Vermont Developmental Disabilities Council

Comprehensive Review and Analysis

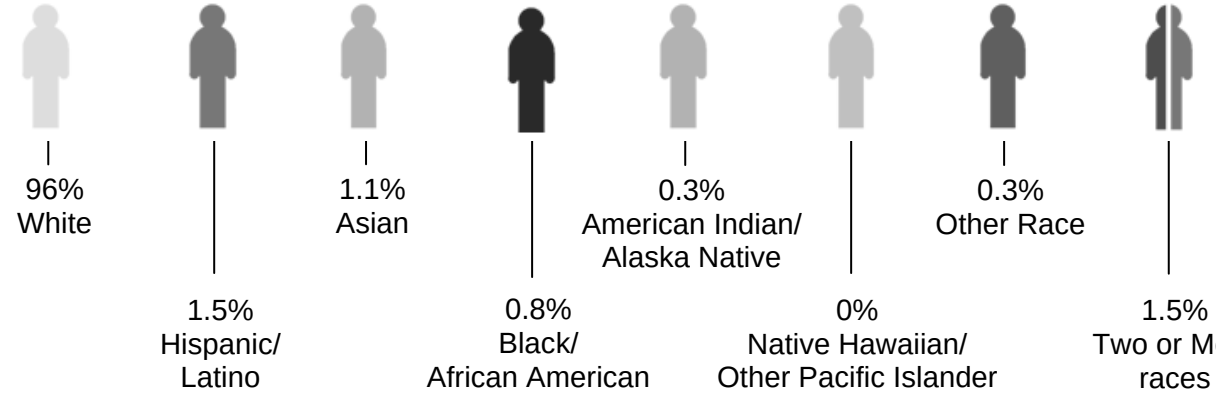
(adapted from federal on-line filing August 15, 2011)

During 2011 VTDDC conducted extensive research and outreach to develop its five year State Plan for the period 2012 to 2016.

This paper compiles the data and information from the four main sources: (1) national data, state reports and a 2011 update to Vermont's 2005 Olmstead Commission Report; (2) survey results from 283 respondents; (3) forums held around the state attended by over 150 people; and (4) priorities developed by key Vermont organizations, including Center for Disability & Community Inclusion, Disability Rights VT's Disability Law Project, VT Coalition for Disability Rights, Vermont Family Network and Vermont Center for Independent Living.

State Data Information

Racial and Ethnic Diversity of the State Population



State Disability Characteristics

Prevalence of Developmental Disabilities in the State:

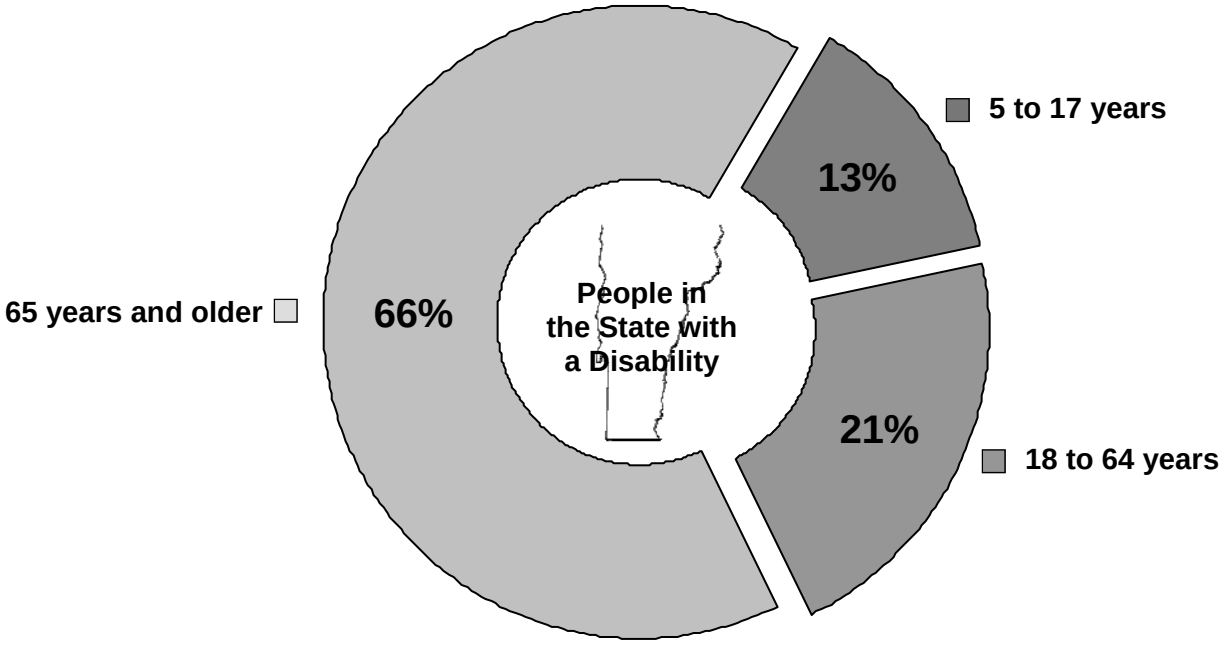
13,141

Of 625,741 Vermont residents,
13,141 (2.1%) have developmental disabilities
(prevalence rates of 1.5% with an intellectual disability and .6% autism) according to the Vermont definition.

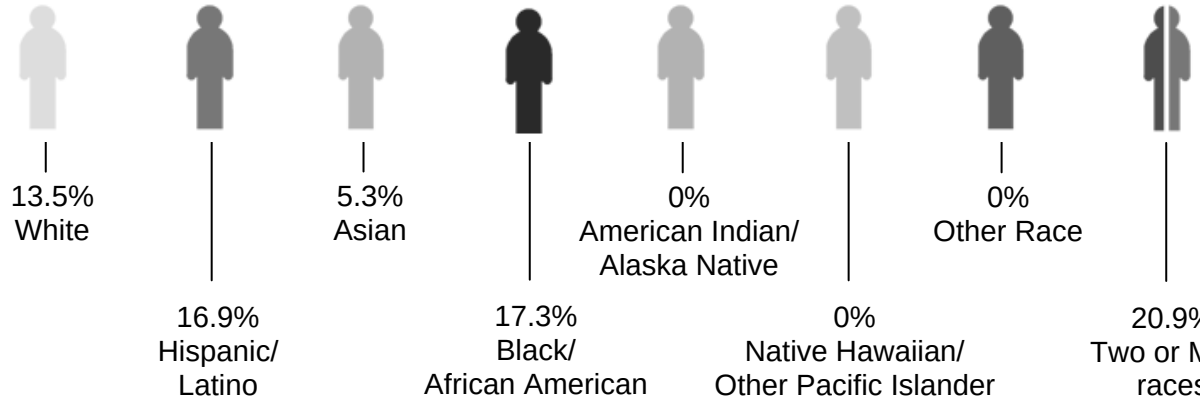
Residential Settings

Total Served	Year	A. Number Served in Setting of 6 or less (per 100,000)	B. Number Served in Setting of 7 or more (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
3,734	2009	249.8	0.0	192.3	23.8
3,329	2010	226.2	0.0	174.4	31.2
3,095	2011	205.1	0.0	157.1	29.5

