported they were lonely. 19% were sad most days. 40% wish they had more friends. 73% reported having a best friend.
- Guardianship:* 80% were happy with their guardian (public or private).



- Service Agency:* 89% were happy with their case managers. 90% felt listened to at their ISA meetings. 20% were aware of their agency's complaint process.
- Activities/Opportunities:* 48% want to know more about self-advocacy. 39% report they never get to learn new things.

³⁷ Not all consumers answered all the questions in their interviews. Percentages are based on the total number of consumers who responded to the questions. Consumer survey data needs to be taken in the same context as any study of satisfaction, as a general reflection of a person's perspective of life.

³⁸ Categories are the grouping of questions based on certain commonalities.

Family Survey

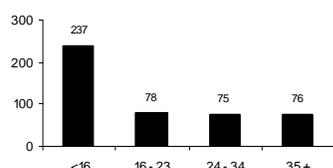
The Family Satisfaction Survey: A confidential statewide family satisfaction survey was mailed out in November 2001 to ask about satisfaction with DDS-funded services. The survey was sent to over 1200 families of individuals with developmental disabilities who live at home and were receiving support. The survey related to a wide range of issues, such as information and planning, choice and control, and access to and delivery of services. The survey allowed for anonymity, but space was provided for written comments and to request follow-up from staff if the respondent desired.

GOALS ACCOMPLISHED

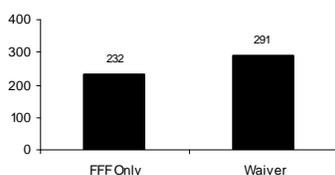
- ✓ There were 539 surveys completed and returned by families for a high response rate of 49%.
- ✓ Data from the 2001 survey show families are significantly more satisfied regarding 15 of the questions asked than in the 1999 survey, and only less satisfied regarding one of the questions.

FAMILY SURVEY RESULTS - 2001

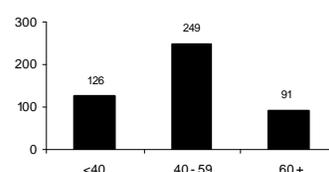
Age of Family Member with a Disability



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:

- Receiving information
- Services help keep family member home
- Informed of complaint/appeal process
- Planning services
- Access to services
- Overall satisfaction with services



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

- Knowledge and effectiveness of staff
- Service coordinator
- Feeling that the family member is happy

Satisfaction in Relation to Age of Family Member

- 67% of families of young children (<16 years old) receive Flexible Family Funding only
- 85% of families of adults (24+ years old) receive Waiver funding
- 22% of family caregivers are 60+ years old

- ✓ Families of young children (<16 years old) report being more satisfied with choice of support workers and wanting more control over the hiring and management of support workers than families of youth and adults (16+ years old).

- ✓ Families of young adults (24 – 34 years old) report being more satisfied with receiving information about services; staff helping figure out what is needed; and receiving help right away in an emergency than all other families.



- ✓ Families of adults (24+ years old) report more satisfaction with services and supports; knowing who to contact; receiving information to help plan services; getting services that are needed when they are needed; and the service coordinator helping get what is needed than families of children and transition age youth (<24 years old).