Demographic Information about People with Disabilities

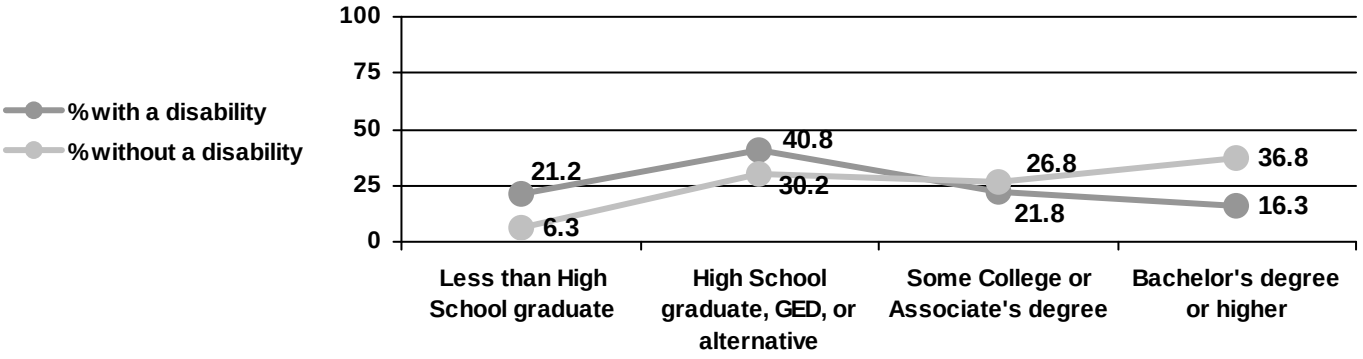


Race and Hispanic or Latino Origin of People with a Disability



Education Attainment

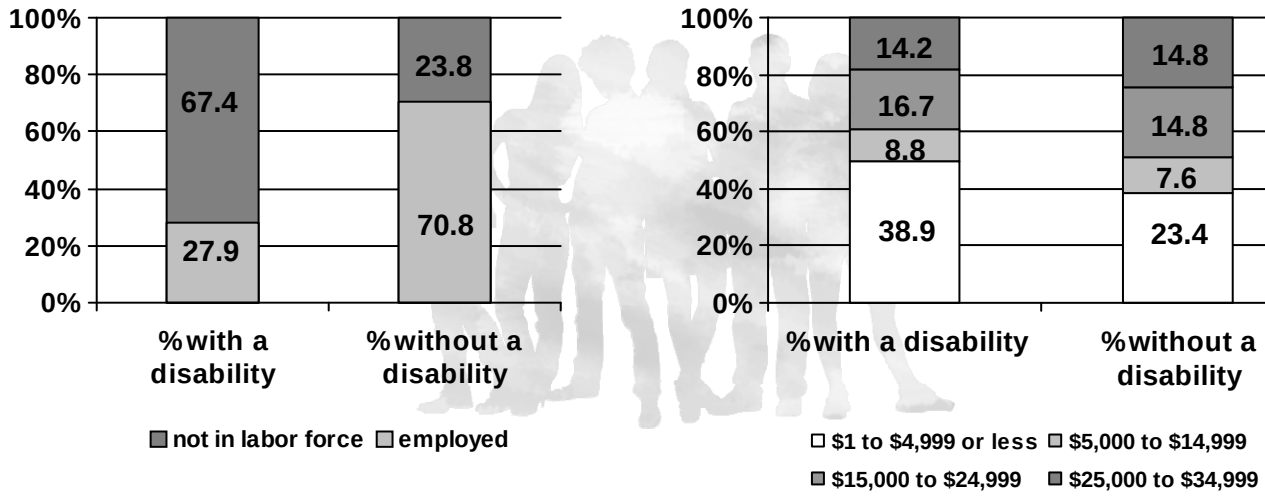
Population Age : 25 and Over



Employment Status

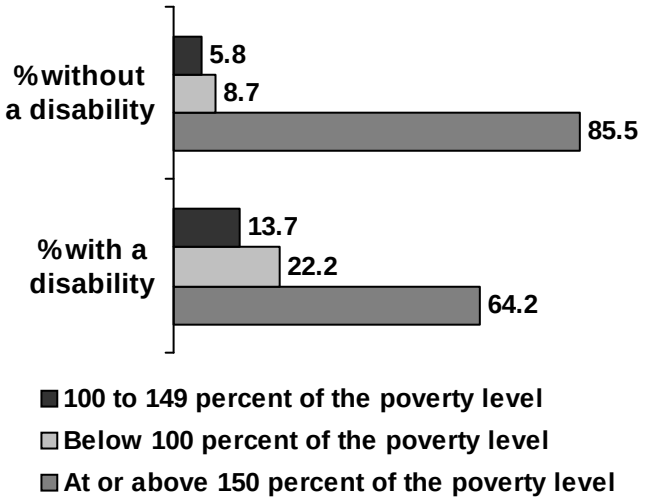
Earnings in the Past 12 Months

Population Age : 16 and Over



Poverty Status

Population Age : 16 and Over



Poverty Rate

Portrait of State Services

1. Health and Healthcare

In FY2011 Vermont became the first state to pass single payer medical coverage. State programs cover 26% of Vermonters, and pay 17% of health care costs (Total $4.7 billion in FY2009):

- Catamount Health Program full pay or premium assistance
- Dr. Dynasaur (Federal Children's Health Insurance Program, known as SCHIP)
- Employer Sponsored Premium Assistance
- Medicaid - 82,748 adults and 62,528 kids including Katie Beckett (569)
- Prescription Assistance.

89.4% of Vermonters with disabilities had health insurance (60.8% public) compared to 87.6% nationwide.

The State of Vermont is the managed care organization for Medicaid.
Medicaid is funded as one large waiver – or block grant – the "Global Commitment", with generous cap. Spending in FY2010 was $1.27 billion. 40.2% of Medicaid goes to two long term care programs: *Choices for Care [C4C]* and *Developmental Services.*

MEDICAID entitlement services include:

- High Tech Home Care, serving 84 children and youth. In FY2009 they also served 25 people over age 21.
- Children's Personal Care [EPSDT] served 2,023 in FY2009

Personal Care Service spending included:

- Children's PCS @ $21.5 million & pilot CCC offering flexible services @ $1.1 million
- Choice's for Care @ $24.8 million.

The Choices for Care [C4C] waiver providing medical and community and home based care for 2,501 seniors and people with physical disabilities. Please also see section on Community Supports [CS.] VT's regional system of 10 DESIGNATED AGENCIES provides mental health, substance abuse and developmental services. There are 2 Home and Community-Based "Waiver" [HCB] programs through the Designated Agencies that provide mental health services:

1. CRT – Community Rehab & Treatment – supports adults with severe and persistent mental illness.
2. Developmental Service Waivers [DS] also include clinical supports to address mental health and behavioral issues. *Part of each DS waiver is pooled to support the VT Crisis Intervention Network [VCIN]. **VCIN helped:**

FY2009

- 96 people with technical assistance.
- 29 people used crisis beds for a total of 559 days. The average stay was 15 days.

the Success Beyond Six program served:

FY2007

- 1,966 students with mental health issues
- 1,832 school age children with emotional disability
- 57 children with an intensive autism spectrum disorder, at the cost of $30.1 million (60% federal Medicaid.)

The federal MATERNAL HEALTH BLOCK GRANT was $1.7 million. It funded:

FY2010

- Teen Pregnancy Prevention
- Healthy Babies Kids & Families public health nursing
- Newborn screening
- Oral Health, which was funded in part through Medicaid school reinvestment
- Prenatal Care for medically high risk
- Children with Special Health Needs Clinics (Cystic Fibrosis, Cleft Palate, Seating, Genetics, Metabolic, etc. 4,950 served)
- In FY2009 the federal WIC nutrition program enrolled 24,239

ACT 264 sets up a system of care for kids with severe emotional disturbance that links human services [Mental Health, Child Welfare, Juvenile Justice, etc.] and public education to involve parents and coordinate services for better outcomes. In 2005 the system was expanded to meet needs of children with disabilities eligible for special education and disability-related services including service coordination. Local Interagency Teams [LIT] meet with families to create an individualized plan. When resources are not available or more intensive services and treatment required, LIT sends cases on to the State Interagency Team for review. **Now the majority of State Interagency Team cases involve children and youth with developmental disabilities:** 13 of 15 cases in FY2010, and 13 of 16 in FY2011.

Access to DENTAL CARE continues to be a problem. 93% of dentists accepted new non-Medicaid patients, but only 65% accepted new Medicaid patients due to the cap on reimbursement rate for adults of $495, with dentures excluded.

The Department of Disabilities, Aging & Independent Living's Developmental Service Consumer Survey showed that 82% of 1197 people interviewed received a physical exam in the past year, but only 57% received dental care in the past six months.

Vermont has an estimated shortage of primary care and specialty physicians in 8 of 14 counties, including 5 of 6 counties in the Northeast Kingdom. 26.5% of State Plan Survey respondents rated healthcare supports as fair to not good, citing Medicaid rates as limiting choice; poor care coordination for adults; few medical homes and practices able to handle complex needs; and difficulties transitioning from pediatric to adult physicians.

VERMONT Blueprint for Health
Smart choices. Powerful tools.

PREVENTION & WELLNESS: VT's Agency of Human Services is committed to prevention. An example is the state and private insurer adoption of the BLUE PRINT FOR HEALTH - to go statewide in 2013 – to improve outcomes for people with chronic medical conditions through self-help using a medical home model backed by regional specialty teams. VT's Dual Eligibles Project will extend it. Developmental Services requires meeting Health and Wellness Guidelines with 26 Standards that include annual medical, dental, Cancer screenings, etc. Some regional provider agencies offer activities like yoga, exercise, nutrition etc; gym, and use one-time funding for community health club memberships. VT Special Olympics offers Healthy Athletes education and screening at its competitions.

2. Employment

According to developmental services supported employment (SE) standards, Vermonters can expect person-centered planning, job development, assistance, negotiating accommodations and modifications, on-the-job training, follow-along, career enhancement and advocacy skills development.

Between FY2003 to FY2010 the number of Vermonters receiving developmental services supported employment rose 709 to 955. However the percentage of working age people in supported employment dropped from 39% in 2007 to 36% in FY2010.

According to the US Census - in 2009 there were 21,701 Vermonters with cognitive disabilities between the ages of 18 and 64. 6,475 people were employed or 29.8%. According to state agency figure from February 2009, representing a loss of 14 full-time-equivalent workers [FTE]. As of March 2011 the national employment rate for people 16 and over with a disability was 17.7%, while the employment rate was 63.4% for people who did not have a disability. The report State of the States in Developmental Disabilities (Braddock, et al) stated that "During January 2009 (the worst month on record for layoffs), 9% of people with disabilities left the workforce compared to 4.7% without a disability."

Vermont has no sheltered workshop, and funds only real job supports. Supported employment is funded by both the Division of Disabilities & Aging Services [D-DAS] and VocRehab [VR], divisions of the Department of Disabilities, Aging & Independent Living [DAIL], with both Medicaid Home and Community Based waiver and federal Rehab Act supported employment funds.

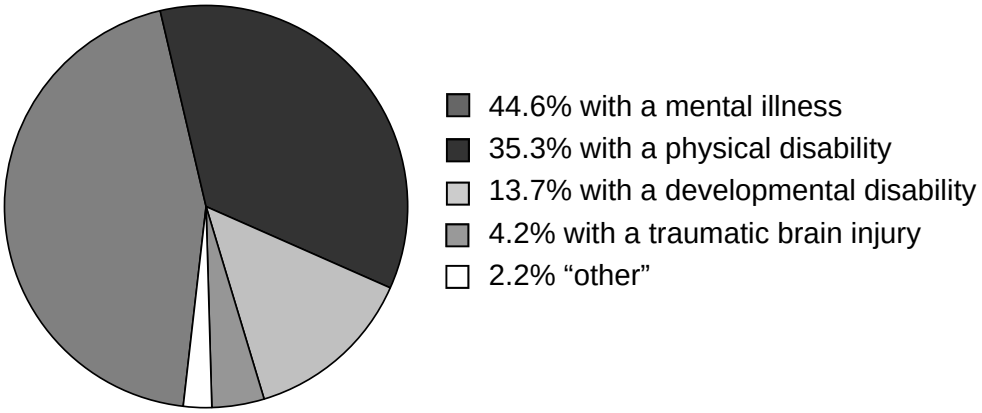
In FY 2009 and FY2010 the average wage for people receiving supports through developmental services waiver was $8.59

The average hours worked per week had dropped in FY2010 to 9, down from 15 hours in 1999. VocRehab averaged 28 hours per week at $10.68 per hour. VR rates of employment for people with disabilities were slightly higher than national averages, except for people with visual impairments, which were down by almost half, and were less than half the national rate.

VR specialties include transition counselor that bridge school to work, and benefits counseling - which helps Vermonters keep benefits while working, avoid work/benefit conflicts, and tap into the Ticket to Work Program. VR supports Vermonters who are eligible for developmental services, but do not meet a funding priority so are not served through a waiver. Federally funded Ticket to Work is an employment program for people with disabilities who Supplemental Security Income (SSI) and Social Security Disability (SSDI) Income. Its goal is to increase opportunities and choices for people who receive SSDI to get work, and support from VR as well as public and private providers, employers, etc. The Social Security Administration provides disability beneficiaries with a "ticket" they can use to obtain services and jobs from "employment networks" like VocRehab, which is Vermont's main provider of services. Vermonters can opt to use networks throughout the country.

Medicaid for Working People with Disabilities (WPWD) is a work incentive, to help inclusion through employment and economic independence. States can opt to provide Medicaid to working people with disabilities when earnings are too high to qualify for Medicaid under existing rules.

2,435 Vermonters received help between January 01, 2000 and September 30, 2008; there were 2,435 individuals total. As of September 30, 2008 there were 624 active enrollees who represented a wide range of disabilities:



Youth in transition from school to work has been a focus of both the D-DAS & VR divisions, increasing regional transition capacity and youth worker expertise as well as anticipating future need. Designated Agency (DA) Youth Transition Teams have been developed that include agency Intake & Supported Employment Coordinators, VR Transition Counselors & Special Education Case Managers. D-DAS also coordinates a Youth Transition Mentor Group, a statewide interagency team that sustains regional infrastructure through training and technical assistance. Outcomes include earlier involvement with students, families and schools; stronger partnership with VR transition counselors; an improved employment rate for students prior to graduation; increased participation in IEP transition planning; and timelier identification and assessments of graduate's eligible for developmental services.

D- DAS does a graduate survey, which is a forecasting tool to project the number of graduates likely to be eligible for developmental services and determine their needs. There are 16 VR Transition Counselors statewide working with students and connecting with developmental and other service systems.

As of 2005 there was a renewed Interagency Agreement between the Department of Education and Agency of Human Services. It establishes the State Interagency Team (SIT) (including D-DAS representatives. It also sets up Local Interagency Teams (LIT) that include VR, developmental service provider agency, (DA) representatives, and service coordinators. Students are identified early, and there are connections between VR transition counselor, school Core Transition teams and designated provider agencies.

73% of developmental service funding enables graduates to maintain employment after graduation. As a result rates of employment at graduation have gone up from 35% in FY2004 to 52% in 2006, 57% in 2007, and 58% in 2008. According to D-DAS between 2004 and 2011 the average number of graduates with developmental disabilities was 219; on average 60 met priorities to receive developmental services.

41.2% of respondents to VTDDC's 2011 State Plan Survey rated Vermont job and employment supports as fair to not good, compared to only 32.1% in 2006.

Vermont's 2010 Developmental Disability Consumer Survey rated work:

- 92% of those who work said they like work
- 100% see their work as important
- 48% want to work more hours
- 95% said they have a job coach

3. Formal and Informal Services and Supports

AGING SERVICES

There are five Area Agencies on Aging that coordinate home and community-based services, including information and referral; meals; transportation; jobs; senior centers; and adult day care. They help adults in need of protection. People with disabilities are served in same program.

DISABILITY SPECIFIC PROGRAMS & ORGANIZATIONS

The State's Division for the Blind and Visually Impaired (DBVI) serves 4,002.

It focused on jobs with 90% of its funds. It helps with:

- Student transition
- Resource & referral
- Technology/Adaptive Aids

DBVI contracts with Vermont Association for the Blind & Visually Impaired to provide independent living service like orientation mobility; Braille instruction; AT; home modification; transportation; and social networking. In 2010 VABVI served 1,397 people in all 14 counties, including 307 children and youth.

Vermont Center for the Deaf & Hard of Hearing (VCDHH) provides education and support services in school and in the community, including:

- Audiology Center
- Interpreter Referral Services
- Mental Health Counseling
- Regional School Consultation
- Sign Language Center & Mentor Program
- Deaf Vermonters Advocacy Services
- Independent Living

Vermont Center for Independent Living (VCIL) uses a peer model to offer:

- AgrAbility
- Info & Referral Line (63)
- Peer Counseling (61)
- Youth Leadership Program (10)
- Home & Community Access (19)
- Meals on Wheels for under 60
- Sue Williams Freedom AT Fund (16)

In FY2009 and FY2010 VCIL served 3,112 peers, including 252 people with intellectual disabilities and 31 with traumatic brain injury.

FAMILY SUPPORT

Vermont Family Network is a state-wide non-profit that supports parents to navigate educational and developmental systems and connect to community resources. It hosts core federal Parent Information Center and Parent to Parent grants, and provides:

- AT services
- Supporting Parents Match Program

The Vermont Federation of Families for Children's Mental Health focuses on children to age 22 who have or are at risk for emotional, behavioral or mental health challenges. It serves over 700 families through support, individual advocacy and systems advocacy for accessible, high quality, family-centered service.

There are unaffiliated ARC groups in three regions that sponsor activities and help people find resources. One of the groups trains and involves people in systems advocacy and hosts a self advocacy group. Another has 1,108 members and focuses on social opportunities including bowling, sewing circle, art and dances.

PEER SUPPORT

Vermont's statewide organization for people with intellectual disabilities is Green Mountain Self Advocates. It has 600 members, holds monthly board meetings, and provides technical assistance to 18 local groups. It helps to train peers to support each other; supports individual and systems advocacy; and helps people to serve on local and state advisory boards, and committees.

COMMUNITY-BASED LONG TERM CARE PROGRAMS:

Choices for Care 1115 Wavier serves 2,501 older Vermonters and adults with physical disabilities in the community. There are three levels of care: highest, high and moderate needs. At times there has been a waiting list for moderate needs. In addition agency based care there is a self-managed option (Flexible Choices), and an integrated health care option (PACE).

Home & Community Based Developmental Services, for people with intellectual disabilities and autism. Vermont closed its institution in 1993. In FY2009 it served 2,372 people:

- Service coordination (2,372)
- Community Supports (1514)
- Employment (909)
- Home supports (1,548)

The average cost was $53,800 per person.

Facts about the developmental services system of care:

Only 69 people self or family-manage *-and-* 272 adults without waivers receive targeted case management

FAMILY SUPPORT

- 586 families get waiver respite funding (that's 414 adults).
- 1,033 families (105 adults) without waivers get Flexible Funding (FFF), which is capped at $1,000 a year. (It went up to $1,300 in FY2008, and then below prior level of $1,122)
- 47% of total 3,734 served had family support, compared to 34% nationally
- National data estimates that there are 5,603 care-giving families of people with intellectual disabilities in Vermont, and 1,546 of them are aging. Support is provided to about 1,602 families, or about 29% of total.

CHILDREN'S SERVICES

Children's waivers were suspended in 2001 except when there is psychiatric stays.

EPSDT has not provided case management. The Bridge program that provides care coordination through regional designated agencies for children under 22 was capped at 162, and had a wait list of 12 in FY2010.

The primary support in Personal Care Services mandated services funded by Medicaid EPSDT.

2023 families receive CPCS that they self-mange, doing recruitment, training and supervision.

In FY2009 the C3 Pilot was capped at 119 participants.

It provides cash equivalent of CPCS allowing for flexible use of funds.

The High-Tech Medical Program has 84 families enrolled.

Unified Service Plans address children and youth with intensive needs by combining CPCS, High-Tech and/or HCBS. 58 were enrolled in FY2009.

Children with Special Health Needs provides respite funding with state general funds for children and youth with physical disabilities. 463 families are enrolled. Total budget is $295,000.

4. Interagency Initiatives

An Interagency Agreement between Vermont's Agency of Human Services [AHS] and Department of Education focuses on children and youth, and includes autism, transition, and early childhood services. (Building Bright Futures is the public/private early childhood partnership.)

➔ TRANSITIONAL YOUTH: The DOE-AHS Interagency Agreement includes close collaboration with the Department of Disabilities, Aging & Independent Living to transition eligible students from high school to the adult developmental disabilities service system of care. *The initiative encompasses:*

- Regional Core Youth Transition Team members that include regional provider (designated agency) intake and supported employment staff, VocRehab and special education case managers.
- DAIL Division of Disabilities & Aging Services [D-DAS] Youth Transition Mentor Group works to reduce barriers between adult & schools by empowering regional teams to establish reciprocity and cooperation.
- Annual D-DAS Graduate Survey projects graduates eligible for funding, promoting early identification and follow-through.
- 16 VocRehab Youth Transition Counselors across Vermont get involved a minimum of 18 months before graduation, to include providing service coordination.
- Act 264 LIT & SIT teams include D-DAS & VocRehab representatives for problem-solving.
- Technical assistance is provided by regional providers, VocRehab, DAIL & DOE to assure jobs on graduation.

An area of concern is meeting intensive needs across school and community. Families are bounced between community and school funding streams. This often results in children being placed in out-of-state residential schools paid by the Department of Education.

➔ The Agency of Human Services also has a Memorandum of Understanding between its departments.