CURRENT PRESSURES ON COMMUNITY SERVICES

Caseload Pressures

In FY 2002, the Division of Developmental Services provided supports to 2,795 people with developmental disabilities in Vermont, approximately 25% of the eligible population. This was accomplished through contracts with fourteen (14) developmental services providers located regionally around the state. System restructuring efforts implemented over the past five 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 112 children are born each year with developmental disabilities³⁹.** The need for supports is generally life long, and only an average of 30 people who are currently receiving services die each year. 
- **Due to financial constraints, services to new children have been suspended since November 2001** (see Attachment H: *System of Care Plan Funding Priority Changes*). As of December 2002, there were 83 individuals on the Applicant List (requesting but not eligible for funding), with a total annualized cost of \$1,040,697 (\$389,533 GF). Approximately half (42) are under age 18. Additionally, applications for children services have dropped off dramatically as people learn that Funding Priorities relating to children have been suspended.
- **Special Education graduates need ongoing supports to keep them employed and living at home⁴⁰.** Large numbers of graduates from Special Education programs 112 in FY '03 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 112, only 61 people are expected to be eligible under current funding priorities for home and community-based waiver funding⁴¹ and 21 for Transition services. Thirty (30) graduates, therefore, are not expected to meet any funding priorities. 
- **Offenders need special supports.** The number of people with developmental disabilities who commit offenses and pose a risk to public safety, and who require specialized supports, has increased (see page 56).
- **People aging need additional supports.** People often need additional supports as they get older. Aging parents who have never asked for help before are seeking support before they die. Significantly, 22% of family caregivers are age 60 or more⁴². 

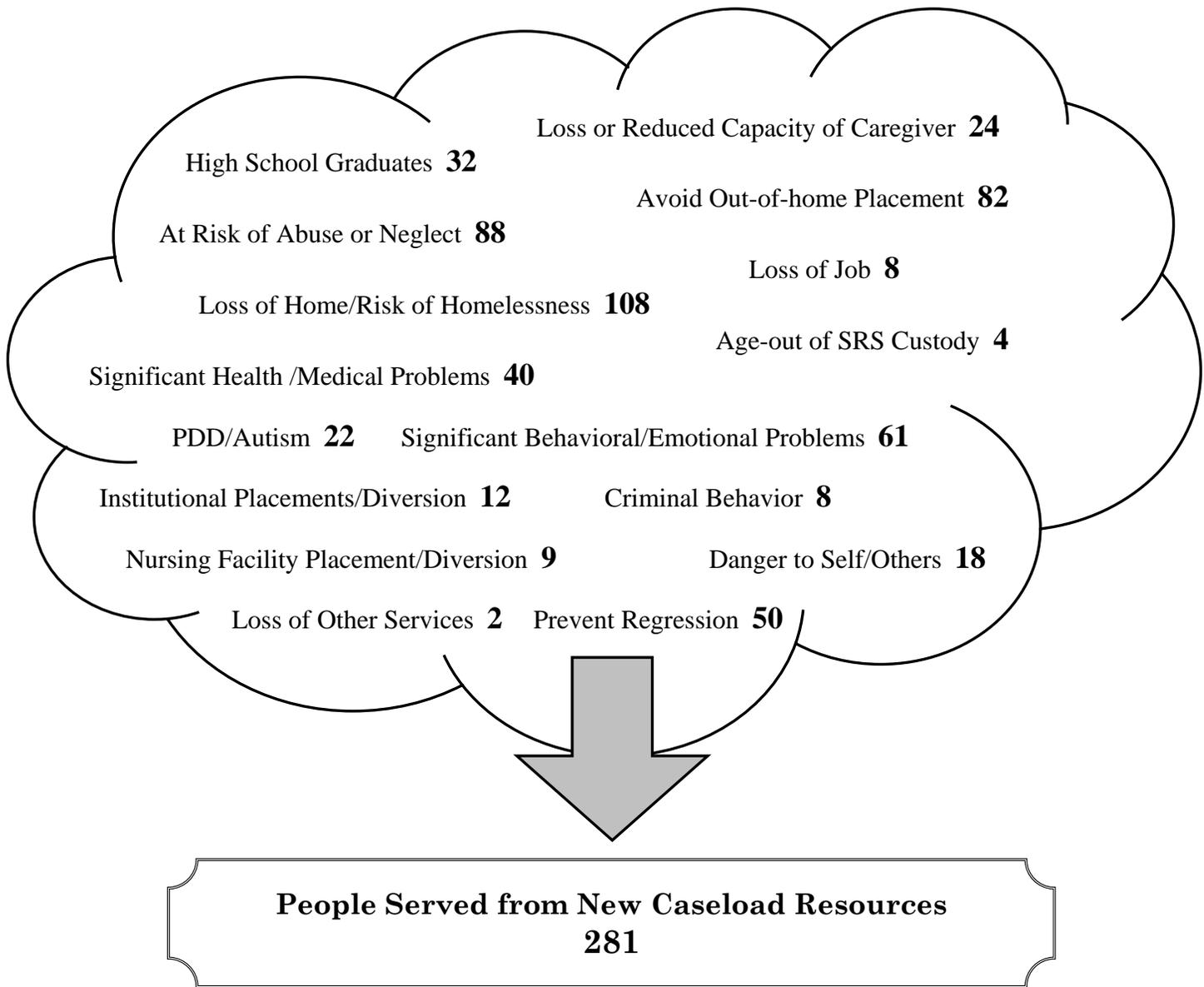
³⁹ Based on a prevalence rate of 1.5% for mental retardation, .22% for Pervasive Developmental Disorders and 6501 live births – State of Vermont 2000 Vital Statistics.