➔ The Act 264 Board is hosted by the AHS Dept. of Mental Health [MH], and has oversight for the system of care for children and youth with severe emotional disturbance. It has also been addressing the needs of children with developmental disabilities and their families, including those with autism, since the Department of Disabilities, Aging & Independent Living [DAIL] ended serving children and youth under its developmental services system of care plan.

The Act 264 Board also acts as advisory group for new INTEGRATED FAMILY SERVICES initiative that crosses five AHS departments [Health; Mental Health; Children and Families; DAIL & Health Access- Medicaid].

➔ Integrated Family Services [IFS] is intended to create an integrated system for ages birth to 22, eliminating barriers by using a multi-disciplinary team, one case manager, and access to cafeteria style supports. It will tap Act 264's Local and State Interagency Teams [LIT & SIT] to integrate services, using Coordinated Family Plans.

Integrated Family Services has three key components:

1. CHILDREN'S INTEGRATED SERVICES, for children birth to six. It is described in the Child Care section at page 17. It is funded at $12 million.

2. ENHANCED FAMILY SERVICES. Funded at $40 million, it combines Departments of Children & Families and Mental Health services and is intended to reach families with multiple needs before crisis. The focus is what fits the family, not the program. It includes:
   - ACCESS mental health crisis
   - Post adoption support
   - Tapping available DCF, mental health and developmental service home and community based "waiver" packages.
   - Intensive Family Based Services
   - Individualized service budgets

   Available supports for out-of-home placements include:
   - High risk pool
   - Hospital inpatient & diversion
   - Private Nonmedical Institutions for Residential Care
   - Waiver
   - Micro residential

3. HEALTH & SUPPORT. Funded at $24 million, it is intended to offer unified intake and assessment, better service outcomes and increased family flexibility by integrating * Personal Care Services *Bridge Case Mgmt *High Tech Nursing *Children with Special Health Needs supports.

➔ The new CREATIVE WORKFORCE SOLUTIONS initiative is the hub for collaboration and coordination of employment efforts across AHS departments and programs (DAIL's VocRehab and Division of the Blind; DCF Reach Up, general assistance and youth in transition programs; Refugee Assistance; Department of Mental Health and DAIL's Supported Employment, JOBS Program and Senior Community Services Employment. It provides * contacts with local employment programs and employers *web tracking of employer outreach and job lead. It is based on a Memorandum of Understanding between the AHS Secretary and department commissioners.

➔ COLLABORATIVE COUNCILS, BOARDS & COMMITTEES: Vermont follows federal law in requiring individual, family and agency representation on boards and councils including the Statewide Independent Living Council; Governor's Committee for the Employment of People with Disabilities; Act 264 Board; State Rehab Council, Vermont Interagency Coordinating Council (advisory for IDEA Part C birth to three program; DAIL Advisory; and local and state standing committees on developmental services.

VTDDC and partners help to recruit members of the disability community to serve on these boards, as well as on task forces and legislative study committees. An example is the study group that includes advocates and people with disabilities that is identifying language and recommendations for phase two of new Respectful Language law that will change statutes.

There have been considerable interagency and organization efforts to try to expand Vermont's Aging and Disability Resource Center federal grant beyond aging to include disabilities, as envisioned in the original application.

5. Quality Assurance

Vermont's developmental service system is based on individual budgets. Each person is required to have an Individual Support Agreement that is structured to promote person-centered values. Quality assurance is essential to realizing the potential of the system of support.

Vermont's developmental services quality assurance system has diminished as the state budget has decreased. The Division of Disability & Aging Services [D-DAS] quality assurance mechanisms include Critical Incident report; Grievance and Appeal procedures; Safety and Accessibility inspections; annual consumer and family surveys; Ethics and Human Rights Committees for oversight; and provider Quality Management reviews. In 1993 each person's services were reviewed each year. Now Quality Management reviews are conducted every other year. The sample is 10%, or 24 of those served at an agency, whichever is less. The review team has decreased to four members, including one nurse, down from ten reviewers and two nurses. There is time only for a home visit and a record review. In the past community venues and employment sites were visited. The capacity of D-DAS to identify trends as well as technical support and training needs is diminished. It is now likely that services will be reviewed once a lifetime for many.

Every four years Designation reviews look at provider infrastructure stability. Each provider has an internal quality management process, as well as a local standing (advisory) and human rights committee.

The Office of Public Guardian [OPG] serves 609 people. It has regular contact with the person and their providers. They review case files annually and advocate for quality medical and health care. Nursing homes are reviewed by the Division of Licensing & Protection [DLP].

DLP's Adult Protective Services unit focuses on abuse and exploitation of vulnerable adults. There are not enough investigators. Some staff had 85 active cases last year. Best practice is 35 active cases. Substantiation rates between 2007 and 2009 averaged 8.3%. The national rate is 43%. The investigation rate was 5% opposed to 40% nationally. Vermont's protection and advocacy organization, Disability Rights VT, cited: poor quality of investigations, unassigned cases, investigations not started in a timely or lawful manner, and inadequate corrective action plans.

Disability Rights VT also investigates complaints of abuse, neglect and rights violations. In FY2010 it served 685 Vermonters. It is concerned about the reduced developmental service monitoring capacity, and the increase in provider agency subcontracts with home providers that make oversight difficult. Other concerns it has noted are: youth with emotional behavioral disturbance removed from school and placed in the criminal justice system; use of restraint and seclusion in schools; poor access to supports for people with developmental disabilities in prison; lack of effectiveness of school administrative complaint procedure; deteriorating relationships between state and developmental service providers; Social Security representative payees not being monitored, resulting in cases of embezzlement; and overall loss of progressive thinking at state developmental services.

D-DAS's Choices for Care waiver serves adults with physical disabilities who receive nursing home level care at home. There are two staff members who do quality assurance reviews. D-DAS certifies case management agencies. Agency standards are reviewed. Selected program participants are interviewed. If the agency meets standards the review schedule is every two to three years. If concerns exist the agency is reviewed annually. There's no critical incident report procedure.

Children with Special Health Needs recently redesigned its database to incorporate a more formal quality assurance process. It partners with Vermont Family Network, which works directly with families and provides a feedback loop about CSHN support.

Organizations that provide quality assurance activities include Vermont Family Network, which provides information. Referral and support as well as advocacy and leadership training for families. Green Mountain Self Advocates (GMSA) provides many high quality self-determination and leadership trainings for advocates, staff and community. Both VFN & GMSA engage in systems advocacy.

The Vermont Communication Support Project provides accommodations to assure equal access to the justice and agency review. They assist in legal/administrative hearings.

The Vermont Center for Independent Living's Peer Advocacy Counseling provides information and peer support aimed at increasing independence, dignity, and human rights. Between 2008 and 2010, 61 people with intellectual disabilities were helped.

6. Education and Early Intervention

Vermont is recognized for its per pupil spending and low classroom size. Education is still grounded in 260 school districts and boards statewide. Vermont does not have county government units. Instead, the state is divided into 60 supervisory unions that group school districts, but may not have a high school.

Vermont funds education through a complicated income sensitive state-wide property tax. There has been resistance to reforms to consolidate school districts for efficiency. Due to budget concerns special education often is a target.

In part due to its rural nature VT has pioneered mainstreaming, but lacks a continuum of placements resulting in high ratio of out-of-state residential schools. Of concern is increased use of alternative schools for students with intensive behavioral needs.

40.5% of State Plan Survey respondents rated special education and transition services as fair to not good. Comments focused on lack of parity.

In FY2011 advocacy resulted in Department of Education rules addressing use of restrictive behavioral interventions.

EARLY ESSENTIAL EDUCATION [EEE] PROGRAM (Age 3 to school)

(Individuals with Disabilities Education Act Part B): Services are based at school districts and supervisory unions.

- 1,753 children were served between age 3 to school entry.
- 21 % of children in Head Start are enrolled in EEE – 310 of 1,456 preschoolers.
- 60.5% of the children were eligible as non-categorical/developmental delay (186); 0.05% with autism (16); and .003% with multiple disabilities (1).

SCHOOL SPECIAL EDUCATION

(Individuals with Disabilities Education Act Part B): Vermont serves youth until their 22nd birthday. The 2010 Child Count showed 12,139 children were served in special education between ages 6 through 22, representing 15% of enrolled students. That includes:

- 2,446 students with a developmental delay.
- 840 students with an autism spectrum disorder.

EARLY INTERVENTION BIRTH TO 3 PROGRAM

(INDIVIDUALS with Disabilities Education Act Part C): The program is now based at Department of Children and Families [DCF], with 12 regional Family Infant Toddler programs hosted at Parent Child Centers [PCC] and other non-profits. Vermont has 11 Head Start and Early Head Start programs.

- In FY2009 there were 776 children birth to 3 children served, representing 3.93% of all Vermont infants and toddlers.
- 23.6% of children in Early Head Start are enrolled in Part C (109 of 460)

Although slightly down, 74.6% of VTDDC State Plan Survey respondents rated early intervention services okay or better.

504 PLANS

for children and youth who need accommodations, but not special education services:

- Grades K to 6th: 1,174 children with plans
- Grades 7 to 12th: 2,615 youth with plans

TRANSITION

Survey comments outlined the inadequacy of transition services, which vary greatly by school district. A 2009 Legislative Report estimated Vermont had 6,855 graduates.

In FY2011, there were estimated to be 199 graduates with developmental disabilities. Of those, only 101 were eligible under Vermont's developmental services definition and of those only 67 were funded. About 10 to 15 additional youth are helped with short term VocRehab job supports.

Little is available for graduates that do not have a job on graduation and do not meet another funding priority.

Per federal requirements in FY2009 the Vermont Department of Education started to track key transition indicators.

Indicator No. 13: Appropriate measurable transition goals in Individual Education Plan [IEP]. Only 22.6% met checklist criteria (30 of 133 youth age 16 and up). Examples are: 90% of students were invited to their IEP meeting; 76% had outside agency representation; 73% had assessment & summary; 57% measurable postsecondary goals; etc.).

Indicator No. 14: The FY2010 population census survey of 889 graduates indicated that one year after graduation 70% of graduates were enrolled in higher education; and that 71% were competitively employed and/or (3) in training (<1%).

PRIVATE SCHOOLS

Vermont has 124 private schools enrolling 11,895 students. 94 are State Approved Independent Schools. 30 are special education day or residential school, and 9 serve some disability categories. A proposed law would require that any school receiving state funding be required to enroll & meet the needs of special education students. That could have a substantial impact because there are a number of school districts that do not have high school, and direct state funds to private schools.

POST-SECONDARY

New in FY2011 is University of Vermont Center for Disability and Community Inclusion's grant funded Think College, offering a college experience at several campuses around Vermont. Also noteworthy is the SUCCEED, a program run by the largest regional agency, that offers a college experience connected with the University of Vermont campus in Burlington. It has 25 students, and a wait list of 25.

Another post-secondary educational opportunity is Global Campus. 200 people with developmental disabilities are involved in seven sites around Vermont, as teachers, learners and leaders.

OTHER EARLY INTERVENTION SERVICES

15 Parent Child Centers serving all areas of Vermont receive state contracts and Medicaid reimbursement to provide information; home visits playgroups, parent education, and advocate for family-centered services in the community. Most offer early education program, pivotal parenting and early education resources.
[See also Interagency Initiatives, Child Care and Informal & Formal Community Support sections.]

7. Housing

Two long term care programs provide HOME SUPPORTS:

CHOICES FOR CARE 1115 waiver serves over 2,000 seniors and people with physical disabilities in the community, with 350 in Enhanced Residential Care Homes with nursing overview

DEVELOPMENTAL DISABILITY HOME & COMMUNITY BASED [HCBS] program (part of Global Commitment waiver) for people with Intellectual disabilities and autism:

- 1,554 of 2,372 people with HCBS get residential supports.
- Another 818 people with HCBS live with family

Vermont averages 1.2 people per setting, which is the lowest in US.

There is a heavy reliance on adult foster care (1,196 = 77%)

- 234 people live in 228 supervised living settings (15%)
- 85 live in 19 group homes (5%)
- 33 people live in staffed living in 19 homes (1%)
- 6 people live in one Intermediate Care Facility/Developmental Disabilities [ICF/DD] with full time staff

HowardCenter

Howard Center Safety Connections is a new home support model for supervised living in the largest region that uses security technology and staff to provide overnight assistance when people live on their own.

An additional 1,200 people who do not get HCBS live with family and get minimal supports. Total living with family has risen from 30% to 47% since 1996, many with aging parents.

In FY2010 spending by type of setting was:

- Adult foster care (Shared living): $33,149,331
- Group living: $7,667,107
- Staffed living: $3,513,538.

Vermont supplements federal SSI payments. It also requires that people with HCBS use most of their SSI to pay room and board to provider. After payment, only about $115 per month is left to the person to spend on essentials.

Vermont's Crisis Intervention Network has substantially reduced population of people with intellectual disabilities at the State Hospital (MH) for acute care, although up since FY06 including stays of one year.

ASSISTED HOUSING DATA - Vermont had 12,380 units of assisted housing.

FY2009

- ♦ 6,004 of the units had no restrictions (about 50%)
- ♦ 3,370 of the units were for elders only (over 55 or 62)
- ♦ 3,006 unites were limited to households with EITHER elders or people with disabilities

NURSING HOMES

27 people with intellectual disabilities were reported as living in nursing homes. That is a rate of 5, which is half the national average.

VERMONT HOUSING FACTS

Vermont has the 4th lowest vacancy rate in the United State, at about 6.1%. In 2011 VT is ranked 17th worst in nation for housing costs as a percentage of income.

- A 2-bedroom apartment costs $990 per month. That requires earnings of $19 per hour to be affordable. That is a 58% increase since 2000, and 7% increase since 2010.
- 53% of occupations have median wages below $19 per hour.
- 47% of renters and 38% of owners pay more than 30% of their income on housing.
- In 2008, a person receiving SSI would need to spend 103% to 128.1% of monthly income on rent.

2,500 Vermonters were reported to be homeless.

SUPPORT FOR HOME MODIFICATIONS

The Choices for Care waiver provides up to $750 per year per individualized service plan

Developmental Disability funds modifications costing up to $10,000. The New System of Care Plan limits the amount of funds that can be paid each year.

VT Center for Independent Living's Home and Community Access Program supported modifications for 19 people with intellectual disabilities in FY2009 and FY2010. It also supported modifications to affordable housing units run by nonprofit providers.

SECTION 8

10 housing authorities manage waiting lists independently, including the VT State Housing Authority [VSHA].

Many of the wait lists are closed. VSHA's closed 10/10 due to backlog.

RECOMMENDATION

Federal Department of Housing and Urban Development's annual budget should support 10,000 new Housing Choice Vouchers for people with disabilities.

Vermont's Division of Disabilities & Aging Services regularly surveys people with waivers, based on the National Core Indicators. Highlights of the latest survey:

- 65% said someone else chose who they live with
- 42% said someone else chose where they live
- 88% said someone else makes the rules
- 51% said someone else decides when visitors come
- 59% live in remote locations not near transportation
- 23% live with a family member.

VTDDC's State Plan Survey & Forum results related to housing; 42.1% ranked housing as fair to not good. Concerns included:

- Section 8 and developmental service rules prevent peers from living together
- More services are available once children or adults have to leave the family home
- There are few options for an independent life, made worse by recent cuts
- Overreliance on the developmental home model that is unregulated
- Home supports used are not the least restrictive environment
- Workforce does not get benefits
- System is inflexible, and is not open to options

8. Transportation

Vermont's Department of Transportation [DOT] funds services in all 14 counties that include ride-match programs; Medicaid transportation; rideshare; para-transit services; fixed route; and demand/ response (DR) ridership where drivers deviate from fixed routes to pick up or drop off people within one mile of the fixed route.

According to DOT in FY2010 overall demand/response ridership was down from FY2009:

- Up 17% in Bennington Count
- Up 8% in Central Vermont
- Up in Franklin/Grand Isle counties (incomplete numbers indicated an increase)
- 30% drop in the Rutland area

The FY2010 range was 3,640 in Addison County to 27,060 rides in the Randolph area.
Medicaid medical transportation is available when no other means are available to travel to an appointment covered by Medicaid. However, people need to plan in advance and contact their regional transportation agency to arrange.

DOT oversees Elderly and Disabled (ED) transportation services through grant funds to regional providers. In FY2011 allocations totaled $3,499,550. The program transports people to meal sites, shopping, non-Medicaid medical events and critical care provider appointments. Each transportation provider kicks in a 20% match, most often through in-kind volunteer driver time. While flexible, ED is not an entitlement and availability depends on the region and funding available. Annually a group of representatives from organizations and groups that include senior centers, hospitals, adult day cares, community mental health agencies, determines priorities for their area.

Transportation options vary by region:

- Free transportation is provided in the Wallingford-area, Windham, and Chittenden Counties.
- Two fully accessible vans in the Champlain Islands
- Good News Garage in Burlington offers used car
- Orange and Windsor counties provides rides in the Gifford Community Health Service area
- Brattleboro provides para-transit services by Bus and Americans with Disabilities Act [ADA]
- A fixed route public system serves the greater Stowe area

Children with Special Health Needs provides funds for family support. Funding is available for out of state travel when no Medicaid transportation dollars are available, including mileage, flight and lodging related to medical appointments. Funds are not a supplement to Medicaid.

Voc Rehab spends 13% of its case dollars on transportation. It provided adapted vans or vehicle adaptations for at least 22 people in 2005. In 2011 it had a budget of $150,000 per year that can cover adapting approximately three vans per year.

The Vermont Association for the Blind & Visually Impaired uses state and federal funds to provide transportation statewide. Rides are available via volunteer and paid drivers, cab, and para-transit services.

Vermont's Divisions of Disabilities & Aging Services regularly surveys people with HCBS, based on the National Core Indicator. In 2010 there were about 156 responses to transportation questions:

"When you want to go somewhere, do you have a way to get there?"

- 82% said almost always
- 17% in between
- 1% "almost never."

"Are there places that you need to go that you can't get to like the doctor, service agency, shopping, pharmacy, etc?"
152 people answered -

- 62% said able to get where they need to go
- 35% said they can't get to places sometimes
- 3% said they can't get where they want to go

Respondents to the 2008-10 Consumer Survey used a number of transportation sources:

- 545 got rides from family/friends
- 80% got rides from staff
- 5% used group transports (vans)
- 16% used para-transit, volunteer or ride-share
- 5% took taxis
- 8% cited "inadequate transportation" as a barrier to Recreational Activity

VTDDC's State Plan Survey asked, "How is Vermont doing providing transportation and related supports to hold jobs and participate in social & leisure community activities?"

- 2.8% said excellent
- 16.8% said very good
- 31.3% said okay
- 24.6% said fair
- 20.1% said not good

Comments included:

- "Concerns related to parents having to provide transportation to social or leisure activities."
- "Lack of consistency of public transportation."

At forums conducted by the Council people in urban areas with bus service had fewer concerns than those in rural areas.
Comments included:

- "There are limited & long routes."
- "Transportation is not available on nights or weekends."

9. Childcare

SUPPLY There are 34,501 child care spaces in Vermont. The State monitors centers and homes through separate regulations.