⁴⁰ 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.

⁴¹ Based on the updated DS *State System of Care Plan* funding priorities effective December 1, 2001. Eight (8) additional people would have been eligible under the currently suspended funding priorities.

⁴² Vermont Division of Developmental Services Family Satisfaction Survey – Statewide Results Fall 2001.

New Caseload Funding⁴³ – FY 2002



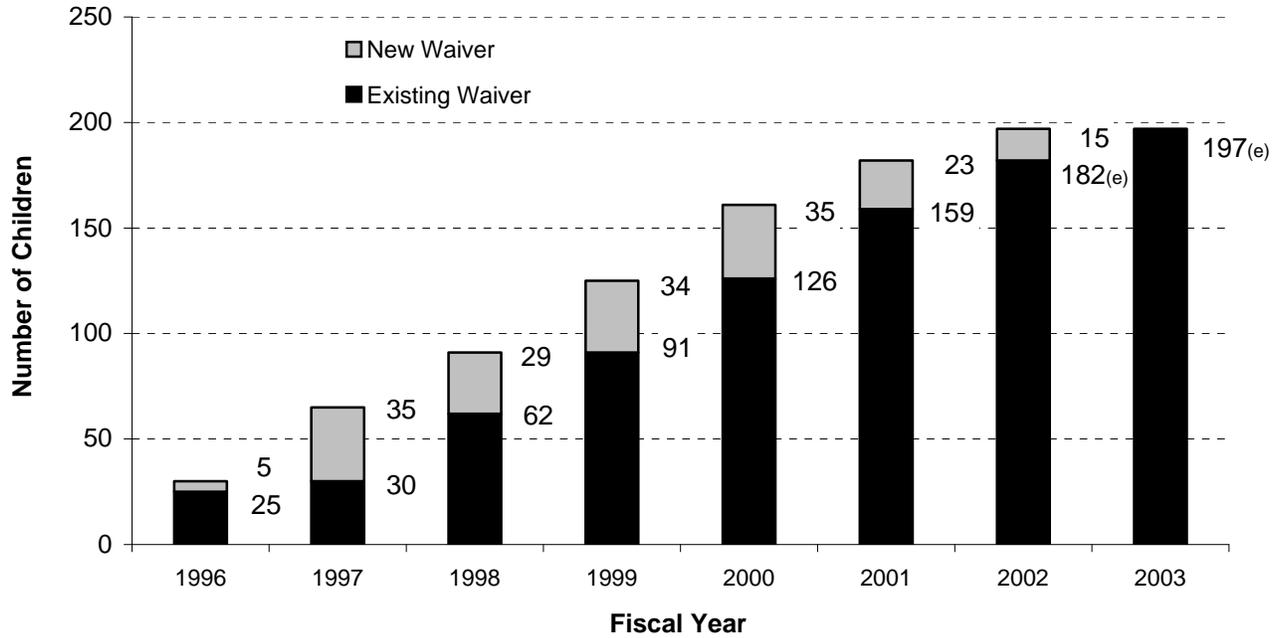
Developmental services resources are being successfully managed:

- New caseload funding goes to those most in need;
- Of the 281 getting new funding, 58% meet the definition of “new consumer;”
- 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*.