- ♦ 71.3% of the spaces are at 672 CHILD CARE CENTERS
- ♦ 12% are accredited, compared to 9.8% nationally
- ♦ 28.7% of the spaces are at 991 FAMILY CARE HOMES
- ♦ 0.8% are accredited compared to 1.4% nationally

The WORKFORCE is 10,000 workers. Average annual income is $22,100.

Child care subsidy payments to providers for working families have not kept up with inflation, and child care providers have joined together to advocate for a law introduced in the current legislative session to negotiate collectively with the State.

TRAINING The State contracts with Child Care Resource & Referral agencies that provided 935 trainings and 1,006 on-site technical assistance visits.

CERTIFICATION Northern Lights Career Development Center acts as the hub for curriculum & instruction as well as career advising. There are 2 credentials: Program Director & Afterschool Professional. Early Childhood Mental Health & Infant Toddle certification is in process.

CHILDREN with DISABILITIES Numbers are not tracked separately. Access to child care includes Department of Children & Families Therapeutic Childcare Centers for kids with emotional/behavioral issues who are unsuccessful at regular childcare. The Centers tap the expertise of mental health clinicians currently available through 5 of 10 regional designated mental health/developmental disability provider agencies. The goal is to expand this service state-wide. *Specialized Childcare is available for:*

- ♦ Children in Department of Children & Families custody
- ♦ Children with specialized health needs identified as a necessity in a medical plan
- ♦ For family support when there is a short term stressor
- ♦ Providers that are designated do specialized child care participate in a training series to develop expertise and receive higher reimbursement rates

Child Care Resource and Referral is open to everyone.
Staff know about openings as well as providers who can meet unique needs.

The Early Intervention system consists of 12 regional Children's Integrated Service] teams that cover ages birth to 6. *It includes:*

- ♦ Birth to 3 Early Intervention (federal IDEA Part C`~ federal Family Infant Toddler Program)
- ♦ Essential Early Education (federal IDEA Part B 3 to 6)
- ♦ Children's UpStream Services, focused on mental health
- ♦ Specialized childcare resource service, that helps find provider to meet unique needs

Kindergarten to 12 before and after school care:

- 41% of K-12 youth are responsible for taking care of themselves after school. (41,394)
- 21% K-12 children participate in afterschool programs. (20,239)
- 26% of all children not in afterschool would participate if an afterschool program were available (21,181)

There are 5 type of after-school care:

- Licensed School-age Care Afterschool Programs
- Licensed School-age Care for ages 5 to 12
- Extra-curricular Activities and Summer Schools that include athletic teams, homework support, and other special-interest clubs.
- Recreational and Single Focus Programs, that include sports leagues and other youth programs run by municipal Parks and Recreation departments; business & organizations
- 21st Century Community Learning Centers that are funded by the Department of Education through competitive grants for up to 5 years with federal funds. Centers focus on program quality, academic links & student outcomes.

10. Recreation

Recreational resources include therapeutic horseback riding, with multiple providers offering this across the state. Vermont Adaptive Ski & Sports [VASS] has over 400 volunteers.

In 2010 over 850 athletes competed in Vermont Special Olympics events, and over 1,700 athletes were registered and eligible to compete. VTSO has 42 programs organized in schools and communities, and offers 12 sports are offered. There are over 2,500 volunteers involved annually. Its Unified Sports program pairs athletes with and without disabilities, offering training, competition, and social interaction. Its purpose is to break down barriers between athletes and peers with and without intellectual disabilities. 18 schools participated in 5 tournaments. In 2006, Unified Sports received a Vermont Principals Assn endorsement.

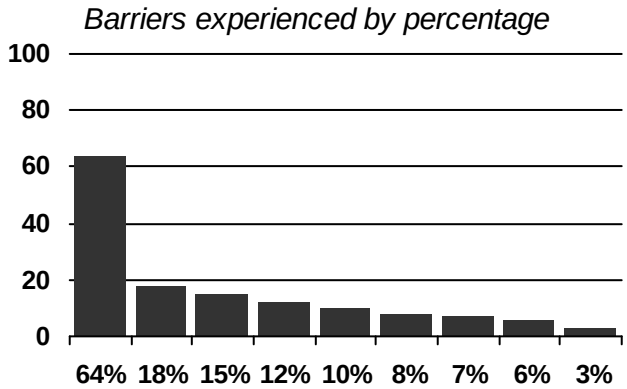
VSA Arts educational programs include preschool arts and literacy program, a family arts program at homeless shelters, and after-school programs. Activities that include adults with developmental disabilities include the Self-Advocacy Theater, for students making the transition to independent adult living; theater for adults seeking self-advocacy skills; and adaptive horse riding and art for children and youth.

Many provider agencies support health club memberships, dances, Global Campus and Voices and Choices annual self-advocate conference attendance, the premier social event of the year. The State of Vermont provides free hunting and fishing licenses to people with disabilities.

Local ARC groups are active in some areas of the state, and hold dances; sewing and arts groups. Many home providers share vacations and recreation activities with the people they support. What is not clear is to what extent people with developmental disabilities have opportunities to try new activities or make informed choices.

2008-10 Vermont Developmental Disabilities Consumer Survey participants assessed barriers to recreation:

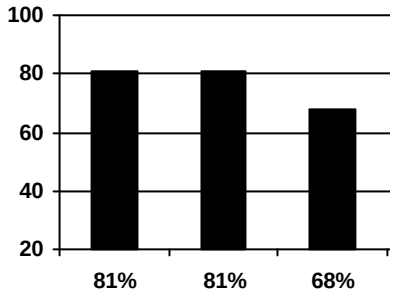
64% said there were no barriers
18% behavioral/emotional
15% social skills limits
12% money/cost
10% health 10%
8% inadequate transportation
7% recreation activity shortage
6% no chaperone
3% ‘other’ barriers 3%



The 2010 Developmental Services Consumer Survey section on activities in the community, with friends and social, groups, and family support saw some increase in satisfaction.

81% Family Home
81% Semi-Independent Living
68% Provider Home

Results by Residential Type in Activities Satisfaction



Here are recreation ratings from respondents to the VTDDC State Plan Survey:

- 59% indicated Vermont was doing Okay, Very Good, or Excellent providing supports for recreation, social, and leisure
- 37.4% rated access to supports as Fair or Not Good

(a majority identified themselves as family members)

Here are some selected comments about recreation and community inclusion:

"[Vermont T is] better than most states but [we] are backsliding into congregate settings."

"Training is terrible to non-existent. It is an embarrassment."

"The lack of training… trips to Cumberland Farms or McDonalds [are considered] community involvement."

"The idea of inclusion in organized recreation and social events has not yet caught on. People still seem to be afraid of liability."

"Lack of connections with peers & social activities are one of the largest problems."

"Social isolation is a huge problem."

"Local recreation department offices are not accessible."

"The pool has no accessible bathrooms."

"The adaptive sailing program is expensive."

"There are few community sponsored activities for children who use wheelchairs."

"I wish there were a program to help kids learn to bicycle, a program to teach kids to train dogs and take care of pets, low-cost groups teaching social skills and including all children, training for teenagers to learn to babysit children with disabilities."

"Providers have to be creative and constantly looking for opportunities. Too many adults are home alone or in isolated activities at some agency."

"Recreation programs need assistance/ advice on inclusion."

"A new adapted bike program is fund-raising to enable any child or adult to ride with family and friends."

"Need funding for transportation and adaptations."

State Issues and Challenges

1. Vermont Criteria for Eligibility for Services

Special Education

EARLY INTERVENTION (Part C)

Families with children birth through 3 who have a developmental delay or a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay.

EARLY ESSENTIAL EDUCATION (Part B)

For children 3 up to 6 meeting at least one of the following:

- Autism Spectrum Disorder
- Deaf-blindness
- Specific Learning Disability
- Emotional Disturbance
- Hearing, Learning or Visual Impairment
- Traumatic Brain Injury
- Multiple Disabilities
- Speech or Language Impairment
- Other Health Impairment

-OR-

- Evaluation and planning team finding of disability caused by a developmental delay presenting need for special education
- Medical condition which may result in significant delays with need for special education

-OR-

- Meets eligibility criteria for children 6 through 21 including determination of a disability, adverse effect on educational performance and need for special education

SCHOOL AGE

Ages 6 through 22nd Birthday, with one or more of the disabilities described in EEE eligibility; the disability results in an adverse effect on the child's educational performance in one or more of the basic skill areas and the child's need for special education to benefit from his or her educational program cannot be provided through the educational support system, standard instructional conditions or supplementary aids and services provided in the school.

VOCATIONAL REHABILITATION: Eligibility is determined by a counselor from the Department of Vocational Rehabilitation [VocRehab or VR]. Any Vermonter may be eligible who has a disability that is a barrier to work, and requires VR services to become or remain employed.

Long Term Care for People with Intellectual Disabilities (Developmental Disability Services)

Vermont defines a developmental disability as an IQ of 70 or below or Pervasive Developmental Disorder, accompanied by substantial deficits in adaptive behavior occurring before age 18. People must also meet Medicaid eligibility requirements as well as at least one priority in Vermont's System of Care Plan. The SOCP is rewritten every 3 years and updated annually. Its funding priorities triage who is funded based on emergencies, with limited funds for high school graduates with jobs. More details are provided above at Informal & Formal Community Supports, and also below.

Long Term Care for Vermonters with Physical Disabilities and Elders

CHOICES FOR CARE [C4C] is a Medicaid waiver program, with care based on level of need.

- HIGHEST NEEDS level – You must be a Vermont resident, 65 years of age or older or 18 years of age with a physical disability & need extensive or total assistance with at least one Activity of Daily Living [ADL] and require at least limited assistance with any other ADL, OR need skilled nursing on a daily basis OR have a severe impairment with decision-making skills OR a moderate impairment with decision - making skills and one behavioral condition which occurs frequently and is not easily altered.
- HIGH NEEDS level requires extensive to total assistance on a daily basis with at least one Activity of Daily Living (ADL) OR skilled teaching required on a daily basis to regain control of, or function with gait training, speech, range of motion or bowel or bladder training OR have impaired judgment or impaired decision-making skills that require constant or frequent direction to bath, dress, eat, use the toilet, transfer or attend to hygiene OR exhibit constant or frequent wandering, behavioral symptoms that are persistent, physically or verbally aggressive or have a condition or treatment that requires skilled nursing assessment, monitoring and care on a less than daily basis and who require an aggregate of other services on a daily basis.
- MODERATE NEEDS level requires a resident be 18 or older who has a physical disability or a limitation due to aging and whose needs cannot be effectively met with existing services.

2. Vermont barriers to full participation of un-served and under-served groups of individuals with developmental disabilities and their families:

Developmental Services

Vermont serves 3,734 people with intellectual disabilities. The State of Vermont estimates that only 29% of people with intellectual disabilities who meet the definition receive supports. Of those, 36% get minimal support.

The State also reports that each year 133 with developmental disabilities are born, and 33 die.

Statistics and actual service numbers were foundation for identifying the following populations:

PEOPLE NOT MEETING DEVELOPMENTAL SERVICES FUNDING CRITERIA: This includes people who are not eligible (have a serious functional disability but have an IQ over 70,or do not have PDD); or those who are eligible but do not meet a System of Care Plan [SOCP] funding priority. [Identified by ★Interviews (Disability Law Project, VCIL, Corrections; AHS Field Service etc.), ★VTDDC survey comments, ★Statistical review.]

HIGH SCHOOL GRADUATES: Estimated 210 graduates each year with a developmental disability.

In FY2010:

- 130 graduates were not eligible for services, and 34 of those eligible did not meet priorities
- 101 were eligible for Developmental Services
- 67 served through a Developmental Services waiver
- 10 – 15 per year get less intensive job services with VR grants

LIVING WITH AGING CAREGIVERS: In FY2009 it was estimated that 1,546 people with intellectual disabilities are aging themselves, and live with aging caregivers. [Braddock estimates 5,606 caregiving families, with only 1602 receiving supports. Meeting this funding priority triggers home supports. Vermont's funding priority is met only when caregiver dies or is incapacitated. In next decades it will be a significant demand on the system.

FAMILIES WAITING FOR FLEXIBLE FAMILY FUNDING: 100 families were on the list in F20Y10 for this minimal support of $1,000 that makes a difference in family capacity to meet needs.

VERMONT'S DEVELOPMENTAL SERVICE PRIORITIES THAT LIMIT SUPPORTS: Vermont does not maintain waiting lists of people currently receiving developmental services funding who live with families and need home supports to live on their own or with others. 818 of people with waivers (34%) lived with family in FY2009.

DEVELOPMENTAL SERVICE CAP ON HOURS OF SERVICE: To save money SOCP capped hours of community and job supports at 25 hours per week -- 5 less than school hours -- impacting people's ability to work and engage in the community.

SUSPENDED DEVELOPMENTAL SERVICE PRIORITIES. Since 1999 SOCP has eliminated or changed priorities that have narrowed access to supports, including:

- Prevent adult or child from regressing mentally or physically
- Keep a child under 18 with his or her natural or adoptive family
- Assist an adult to be independent from DD-funded services, or move to minimal services within 2 years [all suspended 2002 and cut 2005]
- Young adult aging out of State custody eligible & requiring ongoing services (cut 2003)
- Training support for parents with intellectual disabilities to provide training in parenting skills to keep a child home. (limited to $5,000 in 2002)
- Keep a person from losing a job [suspended 2002; limited to high school graduate to maintain paid employment 2005; age raised to 19 in 2006)
- Age for prevention of risk to health or safety raised to 19 (2006)

PEOPLE IN 1115 CHOICES FOR CARE WAIVER WITH A PHYSICAL DISABILITY. Specific data is not available for this subset within of Choices for Care. However, with recent cutbacks this program provides only minimal daily supports, with instrumental activities of daily living and respite caps.

INCREASE IN PEOPLE WITH AUTISM SPECTRUM DISORDERS. Vermont's prevalence rate shows 1 in 110 children have ASD. There has been a 16% average annual increase in children and adults in mental health or developmental disabilities services, with significant demands on capacity of service system to meet identified needs.

PEOPLE IN CORRECTIONS. Estimates are that there are 110 to 120 people in prison with a severe functional impairment, and that 50% of young people under 26 were eligible for special education. They tend to stay in corrections longer due to lack of services on their release. Per recent law and cost saving initiatives Corrections Dept. record review is determining the extent inmates with severe cognitive impairment need support.

NEW AMERICANS. Results of VTDDC's 2011 survey from 10 groups (Bhutanese, Bosnian, Burmese, Burundian, Congolese, Iraqi, Somali Bantu, Somali, Spanish speaking & Vietnamese) indicate that New Americans do not access developmental services due to lack of information and cultural barriers.

- 70% knew someone with a developmental disability
- 38.1% had help
- 23.8% knew people who were not getting help
- Leading barriers: language (95.2%) transportation (71.4%) lack info on services (76.2 %)
- Comments noted stigma, and lack of understanding-acceptance

3. Availability of Assistive Technology in Vermont [AT]

No recent hard data assess assistive technology needs in Vermont. The 2006 Olmstead Report estimated 9% of Vermont households had someone who needs or uses AT to help work, attend school, or manage daily activities.

Vermont's Developmental Services System includes the Communication Task Force, which works with Vermont's 16 provider agencies to focus on communication supports. Not all agencies tap this resource, and funds were cut for technical assistance. There is no comparable initiative for general assistive technology for people who receive developmental waiver services.

Vermont assistive technology resources include:

ASSISTIVE TECHNOLOGY PROGRAM [VTAP], a VocRehab [VR] program funded by the federal Rehabilitation Services Administration to increase access, acquisition and knowledge about AT devices and services. In FY2009 VATP served 6,809 Vermonters, family members, educators and others, including:

- Device Demonstrations
- Device-Equipment
- Information and Assistance
- Public Awareness
- Reutilization/Recycling
- Technical Assistance
- Training

Vermont has 3 AT TRYOUT CENTERS that are hosted by VTDDC's network partner UVM-Center for Disability and Community Inclusion; VTAP (2 locations) and regional VocRehab.

AT TECHNOLOGY REUSE PROJECT, which was funded in FY2010 by VocReb through Medicaid Infrastructure Grant [MIG] grant, and sited at VT Family Network, includes 2 websites:
www.getATstuff.com - an exchange program for new & used AT equipment. In FY2009 estimated savings to users was estimated at $422,000.
www.vtatschoolswap.com - same for schools, used by 29 of 60 Vermont education supervisory unions.
MEDICAID EQUIPMENT REUSE PROJECT, for Medicaid purchased communication devices and durable medical equipment (wheelchairs, hospital beds, standers, lifts etc.) People agree to return to Medicaid when no longer needed.

AUTISM PUZZLE FOUNDATION is a non-profit run by VATP that provides $300 per family for AT equipment and services to children under 18 with an Autism Spectrum Disorder [ASD], helping them to identify needs and purchase. [FY10 reduced from $500.] 40 families received $12,000 in equipment in FY2009.

Opportunities Inc. makes affordable loans available for AT equipment purchase through its INDEPENDENCE FUND.

VT Center for Independent Living and (with Statewide Independent Living Council)'s SUE WILLIAMS FREEDOM provides grants and funding for services and equipment that assist independent living. 262 people accessed the fund in FY09 and FY10 including 16 people with intellectual disabilities.

VT TELECOMMUNICATION EQUIPMENT (VTEDP) provides free telephone equipment to enhance communication & independence to income-eligible Vermonters who are deaf, hard of hearing, have speech or visual impairments or a physical or cognitive disability that makes it difficult to use the telephone. Its FY2011 budget was $36,581, with average spending of $355 per person. People served: 87 in FY2010, 88 in FY2009, & 93 in FY2008. The wait list of 17 is expected to be funded July 1, 2011. Those not income eligible can get a CapTel amplified telephone with written captions for $99.

Vermont's Division of the Blind and Visually Impaired has $75,000 in grant funds for AT equipment, focused on Skpe for those over 55.

Other Funding for AT Evaluations and Equipment

Vermont Medicaid funds rental and purchase of augmentative communication devices or systems to assist people to effectively communicate needs, especially medical, and for Augmentative/Alternative Communication (AAC) evaluation if prescribed by a Medicaid enrolled physician and speech language pathologist.

Some private insurance plans provide coverage for AT evaluations and equipment.

SCHOOLS pay for evaluations and equipment based on IEPs.

HOME TECHNOLOGY: Safety Connection is a home support program run by Howard Center, the regional community mental health agency in Burlington. It allows people with intellectual disabilities to live on their own with individualized home security technology to monitor overnight needs, with staffed center and on-call staff for check-ins. Services are offered to other agencies and populations.

VT TECHNICAL COLLEGE is a national leader, providing AT consultations & software to any student with support needs, national AT trainings for education professionals, & serving limited VR clients.

Network partner UVM-CDCI's recent grant trained professors in universal design teaching that also benefitted students with disabilities.

4. Vermont Waiting Lists Information

What is Vermont's wait-list definition?

Vermont passed regulations in 2011 that clarify that its developmental services waiting list is for people who meet the eligibility definition for developmental services but do not meet a current System of Care Plan funding priority i.e. those waiting for home and community based service packages. The list was formerly called the "applicant list" and was not reported nationally, using the term "wait list" for those waiting for limited Flexible Family Funding [FFF].

How does Vermont select people to be on the wait list?