⁴³ Based on Designated Agencies’ intake information. Individuals may be counted in more than one category.

Children with Pervasive Developmental Disorders FY 1996 – FY 2003



Children with PDD Funded with New Waivers FY '96 – FY '03

Fiscal Year	New Waivers
1996	5
1997	35
1998	29
1999	34
2000	35
2001	23
2002	15
2003	0

- There continues to be a rise in the number of children being diagnosed with Pervasive Developmental Disorders⁴⁴.
- However, as of December 1, 2001, specific Developmental Services *State System of Care Plan* funding priorities regarding children, including those with Pervasive Developmental Disorders, were suspended. No new waiver funding to children has been available since that time. (See Attachment H: *System of Care Plan Funding Priority Changes*.)

⁴⁴ Eligibility for developmental services was expanded in FY '97 to include people with Pervasive Developmental Disorders (PDD).

Offenders with Developmental Disabilities

Most Vermonters with developmental disabilities are peaceful and law-abiding citizens. But, like the population as a whole, the population of people with developmental disabilities contains individuals who commit offenses.

In recent years, the developmental services system has increasingly been expected to perform a correctional function. A survey in the summer of 2000 identified 125 individuals actively supported by Developmental Services agencies who could pose a significant risk to public safety. The number has increased since the date of the survey. This growing responsibility for public safety puts a strain on the developmental service system's resources and energies.

Staff who provide support to offenders with developmental disabilities need specialized training and supports. To meet this need, the Division of Developmental Services offers specialized consultant services to programs that support individuals who have engaged in sexually abusive behavior. These services include onsite consultation and a bi-monthly training and discussion group which discusses best practices and new developments in the field of sex offender treatment for individuals with developmental disabilities.

In its 2001 report to the Legislature, DDMHS concluded that there was an urgent need for advanced training and clinical supervision concerning sex offender treatment. To address this need, DDS applied for and received a grant from the U.S. Department of Justice to develop specialized resources for sex offenders with developmental disabilities. This two year grant contains funding for:

- ❖ ***Best Practices Manual:*** A field manual for staff who work with sex offenders with developmental disabilities, written by Vermonters with expertise in legal issues, sex offender treatment and services for people with developmental disabilities.
- ❖ ***Treatment Progress Scale:*** An instrument to be used by field staff and therapists to measure and track treatment progress and highlight areas for focusing future treatment of sex offenders with developmental disabilities. This first-of-its kind tool is being developed through a combination of experienced Vermont staff and national experts in the field.
- ❖ ***Training in Legal Rights:*** Materials for training individuals with developmental disabilities about their legal rights and responsibilities.
- ❖ ***Collaborative Team:*** A Collaborative Team of representatives from the legal field, Department of Corrections, developmental services programs, law enforcement, victim services and self-advocates to develop a coherent view of systemic approaches to preventing and responding to offenses by individuals with developmental disabilities.

FUTURE DIRECTIONS

The Developmental Disabilities Act of 1996 requires DDMHS, Division of Developmental Services, to adopt a plan describing the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. Specifically, the plan determines the overall initiatives of the system and criteria for individuals to obtain services and funding, including priorities to develop new, and continue current, services and programs. The plan is developed every three years and updated annually. The current plan is the FY 2003 Update to the 3-year State System of Care Plan and covers the period of August 1, 2002 – June 30, 2003. Below is a list of activities from the 3-year plan that require system-wide planning and development to further enhance the developmental services system. For a more detailed description, please refer to the *State System of Care Plan for Developmental Disabilities 3-Year Plan – FY 2002 – FY 2004*.

- ❖ **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 Vermont⁴⁵.
- ❖ **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.
- ❖ **Communication Supports:** Ensure systemic and local means for supporting and enhancing communication skills, technology and training.

⁴⁵ Creating a new respite home in southeastern Vermont is no longer a goal due to FY '03 funding rescissions.

- ❖ ***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.
- ❖ ***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.