The new System of Care Plan changed how priorities for funding were organized. Instead of a single list of priority situations it has 2 groupings ~ one addresses emergency care (example death or incapacity of primary caregiver), and the other addresses positive outcome opportunities (example: job supports for graduating students who have paid jobs.) Anyone who has applied and does not meet a priority would be on the waiting list.

People who do not meet a funding priority would be eligible for Flexible Family Funding, up to a maximum of $1,000. It is distributed to regional agencies, and when they run out of funds people may also be put on a wait list for FFF. Some agencies use "one time funding" i.e. leftover funds to cover extend FFF on a temporary basis until annualized funds are available.

Who collects and maintains Vermont's wait-list data?

Vermont's 10 regional designated provider agencies.

Is a state-wide standardized data collection system is in place?

No

Do individuals on the waiting list receive services?

Two major services individuals and families might receive are:

(1) Targeted Case Management has been extended to 272 adults, but is not tapped by all provider agencies. It provides check-ins and some assistance with basic needs like paying bills.

(2) Flexible Family Funding, which provides up to $1000 per year to be used for whatever will be the greatest support to the individual or family – respite, washing machine, recreation fees, etc. for 928 children and 105 adults.

As described above at Informal and Formal Community Supports, over 2000 children receive an average of 21 hours per week of personal care services [CPCS]. Workers are recruited, trained and supervised by families. Less than 10% of families of children with CPCS receive case management through the Bridge program. 119 families participate in the CCC pilot which provides funding equal to CPCS hours that they can use flexibly for a range of supports including goods i.e. like home and community based services.

What structured activities are available for individuals or families waiting for services to help them understand their options or assist them in planning their use of supports when they become available, for example person-centered planning services?

No.

Did individuals on the wait list have a thorough eligibility and needs assessment?

No. What appears to be happening at the regional non-profit designated agencies (who do intake, determine eligibility, recommend funding packages and provide services) is that people, especially children, are triaged before the full eligibility and assessment process is completed. The application form is one page i.e. a screening tool. Evaluations may be arranged or existing evaluations used to determine eligibility. Objective needs assessment scales are not used; a Needs Assessment form was recently updated, but it appears to be used only after a decision is made that someone meets a priority. Those not meeting a priority are typically told they will get $1000 a year in flexible family funding, and at least at some agencies do not receive a notice that they have not received a home and community based package and can appeal.

Other data or information related to wait lists:

People are told what they are eligible for, and are often not given information about appeal rights. For example, people may receive flexible family funding, or targeted case management. Agencies are not funded to provide person centered planning for people receiving those limited services. There is no expectation that anyone on the wait list will be served until the situation worsens and they meet a priority so planning for future supports appears pointless. Regulations require people contacted yearly but no information or data is reported out on whether that happens. The data on Vermont's wait list reported out nationally is not accurate. Vermont reported that 0 for FY2009, when there 205 people, with numbers rising steadily since FY2003 when there were 106 people. The wait list for FFF is 48.

Information not released nationally shows people waiting for:

- Service Planning (150)
- Community Supports (68)
- Employment Supports (13)
- In home family support (116)
- Supervised Living (4)
- Shared living (9)
- Group Home (1)

Summary of waiting list issues and challenges:

Vermont masks the extent to which people go underserved by relying on regional non-profit agencies to control access through an underdeveloped application process and priority system that does not fully inform people what they are applying for and decisions that have been made on the level of service offered to them. There are strong indicators that there are more people in need of assistance who are not on the waiting list due to the informality of the application process and being discouraged at the intake point. Also, once you meet a priority you are removed from the wait list even if you have not been funded for residential placement or job supports. The state does not track who is currently receiving home and community based services but is in need of additional services such as job or home supports.

5. Adequacy of Vermont's current resources, and projected availability of future resources to fund services:

Vermont has struggled with budget deficits in recent years that were filled by budget reductions, with minimal revenue raising efforts.

In FY2009 the prior Republican Governor chose not to negotiate with the state employees union, and many positions that provided oversight were lost at key Agency of Human Service Departments, including the Department of Disabilities, Aging & Independent Living [DAIL], which oversees key long term care programs. State positions and employee pay are now frozen.

The Governor's budget released in January in the last two years had 5% funding cuts for regional designated agencies that provide mental health, substance abuse and developmental services.

The FY2011 budget proposed:

- significant cuts to children's personal care services
- children with special health needs respite
- developmental services and flexible family funding

The FY2012 budget proposed:

- significant reductions cuts to a range of services and supports including targeted case management for those not enrolled in home and community based services
- significant reductions to the 1115 waiver program for elders and those with physical disabilities (respite and instrumental activities of daily living - IADLs).

The Legislature has been responsive in reallocating funds to partially restore a range of key services (children's personal care; special health needs respite in FY2011; targeted case management in FY2012), but has not kept up with need. Along with the prior Republican and current Democratic Governor, it has chosen not to raise taxes or use rainy day funds to maintain service levels, with deep concerns about looming rollbacks in federal education and other funding. As a result there has been steady erosion in a number of social net programs across the Agency of Human Services, the state's largest. As described above, this has often backfired, resulting in violation of state and federal law and remedial action. Key programs were level funding in FY2011 and FY2012, including elderly and disabled transportation ($3.5 million + $12 million non-emergency medical); VocRehab ($5.9 million.)

The State has launched initiatives to trim education spending that is still largely controlled at the local level, targeting special education and resulting in a decrease in the overall budget from $267.7 million in FY2011 to $264.9 million in FY2012.

Studies by Pacific Health Group of Vermont's regional designated agency system for developmental, mental health and substance abuse services concluded it was a cost-effective system. Their recommended modest increases to sustain care were followed until FY2009, when rescissions were made twice – 2.5% plus 1.25%, and elimination of flexible goods as a line item in all Home and Community Based individualized budgets statewide. The FY2011 Governor's budget threatened 5% cuts -- reduced to 1% by the legislature. Again for FY2012 cuts of 5% were proposed, rolled back to 2.5%. The total reductions from the system since August 2008 total 7.25%. The ups and downs in developmental disability funding have been hard to follow, with a combination of an increased base, cuts, and budget adjustments each year. Base funding increased to $152 million for FY2012, but total rescissions of 7.25% since summer 2008 have impacted people already in the system, and cut key agency staff like job developers. Instead of wait lists for emergency priorities people with HCBS have hours and services cut to fund 100 new people each year meeting system of care priorities. Employment results are down, and more people live with family. A similar pattern has emerged in Vermont's Choices for Care 1115 waiver program—the legislature restored it to the funding level of FY2011 for next FY2012, with cuts to respite and instrumental activities of daily living to be able to fund new people, absorbing any inflation as well. Per Braddock, ***State of the States in Developmental Disabilities***, Vermont's fiscal effort for services for people with intellectual disabilities is consistently at the top. It closed its institution in 1993, and maximizes federal Medicaid funding.

6. Adequacy of Vermont's health care and other services, supports, and assistance that people who live in facilities receive:

Vermonters with developmental disabilities who reside in its one ICF/DD (Intermediate Care Facility - Developmental Disabilities) receive the mandatory health services according to ICF-DD regulations, with oversight by registered nurses [RN] and staff. Services are further monitored by quality assurance review team of the Division of Disabilities and Aging Services (D-DAS) that includes an RN. The ICF/DD must also follow D-DAS's Health and Wellness Guidelines which outline quality standards. People with developmental disabilities living in Vermont nursing homes are monitored by the Division of Licensing and Protection's quality review nurses along with other residents. D-DAS ensures that federally mandated Pre-Admission Screening and Resident Review (PASRR) take place. All nursing facility residents and new referrals participate in PASRR to determine if they have developmental disabilities and/or related conditions and need specialized services. This includes pre-admission screening, development of community placements, and specialized services. These services can greatly improve the quality of life for people by providing support to address social and recreational needs as well as the person's overall wellbeing. Vermonters who meet its developmental disability definition who live in Community Care facilities have services reviewed by DLP and are seen by the quality review team of DDAS.

7. Adequacy of Vermont's home and community-based waivers services

As described elsewhere, both of Vermont 's long term care waivers are underfunded and do not reach many people eligible based on the definition.

The Choices for Care 1115 waiver for elders and people with physical disabilities has tiered services. In the past there has been a waiting list for people deemed "moderate needs." Although that waiting list was cleared recently, services continue to be restricted for those with high needs. The Legislature headed off cuts that would have halved respite to 360 hours per year – 30 hours per month. However, the previous cap of 720 remains in place. Cuts would also have rolled back instrumental activities of daily living from 4.5 to 2 hours per week – without exception. However that represents erosion from 12 hours per week. The caps are inadequate, particularly for people with physical disabilities. The waiver requires that any savings be reinvested, so the State has in effect cut current people to pay for new people entering the waiver.

The home and community based program that is part of VT's Global Commitment waiver serves 2,37 2 people, or about 28% of the people who meet VT's definition of intellectual disability. People must also meet a funding priority, which have narrowed considerably over the past 10 years. As described above, while base funding has increased some, the system keeps absorbing new people by cutting services and staff positions. The system is eroding, with virtually all residential care in unregulated developmental homes; reduction of staff and shift in funds to the providers to arrange and supervise all services including job supports, and increasing use of segregated day programs, undermining VT's individualized services. Employment has slipped, from 40% at an average of 15 hours per week, to 36% at any average of 9 hours per week. Budgets are becoming less individualized with the move towards segregating people in group day services and the removal of goods line items from people's budgets that allowed for flexibility for purchases and activity fees based on individualized needs. 34% of those with funding packages live at home with family, and have no hope for independent housing until their situation worsens in some way and they meet an additional funding "priority." Community and work supports have been capped at 25 hours per week, further limiting people's ability to have work and also be an active participant in their community.